#### Response to the Early Years Strategy Discussion Paper

#### Early Childhood Intervention (ECI) Best Practice Network

The ECI Best Practice Provider Network is a group of fourteen (14) not-for-profit Early Childhood Intervention providers who support over 16,873 children each year. We collectively prepared this response to the Early Years Strategy Discussion Paper on a voluntary basis, through the lens of providers who work with children experiencing developmental delays and disability.

We have prepared the attached *Discussion Paper on Early Childhood Intervention and Therapeutic Supports for Children and Young People under Age 16* which underpins our response to the questions of the *Early Years Strategy* and is referenced in our answers.

Our shared vision is that evidence-based best practices provide the best opportunities for positive outcomes for children. We believe that children must be viewed in the context of their family and that a family-systems approach will achieve the best results. Children thrive when their families thrive.

Our paper takes a 'whole of government' view as children are engaged with multiple service types at different government levels throughout their lives. We strongly support endeavours to break down barriers between departments, agencies and jurisdictions to ensure children and families do not fall through the cracks. While the *Early Years Strategy* is focused on the Commonwealth's role in supporting the early years, we encourage state/federal collaboration to achieve a united, national vision for the early years.

The Early Years Strategy presents an incredible opportunity to establish core principles that can bring together the multitude of frameworks that exist across education, health, mental health, disability and beyond. These core principles can bring about alignment with these parallel strategies and provide an opportunity for outcomes reporting across all domains. Doing so will be especially beneficial for children with developmental delays and disabilities, and their families.

What follows is our response to the questions in the discussion paper.

Submitted by the Early Childhood Intervention Best Practice Network (April 2023)







#### Response to the Early Years Strategy Discussion Paper

#### Do you have any comments on the proposed structure of the Strategy?

We support a structure for the *Strategy* that uses a theory of change approach, underpinned by evidence.

As early intervention providers who work across multiple frameworks, codes of practice, disciplines, and jurisdictions, we support the development of a national vision, set of principles, outcomes, policy priorities and indicators for children that drive investment into the early years and sets the intention for that investment.

We believe that a shared vision and outcomes that can be agreed nationally, by the Commonwealth and all states and territories, will provide the best approach. This national approach is needed to ensure consistent, outcomesfocussed policies and investment.

This must be supported by coordination across and between governments to manage fidelity to the strategy and to mitigate against the risk of children and families falling through the cracks.

As providers of early childhood intervention for children with disabilities and developmental delays, we are particularly concerned about this cohort of children and their families. In our attached *Discussion Paper* we have documented the challenges of the early childhood intervention service system under the National Disability Insurance Scheme (NDIS) and have highlighted challenges and unintended consequences when evidence-based best practice does not underpin policy priorities and funding approaches.

#### What vision should our nation have for Australia's youngest children?

All children in Australia should be given every opportunity to learn, develop and participate. We strongly advocate for children with developmental delays and disabilities to be at the forefront of this national vision.

Best practice in early childhood intervention 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.

As such, we see several key tenets to our vision for Australia's youngest children:

- **Present focus** The focus needs to be on children today. Too often children are viewed merely as precursors to future adults future workforce, future taxpayers, future voters. While we strongly support investment in the early years and the research that demonstrates the return on that investment, we are concerned this overlooks the needs of children today and their rights to a childhood. This vision should be based on a children's rights approach and incorporate the voices of children.
- Family Approach Children exist in the context of their family. They thrive when their family thrives. Where families are disadvantaged, children fall behind. As such, a family systems approach should be incorporated in this vision. By meeting the needs of the family, the child's needs are met. Families exist in communities and cultures. Families must be supported proactively ahead of birth and actively through their child 's first 5 years of life with information, tools and supports so that they can support their child's development and participation. We strongly support a holistic child and family centred approach. We know that all families are not equal, but each family deserves opportunities. Equity and access to services and activities are required, with a safety net to ensure no child is left behind.
- Inclusion and Access Children have a right to participate in family and community life. All children should
  be given the supports needed to be able to access high quality early education that meets their diverse
  needs. Those that need it should also have easy access to early intervention to support their
  development. 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,

<sup>&</sup>lt;sup>1</sup> Dunst, C. J. (2022). Child studies through the lens of applied family social systems theory. *Child Studies*, (1), 37-64 ECI Best Practice Network Response to *Early Years Strategy* (April 2023) Page 2 of 5

interact with others and be a part of their community. This vision should apply to all children in Australia, regardless of their visa status.

• Local community responses – We can better understand what facilitates or hinders early childhood development and outcomes when we make use of what we know about local foundational community factors. This knowledge "can help contribute to decision making and interventions that move beyond the individual-level, which has shown limited sustained success, to the broader community-level (e.g. place-based initiatives)."<sup>2</sup>

#### What mix of outcomes are the most important to include in the Strategy?

As providers working with children with development delay and disability, we advocate for outcomes to be applicable to these children, to ensure they are not forgotten and that outcomes are not framed solely for a typically developing child.

We know that the pathway for lifetime participation is developed in the early years. Children must be able to participate in all areas of society and be included in arts, education, recreational and community activities.

The key to children's participation is in supporting their parents to build their capacities. In our *Discussion Paper* we emphasise the importance of a family-centred approach. Families cannot thrive when they are in poverty and their basic needs such as housing, health and food are not met.

Outcomes also need to be framed around parental choice, empowering them to make decisions about how to raise their children and how much each parent participates in the workforce. We support the parent's right to choose when to return to work or whether to remain at home to manage care and parenting roles for their child who has a developmental delay or disability. However, this is often not a real choice if the parent is not able to find an inclusive early childhood education and care setting that is able to safely meet their child's needs.

As NDIS Registered Providers, we follow their outcomes framework which has been adapted from international evidence<sup>3</sup>. We suggest that the outcomes could include:

#### For children:

- Meaningful participation in family life
- Meaningful participation in community life
- Gaining the skills appropriate to their ability and circumstances
- Self-determination in their everyday lives
- Specialist services assist children to be included in families and community

#### For families:

- Families know their rights and advocate effectively for their children with disability
- Families understand their children's strengths, abilities and special needs
- Families help their children develop and learn
- Families are able to gain access to desired services, programs and activities in their community
- Families enjoy health and wellbeing

#### What specific areas/policy priorities should be included in Strategy and why?

Policy priorities need to include a mixture of universal and targeted support. In our experience we find that children are falling through the cracks, as various departments, systems and jurisdictions do not work collaboratively. As detailed in our *Discussion Paper*, we strongly encourage Commonwealth, States/Territories and their Departments/Agencies to work collaboratively to ensure alignment of policy and seamless service delivery.

Therefore, we would like to see the Strategy support *Best Practice Guidelines in Early Childhood Intervention* and aim to ensure any policies and/or funding models ensure that services can work within this guideline. Currently, services are not funded to enable service delivery to be fully aligned to these guidelines. This is leading to many children with disabilities being left behind.

<sup>&</sup>lt;sup>2</sup> Goldfeld, S., Villanueva, K., Lee, J.L., Robinson, R., Moriarty, A., Peel, D., Tanton, R., Giles-Corti, B., Woolcock, G., Brinkman, S., Katz, I. (2017). Foundational Community Factors (FCFs) for Early Childhood Development: A report on the Kids in Communities Study

<sup>&</sup>lt;sup>3</sup> Bruder, M. B. (2010). Early childhood intervention: A promise to children and families for their future. *Exceptional children*, *76*(3), 339-355. ECI Best Practice Network Response to *Early Years Strategy* (April 2023) Page 3 of 5

#### What could the Commonwealth do to improve outcomes for children – particularly those who are born or raised in more vulnerable and/or disadvantaged circumstances?

We know that children with developmental delays, disabilities or vulnerabilities can face difficulties accessing mainstream services. For example, children with severe and profound difficulties have limited options for care and education and their needs are not met. Services that do support these children are rare, and often do not have resources to provide the level of support required.

Families experiencing vulnerabilities and disadvantage need localised, community-based services that are coordinated, connected, and aligned with evidence-based best practice. As detailed in our *Discussion Paper*, best practice in early childhood early intervention sees children in vulnerable circumstances needing a team around them – a complex network of services, application processes and funding streams to support them.

In an ideal system, these localised services would be focused on 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 are therefore more accessible to families, especially those from multicultural and culturally diverse backgrounds. Their localised nature also enables these service providers to connect personally with families. They have staff with similar backgrounds and experiences, and can connect families with local supports.

Our *Discussion Paper* makes some recommendations to improve outcomes for children with development delay or disability. We would like the *Early Years Strategy* to also support these recommendations:

- **Ensure a 'No Wrong Door Approach'** for families when engaging with early access services. Provide funding to local community-based non-profit services specifically to help families navigate the service system.
- Inclusion Capacity Building Support Ensure all early childhood education services have ongoing capacity building funding to support inclusion. This will build service capacity in inclusive practices to support the individual child and increase their own capacity to include children in the future.
- Inclusion Support in Early Childhood Education settings Ensure all early childhood education services have sufficient funding to ensure inclusion for children with high learning support needs by reviewing the hours funded and the rate of pay per hour. Provide funding for early intervention for children who cannot access the NDIS or other schemes.
- **Funding for preventative programs** Ensure funding is available for preventative programs including prenatal supports and postnatal supports. While state governments may provide limited funding, more support is needed.
- **Funding security** Short term funding agreements are problematic for services. Early intervention requires a skilled workforce. Annual funding agreements do not allow services to plan effectively and create workforce insecurity. The Commonwealth can promote three-to-five-year heads of agreement, with annual accountability/reporting to allow services to operate more effectively.
- Support Workforce Underpinning the Early Years Strategy is the need for a robust and healthy workforce.
  There is a nationwide shortage of early childhood and allied health professionals. While there is a separate
  workforce strategy, more needs to be done to attract, develop and retain professionals working in the early
  years, including untapped workforces such as trained and paid parent peer workers and therapy assistants
  among others.

What areas do you think the Commonwealth could focus on to improve coordination and collaboration in developing policies for children and families?

The Early Years Strategy is an opportunity to establish core principles that can bring together the multitude of frameworks that exist across education, health, mental health, disability and beyond. These core principles can bring about alignment with these parallel strategies and provide an opportunity for outcomes reporting across all domains.

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.

The Early Years Strategy also provides an opportunity to bring together jurisdictions and collapse silos which create barriers for children, families and service providers. For example, the Strategy can underpin a revision of the working protocols between States/Territories and the Commonwealth regarding Tier 2 supports (e.g., supports which are not funded by the Commonwealth) which would reduce the gaps families feel in the system.

In 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.

#### What principles should be included in the Strategy?

The *Early Years Strategy* should be based on the following principles:

- Evidence-based
- Best practice
- Voice of children and families (including co-design)
- Strengths-based
- Inclusion and access

Are there gaps in existing frames or other research or evidence that needs to be considered for the development of the Strategy?

A lot of excellent work has already been done to build an evidence base of best practice for the early years. The *Strategy* should bring together all other strategies and provide guidance for future frameworks.

# **DISCUSSION PAPER**

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

**MARCH 2023** 































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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' 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.

<sup>&</sup>lt;sup>1</sup> 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



- 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.
- 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.
- **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.
- **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.

GPS/PAEDATRICIANS/MEDICARE

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

#### **Short Term**

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

#### **Medium Term**

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

- Separate the ECI Partner role from the NDIA; maintaining the information and advice and assessment functions of the ECI Partner role.
- Require ECI Partners to refer to local registered providers for Short Term Require EUI Partilers to refer to local regions 2. Early Intervention work to give families more choice and control.
- 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**

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

- **107** Develop an accreditation for Key Workers and make that a requirement of delivery of Key Worker services.
- 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.
- Commission research to develop Best Practice Guidelines that cover the ages of 8 to 16 years.

#### **Short Term**

- Expedited visa processes for allied health professions.
- **102** Review NESA requirements to account for this type of community work.
- Review the E*ducational Services (Teachers) Award* to account for this type of community work.
- Provide financial subsidies to providers who employ new graduates for their first two (2) years of employment (similar to other approaches for trainees).
- 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

- 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.
- Development of clear workforce strategy for early intervention and allied health to complement other existing workforce strategies.
- Provide incentives for study in the allied health and early childhood teaching professions.

#### **Long Term**

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 Strenghtsbased Practice
- Culturally Responsive Practice

#### **QUALITY AREA: INCLUSION**

- Inclusive Participatory Practice
- Engaging the Child in Natural

#### **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<sup>2</sup> 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.

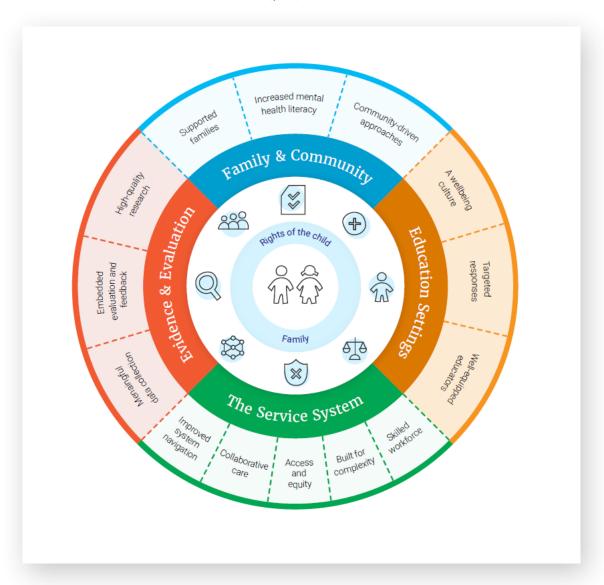
Best practice not only takes into account broad early childhood intervention research, but also evidence relating to the needs of children with a specific diagnosis, such as autism spectrum disorder or cerebral palsy.

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.

<sup>&</sup>lt;sup>2</sup> Page accessed 20/2/2023 - https://ourguidelines.ndis.gov.au/early-childhood/early-childhood-approach/what-early-childhood-intervention

#### **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**

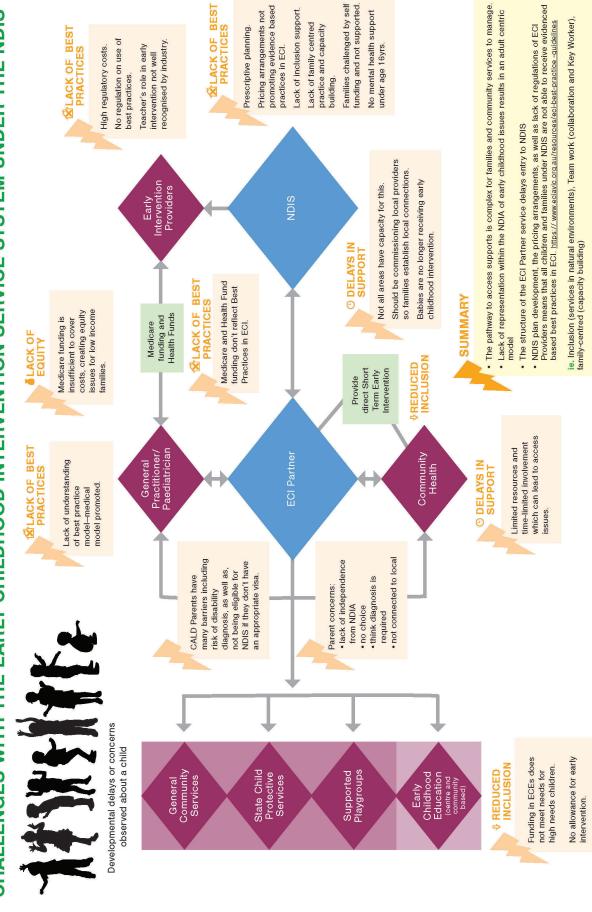
The National Disability Insurance Scheme (NDIS) created the Early Childhood Approach to provide a pathway for children under the age of seven to access supports which will enable parental capacity, inclusion in society, and positive long-term outcomes for the children involved. The system is not designed 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.

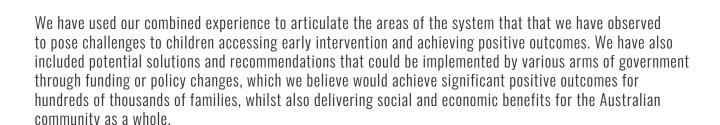
For children experiencing developmental delay or disability, their families and carers are faced with a complex network of services, application processes and funding streams before they can even access early intervention supports. Even with the best of intentions, the current system can be difficult 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



## The System | Opportunities for Improvement



#### 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<sup>3</sup> 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 childhood 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.

<sup>&</sup>lt;sup>3</sup> 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

- **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.
- 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.

- 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.
- **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.
- **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:

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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.

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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.

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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

- Revise working protocols between States/Territories and the Commonwealth regarding Tier 2 supports (e.g., supports which are not funded by the NDIA).
- Increase funding for Child and Family Health Nurses within Community Health and other health services (e.g., Brighter Beginnings in NSW).
- Revise Community Health protocols to include a focus on family health and wellbeing, not just child.
- 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

#### **Short Term**

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

**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

- Separate the ECI Partner role from the NDIA; maintaining the information and advice and assessment functions of the ECI Partner role.
- Require ECI Partners to refer to local registered providers for Short Term Early Intervention work to give families more choice and control.
- 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% 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		
O To see children in natural settings	O The cost of travel is seen as 'reducing' their 'therapy budget' and therefore, families opt for clinic-based models.		
O To appoint a Key Worker to work with a family	O This cost is seen as 'reducing' their 'therapy budget' and families do not understand the value of Key Workers.		
O To support the family unit	• Families are often reluctant to use funding on family support as it is seen as 'reducing' their 'therapy budget'.		
O 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.

<sup>&</sup>lt;sup>4</sup> Data accessed 21/2/2023 for Quarter 1 FY22/23 - https://data.ndis.gov.au/explore-data

#### C. MEDICAL MODEL

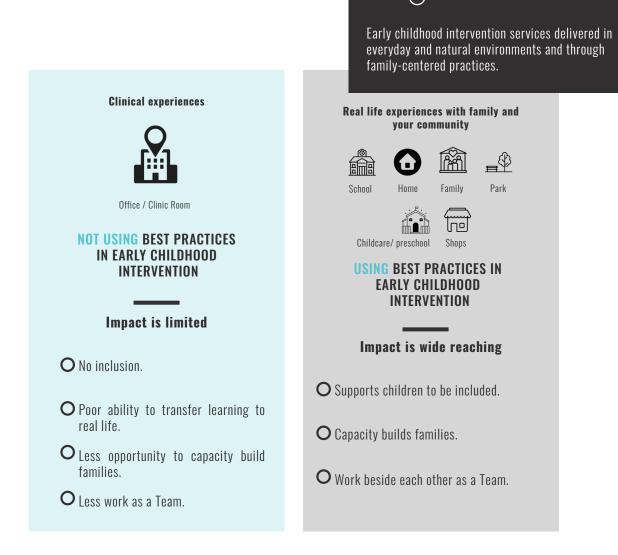
These challenges are underpinned by the 'medical model' which is often widely promoted by medical professionals like General Practitioners and Pediatricians. Families often come to services with the view that they only need 'therapy' and the more of it, the better.

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.



#### D. PRESCRIPTIVE PLANS

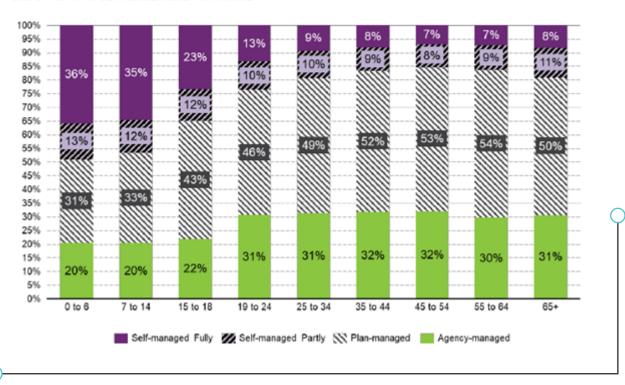
To add to the structural challenges of the price guide, we observe many cases where plans are no longer being designed to be flexible and responsive. Children's NDIA plans can be prescriptive about the number of Speech or Occupational therapy sessions the plan is costed to deliver. For instance, a plan 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<sup>5</sup>. 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



<sup>&</sup>lt;sup>5</sup>Data accessed 21/2/2023 for Quarter 1 FY22/23 - Explore data | NDIS

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.

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#### 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." 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**

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

#### POSSIBLE SOLUTIONS AND RECOMMENDATIONS - NDIS

#### **Medium Term**

- **107** Develop an accreditation for Key Workers and make that a requirement of delivery of Key Worker services.
- 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.
- 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.<sup>7</sup>

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

<sup>&</sup>lt;sup>7</sup> State of the Disability Sector Report 2022, Figure 10, page 31

#### **Short Term**

- **1** Expedited visa processes for allied health professions.
- **102** Review NESA requirements to account for this type of community work.
- Review the *Educational Services (Teachers) Award* to account for this type of community work.
- Provide financial subsidies to providers who employ new graduates for their first two (2) years of employment (similar to other approaches for trainees).
- 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
- 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.
- Development of clear workforce strategy for early intervention and allied health to complement other existing workforce strategies.
- Provide incentives for study in the allied health and early childhood teaching professions.

#### **Long Term**

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

- O 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.
- O The structure of Medicare and NDIA funding does not enable family-support.
- O Early access points in the community are not funded to provide local support to families in either a preventative or responsive way.
- O 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
- O The structure of funding in early childhood education settings does not enable inclusion.
- O Children under 16 with mental illness are excluded from the NDIA.
- O The structure of Medicare and NDIA funding does not enable service delivery in natural settings.
- O 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
- O 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.'
- O The structure of Medicare and NDIS funding does not enable or encourage families to participate in 'capacity-building.'
- O The medical model promoted by health professionals is often clinic-based and does not promote use of Key Worker.
- O Collaboration between mainstream and funded providers is not an expectation that is enforced.

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# QUALITY AREA 4: UNIVERSAL PRINCIPLES

- Evidence base, standards, accountability and practice
- Outcome-based approach
- O The medical model promoted by health professionals is often clinic-based and does not promote use of Key Worker.
- O The structure of the Medicare and NDIS funding unintentionally promotes a 'more is better' approach, rather than focuses on outcomes.
- O There is limited regulation on use of evidence-based practices, including the Best Practice Guidelines, within the NDIS.
- O There are workforce shortages and a lack of support to enable training of new graduates, which limit capacity to achieve objectives.
- O 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:

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

102 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

#### 01

Parent would ring up or walk in the door

OR

- 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
- 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

#### 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

- Pamily 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
- 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.

- Family may (are often) required to get evidence and documentation for access
- Families ring local paediatricians, speech pathologists, psychologists for diagnosis or report but wait 6 months or can't afford the payment for private consultations
- 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
- 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.
- 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).

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

- The challenges of having only one ECEI Partner per region;
- 102 The challenges of having ECEI Partners which also deliver therapeutic services;
- 103 The challenges for multicultural families to access services;
- 104 The lack of local connections for many ECEI Partners;
- How children can 'fall through the gaps.'

# CASE STUDY 5 - INEQUITY OF ACCESS TO ECIPARTNERS

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.

- The inconsistent approach many families experience with trying to seek access;
- The lack of clear guidelines between community health and the NDIA regarding supports;
- 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.

- The varied use and understanding of the Best Practice Guidelines;
- The lack of collaboration experienced with some allied health providers;
- The potential for providers to use funding for diagnosis and assessment which is not the intention of the NDIS funding;
- 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 ECI 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:

- The challenges with no regulation and oversight of self management of funds:
- 102 The potential for system fraud that puts children's wellbeing at risk:
- 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:

The inconsistency in planning and access to funding;

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 faceto-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.

- The lack of oversight of providers to ensure they are following Best Practice Guidelines:
- 102 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	2000*	2300*	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

<sup>\*</sup> An earlier version of this paper was published with errors in this data, this version published 20th March 2023 has been corrected.

#### **APPENDIX C - References**



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