

REIMAGINE EARLY CHILDHOOD



A NATIONAL ACTION PLAN TO 2030 SUPPORTING OUTCOMES FOR CHILDREN WITH
DISABILITY OR DEVELOPMENTAL DELAY AND THEIR FAMILIES



Reimagine Australia acknowledge the traditional custodians of the land across this nation on which we work and pay our respects to their Elders, past and present and to the children and young people of today, who are the Elders of tomorrow.

We acknowledge our gratitude in sharing this land today, our sorrow for some of the costs of that sharing, and our hope and belief that we can move to a place of equity, justice and partnership together, recognising that we walk in harmony with our First Nations brothers and sisters in creating a more just Australian society.



FOREWORD

The Reimagine Early Childhood National Action Plan to 2030 (Action Plan) is a 10-year road map to enable the human services sector, as a whole, to realise its potential to be a responsive, easy to navigate and holistic early childhood development support system. An ecosystem where all children have opportunities to meaningfully participate in family and community life.

Every year an estimated 115,000 families of children¹ with additional needs are confronted and confused by a system that, despite its best intentions, has become inherently complex. Their interaction with the human services system is often described as confronting, difficult and confusing, with no less than 10 service systems to coordinate and navigate.

To ensure that every child is well supported and benefits from the investments all governments make in early childhood development, a well-resourced, all encompassing 'belonging and inclusion' framework is required.

Reimagine Australia (Reimagine) is proud to be tasked with the delivery of the first National Early Childhood 10-year Action Plan. The Action Plan provides a clear road map, to 2030, to support the development of children, optimise social and economic outcomes for children from birth to six years with developmental delay or disability and support their families in a broad range of evidence-informed and innovative approaches.

The Action Plan is grounded in a strong family context, co-designed with families and for families, to support the success of the specialist early childhood development support sector, and to maximise outcomes for the tens of thousands of Australian families and caregivers every year who support a very young child with additional needs.

The consultation process to develop the Action Plan provided an opportunity to hold the first national conversation about the state of the early childhood development support sector in Australia since the introduction of the National Disability Insurance Scheme (NDIS). In designing the Action Plan, Reimagine has utilised the key learnings and deep insights gathered during our extensive consultation process, and has entwined them with contemporary international evidence and existing knowledge and information which has shaped the early childhood development sector across Australia and reimagined it, as a 10-year road map, through the lens of children and families currently using these services.

Children thrive in the context of their families and caregivers. Supported families lead to healthy communities, which in turn provides a social and economic dividend for the Australian community. It is vital that the specialist early childhood development support sector is guided by a transparent, shared and clearly articulated national vision. A vision that will enable the building of family capacity and the achievement of the very best outcomes for families and their children, ultimately ensuring that every child is afforded every possibility to thrive.

Yvonne Keane
CEO, Reimagine Australia.



In March 2019 the Hon. Paul Fletcher, Minister for Families and Social Services, commissioned Reimagine Australia to design and deliver the first national Action Plan (National Blueprint Project) for early childhood developmental care.

The Action Plan has been co-designed with families and for families, to maximise outcomes for the one-in-five Australian children who are developmentally vulnerable, and their families.



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REIMAGINE EARLY CHILDHOOD

Imagine a world of unlimited possibility. A world without barriers, where opportunity is infinite. A world where we can be as responsive as we desire. A world where the benefit of effortless access enables profound social and economic dividends for children, families, community, business and government. A world where children have every opportunity to thrive.

This is the world we dream of.



NOTE

The use of terminology emerged as a central finding from the national consultation that underpins the Action Plan.

‘Early childhood intervention’ (ECI) terminology is more aligned with the medical model of disability, rather than the social model of disability. Moreover, the use of professional language, acronyms and jargon, such as ‘ECI’ makes little sense to families and adds to their sense of overwhelm and confusion.

It is crucial that we move to a nationally consistent language for early childhood development that no longer provides a barrier for families. This language must be culturally sensitive, positive and easy for parents to understand and engage with.

In particular, the word ‘intervention’ was flagged as being associated with negative connotations for some families - particularly for families within Aboriginal communities, due to its historical use. In and of itself, the term can be a barrier for families in accessing vital early childhood developmental supports.

Throughout the conversations that inform the Action Plan, families told us that the term ‘specialist developmental supports’ instead of ‘specialist intervention supports’, and ‘early childhood developmental care’ instead of ‘early childhood intervention’ were more useful and engaging terms that make sense not only to families, but to key referrers and community groups alike.

The Action Plan is deliberate in its decision to honour this insight from families and in starting the necessary first steps down the pathway to using a language that enables, not disables, families.

For this reason, we have chosen not to use the word ‘intervention’ in this Action Plan, as it has been traditionally used, unless necessary. We have instead chosen to commence the journey of migrating the sector to embrace more family-friendly terms such as ‘early childhood developmental care’ instead of ‘early childhood intervention’.

Indeed, as a consequence of the findings of the Action Plan, Early Childhood Intervention Australia (ECIA) has itself reformed to honour the Action Plan and foster better inclusion and empowerment for children with additional needs and their families.

It was evident that the very name of our 37-year-old organisation propagated a divisive term and had outgrown its usefulness. If we were to be a part of the ‘reimagining’ required to achieve the vision of the Action Plan by 2030, we needed to change.

And so, in May 2020, Reimagine Australia was born. Under this banner we will continue our valuable work striving to support and enable the most extraordinary outcomes for developmentally vulnerable children and their families.

EXECUTIVE SUMMARY

The vision of the Reimagine Early Childhood Action Plan (Action Plan) is to ensure by 2030 that Australia has a responsive, integrated and easy-to-navigate early childhood development support system that is well resourced and founded on evidence-based best practice.

Children live and thrive in the context of their families. The parent or caregiver is responsible for representing and advocating for their child in the early years. Family is an essential support system in the child's life. What is required is an ecosystem that is designed upon a whole-of-family approach and that is centred around family capacity building and family goals, as well as parents and sibling goals.

A central priority of the Action Plan is that parents and caregivers have access to a fully inclusive, well-resourced, culturally responsive and innovative early childhood support system. Empowering and supporting families through easily accessible information and resources, that are designed and delivered through the lens of the development and wellbeing of their whole family, will enable optimised outcomes for families and their children.

A family-centred approach, rather than only a child-centred plan and approach in the early childhood years would ensure the entire family unit is viewed and supported as a whole, rather than in select parts. Importantly, outcomes for children would be outcomes for the whole family, which would drive early childhood development services and supports to wrap-around the whole, rather than the individual.

We know that the caregiver's journey is complex and overwhelming. When you add extra layers such as cultural barriers, entrenched disadvantage and poverty to a family's circumstance, the journey becomes dangerously difficult to navigate. Therapeutic and specialised support are recognised as important but are not always the main priority.



Furthermore, it is essential to establish a nationally consistent framework for families requiring support for a child, by driving a coordinated and clear approach across Federal, State and Territory levels.

Importantly, throughout the consultation process, the need to establish a national oversight of the early childhood development system was reinforced. The preference would be for this to occur through a national body to lead the development and implementation of a nationally consistent early childhood development approach across Federal, State and Territory levels, underpinned by a responsive navigation service to guide and enable families, simplifying their journey and driving strengthened outcomes for their children.

The Action Plan provides recommendations for a 10-year strategy for governments to consider, in partnership with stakeholders across the early childhood development sector. The strategy aims to ensure that every child has every opportunity to reach their full potential.

The Action Plan is led by a governing recommendation, which is underpinned by 6 recommendations that fall into 6 Key Priority Areas. Each Priority Area is supported by a set of succinct Action Items.

Actions proposed through the Action Plan are considered to be the first, important steps to deliver a stronger, more collaborative and quality early childhood development sector. Further actions can build from these first steps and other existing work underway across government and the sector, to be implemented iteratively over a ten-year period. The Action Plan has an ambitious vision and will take time to achieve. Considered and collaborative implementation of the recommendations outlined in this Action Plan will be critical to realising this vision.

THE ACTION PLAN

Informed by 12-months of deep conversation with families, human services practitioners, researchers, community organisations, government and other stakeholders, the Action Plan is designed to enable an achievable roadmap to realise a future where every child has every opportunity to thrive.

The findings of our national consultations have been synthesised into six defined priority areas of focus, The Action Plan is led by one governing recommendation, underpinned by 6 ‘priority areas’ aligned recommendations. Each recommendation is supported by a set of targeted actions.



6 KEY PRIORITY AREAS

The Action Plan is led by a governing recommendation, which is underpinned by 6 recommendations that fall into 6 Key Priority Areas. Each Priority Area is supported by a set of succinct action items.

PRIORITY AREA ONE

1 Empowered & Resourced

Caregivers must be empowered with information, resources and choice, to support the development and wellbeing of their whole family.

PRIORITY AREA TWO

2 Meaningful Participation

Children with disability and their families meaningfully participate in their networks, communities, learning and work environments.

PRIORITY AREA THREE

3 Seamless and Integrated

An Early Childhood Development ecosystem for all children, where systems and services work in an integrated and holistic way to support children and their families.

PRIORITY AREA FOUR

4 Responsive and Relational

Families of children with developmental delay and/or disability receive early childhood support as soon as they require, with or without diagnosis.

PRIORITY AREA FIVE

5 Capabilities and Quality

Australia has a skilled, collaborative and diverse workforce that delivers a range of evidence based developmental supports.

PRIORITY AREA SIX

6 Outcomes and Innovation

Meaningful data on developmental and participatory outcomes for children and families drives policy change, research and innovation in Australia.

The Reimagine Early Childhood Action Plan to 2030 makes recommendations for a 10-year pathway for governments, communities and the sector to optimise service system efficacy, realise social and economic benefits for the nation and, importantly, better support families of children with additional needs to participate meaningfully in society.

GOVERNING FOCUS

Governing Recommendation:

Early childhood developmental care for children with additional needs to be a national priority, which is overseen by a robust governance mechanism, reflected in strategic frameworks with a clear overarching vision and strong feedback loops to inform service design and delivery of the Action Plan to 2030.

ACTION ONE

Overarching Governance Mechanism

Establish/utilise governance mechanisms to drive action across Commonwealth and state and territory levels to achieve a coordinated and consistent early childhood developmental care nationally.

ACTION TWO

Embedded in Commonwealth Frameworks

The priorities of young children with disability and developmental delay, and their families, are reflected in strategic Commonwealth and State and Territory policy frameworks.

ACTION THREE

Culturally appropriate response for First Nations People:

Specific approaches explored, co-designed and implemented to deliver early childhood developmental care in a culturally appropriate way for First Nations People



We want the same as any other parents. To be able to care for all of our children, to feel connected, to have access to information, opportunities for our children, to have high quality universal service access and to receive additional support. when we need it.



RECOMMENDATIONS

SUMMARY OF ACTION PLAN RECOMMENDATIONS:

GUIDANCE	Overarching Priority: Early childhood care and support for developmentally vulnerable children to be a national priority which is overseen by a robust governance mechanism, reflected in strategic frameworks with a clear overarching vision and strong feedback loops to inform service design and delivery of the Action Plan to 2030.	
	PRIORITY AREA 1 Empowered & Resourced Caregivers must be empowered with information, resources and choice, to support the development and wellbeing of their whole family.	Recommendation: Establish an easy to navigate pathway for families to access early childhood development supports and information from the beginning of the family journey. Pathways guide families through mainstream and other systems, and have a 'no wrong door approach'.
	PRIORITY AREA 2 Meaningful Participation Children with disability and their families meaningfully participate in their networks, communities, learning and work environments.	Recommendation: Individualised funding must be complemented by a whole range of evidence-based supports in order to build a fully inclusive, holistic, well-resourced and innovative early childhood support system.
	PRIORITY AREA 3 Seamless and Integrated An Early Childhood Development ecosystem for all children, where systems and services work in an integrated and holistic way to support children and their families.	Recommendation: Implement a family navigator service that sits within the universal service system, ² to be the main point of contact from the very beginning for all families of children with developmental vulnerability or concern.
	PRIORITY AREA 4 Responsive and Relational Families of children with developmental delay and/or disability receive early childhood support as soon as they require, with or without diagnosis.	Recommendation: Develop an integrated national screening and response capability across all government systems that interact with children and their families, to ensure that all systems operate in a responsive way to support early intervention and prevention.
	PRIORITY AREA 5 Capabilities and Quality Australia has a skilled, collaborative and diverse workforce that delivers a range of evidence based developmental supports.	Recommendation: Develop a comprehensive workforce strategy that addresses capability, quality and workforce supply.
	PRIORITY AREA 6 Outcomes and Innovation Meaningful data on developmental and participatory outcomes for children and families drives policy change, research and innovation in Australia.	Recommendation: Invest in quality research, data collection and monitoring of early childhood development best practice and outcomes, to build a responsive and innovative sector.

EMPOWERED AND RESOURCED

Caregivers must be empowered with information, resources and choice, to support the development and wellbeing of their whole family.

Empowered and Resourced Recommendation:

Establish an easy to navigate pathway for families to access early childhood developmental supports and information from the beginning of the family journey. Pathways guide families through mainstream and other systems, and have a 'no wrong door approach'

Australia's early childhood system is a complex landscape. For young children with additional needs and their families this period of their lives is often described as confronting, difficult and confusing, with often more than two systems to coordinate and navigate.

All children live and thrive in the context of their families. The parent or caregiver is the voice and guide for their child in the early years. The family and the environment are the most influential and crucial support systems in a child's life. It is essential then, that we develop an ecosystem that is designed upon a whole-of-family approach, that is centred around family capacity building and family goals, this includes parents and sibling goals.³ Evidence highlights the strong link between how well families are able to care for their children and the social and physical circumstances in which they are living.⁴

A central priority of the Action Plan is for parents and caregivers to have access to a fully inclusive, well-resourced, culturally responsive and innovative early childhood support system for their children. Empowering and supporting families through easily accessible information and resources. A support system designed on the foundations of learning, development and wellbeing of the whole family.

The consultation findings support the overwhelming evidence that the caregiver's journey is complex and overwhelming. When additional complexities to service access are present, such as cultural barriers, entrenched disadvantage and poverty, the journey can become difficult or impossible to navigate. Other social determinants include: socioeconomic status, educational attainment, employment status, poverty, geographic location, disability, gender, and social connectivity.⁵ Further, many families are struggling day-to-day to simply meet the basic needs of their family.⁶ It is estimated 3.24 million people (13.6% of the population or over one in eight) are estimated to be living below the poverty line of which 774,000 children under the age of 15.⁷ Therapeutic and specialised supports were recognised as important in consultations but not always the main priority of the family.



Major stress points identified through consultations for families were:

- Waiting times for initial appointments in health, NDIS and education & community supports, diagnosis, services.
- Referral pathways to care and support are time consuming, confusing and eligibility heavy.
- Access to inclusive community & services especially soft entry point supports (such as supported playgroups, early childhood education and care services, child and maternal health services⁸) have been eroded under the NDIS.⁹
- Key transition points in a family's life where there is not enough support such as early childhood education and care ECEC), playgroups & school.

A key finding from the consultation was that the early childhood support system must engage with families in a relational way rather than a transactional way. It must 'meet' families where they are, through mediums they are comfortable with, and use language that families understand.¹⁰ During the national Action Plan consultation, parents reinforced the perception of the NDIS as a 'gated city' that was hard to access and almost impenetrable.

Professional language, acronyms and jargon, such as 'ECI', is impacting on access and engagement. In addition, the word 'intervention' holds negative associations for some families. The term 'intervention' is more aligned with the medical model of disability rather than the social model of disability.¹¹

Families reported mixed messaging as a primary barrier to feeling empowered by information. This was largely in relation to their experiences with the NDIS, however there were issues with inconsistent messaging nationally around early childhood development and community supports. This confusion is exacerbated by significant inconsistency in availability, approach and resourcing across states and territories for developmentally vulnerable children and their families.

“ Access to information is non-existent and not written for an 'everyday' person. Most of us are so burnt out we can't comprehend what is written. We are in survival mode. Unless we are supported by a good Local Area Coordinator or Early Childhood Intervention Australia (now Reimagine Australia), there's no way you would know without them.

The aim of early childhood developmental support is to promote the capacity of caregivers who they spend the most time with, to support their children's learning in the environments in which they live and play.¹² These interactions often fall outside of the one hour of 'therapy' time. However, it has been found that the evidence around effective early childhood developmental support and the evidence of its effectiveness is not widely understood by caregivers.

Caregivers in the early stages of navigating supports for their child with developmental delay and/or disability consistently reported that information and guidance is most effective when delivered through relationships that are, at the core, based upon trust, continuity and safety. (i.e. are non-judgmental).¹³

Families reported receiving a lot of misinformation about what early childhood developmental care and support is with a spectrum of messaging across Australia, including

persistent “fix your child” focused messaging. Families also reported requiring respite in order for the sustainability of caregiving and feeling shame around this and not being able to access it through core supports due to the age of their child.

Schools, health services, early childhood services and other services that families interact with must have the capability to identify concerns early and/or provide meaningful support to families and their children, to ensure they feel connected, included and are participating under an integrated and streamlined framework.

Investment in co-design approaches could leverage upon the key influences, relationships, and unique networks which exist in each localised area, town and remote community. There are unique networks in each community which have been built ‘by the community for the community’ and have trust and cultural expertise at their core. These networks already provide support to children and families but are not always supported or resourced to do so. They require investment to ensure they are appropriately resourced and sustainable. Examples of these networks include Aboriginal Health/Medical Services (or ‘the clinic’) and the school system.

While individualised funding under the NDIS is helping drive increased choice and control for some families, and a higher level of family and caregiver engagement in the services their child accesses, there are also inadvertent impacts of this approach. The Reimagine consultations identified the risk that a market-based model is likely to further exacerbate culturally inappropriate, ad-hoc and inconsistent ‘drive in, drive out’ services, such as those which visit once a month, or a few times a year, with no local workforce assisting the strategies and supports alongside families in rural areas.

Providing support in an ad-hoc manner is not an approach that builds trust and relationships, which are essential to underpin the fundamental principles of family centred partnership and effective early childhood developmental support. The current ‘drive in, drive out’ model is counter-productive to the way in which children learn and develop. Therefore, services need to work through existing networks.

Some First Nation people of Anangu asked for additional specialist and therapeutic services, and many workers noted the lack of these services and the need to make them available regularly and in a culturally appropriate way. Specialist and therapeutic supports are necessary to maximise the development of children with disabilities and to allow them to participate as fully as possible in community life. There were limited Early Childhood Early Intervention (ECEI) services. Many children did not have a diagnosis for their disability, a situation exacerbated by the lack of culturally appropriate assessment tools. All services need to operate in a way that aligns with Anangu cultural expectations.¹⁴

“ I have four kids, three of which have an NDIS plan. I tried to get all the plans on the same day, and they said this was impossible. Then, once I had the plans, I wasn't able to get any support workers to help me whilst I popped to the shops, or even stayed home and did the washing, unless I got three support workers at the same time, drawing down on the three separate plans of my children.



WHAT FAMILIES EXPERIENCE

Language barrier: Professional language, acronyms and jargon, such as 'ECI', not making sense to families, as well as the word 'intervention' being associated with negative connotations for some families.

Low prioritisation: Many families are struggling day-to-day to simply meet the basic needs of their family. Therapeutic and specialised supports are recognised as important but not the main priority of the family.

Mixed messaging: Inconsistent messaging and processes around new referral pathways and NDIS' Early Childhood Early Intervention (ECEI) pathway support nationally.

Limited understanding: Lack of knowledge around ages and stages for children, resulting in delays of identification.

Lack of support: Families experience a lack of support due to the absence of an early childhood development support workforce, such as local community facilitators to provide on the ground support, for example the facilitation of appointments.

Long wait times: Large gaps in time between 'drive in, drive out' visits in remote or underserved areas. Lengthy waiting times for paediatricians and other specialist services, significantly impacts on early childhood service delivery time.

Disconnection from service design: Families and communities feel removed from service design and implementation, having services 'do to' them rather than work in partnership.

“ Everything they do is therapy. If there's no teaching us (parents) in therapy, what's the point? ”

KEY SECTOR CONCERNS

Language: Early childhood development terminology is more aligned with the medical model of disability rather than the social model of disability.

Medical Model vs Best Practice: The unintended consequence of the implementation of the NDIS ECEI approach during the NDIS transition period has been the erosion of outcomes for children with additional needs in their crucial early years, through the promotion of a medical-based model.

Pervasive inequality: The elimination of the persistent and pervasive inequalities of supporting Aboriginal and Torres Strait Islander children must be made a key national priority, building on existing examples of good practice.

Vulnerability at school entry: One in five (21.7%) Australian children start school developmentally vulnerable. This figure doubles for Indigenous children.¹⁵

Targeted commissioning is required: The role of commissioning of services and supports should be considered in rural and remote areas as a priority. Building on local organisations and initiatives that work effectively to support children and families, rather than a market-based approach is required. Commissioning should be considered across rural and remote areas.¹⁶

KEY FINDINGS

Knowledge gap: Early childhood developmental support and the evidence of its effectiveness is not widely understood by caregivers.

System design limitation: Individualised funding alone is not sufficient to build a fully inclusive, holistic well-resourced innovative early childhood support system.

Complexity is a barrier: We know that the caregiver's journey is complex and overwhelming. The need for an independent body to assist parents to navigate and simplify their journey is clear.

Community supports have been eroded: Pre-NDIS family capacity-building community supports, essential to an evidence-based best practice approach, have disappeared under a system that promotes a therapy-based model. This is further exacerbated by the challenges of the NDIS interface with mainstream services and provider organisations.¹⁷

Culturally inappropriate implementation: Services for Aboriginal families are not shaped by Indigenous knowledge and worldview resulting in culturally inappropriate design and implementation.

Language barriers: Professional language, acronyms and jargon, including terms used in the access and planning process for the NDIS, often do not make sense to families. This includes terms such as 'early intervention', 'reasonable and necessary'.

Lack of trust: Aboriginal Torres Strait Islander people and people from Culturally and Linguistically Diverse backgrounds outlined there can be distrust of authorities, and more time is needed to build trusting and collaborative relationships.

Invest in co-design: More investment in co-design with culturally diverse communities to better understand what supports they need and want, and what current assets can be built on and resourced is required. Currently there are limited initiatives and pilots of alternate service models.

“

All along I'm saying the same thing, but no one is listening. They think his speech is the focus but I'm saying that's not a priority for us and his behaviour is the priority. Keeping him safe is the priority.

”

It is not on my bucket list to go on the NDIS. On my bucket list is NOT being on the NDIS!

ACTIONS

PRIORITY AREA	<p>1 Empowered & Resourced Caregivers must be empowered with information, resources and choice, to support the development and wellbeing of their whole family.</p> <p>Recommendation: Establish an easy to navigate pathway for families to access early childhood development supports and information from the beginning of the family journey. Pathways guide families through mainstream and other systems, and have a 'no wrong door approach'.</p>
ACTION ONE	Broad consultation with families to further map barriers, pain points and unnecessary duplication to inform decisions about how to simplify processes and support families to navigate within and between systems.
ACTION TWO	Periodically review the National Guidelines for Early Childhood Intervention, based on latest evidence.
ACTION THREE	Develop targeted tools and communications to help families understand and apply best practice.
ACTION FOUR	Consider designing 'community mapping' approaches that communities can use to identify local needs, strengths and opportunities that can be incorporated into the delivery of early childhood intervention within communities.

MEANINGFUL PARTICIPATION

Children with disability and their families meaningfully participate in their networks, communities, learning and work environments.

Meaningful Participation Recommendation:

Individualised funding must be complemented by a whole range of evidence-based supports in order to build a fully inclusive, holistic and well-resourced innovative early childhood support system.

Children with disability and their families are excluded from their communities, networks and the universal/mainstream services at alarming rates.¹⁸ The Reimagine consultation findings reinforced the existing evidence of the exclusion of children and families from schools, community groups and services.¹⁹

Sollis (2019) found that while generally engaged and included in the family and home environment, children with disability are more likely to be experiencing significant social exclusion both at school and in the community. They are three times more likely to lack relationships with friends, and around two times more likely to have mental health concerns than their typically developing peers.²⁰

Attitudes and beliefs of the community, and the assumptions people hold about ability, potential, learning and inclusion are major barriers for children with disabilities and their families to achieve their goals.

One in five (21.7%) Australian children start school developmentally vulnerable. This figure doubles for Indigenous children.²¹ Further, four-year-old children living in very remote areas of Australia are more than twice as likely as those from major cities to be developmentally vulnerable.²² The elimination of the persistent and pervasive inequalities of supporting Aboriginal and Torres Strait Islander children must be made a key national priority.

Current system design isolates and promotes individualised therapy over best practice which has significantly contributed to the association and misinformation nationally that early childhood developmental support is primarily therapy.

Further, the inclusion mandate from universal services has been compromised with the introduction of the NDIS.²³ Children with disability and/or developmental delay are now being viewed as an NDIS 'problem'.

When families of young children with disabilities have a concern about their child and seek help from the early childhood development support sector, they are likely to be in a state of some distress and disorientation. They will be unfamiliar with the service system and uncertain of their role in relation to professionals. They also lack confidence in their own abilities to help the child and tend to defer to the knowledge of professionals.

Schools, health services, early childhood services and other services that families interact with must have the capability to identify concerns early and/or provide meaningful support to families and their children, to ensure they feel connected, included and are participating under an integrated and streamlined framework.

“A disability is looked at like a disease to be treated versus an aspect of being a human being. We need to go back to basics - to be treated as humans.”

Whilst individualised therapy is a large component of early childhood developmental supports, there are a multitude of other supports and services that are fundamental and complementary to facilitate meaningful participation and inclusion. The erosion of these non-therapy supports have inadvertently contributed to the segregation of children with additional needs, rather than ensuring that the starting place for all children should be to strengthen their participation and experience in their natural settings.

A re-allocation and reprioritisation of investment is required to allow opportunities for families to build up support in their lives so that sustainability, learning, nurturing and participation can occur. This rebalance must involve looking at alternative ways of investing in localised community support and core support for children, rather than a heavy focus on therapeutic support.

The current approach, in particular the NDIS ECEI pathway, has inadvertently stripped away community centred services. Evidence shows that a best practice approach includes both individualised therapy supports and community focused supports, such as playgroups, peer-led supports, drop-in parent groups and social skills groups.²⁴

The Action Plan's consultation process identified the importance of effective parent-to-parent peer support, both for families in similar circumstances, and for early childhood development teams. Families reported that through parent-to parent peer support they felt emotionally supported, empowered to navigate complexity, and that they felt understood. These connections increase a sense of belonging, can minimise isolation and overwhelm and guide families beyond a survival mindset to a thriving mindset on their journey with disability.²⁵

Further, peer-to-peer support provided families with opportunities to learn and develop new knowledge and skills relating to parenting. Further promotion and support of developing a peer-led workforce to support families on their journey is required.

Examples of parent-to-parent²⁶ support include:

- Parent groups that may be led by parents or service provider led.
- Peer workers as key members of early childhood development teams.
- Programs designed to match parents together as formalised support.
- Parents volunteering to be a resource to each other.

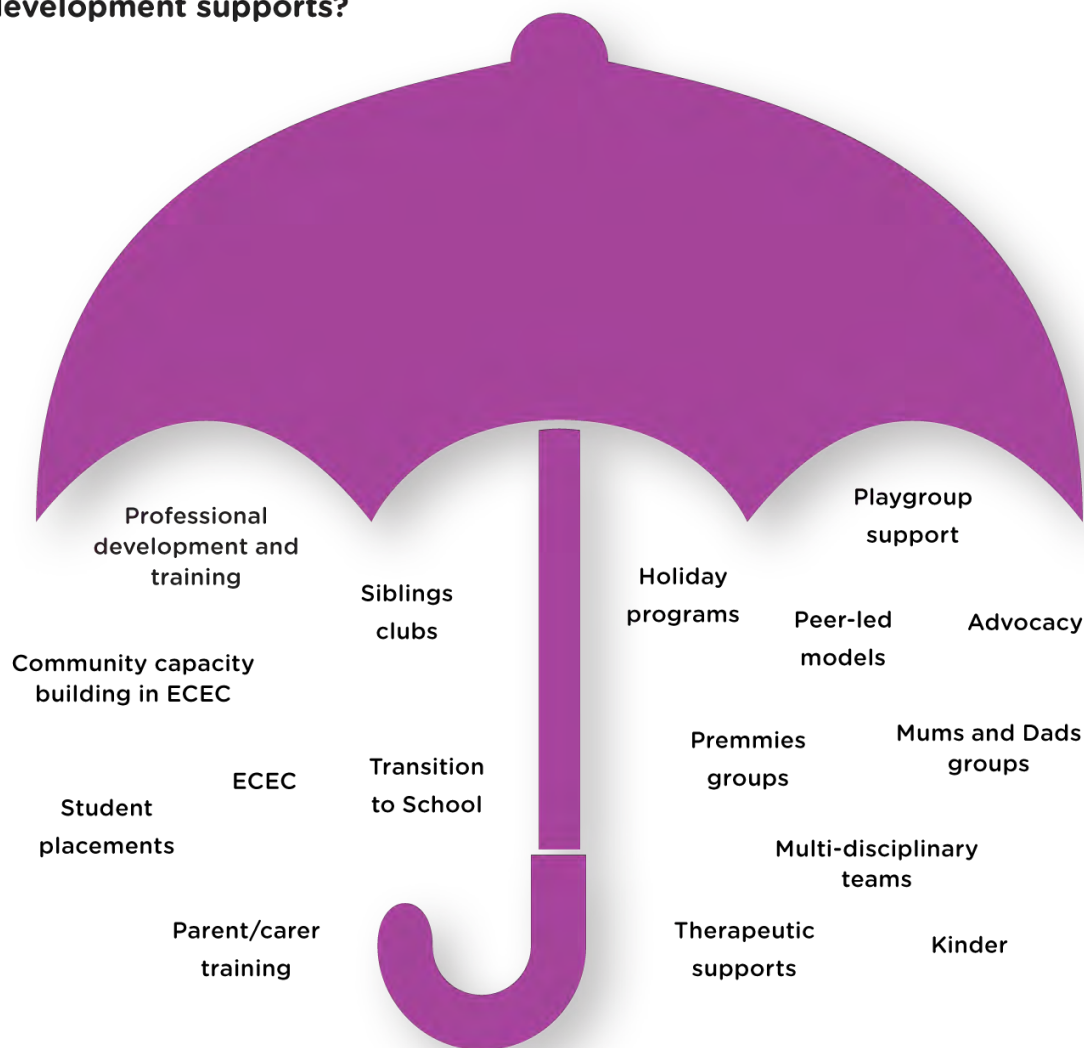
Umbrella of Services

Successful early childhood development is comprised of early childhood development specialists delivering and supporting an umbrella of services

“ *Peer support wasn't just about having a therapy session a week. It's about me learning, not my child and it is learning that what we do at home that matters.*

The fundamental complementary components illustrated below are evidenced to foster meaningful participation in community settings or within group settings and build connection, community and engagement for the whole family.²⁷ These evidence-based early childhood development practices work in partnership and through mainstream services such as early childhood education and care and health settings, community groups and services both universal and targeted such as supported playgroups and active outreach services.

What makes up the umbrella of early childhood development supports?





WHAT FAMILIES EXPERIENCE

Desire for meaningful inclusion: The driver for meaningful participation and inclusion rests on the attitudes, beliefs and actions of communities.

Families have shared common experiences of feeling excluded from their local community: as well the erosion of their family, kinship and informal networks.

KEY SECTOR CONCERNS

Inclusion agenda stalled: Children with disabilities are among the world's most stigmatised and excluded children.

Erosion of community equals erosion of outcomes: The strength of informal support for the family is a better predictor of child outcomes than the strength of formal supports. With the erosion of community-centred supports under the NDIS, we have seen an erosion in outcomes for children nationally.

Families receive little respite: Respite improves the capacity of families and carers to provide quality care and capacity building support to their child and is necessary for the sustainability of families. It is both reasonable and necessary to provide families access to supports in the home and other forms of respite.

KEY FINDINGS

Exclusion: Children with disability and their families are often excluded from their communities, networks and universal and/or mainstream services. Many families have shared common experiences of feeling excluded from their local community, as well the erosion of their family, kinship and informal networks.

Supports beyond 'therapy'/individualised funding: Many families struggle day-to-day to meet the basic needs of their family. Therapeutic and specialised supports are recognised as important but not the main priority for many families. Many families reflected that an individual funding model alone through the NDIS has built up a transactional service system (rather than support based on sustained relationships with providers and support people). This has led to poorer outcomes.²⁸

The introduction of the NDIS approach has inadvertently impacted the delivery of informal and community-centred services: Evidence shows a best practice approach includes both individualised therapy supports and community focused supports, such as playgroups, peer-led supports, drop-in parent groups, social skills groups etc. The strength of informal support for the family is considered to be a better predictor of child outcomes than the strength of formal supports.²⁹

Institutionalisation: The Australian early childhood support system was developed in parallel to the system of institutionalisation. Children with disability were not initially considered in the design of early childhood development support, the system was built with children who had disabilities out of sight. Since the closure of institutions, the early childhood service system has attempted to retrofit the traditional system in order to work for children with disability.

Chronic lack of focused funding investment: A rebalancing of investment is required. All levels of government need to give consideration to the funding of early childhood developmental supports, as a priority, particularly in jurisdictions where there is currently no specifically quarantined or allocated funds. The Information Linkages and Capacity Building grant program is one area where increased funding support for early childhood development projects and initiatives could be considered. Other future funding opportunities may include community capacity building and inclusion grants across all jurisdictions, as well as more targeted investment for early childhood developmental supports through the funding and delivery of maternal and child health systems and early childhood education and care, which are primarily the responsibility of state and territory governments.

ACTIONS

PRIORITY AREA

2

Meaningful Participation

Children with disability and their families meaningfully participate in their networks, communities, learning and work environments.

Recommendation:

Individualised funding must be complemented by a whole range of evidence-based supports in order to build a fully inclusive, holistic, well-resourced and innovative early childhood support system.

ACTION ONE

Service gap analysis to provide a clear picture of Australia's current service and support landscape for families. Analysis against evidence on the best practice suite/umbrella of supports for early childhood intervention will help identify gaps to support Government decision making around commission services and supports.

ACTION TWO

Identify and promote examples of existing best practice, having regard to existing and emerging evidence (and opportunities to scale).

ACTION THREE

Develop tools to help providers/professionals self-assess their understanding of, and self-audit their adherence to, best practice and reflect on whether they are driving quality outcomes for their client families/children.

ACTION FOUR

NDIS ECEI approach to link with service systems outside the NDIS and allow flexibility for telepractice as direct service delivery.



SEAMLESS AND INTEGRATED

An early childhood development ecosystem for all children, where systems and services work in an integrated and holistic way to support children and their families.

Seamless and Integrated Recommendation:

Implement a family navigator service that sits within the universal service system, to be the main point of contact from the very beginning for all families of children with developmental vulnerability or concern.

Australia's early childhood system is a complex landscape. For children with additional needs and their families this period of their lives is often described as confronting, difficult and confusing, with no less than 10 service systems to coordinate and navigate.³⁰

As a whole, and despite the strength and efforts of organisations and individuals operating in the early childhood development space nationally, the fragmented systems that caregivers must navigate has amplified stress for families and frustrated outcomes for them and their children.

Navigating a new service system is intensely difficult. Families trying to find their way often describe feeling overwhelmed and frustrated. Through the Action Plan consultation process, we heard that families feel further burdened by the expectation that they come to government service systems fully equipped to make informed decisions. Families find themselves at a disadvantage when they are expected to understand and then nominate what kind of support they or their child need.

When families of young children with disabilities have a concern about their child and seek help from the early childhood development support sector, they are likely to be in a state of some distress and disorientation. They will be unfamiliar with the service system and when you layer this level of complexity, heightened stress and disorientation with the need to interact with several separate service systems at once, the pressure and demand on families is exponentially increased.

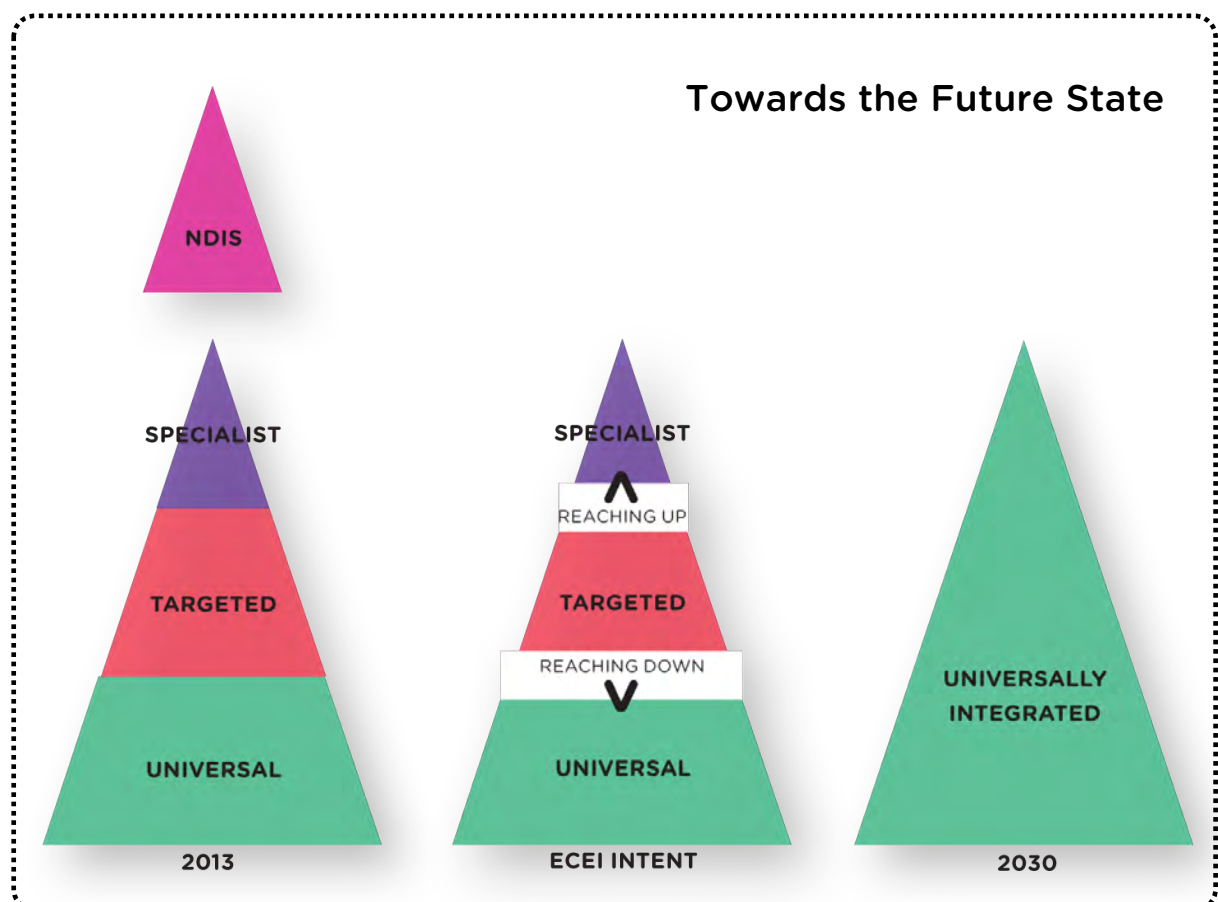
Children and families cannot thrive, build capacity and achieve optimal outcomes in the current service system framework. Integrated governance arrangements must be prioritised, including collaborative forums with all levels of government, families and the sector. These arrangements should be underpinned by principles of shared responsibility and accountability for policy, planning, implementation and evaluation. The Action Plan calls for a strengthening of the current nationally-consistent arrangements, anchored in the universal service system, with clear points of contact from the very beginning, to support all families of children with developmental vulnerability or concern.

The current service system environment and how it interacts with families requires reimagining. This new environment should be designed as an all-encompassing early childhood development system. It should support, guide and develop the capabilities, quality and service models of the early childhood development sector, working to support children and their families achieve optimal outcomes in the child's early years.

The Future State

Ensuring that the foundations are solid in Australia for children and their families with disability to have opportunities to connect and engage in their local community, including the universal service system is paramount.

These foundations need to be strong before an effective targeted system of support can be built on top. An integrated system is required to correct the segregation of children who largely access the top tier of support rather than being fully engaged and participating in all tiers.





The Australian early childhood support system was developed in parallel to the system of institutionalisation. To align with international evidence, early childhood developmental supports should be viewed through an all-encompassing early childhood development system for children and their families. The tiered model would have seamless integration and investment in a whole range of support and services from universal through to specialised. The NDIS has inadvertently segregated specialised support from the universal service system.³¹

It is vital that early childhood development is reclaimed from being seen largely through the NDIS lens, within a reimagined, all-encompassing and strengths-based 'early childhood development' system.

For the purposes of the Action Plan, we have drawn on the tiered model of public health, as a framework to guide the future state of the early childhood and specialist support system for families and children with a developmental delay and/or disability from 2020 to 2030. (See diagram on previous page)

“ The NDIS feels like an impossible gated city, they open it for the planning meeting but the door never opens again. Nobody has an understanding of early childhood disability.

“ The NDIS wants reports, but we don't have funding for it. The specialist is \$200 to \$300 each time and not covered by NDIS. We are threatened with loss of funding if we don't provide it

“ The whole system is a constant fight that you shouldn't have to have.

Service isolation, disconnect, bottlenecks and confusion: Isolated service systems with no thread between them are challenging for families to navigate. Families report significant service system gaps, that result in them feeling lost. For example, the NDIS, health, education and child protection systems often operate in isolation from one another, each with 'set responsibility' rather than 'shared responsibility'. Multilayered systemic bottlenecks from access and eligibility, to assessment and service delivery across and within systems.

Navigation fatigue, complexity and overwhelm: Too many systems that are interfacing with each other on local, State and Commonwealth levels, with no coherent shared planning model or integrated governance in place.

“ By the time help was provided, we were so burnt out.

Lack of system integration: Early childhood supports cannot be delivered in isolation by the National Disability Insurance Agency (NDIA), Social Services, Health or Education departments. Integrated governance arrangements must be prioritised, including collaborative forums with all levels of government, families and the sector. These arrangements should be underpinned by principles of shared responsibility and accountability for policy, planning, implementation and evaluation

Segregation: The NDIS has inadvertently segregated specialised support from the universal service system.

Flawed system design: The Australian early childhood support system was developed in parallel to the system of institutionalisation. Children with disability were not initially considered in the design of early childhood development support, the system was built with children who had disabilities out of sight. Since the closure of institutions, the early childhood service system has attempted to retrofit the traditional system in order to work for children with disability.

KEY FINDINGS

There is a need to establish one all-encompassing early childhood development system: This 'system' must be viewed through an early childhood development lens, instead of through the disability lens.

Service isolation, disconnect, bottlenecks and confusion: The current system is geared toward waiting for more concerns to show to prove eligibility, rather than receiving support straight away. Early childhood supports cannot be delivered in isolation by the NDIA, Social Services, Health or Education and the gaps between these should be as minimal as possible. Fully integrated governance arrangements, including collaborative forums with all levels of government, driven and overseen by a responsible governance mechanism is required.

Early Childhood Partner (EC Partner) Approach requires resetting: The EC Partner function is largely inconsistent. The original vision was for the EC Partner approach to be a 'pathway' for families, not the 'gateway' that it has become.

Family Navigator Service required: Families are calling for a single point of contact that they can approach for advice, information and support in relation to concerns they may have about their child's development, or recently identified/diagnosed disability. Support to identify, connect with and navigate the various services and supports they need to access across systems (health, education, disability/NDIS) is required.

Institutionalisation: Australia has not yet deinstitutionalised its systems, services and community mindsets. The current fragmented service system, post-NDIS implementations, has unintentionally segregated children. Moving the current tiered model to the future state model would provide for seamless integration and investment in a whole range of support and services from universal through to specialised.

The focus has shifted from 'early childhood development' to 'disability' under the NDIS: The shift from an early childhood lens in some states and territories to being retrofitted into an adult-centric NDIS system, has seen a wholesale erosion of the early childhood system, early childhood policy and indeed, outcomes for families and their children. It is vital that the governments rehome early childhood development, within a reimagined, all-encompassing and strengths-based 'early childhood development' system.

No North Star: There is currently no shared vision and strategy between government, families and the sector. The sector is looking to the governments to establish, resource and support a clear path to ensure the best outcomes are realised for children with a developmental delay and/or disability and their families.

ACTIONS

PRIORITY AREA

3 Seamless and Integrated
An Early Childhood Development ecosystem for all children, where systems and services work in an integrated and holistic way to support children and their families.

Recommendation:

Implement a family navigator service that sits within the universal service system, to be the main point of contact from the very beginning for all families of children with developmental vulnerability or concern.

ACTION ONE

Build the evidence base on the role and effectiveness of 'community hub' and 'navigator' omni-channel services in providing wrap around supports to help families to navigate service systems across local, state and federal jurisdictions.

ACTION TWO

Co-design with families an online information portal that brings together consistent and accurate messaging and acts as a clear single point of contact for all families who have questions or concerns about their child's development. Info delivered in a variety of accessible ways (including 1800 number) and links families to more targeted/intensive supports that meet their needs.

ACTION THREE

Clarify and enhance the role of the ECEI approach for families – ECEI partners reach out to families and, where required, families are connected to immediate family-centred supports outside an NDIS plan.

RESPONSIVE AND RELATIONAL

Families of children with developmental delay and/or disability receive early childhood support as soon as they require, with or without diagnosis.

Responsive and Relational Recommendation:

Develop an integrated national screening and response capability across all government systems that interact with children and their families, to ensure that all systems operate in a responsive way to support early intervention and prevention.

Australia does not currently have a responsive early childhood developmental support & prevention system. Despite the strength and efforts of organisations and individuals operating in the early childhood development space nationally, the implementation of timely early childhood supports across Australia is not being realised. Families need the “right support at the right time” and that support needs to be enduring.

The support systems across health, education and community services are skewed to acute and crisis support (80% investment), rather than early support and prevention (20%) investment. The cost of late action in Australia is estimated at \$15.2 billion.³²

A strong influence on children not receiving support as soon as possible are the multiple bottlenecks, complex navigation to access help and a ‘tick-box’ culture of eligibility, which are causing significant delays in accessing support for specialised services. There are significant waiting times for appointments with paediatricians, specialists and services, which are reported to be up to and beyond 12 months.

This is compounded by a ‘wait and see’ culture surrounding early childhood development in Australia.

The ‘wait and see’ culture is a complex, multilayered issue to address, however the Action Plan consultations identified key factors which have significantly impacted on the provenance of this culture.

“ I want real people who are engaged who are listening, and who see my son for who he is. And, I want people who want to work together.

There exists a poor understanding across communities nationally, and in the early childhood field, of developmental ‘ages and stages’ for children. A greater understanding by parents and caregivers of how children develop over time may positively change the culture of uncertainty and waiting for more concerns to show.

‘Wait and see’ culture is exacerbated by the systems families interact with, where there is a heavy focus on waiting for signs of delay or disability to increase enough for diagnosis or more ‘proof’. A deeper understanding of childhood development and the importance of early childhood support is required across all systems that intersect with developmentally vulnerable children.

Across Australia, families are reporting confusion regarding eligibility requirements to access supports under an NDIS plan. This includes a lack of understanding that diagnosis is no longer a requirement for children under 6 years of age to access support. Families can receive help and assistance under the NDIS ECEI pathway without an NDIS plan. Yet, there is still a strong emphasis on seeking diagnosis first and then seeking help later.

A greater shared understanding across all systems that interact with families and children is required, which emphasises that all children develop, and that some children require additional support for their development. Normalising development, differences in development and neurodiversity may positively impact a shift in culture towards seeking help.

Further, there is no national consistency around screening tools and identifiers in the early years, embedded within universal services. A nationally-consistent approach could help to relieve the upward pressure on the numbers of children presenting at school with developmental concerns that should have been identified prior to school commencement.

The universal early childhood development support system is fundamentally geared toward waiting for more concerns to present in order to prove eligibility for supports, rather than receiving support straight away. The strong emphasis on seeking diagnosis first and then seeking help later is contrary to the best practice approach of the NDIS ECEI approach and is frustrating early intervention and prevention.

The lack of coordination and integration between jurisdictions and service systems, addressed in Priority Area 3 of this document, has amplified and further frustrated the ability to provide a timely response for families and their children. An example of this is the delays that families experience in accessing screening and securing identification, for which responsibility rests with States and Territories. Revision is required through the lens of a nationally coordinated approach, to ensure consistency of developmental screening tools.



WHAT FAMILIES EXPERIENCE

Endemic and significant waiting times: Significant waiting times for appointments with paediatricians, specialists and services are an endemic barrier for families to access advice and support.

Wait and see culture: A 'wait and see' culture in Australia is woven into community and professional mindsets resulting in delays to children accessing early help.

No one central coordinator: There is no 'go to' person or service for support and guidance. Families work with multiple professionals who do not communicate with one another.

“ The referral process was a pain. There aren't enough paediatricians and child psychologists who can diagnose. It's a long wait”.

[After being referred to a particular paediatrician, with whom they went back and forth with and needed to wait for 6 months.]

“ If the NDIS is not currently guiding early childhood policy, then who is guiding it?

Medical Terminology: Terminology used is more aligned with the medical model of disability rather than the social model.

Poor messaging regarding access to the ECEI pathway: EC Partners, key referrers and families largely not aware diagnosis is not necessary to access the ECEI pathway under the NDIS.

EC Partner inconsistency: EC Partner function is largely inconsistent and its purpose has been redefined as a 'gateway' rather than a pathway, as the original partner vision set out.

Lost time: The current approach is littered with bottlenecks, barriers and delay. The needs of young children must be met by a responsive and flexible system that recognises that the child is constantly developing and changing in their early years.

Trust building: Aboriginal and Torres Strait Islander people and people from Culturally and Linguistically Diverse backgrounds outlined that there can be a distrust of authorities, and that more time is needed to build trusting and collaborative relationships, particularly with local organisations, leaders and role models, before moving on to more formal discussions around access and planning processes. ³³

KEY SECTOR CONCERNS

KEY FINDINGS

Unresponsive system: Multiple bottlenecks and a ‘tick-box’ culture of eligibility are causing significant delays in accessing support for specialised services. The early childhood development system is geared toward waiting for more concerns to show to prove eligibility rather receiving support straight away.

Lack of investment: Support systems across health, education and community services are skewed towards crisis management rather than prevention and support. A rebalancing is required.

Lack of national coordination and shared responsibility: Screening and identification of developmental delay is the responsibility of States, which results in different approaches and experiences for families across jurisdictions. There needs to be greater consistency reached with developmental screening tools.

Wait and see culture: The emergence of the ‘wait and see’ culture is significantly frustrating the ability for prevention and early support to thrive.

The ‘first you gain diagnosis, then you access support’ myth: The strong emphasis on seeking diagnosis first and then seeking help later is contrary to the best practice approach of the NDIS ECEI approach and is frustrating the ability for children and their families to benefit from early childhood support and prevention.

“ *You can’t get started without a diagnosis and can’t get one until 12 months. You get a referral to a specialist to get a letter, a signature on a tick box with 9 months wait. And, if you lose that one piece of paper you can’t get funding.* ”

“ *[On trying to find a doctor that understands Down’s syndrome] They give the impression the child’s not worthy of treatment.* ”



ACTIONS

PRIORITY AREA

4 Responsive and Relational
Families of children with developmental delay and/or disability receive early childhood support as soon as they require, with or without diagnosis.

Recommendation:
Develop an integrated national screening and response capability across all government systems that interact with children and their families, to ensure that all systems operate in a responsive way to support early intervention and prevention.

ACTION ONE

Introduce a nationally consistent developmental screening approach for inclusive universal health checks, based on a stocktake to understand current approaches used in various jurisdictions and builds on existing effective screening approaches.

ACTION TWO

Build awareness in relevant mainstream settings around child development 'Ages and Stages', aligning with 1000/2000 days policy framework, so that developmental concerns can be identified, and acted upon, at the earliest possible stage in all settings (tools/training?)

CAPABILITIES AND QUALITY

Australia has a skilled, collaborative and diverse workforce that deliver a range of evidence based developmental supports.

Capabilities and Quality Recommendation:

Develop a comprehensive workforce strategy that addresses capability, quality and workforce supply.

The specialist early childhood development workforce is currently in crisis.

The Action Plan consultations identified key impediments to achieving a high-calibre, well-resourced and growing early childhood development workforce that best supports families and children. Our consultation found a lack of national consistency, with vastly different approaches to early childhood development service delivery, within and across states and territories. This inconsistency is underpinned by persistent workforce supply and quality issues across Australia, which is significantly magnified for regional, rural, remote and very remote communities.

The fundamental complementary components of early childhood developmental supports (illustrated in 'The Umbrella of Services' section on page 24) are evidenced to build connection, community and engagement for the whole family in partnership with early childhood education and care settings, key referral agencies and soft entry points. Historically early childhood educators, teachers, peer-led models, health assistants, and family support workers have all been a part of early development support. A successful workforce strategy needs to reflect this diversity and combat the current intensive focus on the allied health workforce.

The shift to individualised therapy-focus and misinformation as to what families require to reach strong outcomes, has resulted in these positions no longer being viable to fund and become redundant. Allied health disciplines are now privileged as the sole workforce delivering early childhood developmental supports, which is incentivised through individualised therapy funding. This is resulting in significant demand, limited supply, waitlists, workforce recruitment and retention challenges and quality issues, which is significantly magnified for regional, rural, remote and very remote communities.



A well-resourced and fertile early childhood development support market requires a whole range of supports, including therapy, to be present. The consultations found that there is no 'one size fits all' approach for the successful delivery of early childhood services across all tiers of support in all communities. These supports work in concert to strengthen, educate, connect and support the whole family and child. Not all of these services will be delivered by specific early childhood developmental support providers. Many organisations and local councils offer components of early childhood developmental support in their communities.

Additionally, with the NDIA, EC Partners, health, education and aged care sectors are all currently pulling from the same Allied Health workforce, which is placing this particular workforce under unsustainable pressure.

Further, it is evident that the lack of clarification and coordination of the roles of the different government agencies involved in market stewardship has played a key role in exacerbating the workforce crisis. This further strengthens and reinforces the requirement of establishing an authority with a mandate to coordinate the specialist early childhood sector nationally, which is outlined in Priority Area 3: Seamless and Integrated.

“ Our daycare provider is scared to offend parents and they don't have an idea how to express concerns if there is a development or learning need. They really should have told us what was going on when they held concerns for six months that our child might be on the spectrum. They see kids in social context and how they react to changes and transitions.

The strategic approach required to address the current workforce crisis across the early childhood developmental support sector must include a multitude of cohesive solutions, such as:

- targeted commissioning in thin markets where other national workforce strategies may have less of an effect;
- improving workforce capability, building on frameworks in development by the NDIA and NDIS Quality and Safeguards Commission – with a clear approach to implementation for the early childhood development workforce;
- the development of communities of practice to create opportunities for collaboration, partnership, cross pollination of practice and the sharing of resources, and;
- investment in tertiary education and professional development.

Collaboration must be prioritised. The Action Plan consultation process observed several strong partnerships, integrated models, co-located, place-based and hub models across Australia. Yet, there is no avenue for the sector to collaborate and cross pollinate ideas.

The individualised funding model does not incentivise organisations to build networks, collaborate and learn from each other as they have historically. Best Practice Principles outline evidence and the 'why', but do not guide practitioners on the 'how'. States and territories all work differently. With a changing workforce, a nationally-consistent guide on good practice under the NDIS and in the sector more broadly is necessary.

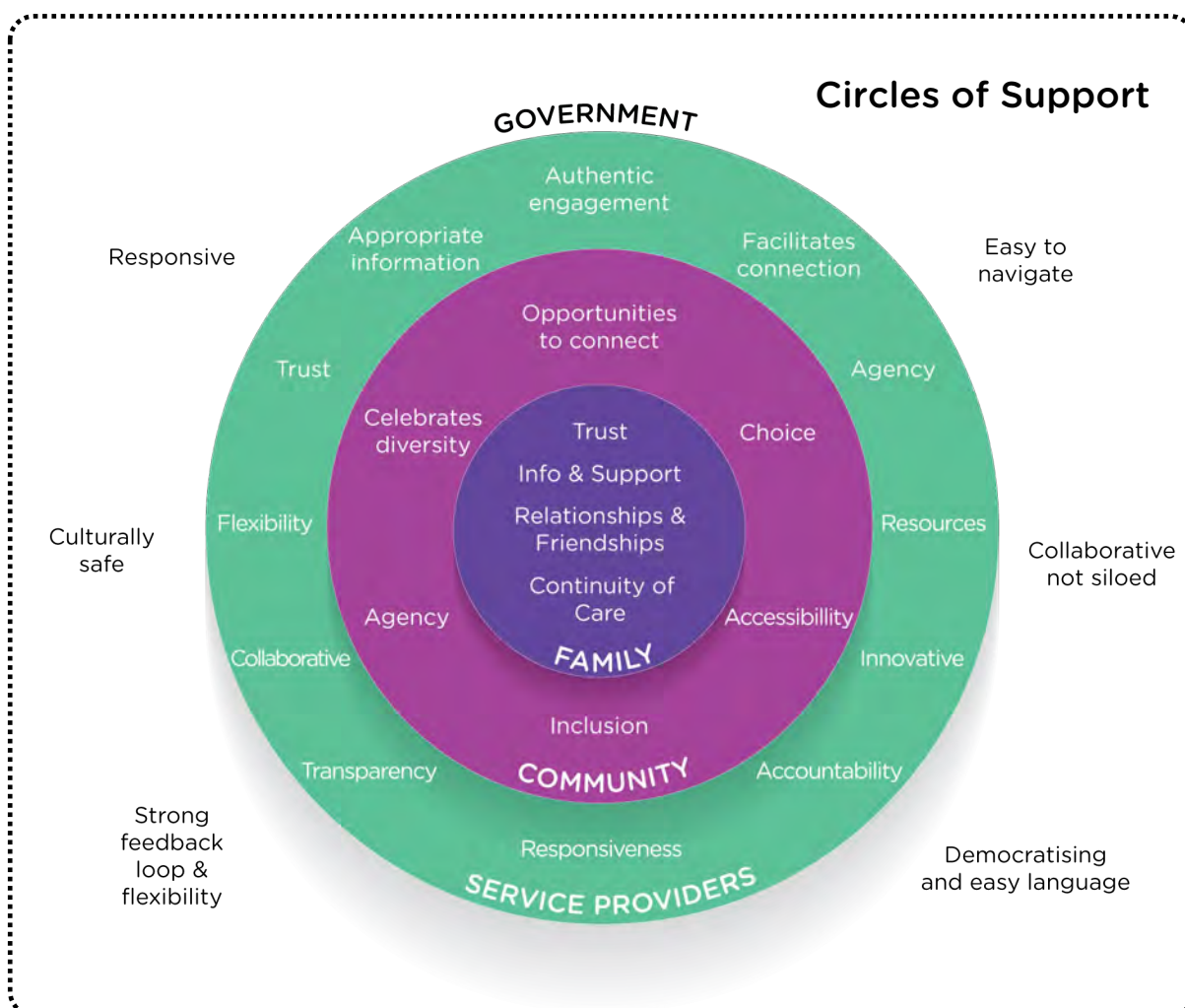
Circles of Support (What families need)

The 'circles of support' diagram was developed with families through the consultation process to highlight what families require to be fully supported to achieve the best outcomes for their child and their family.

The strength of informal support for the family is a better predictor of child outcomes than the strength of formal support. With the erosion of community-centred support under the NDIS, we have seen an erosion in outcomes for children nationally.³⁴

The consultations identified the more complex the needs of the child and family, the more professionals are often involved. This creates an imbalance, building up the outer 'circle of support' for a family, instead of strengthening the inner circle of family life. We are witnessing an erosion of family, kinship, informal networks and inclusion.

The Action Plan consultations found that the dominant funding model (the NDIS), has inadvertently built up the outer circle of service provision for a family. A re-balancing is required to allow families opportunities to build up the inner 'circles of support' in their lives so that sustainability, learning, nurturing and participation can occur.



WHAT FAMILIES EXPERIENCE

No familiarity with best practice in action: Families have limited information around best practice and how this looks in action.

Inconsistent service approaches and “fix” focused messaging: Vastly different approaches to early childhood support service delivery across Australia, different within **states and across states**. **Providers marketing services that promise to ‘fix’ children** is swaying parent choice, often away from best practice.

Substitution of therapy for respite: Families report feeling exhausted and wanting the focus to be on services working with children not with the parent. For families accessing the NDIS ECEI pathway, this is more a result of the models of support they are receiving, than the funding itself. Therapy can be seen as a time for a break for parents who are unable to access what they require through core supports.

Service wait times: Considerable waiting times for services post planning.

KEY SECTOR CONCERNS

Appropriate workforce strategy is required: The workforce pendulum needs to swing back from only allied health to once again supporting a diverse workforce that includes early childhood educators, teachers, peer-led models, health assistants, family support workers.

No shared language: Lack of shared language between early childhood development practitioners and early childhood education and care professionals.

Competing policies at play: Many families have competing priorities. Policies that promote parents returning to the workforce as a priority, can at times be in conflict with parents being active participants in their child’s development.

Framework required to build service provider capability and quality: At present there is porous overview of the quality of services being provided through NDIS funding. The current framework provides overview of registered providers only, which does not provide an accurate reflection of the quality of the market as a whole. Providers who are not registered are not asked to show that they are delivering services in ways that are consistent with best practice. An all-encompassing early childhood capability framework, which is not dependent upon NDIS registration, is required. This could build on the NDIS Workforce Plan and the NDIS Workforce Capability Framework, which are currently in development in consultation with NDIS providers and participants including early childhood development service providers. Once released, there may be opportunity to consider targeted implementation to drive improvements in quality and capability across the early childhood development sector.

Safeguarding best practice: The Action Plan consultations raised significant concerns from the sector around the quality and safeguard mechanisms, which were supported in stories from families who were trying to navigate the maze of best practice.

Early childhood support is more than just the NDIS ECEI approach: The perception that responsibility for early childhood development sits solely in the NDIS ECEI approach and within an individualised funding model, is frustrating outcomes. It is necessary to improve the capacity of all systems that engage with developmentally vulnerable children to adjust and respond to the needs of those children and their families.

Re-evaluation of current service delivery responses: Re-evaluation of current models being trialled and/or rolled out across rural and remote areas, such as telepractice which has traditionally had limited uptake, to ensure that the needs of the community are being met through the responses that government are investing in. There is emerging evidence that the adoption of telepractice as a delivery of service has increased significantly during COVID-19, with providers moving to online practice and supporting families to access technology during this process. Further investigation is required to better understand how these changing models have impacted on families unable to access in person services.

KEY FINDINGS

Diversity of approach is required: The Action Plan consultations found that there is no 'one size fits all' approach for the successful delivery of early childhood services across all tiers of support in all communities. Collaboration must be prioritised. The Action Plan recommends the sector interrogate their service models in new ways, using creative tools to map principles of practice against the operationalisation of their service models to celebrate, innovate and drive quality practice.

No national consensus: The orientation of all service models to the NDIS has meant that there has been no consensus nationally about what families, early childhood development practitioners or early childhood education and care professionals are working towards. Approaches and models of early childhood supports differ across and within states and territories. Some providers market services that promise 'quick fixes', which can sway parent choice and have dangerous or damaging outcomes.

Practical tools are required: Best Practice Principles outline evidence and the 'why', but do not guide practitioners on the 'how'. Families reported having limited information around best practice and how this looks in action.

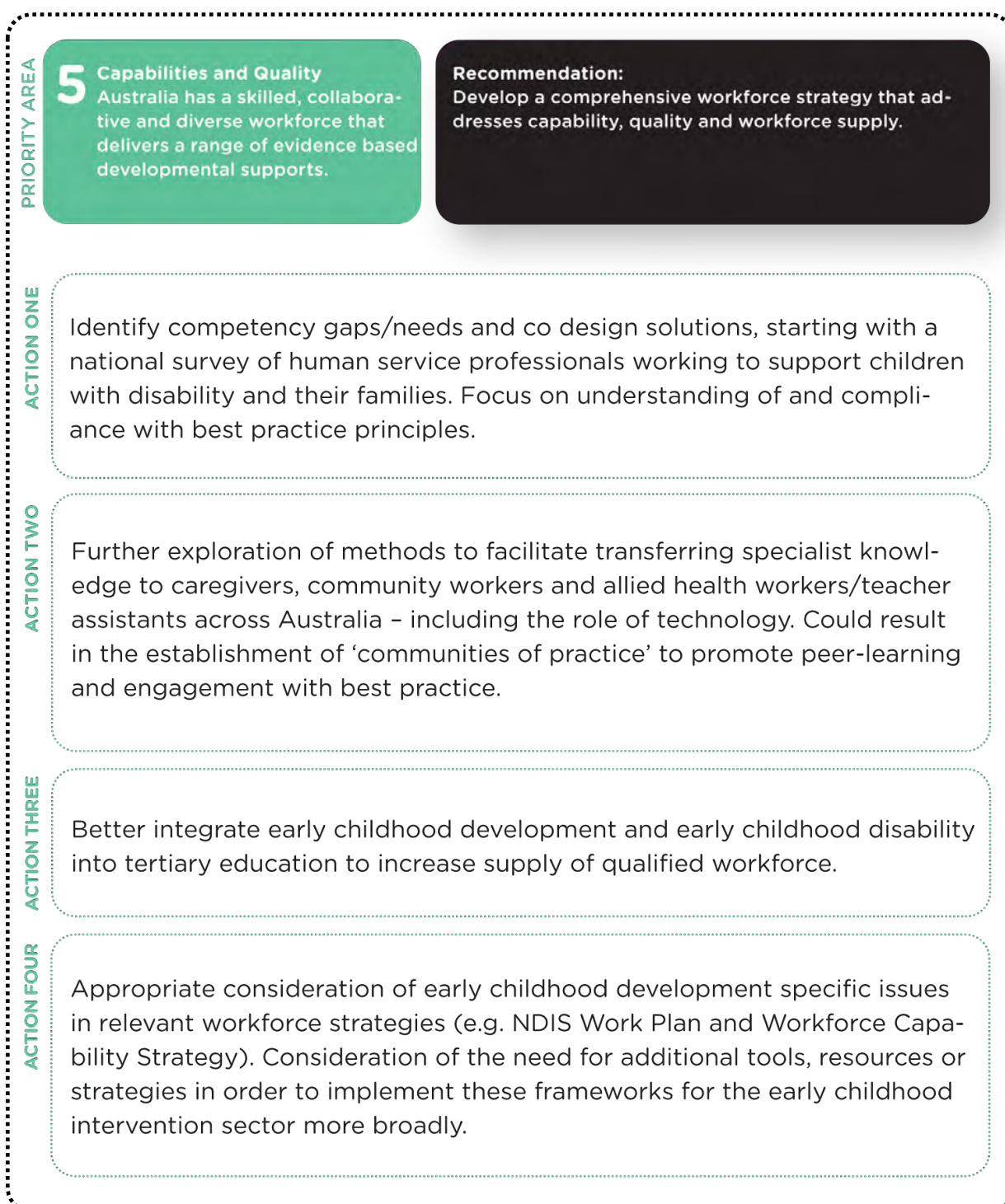
NDIS ECEI funding must support best practice-based service delivery: The individualised funding model does not allow for organisations to build networks, collaborate and learn from each other as it had historically. States and territories all work differently. With a changing workforce, a nationally consistent guide on practice under the NDIS is necessary.

Quality early childhood development principles must underpin service models: It is widely accepted what best practice is in early childhood developmental support, however it is not widely known how this is being implemented and operationalised.

A diverse workforce must be fostered: The early childhood development workforce should not solely be comprised of allied health practitioners. A healthy early childhood development workforce should also include early childhood educators, teachers, peer workers, health assistants and family support workers etc.

Fundamental shift in policy focus is required: Government policy that is focused on getting parents back into the workforce is often seen to create tensions with the priority of accessing early childhood developmental supports where families are required to be an active participant in their child's development. Further, NDIS pricing and policy changes, such as travel and cancellation costs are considered to be a barrier to a family-centred approach and the delivery of services in natural environments, and favouring clinic-based models.

ACTIONS



OUTCOMES AND INNOVATION

Meaningful data on developmental and participatory outcomes for children and families drives policy change, research and innovation in Australia.

Outcomes and Innovation Recommendation:

Invest in quality research, data collection and monitoring of early childhood development best practice and outcomes, to build a responsive and innovative sector.

A comprehensive system to collect and evaluate meaningful data is essential to drive and optimise outcomes for children and their families, and to effectively underpin research and innovation across the early childhood development support sector, is required.

The Action Plan consultations identified that evaluation of services, meaningful outcomes and social impact is inadequate across the entire sector. There is a critical need to establish a comprehensive evidence-base to support decision making and planning, and ultimately to ensure optimal outcomes for families and their children.

Access to data, and evidence of effectiveness of investment, is essential to ensure that the right behaviours are stimulated and incentivised in the market.

For services to adequately engage in quality systems and outcomes measurement, investment is required in both the systems and the high-quality data collection mechanisms that manage and report data in a meaningful way. Achieving the best outcomes for children and families while maximising public value and public accountability is critical and currently not being fully realised.

There is a need to establish a nationally consistent approach to gaining feedback from families. The process of gaining feedback in a meaningful way, and subsequently adapting strategies and supports, is an area that requires sector support. Meaningful data requires meaningful conversations that require trust, deeper inquiry and are balanced in power.



An example of a current feedback mechanism: The 2019 Quarterly report released in September, found that 100% of parents and carers thought that the NDIS improved their child's development - for children aged birth to 6 years of age.³⁵ The Action Plan findings suggest this figure is influenced heavily due to the context in which this information is gathered. If the feedback is sought during a planning meeting or through an NDIA representative, when families are required to demonstrate outcomes in order to get funding support for the final year, then this is not an appropriate way to gather data.

The Action Plan consultations found that families experience high levels of stress and worry that they will not be able to receive ongoing NDIS support if their child is not making progress against the goals. The Action Plan calls for a different approach to seek meaningful feedback from families in order to get a more accurate representation of how children are tracking.

Further, accurate data can be used to drive investment in research, innovation and ongoing training and development across the sector.

Responsibility for the design, implementation and administration of a national data collection system should rest within an overarching collaborative governance mechanism, involving governments, services providers and families, as outlined in Priority Area 3 (Seamless and Integrated).

“

There is always a gap between the rhetoric and reality in such cases, so it is likely that there are some providers who believe or claim that they are observing family-centred practice when they are not doing so. Until we gather data on how services are being delivered, we will not know.

WHAT FAMILIES EXPERIENCE

No mechanism to measure outcomes: There is no adequate measurement for developmental and participatory outcomes for children and families receiving support through the NDIS ECEI approach.

KEY SECTOR CONCERNS

Lack of appropriate language: The migration to more accessible language, that is less reliant upon medical terminology, jargon and acronyms, by practitioners and government requires focus and investment.

Data needs to be collected in an appropriate way, using good quality practices: The sector has questioned the way in which the NDIA collects data from families. Refer to the NDIS Quarterly Report feedback mechanism example cited above.

No national approach: There is no nationally consistent approach to gaining feedback from families, service providers and sector stakeholders.

Continuing the 'conversation': The sector views the Action Plan consultation as the beginning of a family-led national conversation, which requires further investment and ongoing conversation to continue to understand the needs of families of diverse backgrounds.

KEY FINDINGS

No adequate national data collection systems: Evaluation of services, meaningful outcomes and social impact is inadequate across the entire sector. A comprehensive system to collect and evaluate meaningful data is required. This system would drive increased outcomes for children and their families. Critically, it would establish a comprehensive evidence-base to support decision making and planning.

Opportunity to improve current NDIS and early childhood program data collection activity: It was noted that surveys conducted as part of planning processes are likely to undermine the independence and reliability of data collected.

Robust data gathering is required to maximise public accountability: Achieving the best outcomes for children and families while maximising public value and public accountability is critical and currently not being fully realised under a predominantly NDIS-oriented approach. Investment in a national system, with built-in accountability is required.

Lack of meaningful evidence-driven support around family wellness: Feedback which includes questions relating to family quality of life is currently not present. The collection and evaluation of wellness data is essential for the success of the early childhood development sector and would influence how we invest in training and how we build services with family wellness embedded at the heart.

ACTIONS

PRIORITY AREA	6 Outcomes and Innovation Meaningful data on developmental and participatory outcomes for children and families drives policy change, research and innovation in Australia.	Recommendation: Invest in quality research, data collection and monitoring of early childhood development best practice and outcomes, to build a responsive and innovative sector.
ACTION ONE	Establish baseline data to understand the social return on investment and the economic contribution of the national early childhood developmental care market.	
ACTION TWO	Invest in translational and collaborative research on early childhood developmental care that both expands the evidence-base and leads to innovation around solutions to challenges and information and tools for families, providers and professionals.	
ACTION THREE	Develop a high level outcomes framework to communicate the expected benefits of quality early childhood developmental care to all stakeholders, and sets clear metrics to measure success.	
ACTION ONE	Evaluate and report on priority areas in the Reimagine Action Plan including associated projects and activities from 2020-2030. An appropriate evaluation approach should be designed, including metrics and evaluation questions, and collection of baseline and wave data. Findings at various stages would provide evidence to inform government decision making around investment and action.	

APPENDICES



GUIDING DOCUMENTS

REPORTS

The Shut Out Report

The Tune Review

Productivity Commission Disability Care and Support Inquiry Report (2011)

National Disability Strategy 2010-2020

National Guidelines: Best Practice in Early Childhood Intervention

Tjitji Atunymankupai Walytja Tjutangku, Looking After Children with Disabilities from the NPY Lands Report

Belonging, Being and Becoming - The Early Years Learning Framework (EYLF)

Common Approach - ARACY

The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (Disability Royal Commission)

COAG Early Learning Reform Principles

Productivity Commission Mental Health Inquiry Draft Report

Lifting our Game Report

UNICEF: The State of the World's Children 2013: Children with Disabilities

NATIONAL LEGISLATION

Disability Discrimination Act, 1992

National Standards For Disability Services (NSDS), 2014

National Disability Insurance Scheme Act, 2013

INTERNATIONAL CONVENTIONS

United Nations Convention on the Rights of the Child

United National Convention on the Rights of People with Disability (UNCRPD)

The United Nations Sustainable Development Agenda³⁶

METHODOLOGY

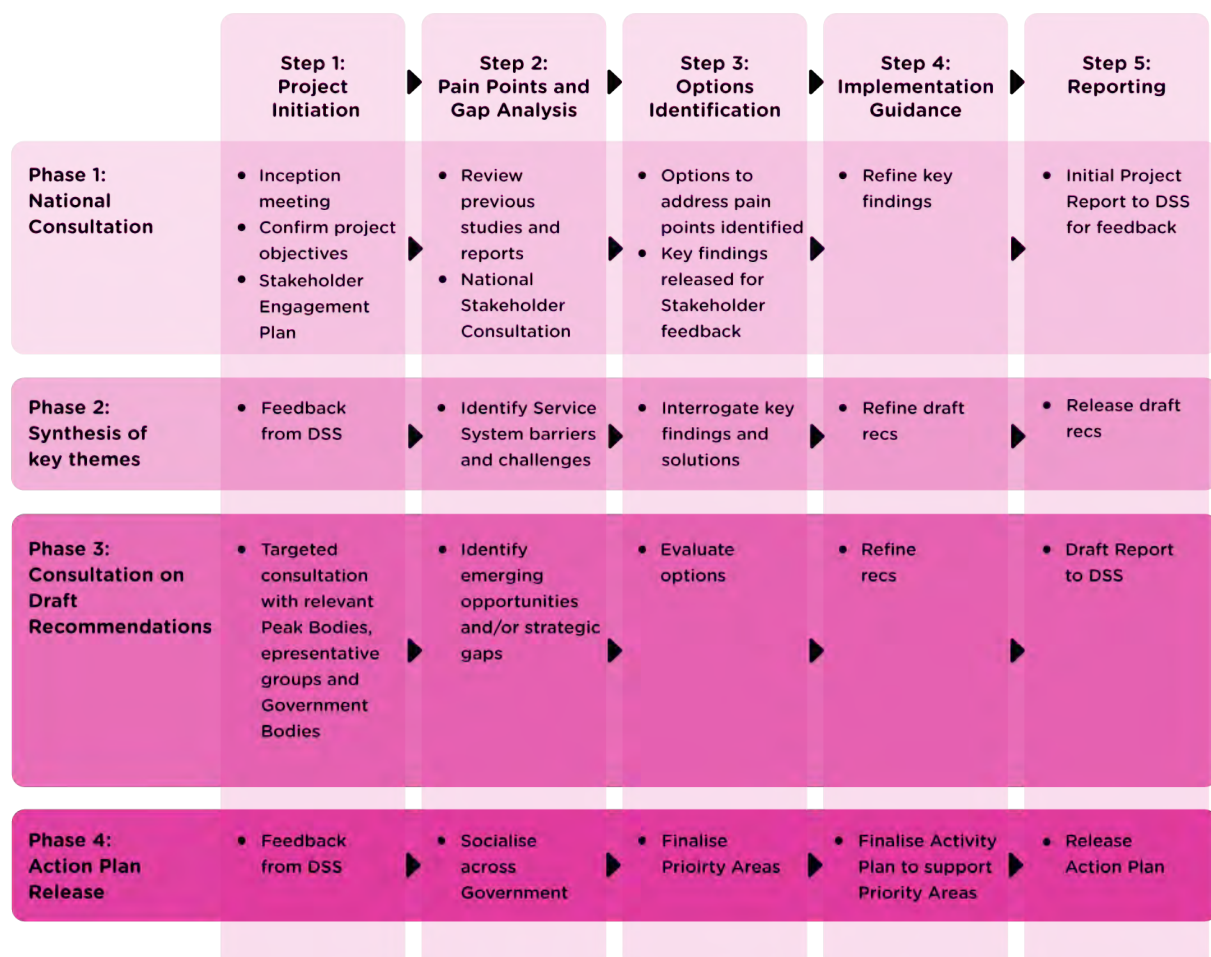
Reimagine Australia utilised a phased consultation approach to inform the Action Plan.

The Action Plan has been fundamentally co-designed by families, for families. Across Australia, families generously gave of their time and shared their stories to paint a visceral picture of what is and isn't working across the current early childhood development support systems.

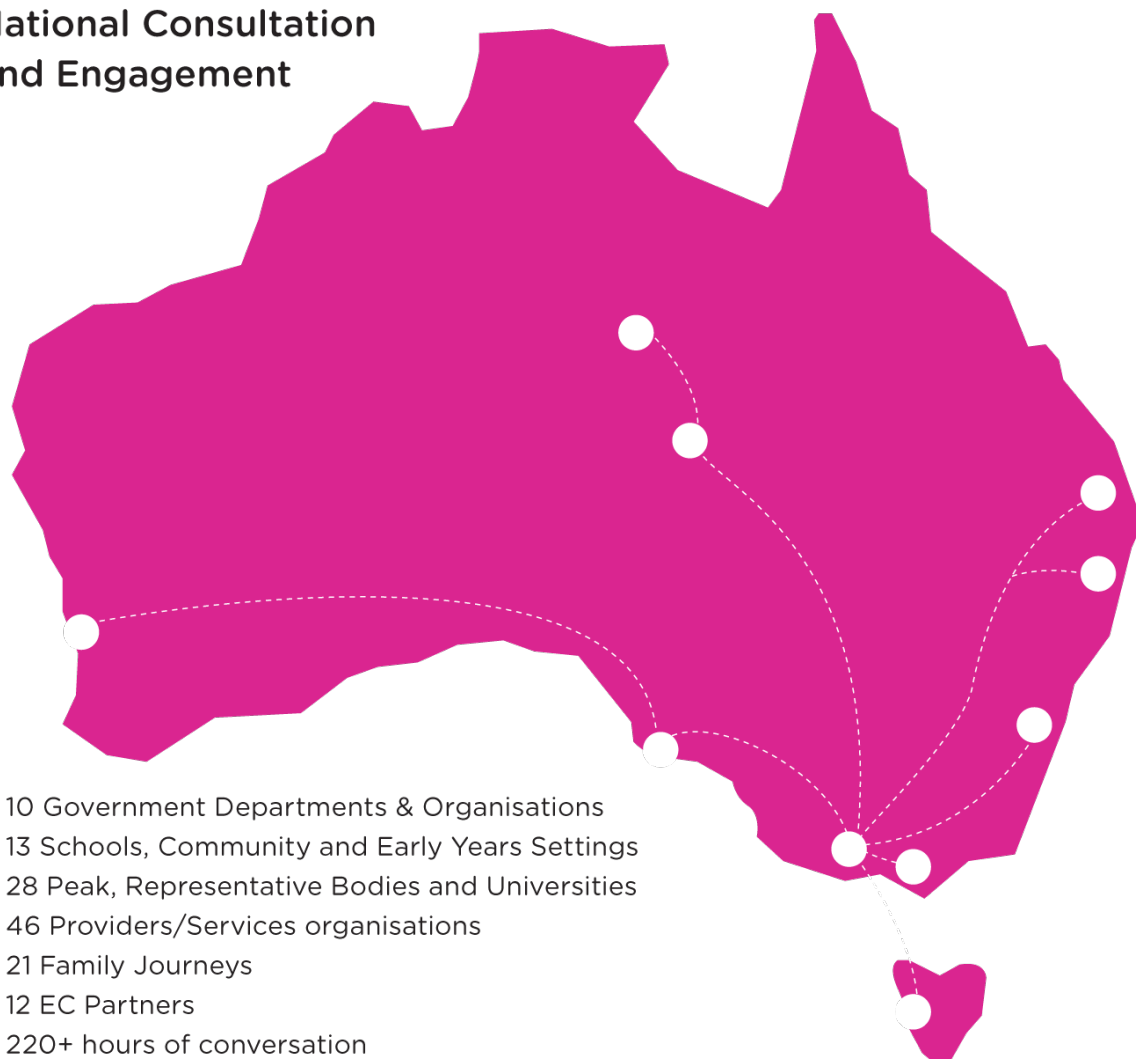
During our consultations, Reimagine Australia was committed to asking questions from the perspective of family experience, gathering insight and understanding around the whole family of children with additional needs, inquiring into their connection to their community and their experiences as a whole.

To build a responsive and integrated system into the future, it is fundamental that the Action Plan is grounded in an understanding of the unique nature of every family, their language, culture, routines.

The insights and learnings gained from families in the National Consultation phase of the project then formed the basis of our consultation with early childhood practitioners and educators, industry and peak associations, community organisations and government.



National Consultation and Engagement



- 10 Government Departments & Organisations
- 13 Schools, Community and Early Years Settings
- 28 Peak, Representative Bodies and Universities
- 46 Providers/Services organisations
- 21 Family Journeys
- 12 EC Partners
- 220+ hours of conversation
- 35,000 kms travelled
- 39 submissions

It quickly became apparent that the need for a national discussion was underestimated in terms of the acuteness of issues currently faced, the disparity which exists across Australia and the eagerness of families to voice their spectrum of experiences.

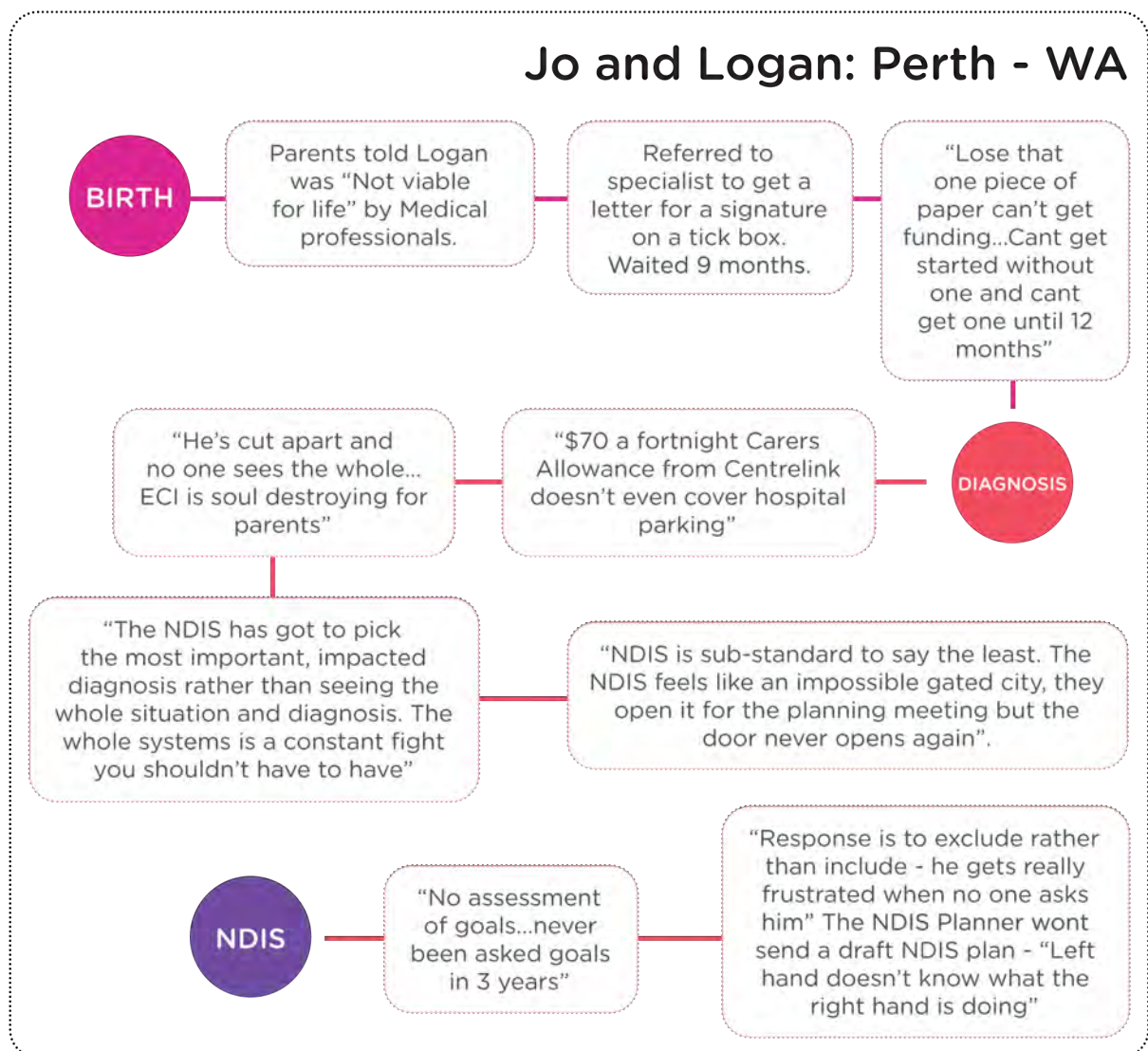
It is important to note that the data collected during consultation phases that underpin the Action Plan, has been reinforced by a significant and pre-existing body of work from Australia and across the world. The Action Plan has drawn heavily from a number of guiding documents, listed below.

The findings have been synthesised into six priority areas, under which key recommendations sit. Each recommendation is supported by a set of targeted actions designed to support the realisation of each of the key priorities by 2030.

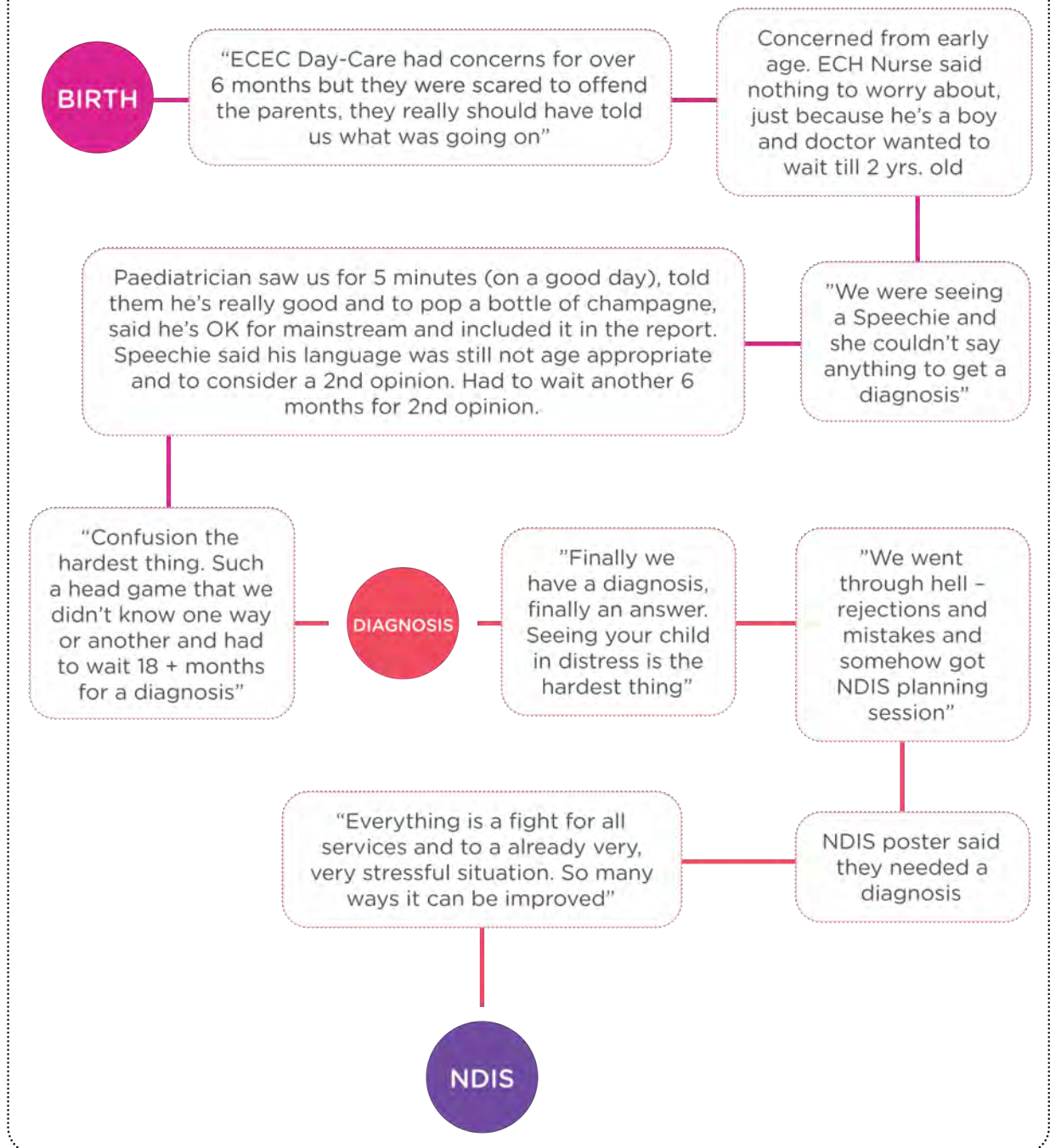
FAMILY JOURNEY MAPPING

Reimagine Australia is grateful to the 21 families of children with a disability and/or developmental delay from across the nation who generously gave of their time to share their deeply personal experiences to shape the Action plan.

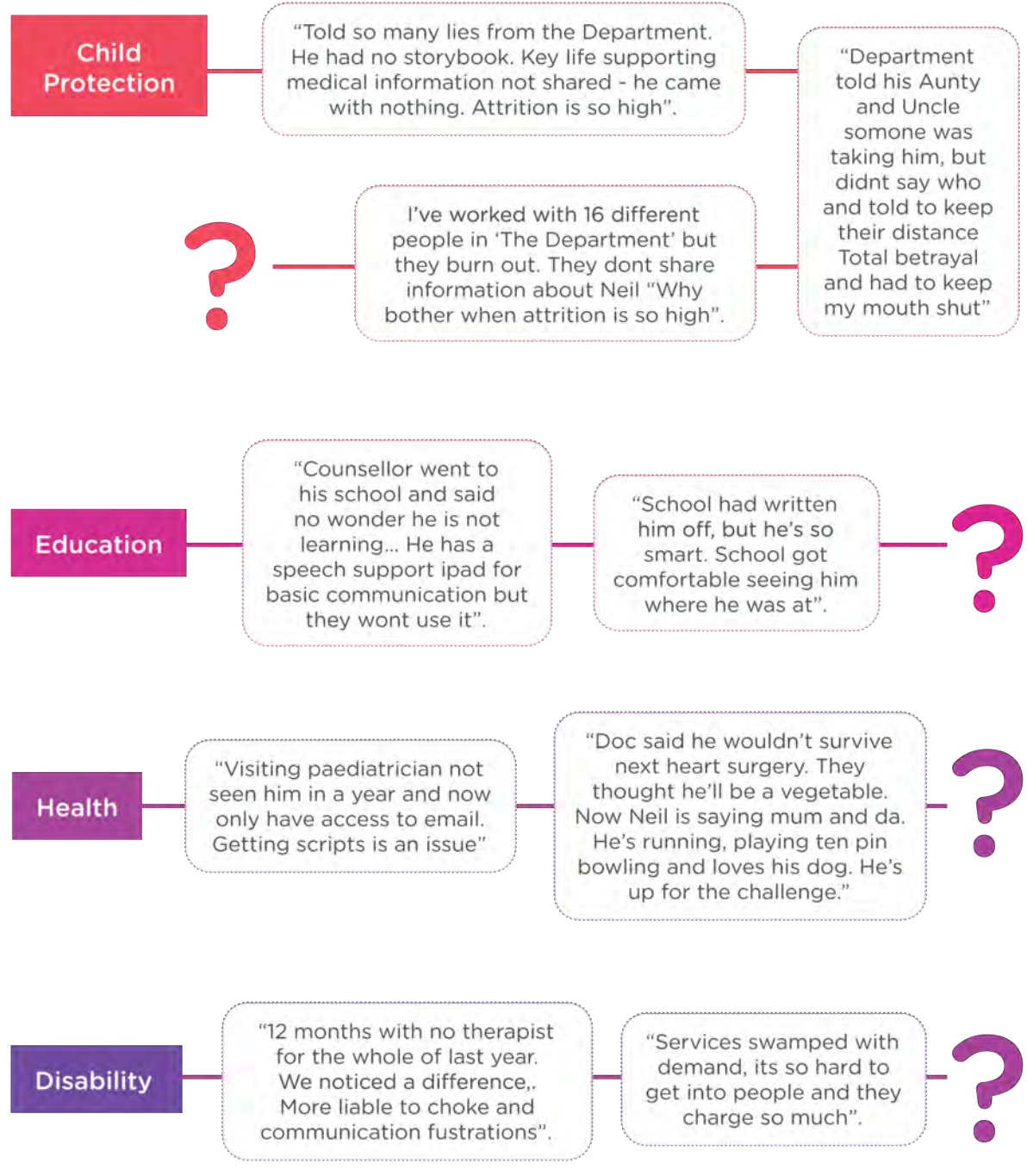
Each journey was mapped by the Reimagine Australia Project Team. Below you will find a sample of three family journeys, which we hope will provide rich context for the Action Plan.



Jacqui and Ezra: Perth - WA



Kathy and Neil: Rural - QLD



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REIMAGINE AUSTRALIA'S ACTION PLAN TEAM

Chief Executive Officer: Yvonne Keane

Project Director: Anna McCracken

Project Manager: Laura Harris

Early Childhood Education and

Care Advisor: Bethan Rees

Project Artist/Conceptual

Designer: Amunda Gorey

CONTRIBUTING FAMILIES

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JOURNEY MAPPING AND SUBMISSIONS

Noah's Ark Inc

RESEARCH AND ACADEMICS

Research & Academics
Kim Bulkeley - Sydney University
Janene Swawell - Monash University

Jane Warren - University of Wollongong
Tim Moore - Murdoch Childrens Research Institute

CONTRIBUTING ORGANISATIONS

Onsite Consultations
Autism Association of Western Australia
Biala Peninsula
Cerebral Palsy Alliance
Goodstart Early Learning Centre
Healthy Strides Foundation
National Disability Insurance Agency
Northcott
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Journey Mapping and Submissions
Aruma ECI & Therapy Supports
Autism Spectrum Australia
Brotherhood of St Laurence
Bush Kids
Charles Darwin University
Chorus Music Therapy
Developmental Play Therapy
Early Bird Therapy
Early Connections - Coffs Coast
Early Ed
Glen Innes Public School
Goodstart Early Learning
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Kurrajong Therapy Plus
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Samaritans Foundation
Scope
Shaping Outcomes
Splash Therapy
Step by Step Interventions
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Vision Australia

ONSITE CONSULTATION

Firstchance

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AUSTRALIA