



# National Disability Strategy

[Stage 2 Consultation]

**SUBMISSION**

October 2020

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# 1. Executive Summary

Every year an estimated 115,000 families of children<sup>1</sup> 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 and targeted early childhood strategy is required as part of the broader National Disability Strategy.

Reimagine Australia (Reimagine) was proud to be tasked with the delivery of the first National Early Childhood 10-year Action Plan. [The Reimagine Early Childhood National Action Plan](#) (National 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 National 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 improve outcomes for the tens of thousands of Australian families and caregivers every year who support a very young child with additional needs.

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 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, ensuring every child can thrive.

Reimagine Australia welcomes the opportunity to contribute to the National Disability Strategy. We have intentionally aligned the content of this submission with the key priority areas of the National Action Plan.

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<sup>1</sup> **Peter De Natris - '2020:** The Road Map for ECI Practitioners', Keynote Presentation at 2019 Early Childhood Intervention Australia National Conference  
<https://www.flipsnack.com/earlychildhoodintervention/peter-de-natris-2020-the-road-map-for-eci-practitioners/full-view.html>

We strongly recommend:

1. An early childhood specific strategy be embedded in the National Disability Strategy and, further, that early childhood disability is embedded in policy and frameworks at all levels of government.
2. The vision of the strategy specifically includes the role of families and caregivers.
3. That strategy centres around the lived experience of people with disability, including families and caregivers of children with disability.
4. Changing community attitudes to be a national priority.
5. A Revision of the 2015 Applied Principles to shared agreements, as opposed to set agreements and the adoption of integrated governance arrangements.
6. The investment in, and support of, a national body to guide the actions of the early childhood strategy.
7. Long term resourcing of advocacy organisations to support the actions of the strategy and community led initiatives.
8. Cessation of the use of the term 'intervention' in the next strategy when referring to early childhood specialist supports.
9. Targeted commissioning in thin markets where other national workforce strategies may have less of an effect.
10. 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.
11. The development of communities of practice to create opportunities for collaboration, partnership, cross pollination of practice and the sharing of resources across Australia to drive change, and investment in tertiary education and professional development.
12. An outcomes framework with a comprehensive set of performance indicators to measure progress against the six key priority areas of the National Action Plan
13. Establishment of baseline data to understand the social return on investment and the economic contribution of the national early childhood developmental care market.
14. 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.

## **1.1 Background on Reimagine Australia**

Reimagine Australia, formerly known as Early Childhood Intervention Australia (ECIA), has been the leading Australian body for early childhood outcomes for young children with a developmental delay or a disability and their families, since 1986.

As the singular national organisation that works with families, government, service providers, and mainstream support services to obtain the very best outcomes for children and their families, Reimagine Australia has been leading the early childhood sector in embedding best practice and inclusive systems design for over 35 years.

Reimagine Australia's purpose is to ensure that children with disability and/or developmental delay, and their families, have the opportunity to reach their potential in life. We do this by supporting families and practitioners, whilst reimagining communities in which we live, work and play through strategic and inclusive design.

## **1.2 Reimagine Early Childhood National Action Plan to 2030**

The vision of the Reimagine Early Childhood National Action Plan to 2030 is to realise a responsive, high-quality and easy-to-navigate early childhood development system which places families at the centre, embraces the diversity of all children and enables optimised outcomes.

The National Action Plan is designed to support 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.

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 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.

The National Action Plan is led by a governing recommendation and underpinned by Key Priority Areas. Each Priority Area is supported by a set of succinct action items.

Reimagine Australia has aligned this submission with the National Action Plan for children with disability and/or developmental delay. Reimagine Australia believes the National Disability Strategy is strongly aligned with the vision of the National Action Plan. Reimagine Australia welcomes the opportunity to assist in the development of outcomes that are specific for early childhood that will drive change over the next ten years.

## Overarching Priority & Action:

### PRIORITY AREA ONE: Empowered and Resourced

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

### PRIORITY AREA TWO: Meaningful Participation

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

### PRIORITY AREA THREE: 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: 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: Capability and Quality

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

### PRIORITY AREA SIX: Outcomes and Innovation

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

## 1.3 Submission Purpose

Reimagine Australia welcomes the opportunity to contribute to this year's National Disability Strategy position paper, to highlight the rights of children with disability or developmental delay and their families. We believe that Australia can have a responsive, integrated and easy-to-navigate early childhood development support system, which is well resourced and founded on evidence-based best practice.

To achieve this, Reimagine Australia recommends an early childhood specific targeted strategy is required to adequately cover the protection and needs of children and their families and reimagine a different future over the next ten years.

## 2. Early Childhood Disability as a National Priority

Reimagine Australia would like children who require developmental supports and their families to be recognised as a national priority.

This recognition would include;

- an early childhood targeted strategy within the broader framework
- a robust governance mechanism and guiding body
- children with developmental needs and their families reflected in key strategic frameworks such as the National Disability Strategy
- Clear stewardship of the meaningful participation and inclusion for children with disability and/or developmental delay across government
- Strong feedback loops across areas of disability, health, education and other interfacing systems to inform service design and outcomes for current and future action.

### National Action Plan Priority Area Three: Seamless & 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.

Reimagine Australia Recommends:

- 2.1 An early childhood specific strategy embedded in the National Disability Strategy
- 2.2 Embedded in Policy & Frameworks at all levels of Government
- 2.3 Revise the 2015 Applied Principles to shared agreements not set agreements.
- 2.4 Adopt Integrated Governance Arrangements
- 2.5 Invest in a National Body to guide the actions of the early childhood strategy
- 2.6 Invest in advocacy organisations to support the actions of the strategy

### 2.1 An early childhood targeted strategy

Reimagine Australia believes the National Disability Strategy is a key guiding framework which can work to bring the required actions for the next ten years for children with disability and/or developmental delay to life.

Reimagine Australia would like to see the development of a targeted plan to exist within the broader National Disability Strategy which acknowledges and is relevant to children birth to eight years of age and their families.

The targeted plan would acknowledge the central role that families play; the unique journey of developmental concerns and accessing support and diagnosis in the early years; and, the priorities that differ from those of young people and adults with disability.

The plan would acknowledge that some children who receive disability supports and require the protection of disability frameworks, may not have a diagnosis.

Reimagine Australia would like the future strategy to reflect this reality which so often leaves children excluded from the support they require due to a traditional culture of disability diagnosis required for support. We know that 56 per cent of children entering the NDIS birth to six as a participant are developmentally delayed but do not have formal diagnosis yet, and may never have a diagnosis.

## 2.2 Embed in policy and frameworks at all levels of government

Reimagine Australia would like to see the priorities of children with disability and developmental delay, and their families reflected in Commonwealth, state and territory policy frameworks. Reimagine Australia acknowledges that an early childhood specific strategy as part of the National Disability Strategy could further promote and strengthen the representation and resourcing for support across systems at all levels of Government.

## 2.3 Strengthen accountability and shared responsibility in applied principles

Reimagine Australia recommends the 2015 Applied Principles and Tables of Support be revised to adopt shared responsibility (rather than set responsibility) and reflect the true realities for families falling across systems. Reimagine Australia is concerned the National Disability Strategy will not fully achieve the outcomes and goals it sets forth over the next ten years within the current set of applied principles. Set responsibility and the passing of responsibility between systems is challenging for families to navigate.

The National action plan consultations heard multiple experiences of families falling through the 'black hole' which can be created when multiple service systems are involved in a family's life. Reimagine Australia is concerned that there is no easy thread for families to be able to weave their services and support together, within the same system and across systems. We would like to see seamless integration across systems a priority over the next ten years.

*"The whole system is a constant fight you shouldn't have to have"  
"Should be a lot easier as life is already hard"*

## 2.4 Integrated governance arrangements

Reimagine Australia recommends an establishment of integrated governance arrangements, shared responsibility and accountability for policy, planning,

implementation and evaluation in early childhood disability.<sup>2</sup> Integrated governance would include shared planning and collaborative design between all governments with formal and informal relations to manage affairs between all levels of government and non-government organisations.

Reimagine Australia recommends the targeted early childhood strategy could support and guide the reforms in the children and families more broadly. These would include reforms currently being progressed by the Council of Australian Governments.<sup>3</sup>

## **2.5 Invest in a national body to guide the actions of the early childhood strategy**

Reimagine Australia recommends funding a body to lead the reimagining of the early childhood specialist development sector in partnership with the government, service providers and in collaboration with partners already established in guiding work for children and families in unique and interfacing sectors. The body would support, guide and develop the capabilities, quality and service models of the sector working to support the development of children with disability and their families. Reimagine Australia recommends this body take on the role as an innovation hub, being able to resource through a 'pitch style' fund, initiatives and research in order to drive Australia forward as a world class system for children with disabilities and their families.

As Early Childhood Intervention (ECI) Peak support, was previously the main responsibility of States and Territories, there is now a void on a national level.

Reimagine Australia envisions this body heavily supporting the realisation of the outcomes set forth in the early childhood specific strategy within the National Disability Strategy.

## **2.6 Invest in advocacy, peak and representative bodies to drive change**

Reimagine Australia is concerned that advocacy, peak and representative bodies across Australia are not resourced enough to be able to lead and shape the change required. These organisations are fundamental in leading change across the sectors and groups they represent. Leveraging on their knowledge, networks and passion for change, they play a key role in delivering aspects of the national disability strategy and also accountability around the actions set out for the next ten years.

Reimagine Australia recommends the investment in these bodies would be most effective if offered in longer term funding cycles than the ones available currently, so that organisations can engage, implement and measure long term change rather than be caught in loops of uncertainty, funding and project changes.

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<sup>2</sup> ARACY- Inverted Pyramid

<sup>3</sup> in areas such as National Partnership Agreement on Early Childhood Education, National Partnership Agreement on the National Quality Agenda for ECEC and the National Partnership Agreement on Indigenous Early Childhood Development, Child Protection, Health and Justice reforms.

### 3. Family centred vs adult centric - a different approach for early childhood

#### National Action Plan Priority Area One: Empowered and Resourced

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

Reimagine Australia Recommends:

3.1 A vision for the strategy which includes families and caregivers

3.2 Consideration of Guiding Principles for government and non-government

3.3 Centring lived experience in decision making and design

#### 3.1 A vision which includes families and caregivers

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/or caregiver 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.<sup>4</sup> 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.<sup>5</sup>

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<sup>4</sup> **Bronfenbrenner, U.** (1986). Ecology of the family as a context for human development: Research perspectives. *Developmental Psychology*, 22(6), 723-742. doi:[10.1037/0012-1649.22.6.723](https://doi.org/10.1037/0012-1649.22.6.723)

**Bronfenbrenner, U.** (1992). Ecological systems theory. In Vasta, Ross (Ed), (1992). *Six theories of child development: Revised formulations and current issues*. London, England: Jessica Kingsley Publishers.

**Bronfenbrenner, U. and Morris, P.** (2006). The bioecological model of human development. In W. Damon and R. M. Lerner (Eds.), *Handbook of Child Psychology* (6th ed.), Vol. 1, pp. 793-828. Hoboken, New Jersey: John Wiley and Sons.

**Marmot, M. and Wilkinson, R.** (Eds) (2006). *Social Determinants of Health* (2<sup>nd</sup> Ed.). Oxford, UK: Oxford University Press.

<sup>5</sup> **Ratcliff, K.S.** (2017). *The Social Determinants of Health: Looking Upstream*. Cambridge, UK: Polity.

**Moore, T.G., McDonald, M., Carlon, L. and O'Rourke, K.** (2015). Early childhood development and the social determinants of health inequities. *Health Promotion International*, 30 (suppl 2): ii102-ii115. doi:10.1093/heapro/dav031 [http://heapro.oxfordjournals.org/content/30/suppl\\_2/ii102.full.pdf+html](http://heapro.oxfordjournals.org/content/30/suppl_2/ii102.full.pdf+html)

**Moore, T.G., Arefadib, N., Deery, A., and West, S.** (2017). *The First Thousand Days: An Evidence Paper*. Parkville, Victoria: Centre for Community Child Health, Murdoch Children's Research Institute. <https://doi.org/10.25374/MCRI.5471779> <http://www.rch.org.au/uploadedFiles/Main/Content/ccchdev/CC-CH-The-First-Thousand-Days-An-Evidence-Paper-September-2017.pdf>

A central priority of the National 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.

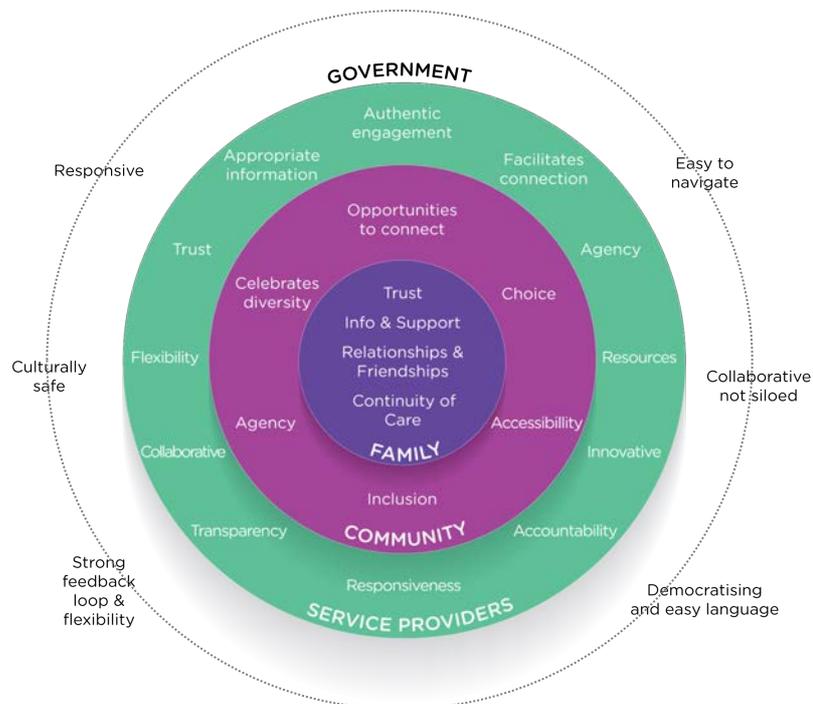
It is vital that the National Disability Strategy is relevant to children with disability and the central role and experiences of families. Reimagine Australia recommends the vision of the strategy acknowledges the caring role of families and the barriers which exist of having a child and sibling as a disability in fulfilling their potential as members of the community.

Therefore, the proposed new vision for the strategy is:

*An inclusive Australian society that enables people with disability, their families and caregivers to fulfil their potential as equal members of the community.*

### 3.2 Guiding principles for government & non-government organisations

The diagram below was developed through the National Action Plan conversations. Families were asked what were the key qualities and capabilities they wanted and needed from their communities, service providers and government systems, Reimagine Australia recommends the adoption of this diagram when considering the co-design processes that will take place if an early childhood specific strategy is adopted by the Commonwealth as part of the National Disability Strategy.



### 3.3 Centring lived experiences in the guiding principles

Reimagine Australia welcomes the guiding principles set out in the position paper. We would like to suggest the addition of another principle which we believe is fundamental to designing, implementing and evaluating the next strategy.

Reimagine Australia recommends 'centring lived experience' be a guiding principle. Reimagine Australia believes children with disability and their families and people with disability should be engaged beyond the traditional consultation method, into advisory and leadership roles to drive the change. Reimagine Australia took a co-design approach for the national action plan and families were involved during development. Reimagine Australia believes in codesign approaches as well as the recruitment and commitment to centring lived experience is what Australia needs to reform.

Reimagine Australia has attached family journey experiences to this submission as a demonstration of ways in which lived experience can be centred to inform a national strategy. (See Appendix 1)

## 4. Australia embraces the social model of disability

### National Action Plan Priority Area Two: Meaningful Participation

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

Reimagine Australia recommends:

- 4.1 Invest in changing community attitudes
- 4.2 Ensure legislative frameworks support inclusion
- 4.3 Invest in community-led initiatives

### 4.1 Invest in changing community attitudes

Children with disability and their families are excluded from their communities, networks and mainstream services at alarming rates. The consultation findings for the National Action Plan reinforced the existing evidence of the exclusion of children and families from schools, community groups and services.<sup>6</sup> 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.

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.

*“We promise we will support you no matter what at this school, whilst also pushing me out the door to the special school.”*

*“The school is only a couple of minutes down the road and I want him to go there with his brother and sister. The school said they don’t have the resources. But I have seen them get new solar panels, fixed the basketball courts, do something to the halls, yet they can’t put a support person in to include him.”*

We strongly advocate for further awareness around the social model of disability and the application of this in everyday environments, moving it from theory to practice.

Reimagine Australia believes community beliefs and mindset are largely shaped by the medical model. Reimagine Australia has included a case study with this submission which demonstrates how the medical model of disability impacts children and families in everyday context (See Appendix 2).

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<sup>6</sup> Sollis (2019)

## 4.2 Ensure Legislative frameworks support inclusion

Reimagine Australia recently [submitted](#) to this year's Review of the Disability Standards for Education 2005, to highlight the rights of children with disability or developmental delay and their families. One of the findings of this process was that legislative frameworks such as the Disability Standards for Education is intended to uphold the rights and obligations under the Disability Discrimination Act. However, these standards are not fully embedded in everyday practice through guiding frameworks such as the Early Years Learning Framework and the National Quality Standards, teaching practices and school culture.

Reimagine Australia have raised this point in this submission to ensure the National Disability Strategy acts as an accountability tool, weaving together the key protective frameworks across systems for children with disability and how they are to be interpreted and applied in a practice level in education, health, justice, child protection and community settings. This includes consistent eligibility and application processes across systems.

## 4.3 Invest in community led initiatives

Reimagine Australia acknowledges the role of significant funding initiatives such as the Information, Linkages and Capacity (ILC) building process and the opportunity this provides to community areas to lead initiatives. Reimagine Australia is concerned that there are not enough local initiatives and encourages the strategy to look at ways local, state and commonwealth governments can work together to provide seed funding and targeted funding for community led ideas.

Further, Reimagine Australia would like to see longer term funding cycles, so that organisations and initiatives can engage, implement and measure long term change rather than be caught in loops of uncertainty of funding leading to short term impact.

## 5. Relationships instead of transactions

### National Action Plan Priority Area Four: 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.

Reimagine Australia recommends:

5.1 Address the 'wait and see' culture

5.2 The term 'intervention' should not be carried forward

### 5.1 Address the 'wait and see' culture in early childhood disability

Australia does not currently have a responsive early childhood development support and prevention system. Despite the strength and efforts of organisations and individuals operating in the early childhood development space nationally, early childhood support across Australia is not being implemented. Families need the "right support at the right time" and that support needs to be sustainable.

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.<sup>7</sup>

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 start of this culture.

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. Community attitudes and judgement toward disability exacerbates this complex issue.

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<sup>7</sup> Telethon Kids Institute, How Australia can invest in children and return more; A new look at the \$15bn cost of late action, 2019 <https://colab.telethonkids.org.au/siteassets/media-docs---colab/coli/summary-report---how-australia-can-invest-in-children-and-return-more.pdf>

The '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.

Reimagine Australia recommends schools, health services, early childhood services and other services that families interact with have the capability to identify concerns early and provide support to families and their children, to feel connected and that they are participating under an integrated framework.

## 5.2 Awareness around language

Reimagine Australia would like the National Disability Strategy to honour this insight from families, supported by the early childhood sector to using a language that enables, not disables, families. We recommend the targeted national strategy for early childhood does not use the term 'intervention' in the context of specialist development support for children with disability.

'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 development support.

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 developments supports' 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.

## 6. A high quality, diverse workforce across early childhood disability

### National Action Plan Priority Area Five: Capability and Quality

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

Reimagine Australia recommends:

6.1(a) An early childhood specific workforce plan:

- 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 across Australia to drive change, and;
  - investment in tertiary education and professional development.

6.2(b) Market stewardship:

- targeted commissioning in thin markets where other national workforce strategies may have less of an effect;

### 6.1 An early childhood specific workforce plan and market stewardship

Reimagine Australia believes the specialist early childhood development workforce is currently in crisis.

The National 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 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 in early intervention. A successful workforce plan under the National Disability Strategy needs to reflect this diversity and combat the current intensive focus on the allied health workforce.

Additionally, with the National Disability Insurance Agency, early childhood early intervention 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, Reimagine Australia is concerned 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 a body with a mandate to coordinate the specialist early childhood sector nationally, which is outlined in Priority Area: Seamless and Integrated within the National Action Plan.

A strategic approach is required to address the current workforce crisis across the early childhood development support sector. This 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 to drive change, and;
- investment in tertiary education and professional development.

## 7. Meaningful data and outcomes for children and their families

### National Action Plan Priority Area Six: Outcomes and Innovation

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

Reimagine Australia recommendations:

7.1. Development of an outcomes framework:

- With a comprehensive set of performance indicators to measure progress against the six key priority areas of the National Action Plan.
- Establish baseline data to understand the social return on investment and the economic contribution of the national early childhood developmental care market.
- 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.

### 7.1 Development of an outcomes framework

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 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. Reimagine Australia recommends the strategy works to establish baseline data to understand the social return on investment and the economic contribution of the national early childhood developmental care market.

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.

Reimagine Australia recommends the strategy includes a high-level outcomes framework for families, services and government to meaningfully understand and contribute to. This would also work to communicate the expected benefits of quality early childhood developmental care to all stakeholders and set metrics to measure success.

## Conclusion:

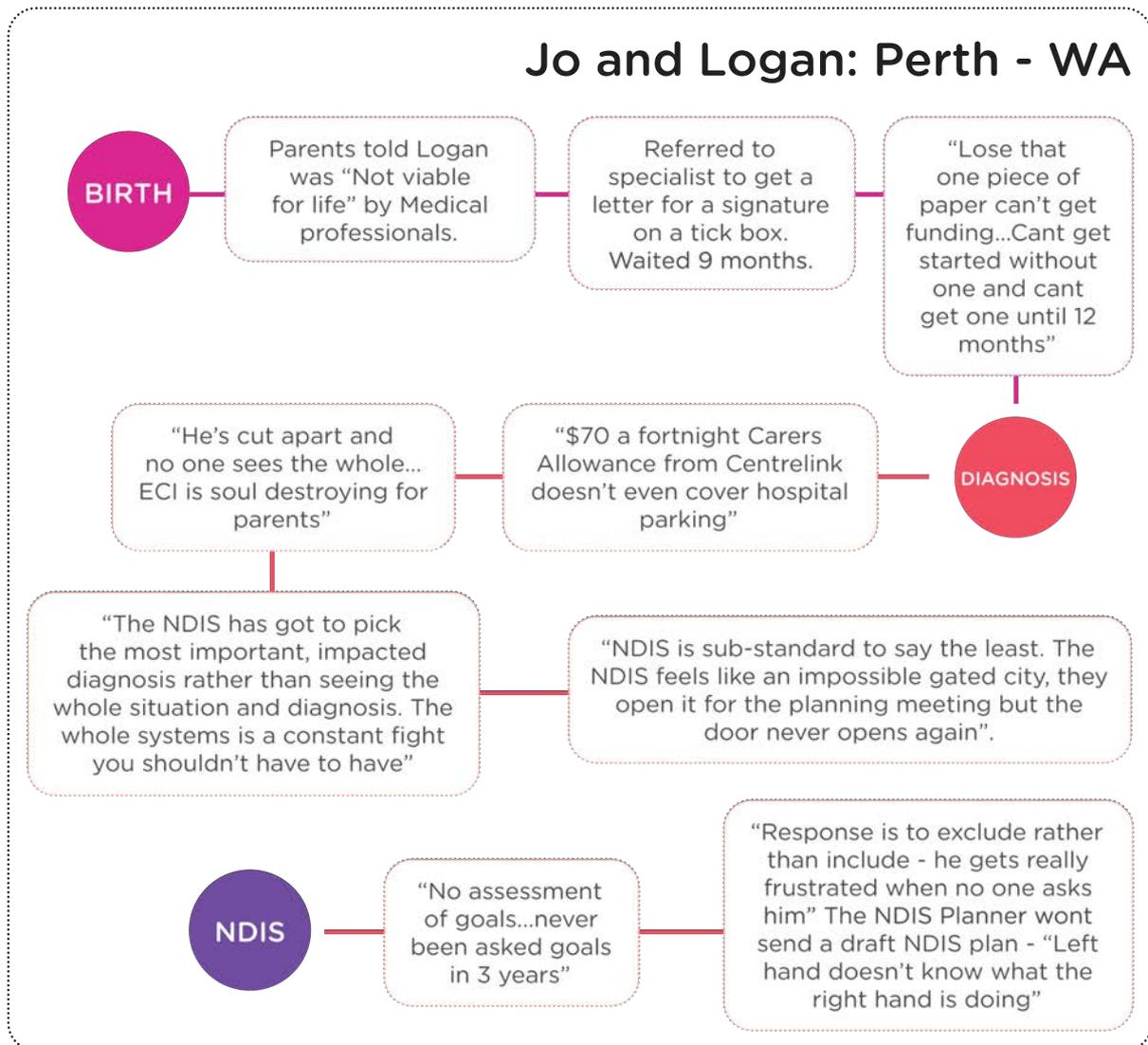
Reimagine Australia believes an early childhood specific targeted strategy would protect the needs of children and their families. We believe this would breathe-to-life a different future for children with disability or developmental delay and their families, over the next ten years.

In order to improve outcomes for children with disability and their families, we strongly recommend that the National Disability Strategy to 2030 adopts the following;

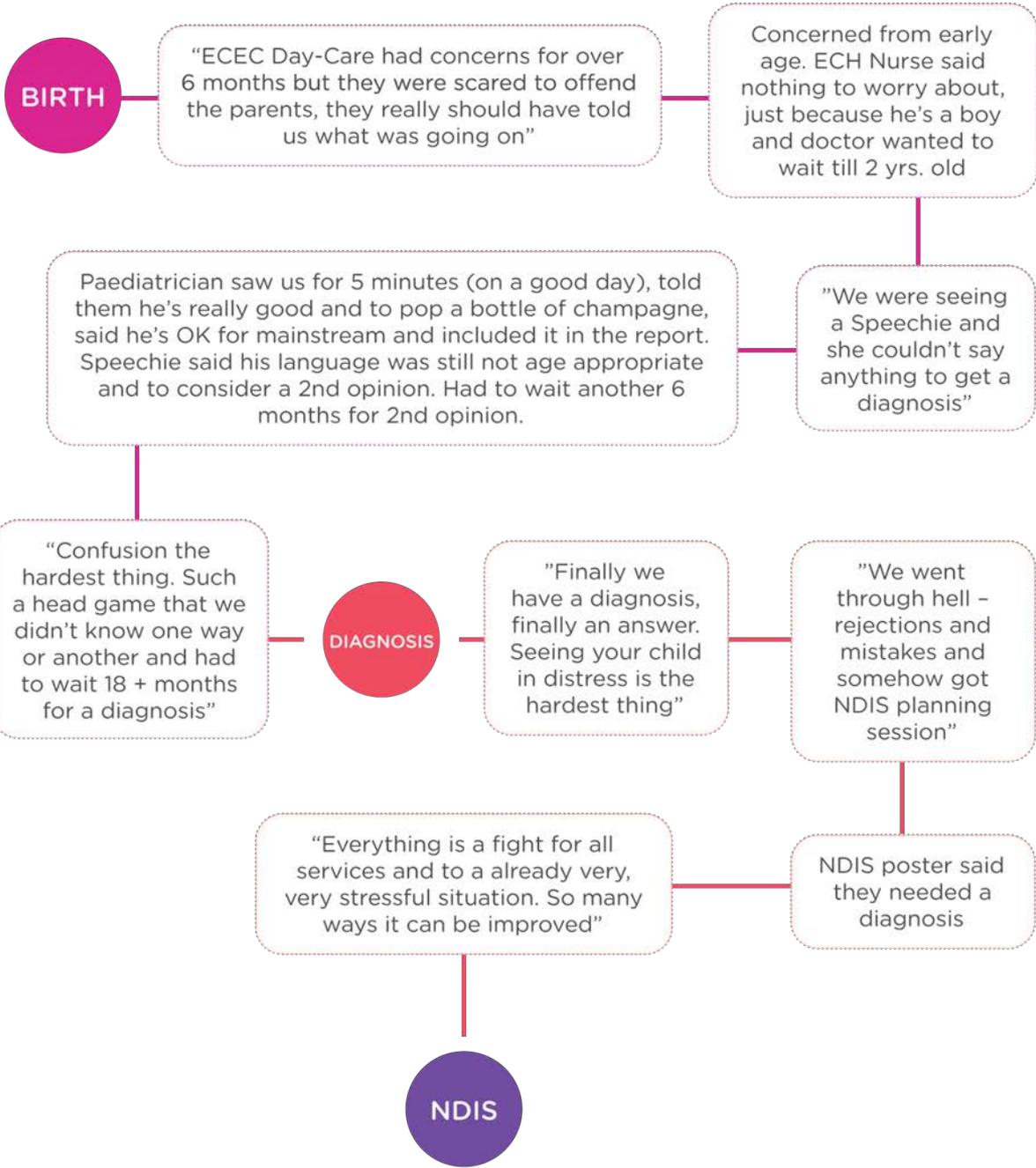
1. An early childhood specific strategy embedded within the National Disability Strategy, with a recommendation that early childhood disability is, in-turn, embedded in policy and frameworks at all levels of government.
2. The vision of the strategy specifically includes the role of families and caregivers.
3. Centring on the lived experience of people with disability, including families and caregivers of children with disability.
4. The focus on changing community attitudes to be a national priority.
5. A revision of the 2015 Applied Principles to shared agreements and the adoption of integrated governance arrangements.
6. The investment in, and support of, a national body to guide the actions of the early childhood strategy.
7. Long term resourcing of advocacy organisations to support the actions of the strategy and community led initiatives.
8. Cessation of the use of the term 'intervention' in the next strategy when referring to early childhood specialist support.
9. Targeted commissioning in thin markets where other national workforce strategies may have less of an effect.
10. 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.
11. The development of communities of practice to create opportunities for collaboration, partnership, cross pollination of practice and the sharing of resources across Australia to drive change, and investment in tertiary education and professional development.
12. Propose an outcomes framework with a comprehensive set of performance indicators to measure progress against the six key priority areas of the National Action Plan.
13. Establish baseline data to understand the social return on investment and the economic contribution of the national early childhood developmental care market.
14. 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.

# Appendices:

## Appendix 1 Family Journey Maps



# Jacqui and Ezra: Perth - WA



## Kathy and Neil: Rural - QLD

### Child Protection

"Told so many lies from the Department. He had no storybook. Key life supporting medical information not shared - he came with nothing. Attrition is so high".

"Department told his Aunty and Uncle someone was taking him, but didnt say who and told to keep their distance Total betrayal and had to keep my mouth shut"



I've worked with 16 different people in 'The Department' but they burn out. They dont share information about Neil "Why bother when attrition is so high".

### Education

"Counsellor went to his school and said no wonder he is not learning... He has a speech support ipad for basic communication but they wont use it".

"School had written him off, but he's so smart. School got comfortable seeing him where he was at".



### Health

"Visiting paediatrician not seen him in a year and now only have access to email. Getting scripts is an issue"

"Doc said he wouldn't survive next heart surgery. They thought he'll be a vegetable. Now Neil is saying mum and da. He's running, playing ten pin bowling and loves his dog. He's up for the challenge."



### Disability

"12 months with no therapist for the whole of last year. We noticed a difference.. More liable to choke and communication frustrations".

"Services swamped with demand, its so hard to get into people and they charge so much".



## Appendix 2 Case Study - Charlie

Charlie is a bright and vibrant 9 year old girl who has sensory needs and does not have a diagnosis. Charlie experiences heightened sensory discomfort, which includes constant itching and a burning sensation, when wearing socks, tights and/or enclosed shoes. In her life outside of school, Charlie does not wear socks, tights or enclosed shoes.

Charlie is in Year 4, and every morning since Kindergarten she and her family have battled the 30 minute ritual of putting her socks and shoes on in the most precise way, so as to cause her the least discomfort. Despite being minimised, the sense of discomfort remains a distraction to Charlie throughout her school day.

Charlie's school has a strict uniform code, and all students must wear socks that can only be purchased through the school uniform shop. This year the China-based supplier of the school socks has supplied incorrectly sized socks. The result was that the smallest size of the girls' formal school socks are so large that they would comfortably fit a high school student. Charlie is very small for her age and the formal socks are enormous on her, sitting all the way up to her knees, rather than just above ankle height.

COVID-19 has interrupted the fresh supply of socks to the school, with the supplier advising that they are unable to supply correctly sized socks until Term One of 2021. Charlie's parents, in witnessing her increasing distress and ongoing discomfort, reach out to school staff to ask if an adjustment could be made for her, such as allowing her to wear the school sports socks in place of the formal socks, and to do so without receiving a demerit for being "out of uniform".

The appeal for adjustment was met with a request from the school for a formal diagnosis, even though Charlie's parents had advised the school that they did not wish to seek a diagnosis for their daughter as they felt the label would likely be more disabling for Charlie than her sensory discomfort was.

The school then instructed the manager of the uniform shop to call Charlie's parents about the socks. This conversation culminated in a request from the manager for Charlie to attend the uniform shop wearing the socks so she could see for herself, despite being told that wearing the socks would cause Charlie emotional distress and physical discomfort. Charlie's parents felt that their testimony wasn't valued by the school, and that socks themselves were a higher priority to the school than their daughter's well-being and ability to thrive in her school environment.

In desperation, Charlie's parents wrote to the School Principal to outline the three weeks of communications they had with the school over the request for an adjustment,

without resolution. During this period, Charlie had been attending school wearing her sports socks and had received several demerits for being out of uniform, which was adding to her emotional distress.

With the matter raised to the level of School Principal, 4 weeks after the initial request to the school for an adjustment Charlie was granted permission to wear sports socks to school in place of the formal socks.

Despite Charlie's parents possessing excellent advocacy skills in seeking what they thought would be a very straight forward adjustment for their child, they felt extremely challenged and frustrated by the way the school responded.

Reimagine Australia believes the medical model of disability, which the standards currently align with, inadvertently results in limitations to the response and support for all children in the education system that have diverse needs.

Charlie's example of a child with sensory needs who does not have a diagnosis and who is denied reasonable adjustments on the basis that she does not have a diagnosis, has been mapped in the table on the next page to succinctly illustrate how the medical model of disability differs in approach and potential outcomes to the social model of disability.

Table: Medical Model vs Social Model of Disability for Charlie

<b>Medical model thinking</b>	<b>Social model thinking</b>
<p><b>“Disability is the problem located in the individual”</b></p> <p>Charlie needs a diagnosis as she is the problem</p>	<p><b>“Disability as a social construct located not in the individual but in the environmental barriers and discriminatory practices of society”</b></p> <p>The school does not have adequate supports and understanding to alleviate environmental factors that are disabling for Charlie.</p>
<p><b>Child is faulty</b></p> <p>Charlie is the problem</p>	<p><b>Child is valued</b></p> <p>Charlie is a valued member of our school community and we want to ensure the environment is enabling for her to thrive.</p>
<p><b>Diagnosis from a professional</b></p> <p>We believe that professionals and labels will prove that Charlie is disabled and has a problem.</p>	<p><b>Strength and needs identified by self and parents</b></p> <p>We trust the voice of Charlie and her parents who know her best and we are responsive to her individual needs. We do not need ‘expert’ advice on how to respond to what support she requires to feel like she can learn and grow here.</p>
<p><b>Labelling</b></p> <p>Charlie needs a label so we can then justify the adjustments that ‘do not fit with our business as usual’</p>	<p><b>Identify barriers and develop solutions</b></p> <p>Let’s work together with the needs Charlie has today so that the environment can support her and other children.</p>
<p><b>Impairments becomes focus of attention</b></p> <p>Charlie needs a diagnosis</p>	<p><b>Outcome based program design</b></p> <p>Charlie has needs that require an outcome for her so she can learn and thrive at school, let’s work together to make this happen as soon as possible.</p>
<p><b>Assessment, monitoring, programs of therapy imposed</b></p> <p>Charlie needs a diagnosis, an assessment and an expert and therapy to fit the mould of the school, that all children have to fit in to.</p>	<p><b>Resources are made available universally to all</b></p> <p>Let’s support Charlie and see if any other children are feeling this way with sensory needs.</p>
<p><b>Segregation and alternative services</b></p> <p>Charlie is to report to the uniform officer and is punished with a demerit for her different needs.</p>	<p><b>Training for parents and professionals</b></p> <p>What training and professional development does the school staff require to support Charlie’s needs.</p>
<p><b>Ordinary needs put on hold</b></p> <p>No compassionate response to her actual needs with focus on her not complying.</p>	<p><b>Relationships nurtured</b></p> <p>How can we build a relationship and trust with Charlie, so she is able to express her needs and reach an outcome?</p>
<p><b>Re-entry if normal enough or permanent exclusion</b></p> <p>Demerits for Charlie until she is suspended or until she ‘follows the rules like all the ‘normal’ &amp; ‘good’ kids’</p>	<p><b>Diversity welcomed Child is included</b></p> <p>Charlie has gifts that are to be celebrated and needs that require support to ensure she belongs and is thriving at our school.</p>
<p><b>Society remains unchanged</b></p> <p>School system churns out compliant, cookie cutter children and we continue to see declining outcomes for children in Australia.</p>	<p><b>Society evolves</b></p> <p>Our society evolves from diverse children of today who are diverse leaders of tomorrow and all people grow up feeling they belong and are celebrated for their individual gifts.</p>



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