



# **Submission to inform a new National Disability Strategy**

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## **About Noah's Ark**

Noah's Ark is a non-government organisation that was founded in 1971. We provide services to children with disabilities and other additional needs (0-12 years) and their families and carers.

Noah's Ark provides National Disability Insurance Scheme (NDIS) services from 20 locations across metropolitan and regional Victoria, ACT and Albury NSW. Last year these programs reached over 2,500 families. We have been involved in NDIS from its commencement, in the Barwon and ACT trials.

Noah's Ark is also involved in the Victorian Kindergarten Inclusion Support, Pre-School Field Officer and Parent to Parent Programs. We provide training and resources nationally and internationally.

Noah's Ark has played a major role in the introduction of best practice services and support for inclusion in children's services for young children with a disability in Victoria and nationally. We have strong links to early childhood intervention researchers and fields internationally.

Noah's Ark welcomes the opportunity to comment on the development of the next National Disability Strategy (NDS).

*John Forster CEO*

## Introduction

According to the last National Disability Strategy (NDS)<sup>1</sup>, the purpose of an NDS is to:

- establish a high level policy framework to give coherence to, and guide government activity across mainstream and disability-specific areas of public policy
- drive improved performance of mainstream services in delivering outcomes for people with disability
- give visibility to disability issues and ensure they are included in the development and implementation of all public policy that impacts on people with disability
- provide national leadership toward greater inclusion of people with disability.

Its role is to provide a unifying vision across services and community, supporting the transition from the social exclusion of the institutional period towards the inclusion and participation promoted by a human rights framework.

The previous NDS was developed amidst recognition of how far Australia still had to travel in that transition. The Strategy was developed following extensive consultation conducted in 2008-09 by the National People with Disabilities and Carer Council, which led to their landmark report *Shut Out: The Experience of People with Disabilities and their Families in Australia*.<sup>2</sup> The key message of the report was that while people with a disability were no longer shut in institutions, they remained shut out of the broader community.

The framework adopted in the last Strategy recognised the breadth of areas impacting on the lives of people with disabilities and the magnitude of changes that were still required.

The policy areas identified were:

- Inclusive and accessible communities
- Rights protection, justice and legislation
- Economic security
- Personal and community support
- Learning and skills
- Health and wellbeing

Each area addressed a range of individual and social opportunities and choices.

The context for the current Strategy is significantly different, although the underlying issues are not.

The past decade has seen a major reform in services for people with disabilities with the introduction of the National Disability Insurance Scheme (NDIS). The NDIS has been celebrated for introducing generational change, including substantially increasing the level of funding available and shifting to a market model aimed to increase the 'choice and control' of people with disabilities. The new market model has significantly and intentionally disrupted the previous services available to people with disabilities. Currently, approximately half of the participants in the NDIS are between the ages of 0-18 years. 16% of participants are in the 0-6 years age group.<sup>3</sup> The NDIS was considered the most significant reform since the introduction of a national health system and the ramifications of change of this scale we continue to require attention for the period of the next NDS.

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<sup>1</sup> Australian Government. (2011). *2010–2020 National Disability Strategy*. Retrieved from:

[https://www.dss.gov.au/sites/default/files/documents/05\\_2012/national\\_disability\\_strategy\\_2010\\_2020.pdf](https://www.dss.gov.au/sites/default/files/documents/05_2012/national_disability_strategy_2010_2020.pdf)

<sup>2</sup> Deane, K. (2009). *Shut out: the experience of people with disabilities and their families in Australia*. *National Disability Strategy Consultation Report*. The National People with Disabilities and Carer Council: Commonwealth of Australia, Canberra.

<sup>3</sup> National Disability Insurance Scheme. (2020). *NDIS participant data*. Retrieved from <https://data.ndis.gov.au/explore-data/participant-data>

The introduction of the NDIS has changed the role of State and Territory governments in relation to people with disabilities by reducing their responsibility for the administration of direct services. The role State and Territory Governments previously played in providing practical assistance brought them in touch with the barriers that people with disability face and the need for policy reform. In this new environment, there are two questions. How will State and Territory governments remain engaged in policy issues? What are the challenges created by the new divide between the level of government providing direct support for people with disabilities and the level of government providing support for many of the mainstream social and community services? The new NDS can support the bridging of this gap.

The third contextual factor is that the new Strategy is being developed at a time when the Disability Royal Commission is investigating widespread reports of violence against, and the neglect, abuse and exploitation of, people with disability. The Disability Royal Commission is investigating how Australian society might better prevent and protect people with disability from the experience of violence, abuse, neglect and exploitation, how to better respond to these occurrences and how to promote a more inclusive society that supports people with disability to be independent and free from different forms of abuse. The scope of the Royal Commissions investigations includes family homes, schools, workplaces, day programs, group homes or boarding houses, jails and detention centres, secure disability and mental health facilities and hospitals. The issues identified by the Royal Commission will shape our understanding of the needs of people with disabilities.

## **The National Disability Strategy and Children**

The focus of our submission is the role of the NDS in promoting the opportunities and choices of children and young people aged between 0 – 12 years, or the period from birth to the end of primary school. As well as having a professional interest in this age group, we understand that it is foundational to the developmental and social opportunities of an individual. What an individual experiences during this time will shape their expectation about what is possible in the future. One of the critical messages from both a rights perspective and an educational perspective is the importance of high expectations.

Our broad observations are that:

- The development of a coherent policy framework to guide governments at all levels and across mainstream and disability-specific areas following the disruption of the NDIS is now essential.
- Identifying and delivering outcomes for children with disability across mainstream and specialist services is vital.
- The visibility of disability issues for children within the broader family and children policy area needs specific attention given changes in governmental responsibilities.
- National leadership toward greater inclusion of children with disability is critical.

We support the framework of the last Strategy, although there was insufficient detail on the issues faced by children, young people and their families. Importantly, the Strategy recognised the principles of the Convention on the Rights of Persons with Disabilities (CRPD): ‘respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.’<sup>4</sup> (p. 22)

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<sup>4</sup> United Nations (2007). *Convention on the Rights of People with Disabilities*.

It also reported that the National Framework for Protecting Australia's Children 2009–2020 included enhanced support for children or parents with a disability to protect their rights, particularly the right to a safe, healthy childhood free from abuse and neglect.<sup>5</sup>(p. 40)

Within the actual policy areas of the last NDS, there was an adult-centric approach.

In policy area four in the Strategy, 'Personal and community support', there is an acknowledgement of the important role of families and carers. However, the discussion does not recognise the critical role of families and carers in supporting the development of children and young people. The relationship between family and people with disability is discussed as one of mutual support, which does not recognise the level of dependence involved in the care of children. The important and ongoing role of families as carers is discussed, but not their role in supporting their child's development.

In policy area five, 'Learning and skills', there is an important discussion of reducing the gap between students with disability and other students and how essential this is to improve the social wellbeing and economic security of people with disability, their families and carers. However, this section did not acknowledge the ongoing problem of Childcare in Australia being identified as a labour market program and thereby avoiding a commitment to the inclusion of children with a disability on a basis which supports their development alongside their peers. Another focus is on improving pathways for students with a disability, however, this section does not address the transition to school and the continued pressure on families to put their children into specialist settings, rather than join the mainstream, based on historical attitudes, levels of resources and the preferences of schools.

In policy area six, 'Health and wellbeing', the critical importance of early intervention and rehabilitation for people with disability is identified. However, there is no acknowledgement of the role of early intervention for children, which may reflect the Commonwealth's lack of involvement in this area. The Strategy does note the Commonwealth Governments involvement in the Helping Children with Autism initiative. That initiative was introduced as supplementary to the existing family centred early intervention services provided by State and territory governments. It adopted a medical or therapy focus. Some of its components, such as establishing eight Autism Specific Early Learning Centres across Australia, have been regarded as contrary to a commitment to inclusion<sup>6</sup>.

## **The new National Disability Strategy**

The components needed for the next NDS to represent the interests of children and young people include:

- A focus on the rights of the child, specifically the Convention on the Rights of the Child<sup>7</sup>
- An acknowledgement of the nature of childhood, the developing child and the importance this has for future opportunities and choices
- An acknowledgement of the role of families during childhood
- A commitment to the voice of the child
- A commitment to inclusive education and childcare
- Integrated policies, plans, programs, and service systems

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<sup>5</sup> Ibid

<sup>6</sup> Mackenzie, M., Cologon, K., & Fenech, M. (2016). 'Embracing everybody': Approaching the inclusive early childhood education of a child labelled with autism from a social relational understanding of disability. *Australasian Journal of Early Childhood*, 41(2), 4-12.

<sup>7</sup> Assembly, U. G. (1989). *Convention on the Rights of the Child*. United Nations, Treaty Series, 1577(3).

## 1. Children's rights

Children with a disability share universal rights with all people as described in the Universal Declaration of Human Rights (UDHR)<sup>8</sup> and share the additional rights of all children as identified in the Convention on the Rights of the Child (CRC).<sup>9</sup> They also have specific rights as expressed in the Convention on the Rights of Persons with Disabilities (CRPD).<sup>10</sup>

The first human rights treaty to devote an article concerning children with disabilities was the CRC. The CRC and CRPD have been written to operate in tandem<sup>11</sup>, with links between the two outlined in the CRPD preamble which recognises that:

*...[C]hildren with disabilities should have full enjoyment of all human rights and fundamental freedoms on an equal basis with other children and recalling obligations to that end undertaken by States Parties to the Convention on the Rights of the Child.*<sup>12</sup>

In 2019, the Australian Human Rights Commission published a scorecard which tells the story of how well children's rights are protected and promoted across Australia and indicated that:

*"while most Australian children live in safe and healthy environments and do well, there are some groups of children whose rights are not adequately protected, which impacts negatively on their wellbeing and ability to thrive. This includes Aboriginal and Torres Strait Islander children, children with disability, those from culturally and linguistically diverse backgrounds, and lesbian, gay, bisexual, trans and intersex (LGBTI) children".*<sup>13</sup>

The NDS Position Paper indicates that the current NDS (2010-2020) is the primary mechanism through which Australia implements its obligations under the CRPD. The new NDS needs to recognise Australia's obligations as a party to the CRC and the interaction between the CRC and CRPD. This is in line with the concluding observations of the CRPD on the combined second and third periodic reports of Australia. The committee recommends that the Australian government:

*"Include a focus on the rights of children with disabilities in any national plan of action for the realization of the rights of the child".*<sup>14</sup> (p4. Article 7. 14a)

Concluding comments from a recent paper by McCallum (2020) that provides as assessment of Australia's level of compliance on the CRPD and endorses the committee's recommendation:

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<sup>8</sup> Assembly, U. G. (1948). *Universal declaration of human rights*. UN General Assembly, 302(2).

<sup>9</sup> Ibid

<sup>10</sup> Ibid

<sup>11</sup> McCallum, R. (2020). *The United Nations Convention on the Rights of Persons with Disabilities: An Assessment of Australia's Level of Compliance*. Retrieved from: <https://disability.royalcommission.gov.au/publications/united-nations-convention-rights-persons-disabilities-assessment-australias-level-compliance>

<sup>12</sup> Ibid

<sup>13</sup> Ibid

<sup>14</sup> Ibid

*“ It is suggested that to fully comply with article 7 of the CRPD, the Australian Government should examine its policies and relevant legislation, in order to take steps to incorporate the human rights approach to children with disabilities into its policies, plans and frameworks”.<sup>15</sup>*

**Recommendation:**

That the NDS formally acknowledge the Convention on the Rights of the Child.

## **2. An acknowledgement of the nature of childhood**

Good practice in the provision of services and supports for children with a disability has a dual focus: promoting their learning, development, well-being and increasing independence, and building the capacity and supporting the wellbeing of their family.<sup>16</sup>

For children with a disability, the aim of services and support is to promote the child's development of functional skills that will enable them to participate meaningfully in family, education, and community life. Not providing such support effectively can incur costs in several ways:

- In some instances, providing support early in life can address an emerging developmental problem so effectively that the problem is resolved, and the child no longer needs more intensive levels of support. Without such support, problems will escalate and become increasingly difficult (and costly) to manage.
- In most instances, children's developmental disabilities are not transient and are sufficiently severe to require ongoing support. Appropriate services and support early in life can ameliorate the impact of the developmental disabilities on children's development and ability to participate meaningfully, thereby reducing the demands on the family and other services, and their associated costs.
- Children with developmental disabilities are at their most vulnerable when they are very young and their relationship with their caregivers is just developing and most at risk of being compromised. When relationships and attachment with the key adults in the child's life are not secure, there are lifelong negative implications.

Overall, the failure to provide effective services and supports for children with disabilities will have long term negative consequences for their development and capacity to participate with their family, education settings and broader community. It will result in them needing more costly forms of care and support across the life span.

**Recommendation:**

That the NDS specifically acknowledge the nature of childhood.

## **3. An acknowledgement of the role of families during childhood**

Children are legally, functionally, and emotionally dependent on their families, and their wellbeing is profoundly inter-twined with family wellbeing. For families, good practices support quality of life and builds parent capabilities during the difficult period

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<sup>15</sup> Ibid

<sup>16</sup> Early Childhood Intervention Australia (2016). *National guidelines: Best practice in Early Childhood Intervention*. Retrieved from <https://www.ecia.org.au/Resources/National-Guidelines-for-Best-Practice-in-ECI>

starting from the identification of the child's developmental disability, seeking diagnosis, the realisation of the potential implications of the condition and their ongoing role in raising their child to thrive. Families of children with a disability experience a range of additional stressors, including: the need to for more information about their child and what to do; interpersonal and family distress; the need for additional resources and threats to their confidence in parenting their child.<sup>17</sup> The impact of these stressors varies according to the experiences of parents, the size of family networks and the resources available to them. The stressors experienced by the parents or carers of young children with a disability are in addition to the significant demands of raising any child. Stressors can reduce the ability of families to provide the essential developmental experiences needed by children to grow and learn successfully.<sup>18</sup> When effective support is not provided, there are likely to be worse outcomes for the family and the wider society. These can take several forms:

- The demands of parenting a child with developmental disabilities often prevents one of the parents (usually the mother) from working, thereby reducing both the family income and the contribution that the family makes to social productivity as workers and taxpayers.<sup>19</sup>
- Having a child with developmental disabilities increases the level of stress on parents, leading to higher incidence of depression and other stress-related conditions, all of which have additional treatment costs to society.<sup>20</sup>
- Children with developmental disabilities are more likely to be neglected or abused<sup>7</sup>, with adverse effects upon their development and well-being and higher societal costs in the form of child protection and other services.<sup>21</sup>
- In some instances, families find the experience of having a child with a disability so burdensome that they relinquish the child into state care, which has a very high cost.

Overall, the failure to provide appropriate and effective support to families will lead to poorer outcomes for children and their family, and additional costs will be borne by the family and the wider society.

Furthermore, the introduction of the NDIS has led to a loss of best practice. The new NDS needs to include a commitment to ways of engaging with children and young people with disabilities and their families that promotes their capabilities, addresses their priorities, and works in their everyday environments

#### **Recommendation:**

That the NDS acknowledge the role of families during childhood.

## **4. Child Voice**

The voices of children with a disability are often missing from policy, research, compliance frameworks, service provision and programming. It has been proposed that the social

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<sup>17</sup> Guralnick, M. J. (2019). *Effective Early Intervention: The Developmental Systems Approach*. Brookes Publishing Company. PO Box 10624, Baltimore, MD 21285.

<sup>18</sup> Ibid

<sup>19</sup> Australian Bureau of Statistics. (2012). *Australian Social Trends*. Retrieved from <https://www.abs.gov.au/AUSSTATS/abs@.nsf/Lookup/4102.0Main+Features30Jun+2012>

<sup>20</sup> Totsika, V., Hastings, R., Emerson, E., Lancaster, G., & Berridge, D. (2011). A Population-Based Investigation of Behavioural and Emotional Problems and Maternal Mental Health: Associations with Autism Spectrum Disorder and Intellectual Disability. *Journal of Child Psychology and Psychiatry*, 52(1), 91-99.

<sup>21</sup> Moore, S., Scott, J. G., Ferrari, A. J., Mills, R., Dunne, M. P., Erskine, H. E., . . . Norman, R. E. (2015). Burden attributable to child maltreatment in Australia. *Child Abuse & Neglect*, 48, 208-220. 6

constructs of Adultism and Ableism may be to blame.<sup>22</sup> Adultism suggests that the voices of children in general are not commonly sought as adults doubt their ability to provide accurate and useful information. Ableism compounds this missing voice when children have a disability. Adults are often asked to speak on behalf of children, rather than supporting them to make decisions and contribute.<sup>23</sup> These assumptions need to be challenged if we are to uphold children's rights and safety, and scaffold supports in order for them to play a genuine role in decision-making. Ultimately, we need to support children and young people to fully exercise their rights and ensure we continue to evolve our services to best meet their needs by seeking their input on decisions that are important to them. We need to not only provide children with the opportunity to communicate ideas and opinions, but also the power to influence change. The vision of the NDIS is of fully empowered adults with disabilities able to make choices as to the services they receive. To arrive at adulthood able to play such a role, children need to be given more and more of a say about their care and education as they get older. This pathway to empowerment needs to be articulated and built into all procedures.

There are good examples from the early childhood field in Australia of ways in which children can be supported to express their views on matters that affect their rights or interests appropriate to their developmental ability. The Victorian State Government, amongst many others, also provides guidance and resources to empower children through voice, agency, and leadership.<sup>24</sup>

Data from the NDS Consultation report indicates that "there was a good representation of different ages among respondents" to the standard online survey.<sup>25</sup> However, it appears that only 0.3% of respondents to the survey were under the age of 18 years. It is unclear the extent to which children and young people with disabilities participated in the face-to-face workshops and therefore helped to inform the Position Paper. The possibility that children will be under-represented in the development of the NDS is a concern, not only for young people with a disability who may increasingly have a voice in matters that are important to them, but also for younger children who can contribute in ways appropriate to their evolving capacities.

The NDS needs to develop mechanisms for the Strategy to be informed by children and young people with a disability. This is in line with the CRPD committees concluding observation on the combined second and third periodic reports of Australia in 2019, noted a lack of disability- and age-appropriate assistance for children with disabilities to participate and express their views. The committee recommended that the State party:

*"Amend all legislation to guarantee that children with disabilities are provided with age-appropriate support and accommodations to express their views in all matters that affect their rights or interests".<sup>26</sup>*

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<sup>22</sup> Stafford, L. (2017). 'What about my voice': emancipating the voices of children with disabilities through participant-centred methods. *Children's Geographies*, 15(5), 600-613.

<sup>23</sup> Moore, T., McArthur, M., Noble-Carr, D., & Harcourt, D. (2015). *Taking us seriously: Children and young people talk about safety and institutional responses to their safety concerns. A report for the Royal Commission into the Institutional Responses to Child Sexual Abuse*. Institute of Child Protection Studies and Australian Catholic University.

<sup>24</sup> State Government of Victoria. (2016). *Amplify: empowering students through voice, agency and leadership*. Retrieved from:

<https://www.education.vic.gov.au/Documents/school/teachers/teachingresources/practice/Amplify.pdf>

<sup>25</sup> The Social Deck Pty LTD. (2019). *Right to opportunity: Consultation report to inform the next national disability strategy*. Retrieved from: <https://www.dss.gov.au/disability-and-carers-a-new-national-disability-strategy-reports/right-to-opportunity-consultation-report-to-help-shape-the-next-national-disability-strategy-full-report>

<sup>26</sup> Ibid

Concluding comments from a recent paper by McCallum (2020) which provides an assessment of Australia's level of compliance on the CRPD supports this recommendation and states that:

*“ It is suggested that to fully comply with article 7 of the CRPD, the Australian Government should ...provide children with disabilities with age appropriate assistance to express their views, not solely in family disputes, but in all aspects of life, having regard to their evolving capacities”.*<sup>27</sup>

Supporting children with a disability to develop their skills and confidence in communicating their views is a step towards children playing a genuine role in decision-making, ultimately fully exercising their rights.

**Recommendation:**

That the NDS is informed by children and young people with a disability through targeted engagement strategies.

## **5. Inclusive education and childcare**

There has been a growing focus on children's access to universal services since the 80's when children were routinely segregated and institutionalised. Since that time, we have moved beyond thinking about access, to better understanding the principles of inclusion and participation described in the CRC, CRPD and General Comment No 4. on the 'Right to inclusive education'.<sup>28</sup> These approaches have now been clearly articulated and supported through national policies and frameworks that provide a strong foundation for children's inclusion and participation.

The NDS Position Paper shows a commitment to developing and supporting the capacity of people with a disability to participate in community life and proposes that the outcome area of 'inclusive and accessible communities' continues in the 2020-2030 Strategy. However, there is no reference to how participation relates to the particular needs of children. For children, participation is key to their learning, development, and wellbeing. Their participation begins in interactions with parents and expands to include participation in family life, early childhood education programs, schools, and community activities. Children's inclusion and participation need to be at the very forefront of the NDS in order to guide governments, particularly in relation to children's inclusion and participation in education settings, through the development of a National Inclusive Education Plan.

Formal education in early childhood programs and schools is an integral part of life for most children. All children have the right to an education without discrimination based on equal opportunity under international law as described in the CRPD and General Comment No 4. on the 'Right to inclusive education'.<sup>29</sup> However, access and participation are not always available to all children.

The children that most commonly miss out on early childhood education programs are those with a disability or developmental delay and those from low socioeconomic circumstances at

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<sup>27</sup> Ibid

<sup>28</sup> UN Committee on the Rights of Persons with Disabilities (2016). *General comment No. 4. Article 24: Right to inclusive education.*

<sup>29</sup> Ibid

risk of abuse, neglect and developmental disadvantage.<sup>30</sup> Children from Culturally and Linguistically Diverse (CALD) backgrounds also access early childhood education programs at lower rates.<sup>31</sup>

Furthermore, exclusion and segregation continue to be a significant problem.

The UN General Comment No 4. differentiates between:

- Exclusion – when a child is directly or indirectly excluded from or denied access to education
- Segregation - when the only option open to a child with a disability is an isolated program for children with a disability
- Integration – when a child can attend an educational setting along with other children, but the program is pre-established and will not be adapted to consider the child's needs as a learner
- Inclusion – when there is systematic modification or adaptation of all the elements of an educational program so all students have relevant learning experiences.<sup>32</sup>

Decades of research has demonstrated that an inclusive education has benefits for the academic, communication, social and behavioural development of children with a disability.<sup>33</sup> Benefits for their peers, their teachers and the broader community are also reported in the literature.<sup>34</sup> However, parents of children with disability have reported experiencing considerable resistance and extensive gatekeeping practices when enrolling their child in mainstream school.<sup>30</sup> Special school placements in Australia have substantially increased following the introduction of the Disability Discrimination Act (DDA) and students are segregated at significantly higher rates than the wider group of students with a disability, and the rate at which their segregation is rising is much more rapid.<sup>31</sup> In Australia, the number of special schools for students with disability has increased from 4.1% of all schools in 1994<sup>32</sup> to 5.1% in 2019.<sup>35</sup>

The Committee on the CRPD<sup>36</sup> indicates that the right to inclusive education is a fundamental human right of all learners and poses challenges to our practices in Australia. For example, the CRPD indicates that education is the right of the individual learner, and a child's right to inclusive education takes precedence over the responsibilities of parents and carers. In Australia it is the parent's choice whether to enrol their child in a mainstream or specialist and segregated school.

Secondly, the Committee comments on the responsibility of education settings to make 'reasonable adjustments.' In Australian anti-discrimination legislation requires educational settings to make 'reasonable adjustments' to include students with a disability. However, there is considerable debate about what is 'reasonable', particularly what is a 'reasonable' cost. The Committee clarifies that a lack of resources or financial crisis is not sufficient justifications for a failure to make progress towards inclusive education.

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<sup>30</sup> Gilley, T., Tayler, C., Niklas, F., & Cloney, D. (2015). Too late and not enough for some children: Early childhood education and care (ECEC) program usage patterns in the years before school in Australia. *International Journal of Child Care and Education Policy*, 9(1), 9.

<sup>31</sup> Baxter, J., & Hand, K. (2013). *Access to early childhood education in Australia*. Melbourne: Australian Institute of Family Studies.

<sup>32</sup> Ibid

<sup>33</sup> Hehir, T., Grindal, T., Freeman, B., Lamoreau, R., Borquaye, Y., & Burke, S. (2016). *A Summary of the Evidence on Inclusive Education*. Abt Associates.

<sup>34</sup> Ibid

<sup>35</sup> Australian Bureau of Statistics. (1994). *Schools Australia*, 4221.0. Retried from: <http://abs.gov.au/AUSSTATS/abs@.nsf/allprimarymainfeatures/658A4AC9E30714AACA25722E001A3AB7?ope ndocument>

<sup>36</sup> Ibid

The Committee also notes that under international law there is an imperative on schools to achieve the rights of people with a disability to inclusive education in the quickest way possible. It observes that funding both mainstream and specialist/segregated settings when resources are scarce is incompatible with making maximum progress towards inclusive education. However, slow progress on inclusion is often blamed on a lack of resources while state and territories continue to build new specialist schools.

In its Concluding Observations on Australia's Initial Report to the CRPD Committee the CRPD Committee was concerned that:

*"... [S]tudents with disabilities continue to be placed in special schools and that many of those who are in regular schools are largely confined to special classes or units. ... [And] that secondary school completion rates for students with disabilities are about half those for people without disability".<sup>37</sup>*

The CRPD Committee recommended that Australia:

*"Increases its efforts to provide reasonable accommodation ... Conducts research into the effectiveness of current education inclusion policies ... [and] sets targets to increase participation and completion rates by students with disabilities in all levels of education and training".<sup>38</sup>*

The CRPD Committee also recommended that a national action plan for inclusive education be developed.<sup>37</sup>

Children's inclusion and participation need to be at the very forefront of policy and practice.

**Recommendation:**

That the NDS guides governments and the broader community in actions and reforms to ensure policies, programs and services remove barriers to an inclusive education for children with a disability, through a National Inclusive Education Plan.

## **6. Integrated policies, plans, programs, and service systems**

The NDS has an important role in guiding governments to make sure all their policies, programs and services consider the needs of people with disability. It also has an important role in supporting the clarification of roles and responsibilities and the development integrated policies and outcomes of at various levels of government across disability policy and service delivery.

In particular, there is an important role for the NDS to play in assisting a cohesive approach between different level of government to best provide opportunities and choices across specialist and mainstream services. The NDIS has disrupted the connection between specialist and mainstream services, particularly for children and young people. Children and young people spend most of their time outside their family in early childhood services and schools, which, except for childcare, are administered by State and Territory governments. Early childhood educational services and schools function within State and Territory policy frameworks.

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<sup>37</sup> Ibid

<sup>38</sup> Ibid

In championing an NDIS, the Productivity Commission called the services for people with disabilities: underfunded, unfair, fragmented, and inefficient.<sup>39</sup> The NDIS has brought together payments for disability supports within one organisational structure. It has also changed the interface between disability supports and mainstream services in ways which risk different forms of fragmentation and inefficiency.

Developing new mechanisms for joining up levels of government and specialist and mainstream services is now a priority. There are different ways that this can be accomplished. The development of overarching policy frameworks which provide shared outcomes is one model. Another is introducing planning requirements that ensure the individual is at the centre of services, and funding programs work together to meet needs and reduce gaps. The NDS, and its linkages with the State Disability Plans, provides an important opportunity to put in place mechanisms for joining up supports.

The development of mechanisms for joining up supports is critical for children. Early childhood disability services, or early childhood intervention, previously shared a policy platform with mainstream children's services, particularly when early childhood intervention was managed within Education Departments. Within the State policy framework, programs for children with disabilities were part of a continuum of services for families and children. The introduction of the Australian Early Years Learning Framework (EYLF)<sup>40</sup> created a set of outcomes for the development of all children and developed a shared language and purpose across all professional working with young children. This encouraged collaboration and a holistic view about how to support a child's development.

The learning outcomes for young children were:

- Children have a strong sense of identity
- Children are connected with and contribute to their world
- Children have a strong sense of wellbeing
- Children are confident and involved learners
- Children are effective communicators

The EYLF embedded an understanding of child development that included family, community, culture and place, and the importance of relationships, particularly within families, to a child's early development. It recognised that over time children develop their own interests and develop their own identities and understandings of the world.

The risk that is introduced by the NDIS and disability supports sitting in a different level of government is a policy disconnect between the purpose of specialist and mainstream services. Rather than disability supports being relevant to, and therefore supportive of, participation in mainstream services, they become an end in themselves. Professionals in specialist services do not have shared frameworks and language through which to communicate with professionals in mainstream services. Families are confused by different languages, advice, and priorities.

There is only the one child who should be being supported to participate to the best of his or her ability in both specialist and mainstream services. It is the combined impact of these services that will most benefit the child. However, without a commitment to achieving the same outcomes, services end up being driven by their own agenda, exposing a child to competing priorities which are confusing and inefficient.

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<sup>39</sup> Productivity Commission (2011). *Disability Care and Support, Report no. 54*, Canberra.

<sup>40</sup> Australian Government Department of Education (2019). *Being, Belonging, Becoming: Early Years Learning Framework*. Retrieved from: [https://www.acecqa.gov.au/sites/default/files/2018-02/belonging\\_being\\_and\\_becoming\\_the\\_early\\_years\\_learning\\_framework\\_for\\_australia.pdf](https://www.acecqa.gov.au/sites/default/files/2018-02/belonging_being_and_becoming_the_early_years_learning_framework_for_australia.pdf)

The risks in this situation is evident in the following description of what the NDIS and school system will support. The following comes from the NDIS website.

#### **The NDIS funds**

- Self-care at school related to the student's disability, like support with eating.
- Specialised training of teachers and other staff about the specific personal support needs of a student with disability.
- Specialist transport required because of the student's disability (does not substitute parental responsibility).
- Transportable equipment such as a wheelchair or personal communication devices.
- Therapies a family and school have agreed may be delivered during school time but are not for educational purposes.

#### **Education systems fund**

- Teachers, learning assistants and other supports such as Auslan interpreters.
- General support, resources and training for teachers, tutors and other staff.
- Therapy delivered in schools for education or training purposes, such as allied health practitioners helping teachers and trainers adjust curriculums.
- Aids and equipment to make curriculums accessible, such as modified computer hardware, software and Braille textbooks.
- Adjustments to buildings such as ramps, lifts and hearing loops.
- Transport for educational or training activities such as excursions, field trips and sporting carnivals.
- Day-to-day supervision of students at school, including behavioural support.<sup>41</sup>

This problem is not restricted to Australia or to the NDIS. The UK Government has tried to address it through the introduction of Education, Health and Care (EHC) plans. These plans are for children and young people aged up to 25 who need more support than is available through special educational needs support. The EHC plans identify educational, health and social needs and set out the additional support to meet those needs. They require a cooperative process across the three departments involved to meet the individual needs of the child or young person and ensure the structure of departmental programs do not create gaps.<sup>42</sup>

The success of the NDS for children with a disability and their families depends on a strong interface between the NDIS and mainstream services. A new policy framework that reinvigorates cooperation and coordination between mainstream services, community programs and supports provided through the NDIS is essential. This includes the development of policies that articulate how all state, territory and national government departments and community services can contribute to enhancing the opportunities and participation of children with a disability. Reforms must ensure the participation and contribution of children with a disability in the same community activities, early childhood services and schools as their typically developing peers. This aspiration needs to be supported by clear, consistent, and accountable approaches to increasing the participation of children with a disability.

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<sup>41</sup> NDIS: <https://www.ndis.gov.au/understanding/ndis-and-other-government-services/education>

<sup>42</sup> Government of United Kingdom. *Children with special educational needs and disabilities: Education, Health and Care (EHC) plans*. Retrieved from: <https://www.gov.uk/children-with-special-educational-needs/extra-SEN-help#>

This important issue has been recognised by the Australian Government in its recent review of the NDIS Act:

*“Rather, it should be recognised that the Strategy’s focus on improving mainstream services and community access will be vital to ensuring the long-term viability and effectiveness of the NDIS in improving outcomes for people with disability. This is because people with disability use a broad range of Commonwealth, state and territory government-funded services and supports that are outside the scope of the NDIS and all governments have an ongoing responsibility to support the accessibility and inclusion of people with disability in all aspects of their community”.<sup>41</sup> (p.178)*

The NDS Position Paper suggests there is a need for “*all governments to work toward aligning the timeframes of their disability inclusion plans to allow for a nationally consistent approach to implementation, reporting and review*”.<sup>42</sup> Aligning the NDS with state and territory disability plans, including the timeframes, is important. In relation to children with a disability and their families it is also important to ensure the national and state disability plans align with frameworks that relate to children.

### **Recommendations:**

That the NDS includes the development of a National Early Years (0-8 years) Disability Development Framework, that combines general and disability specific development to provide a unifying policy framework.

That the NDS includes the development of a National Children and Young Peoples (9 – 18 years) Disability Development Framework, that combines general and disability specific development to provide a unifying policy framework.

## **Response to the proposals in the discussion paper**

The strategies suggested in the NDS position paper are helpful.

We support a stronger emphasis on improving community attitudes across all outcome areas, however we believe that the first steps for children and young people are recognition and the alignment of policy.

Clearly outlining what each government is responsible for will make it easier for people with disability to access the supports and services they need, however without a unifying policy framework there is a high risk that gaps will appear between what services and funding programs provide.

The Strategy should not support the devolution of responsibility for outcomes to the non-government sector unless there is a clear unifying policy framework. Without such a framework there can be no shared outcomes and services will become fragmented and inefficient.

Regular reporting on the Strategy’s progress by governments to the public will make it more likely that the strategies are progressed. Reporting on tangible achievements is more important than the frequency of reporting.

Targeted Action Plans that focus on making improvements in the situation for children and young people would be welcome.

## **Recommendations**

That the 2020-2030 National Disability Strategy:

- Formally acknowledge the Convention on the Rights of the Child
- Specifically acknowledge the nature of childhood
- Acknowledge the role of families during childhood
- Is informed by children and young people with a disability through targeted engagement strategies
- Guides governments and the broader community in actions and reforms to ensure policies, programs and services remove barriers to an inclusive education for children with a disability through a National Inclusive Education Plan
- Includes the development of a National Early Years (0-8 years) Disability Development Framework, that combines general and disability specific development to provide a unifying policy framework across specialist and mainstream services and funding programs
- Includes the development of a National Children and Young Peoples (9 – 18 years) Disability Development Framework, that combines general and disability specific development to provide a unifying policy framework across specialist and mainstream services and funding programs.