

Submission to the Independent Review of the National Disability Insurance Scheme

January 2023

About Noah's Ark Inc

Noah's Ark Inc was established in 1971 by the parents of children with disabilities. It was started to provide community-based support to families who had children with disabilities. It was the end of the routine institutionalisation of children with disabilities. For the past 50 years it focused on young children, with an increasing role in early childhood intervention and inclusion in early childhood services. Noah's Ark has been active in the NDIS since the trial sites. It currently works with children from birth to 14 years in the NDIS and continues to support inclusive educational services.

John Forster has been the CEO of Noah's Ark for the past 20 years. He is a former national President of Early Childhood Intervention Australia. He was a member of the Victorian Disability Advisory Council and the Victorian Government's NDIS Implementation Taskforce. He presents nationally and internationally.

Introduction

Noah's Ark welcomes the opportunity to comment on the Independent Review of the National Disability Insurance Scheme (NDIS). We recognise that the NDIS is a generous funding program. There are many issues for children with disabilities and their families in the way the NDIS is currently implemented.

The purpose of this paper is to discuss the lack of an Australian blueprint or strategy for children with disabilities and their families. The absence of such a policy framework has had a significant impact on both the design of the NDIS and its implementation. While such a strategy should be broader than individual funding programs such as the NDIS, the nature of an NDIS for children means it will be most beneficial when it operates within a framework and design that allows it to complement how children with disabilities are supported within their families, community and learning environments.

The NDIS is a key resource for young children and their families and for children. However, it sits alongside other major systems, particularly education and health. It is unclear how a NDIS market for children can be effectively commissioned without there being clarity about the role of the NDIS within a broader strategy. This includes clarifying its intersection with families, the community, and educational services.

Background

Children with disabilities have been living in the community and with their families, or in care, since the 1970s. Since then, there has not been a national strategy clarifying what children with disabilities might expect from their participation in the community and which agencies are responsible for supporting this to occur. There remains been a multitude of small funding programs, developed at both Commonwealth and State levels which are fragmented and not joined up. For example, the parents of a young child with a disability will likely go through at least four application processes for additional support by the time a child starts school. These include the NDIS and for inclusion support in childcare, preschool and school. Each service uses different eligibility criteria and different language about disability or developmental delays. Prior to the introduction of the NDIS, each State and Territory adopted its own approach to Early Childhood Intervention programs.

In the disability area the main policy approach has been through National, State and Territory Disability Plans. However, the Disability Plans were for adults and did not address issues to do with children and families. The recent Early Childhood Targeted Action Planⁱ is a welcome recognition that more needs to be done. In its present form, it is a series of service-based initiatives rather than a strategy.

The NDIS was developed using the National Disability Strategy as a context. The Australia's Disability Strategy 2021-2031ⁱⁱ continues to be the point of reference for the Independent Review. While this is important in looking at the context of adults, it is not helpful for children.

Strategies for children and young people

While there is no national strategy for children with disabilities, there has been an increase in the number and sophistication of national strategies for children. The most recent, and perhaps comprehensive, is the National Children's Mental Health and Wellbeing Strategy (2021). It builds on the National Action Plan for the Health of Children and Young People (2019), which recognises children and young people living with disability and chronic conditions as a priority group. The National Framework for Protecting Australia's Children (2021) also recognises children and families with complex and multiple needs and children and young people with disability, or parents/ carers with a disability, as two of its four priority groups. The fact that children and young people with disabilities are identified as a priority in other strategies but do not have their own is an anomaly.

What should a national strategy for children need to include?

The current national strategies and action plans for children provide a strong basis for a national strategy for children with a disability.

National Action Plan for the Health of Children and Young People 2020 – 2030

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The National Action Plan for the Health of Children and Young People (NAPH) is helpful in identifying the different dimensions of risk and protective factors for child development and health outcomes, including:

- Individual child
- Parent/carers
- Family
- Community
- Societal factors

It also draws on recent evidence to identify that the optimum opportunities for supporting change during this period of life include:

- A focus on prevention and early intervention particularly in the first 2000 days
- Mitigating other risks factors by enhancing parenting support and skills development to help children and their families at and across the different life stages
- Supporting children and young people to develop skills that help them maintain positive social and emotional wellbeing.

The NAPH identifies key life stages that are important that are:

- Pre- conception to birth and early childhood to the second year of life
- Early education and the transition to school
- School entry to the end of primary school, including the transition to secondary school
- Secondary school to entry into adult life
- 18 – 24 years

Children and young people with disabilities are identified as a priority group in the NAPH because they are more likely to be deprived across multiple wellbeing domains, most commonly health, education and participation. According to the NAPH, approximately 85% of children and young people with a disability attend mainstream schools, but more than 75% of school principals report they do not have enough resources to meet the needs of students with a disability.

National Framework for Protecting Australia’s Children 2021–2031 ^{iv}

The National Framework for Protecting Australia’s Children (NFPC) and its predecessors focus on reducing child abuse and neglect and its intergenerational impacts. The framework is a useful model of a guiding document that focuses on the broader societal responsibilities in its area of concern. It also acknowledges that State and Territory governments manage the child protection systems. Its audience includes all levels of government, non-government organisations, service providers, researchers and Australian families and communities.

A priority for the NFPC is addressing the over-representation of Aboriginal and Torres Strait Islander children in child protection systems.

The NFPC includes children with disabilities in two of its four priority areas. These are:

- Children and families with multiple and complex needs, which can be due to mental health issues, alcohol and drug misuse, domestic and family violence, disability, social exclusion, poverty, housing uncertainty, unemployment and underemployment, and constitute the main clients of child protection services.
- Children and young people with disability and/or parents/carers with disability, with the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability hearing that on average 12% of children in out-of-home care were reported as having a disability which means they are significantly overrepresented.

The NFPC's core principles are consistent with the United Nations Convention on the Rights of the Child (UNCRC). These include:

- non-discrimination
- the right to life
- survival and development
- respect for the views of the child
- a commitment to act in the best interest of the child.

The acknowledgement of the UNCRC is an important in the development of a national strategy for children with disabilities. While the NDIS acknowledges the Convention on the Rights of Persons with a Disability as foundational, its recognition of the UNCRC is limited, including in the current independent review. The UNCRPD was developed earlier and has specific, as well as the general, provisions relating to children with disabilities.

The NFPC also promotes the importance of:

- Access to quality universal and targeted services designed to improve outcomes for children, young people and families
- Excellence in practice and policy development, based on evidence, data and information sharing
- Listening and responding to the voices and views of children and young people, and the views of those who care for them
- Clear responsibilities and strong monitoring, evaluation and achievements of outcomes
- Trauma-informed, culturally safe, and inclusive policies and actions
- Embedding the five elements of the Aboriginal and Torres Strait Islander Child Placement Principle — Prevention, Partnership, Placement, Participation and Connection

National Children's Mental Health and Wellbeing Strategy ^v

The National Children's Mental Health and Wellbeing Strategy (NCMHW) uses an ecological framework. This approach recognises that the people with whom, and places where, a child spends their time most influences their development. The NCMHW has three operational areas of focus and a fourth devoted to system improvement. The four focus areas are:

- *Family and Community*, which recognises the importance of parenting and how services can connect with families and communities better
- *The Service System*, which looks at the gaps in services and how it can become easier for children and their families to get help, particularly when they have multiple complex issues or face barriers to getting help
- *Education Settings*, which highlights the importance of school and early learning environments, and these environments can better set up to support children
- *Evidence and Evaluation*, which looks at how services can improve through feedback from people who have used the services and what additional research is needed.

The NCMHW also has a child orientated set of objectives. They include:

- Child-centred – the interests and needs of children are the priority
- Strengths-based - services builds on child and family strengths, to inform a holistic and family-centred approach
- Prevention – there is a combination of universal and targeted prevention
- Equity and access - all children and families have access to health, education and social services
- Universal - programs and services are developmentally appropriate, culturally responsive and treat children in the context of families and communities
- Evidence-informed – the use of identified best practice supported by continuous quality evaluation
- Early intervention - for those in need
- Needs based, not diagnosis services focused on individual needs and a reduced focus on a diagnosis to access services.

The NCMHW is consistent with the National Action Plan for the Health of Children and Young People in its focus on the importance of parenting. This includes:

- Supporting families with addressing risk factors and challenges from conception to when a child is one year old
- Identifying parents who may be struggling and assisting them
- Promoting parenting programs to all families at key developmental stages as a way of supporting child development
- Providing universal supports, such as parent helplines and courses, which are available in multiple languages
- Reaching out to children not engaging with early childhood learning or primary school and their families.

Insights into children with a disability – Reimagine Australia

Some initial thinking about a national strategy for children with disability has been undertaken by the organisation Reimagine Australia, formerly Early Childhood Intervention Australia. Its project notably involved a broad consultation with families. Its proposed National Action Plan^{vi} included six priority areas:

- Empowered and Resourced - Caregivers supported with information, resources and choice
- Meaningful Participation by children with disability and their families in their networks, communities, learning and work environments
- 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
- Families of children with developmental delay and/or disability receive early childhood support as soon as they require, with or without diagnosis
- Capability and Quality - a skilled, collaborative and diverse workforce that delivers a range of evidence based developmental supports
- Outcomes and Innovation - including meaningful data on developmental and participatory outcomes for children and families

Conclusion

The development of a national strategy for children with disabilities is critical for the development of the NDIS at several levels.

Sustainability

A national framework would help clarify the roles and responsibilities of the numerous government agencies involved in supporting children with disabilities. It would help define the role of the NDIS, which would assist in its sustainability. The NDIS cannot and should not attempt to meet the needs of children with disabilities in isolation. Children with disabilities are a priority focus group across in a number of areas. This includes health and protection, as identified above, and education, which has not been considered here. The one area in which children has not been identified as a priority group is in disability policy.

Aligning the NDIS to what benefits children

A national strategy for children with disabilities would assist the NDIS to design markets which are consistent with what is understood to be beneficial to children. There is a strong consensus about what supports children across the existing national strategies. The existing strategies provide clear guidance to what is effective including: understanding the different dimensions of risk factors, what creates optimum opportunities for support, the importance of key life stages, the importance of recognising the Convention on the Rights of the Child, the use of an ecological approach, the principal that should underpin services for children and the importance of supporting parenting. The main influence on the NDIS appears to be disability

policy and the NDIS has remained adult centric. For example, the NDIA website does not reflect an organisation that works for children. There appears to be inflexibility in adapting the NDIS to better meet the needs, for example by taking a life stages approach. There appears to be an overriding a commitment to one approach for everyone.

Addressing current areas of concern

The way in which the NDIS has been established is having consequences which are not in the interests of children with disabilities or their families. These consequences are related to parent wellbeing, the intersection between the NDIS and schools and service coordination.

Family wellbeing

There is growing information that the wellbeing of parents and carers looking after children in the NDIS is declining each year they are in the NDIS. The NDIA's 2021 report on outcomes for families and carers indicated that for each year the parents of children aged 0 -14 years were using the NDIS:

- their rating of their health declines
- they have a declining number of people they can ask for practical help
- there is no change in the number of people from whom they can ask for emotional support

Parents rating of their health for parents in the NDIS between 2017 and 2021 showed a decline of 13.3%.

Similar results were found in the early evaluation of the NDIS undertaken by Flinders University in 2018. That evaluation found that while the NDIS led to some improvement in the wellbeing of participants, there was no improvement in the wellbeing of families and carers generally, and it had a negative impact on the wellbeing of those caring for children.

Educational services

As identified in the frameworks about, one of the areas that are important to address in the lives of children are educational settings. The main places that children live in are at home and in childhood services such as preschools and schools. These are now split between the Commonwealth NDIS and the State run early childhood and school services. In the introduction of the NDIS there was an agreement to work closely at the local level to plan coordinated streamlined services for individuals requiring both school education and disability services. The NDIS market model means there are no clear expectations about how NDIS funded services should interact with children's services or schools. Similarly, schools make their own decisions about coordination. The result is one of three interactions between the services:

- no interaction
- a service based on withdrawing the child from their activities
- a level of cooperation.

In the worst-case scenarios this has led to situations which are detrimental to a child's development, including a child who has one behaviour support program for school and a different one at home and a child who has one communication device at school and a different one at home.

Coordinated services

One of the features of children's services in general has been recognition of the need to have a coordinated service response. There is significant anecdotal evidence that the NDIS is encouraging participants to have multiple service providers with the result that there is limited communication.

A better future

A NDIS that operates within the context of a national framework for children with disabilities would be designed in a way that complements the other components of a child's life, including their family, community, and educational settings. That would lead to a truly world class service.

Attached paper

The consequences discussed above and a discussion of a broader context for this paper can be found in the attached paper **Policy to practice: Implementing an Australian vision for children with disabilities** by John Forster, CEO, Noah's Ark Inc. Presentation to PRECI inaugural national conference, 17 – 19 November, 2022.

References

ⁱ Australia's Disability Strategy 2021-2031 - Early Childhood Targeted Action Plan

<https://www.disabilitygateway.gov.au/sites/default/files/documents/2021-12/1886-tap-early-childhood.pdf>

ⁱⁱ Australia's Disability Strategy 2021-2031

<https://www.disabilitygateway.gov.au/sites/default/files/documents/2021-11/1786-australias-disability.pdf>

ⁱⁱⁱ National Action Plan for the Health of Children and Young People (2019)

[https://www1.health.gov.au/internet/main/publishing.nsf/Content/4815673E283EC1B6CA2584000082EA7D/\\$File/FINAL%20National%20Action%20Plan%20for%20the%20Health%20of%20Children%20and%20Young%20People%202020-2030.pdf](https://www1.health.gov.au/internet/main/publishing.nsf/Content/4815673E283EC1B6CA2584000082EA7D/$File/FINAL%20National%20Action%20Plan%20for%20the%20Health%20of%20Children%20and%20Young%20People%202020-2030.pdf)

^{iv} National Framework for Protecting Australia's Children 2021–2031

https://www.dss.gov.au/sites/default/files/documents/12_2021/dess5016-national-framework-protecting-childrenaccessible.pdf

^v National Children's Mental Health and Wellbeing Strategy

<https://www.mentalhealthcommission.gov.au/getmedia/5b7112be-6402-4b23-919d-8fb9b6027506/National-Children%E2%80%99s-Mental-Health-and-Wellbeing-Strategy-%E2%80%93-Report>

^{vi} Reimagine Australia proposed National Action Plan

<https://engage.dss.gov.au/wp-content/uploads/2020/11/Reimagine-Australia-Submission-National-Disability-Strategy-October-2020.pdf>