



Building better futures  
for children with disabilities

# Submission on Interventions for children on the autism spectrum

Noah's Ark Inc  
May 2021

## 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. 32% of our current clients have a diagnosis of Autism Spectrum Disorder (ASD). 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 Strengthening Parent Support Program. 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.

*John Forster, CEO*

## Introduction

Noah's Ark welcomes the opportunity to provide feedback on the National Disability Insurance Scheme (NDIS) Consultation paper 'Interventions for children on the autism spectrum'. In recent months we have also made submissions to the Early Childhood Early Intervention (ECEI) Implementation Reset (NDIS, 2020a), the Independent Assessments Consultation (NDIS, 2020b), and the Planning Policy for Personalised Budgets and Plan Flexibility Consultation (NDIS, 2020c).

Noah's Ark has been involved in NDIS from its commencement and currently provide NDIS services to over 730 children with Autism Spectrum Disorder (ASD) and their families. With this breadth of experience, we are deeply concerned about several elements of the current proposal.

This submission on interventions for children on the autism spectrum aims to:

1. Provide comment on three key issues from the consultation paper.
  - A rationale for the proposal
  - A developmental approach for children with ASD
  - The role of families
2. Raise four overarching systemic problems that require urgent attention.
  - An outcomes framework
  - An integrated service system
  - A strong and capable workforce

## Noah's Ark recommends that the NDIS:

- Implements funding models that are based on function, not disability type.
- Provides transparent information about how the proposed approach for children with ASD will impact on other children with a disability and interacts with independent assessments and the ECEI approach.
- Reflects in policy an understanding that good practice in the provision of services and supports for children with a disability, including those with ASD, has a dual focus:
  - promoting the learning, development, well-being, participation, and independence of the child, and
  - strengthening, preserving, and promoting the capacity, and supporting the wellbeing, of their family.
- Supports the development of a second tier of services for children with developmental needs who are not participants of the NDIS, in cooperation with State and Territory governments.
- Develops a specific outcomes framework for children and their families that recognises the importance of inclusion, functional independence, relationships, and children's participation in family and community life.

- Develops a new policy framework and implementation plan to reinvigorate cooperation and coordination between mainstream services, community programs and supports provided through the NDIS.
- Supports the clarification of roles and responsibilities and the development of integrated policies and outcomes across various levels of government, and specialist and mainstream services, including a clearer, stronger, and more accountable agreement of responsibilities and integrated policies, plans, programs, and service systems.
- Develops a comprehensive approach to build a skilled workforce to work with children with disability or developmental delay and their families which is included in the upcoming National Workforce Plan.

## 1. Issues from the consultation paper

### 1.1 A rationale for the proposal

The 'Interventions for children on the autism spectrum' consultation paper provides an approach for funded supports specifically for children with ASD that is discrete from funding approaches for all other children eligible for the Scheme. There is no clear explanation for the need to have a separate approach and it appears at odds with a Scheme that is designed to be individualised and based on function rather than disability type. It also incongruent with legislation outlined in the NDIS Act that does not differentiate between disability type but does consider the best interests of the child as paramount (Australian Government, 2013). Without explanation of the purpose of this approach it is hard not to conclude it has been designed simply to manage NDIS budgetary constraints, given that the NDIS is reporting that a higher volume of children than expected are in receipt of funded support through the Scheme and over 50% of 0–14-year-old participants have a diagnosis of ASD (NDIS, 2021b). By implementing discrete funding approaches based on disability type, the NDIS would be failing to consider the needs and best interests of children with ASD and their families.

Furthermore, there are significant gaps in the description of the proposal that require clarification if the NDIS is to address one of the current challenges described in the ECEI Reset paper about the lack of transparency around how the NDIA makes decisions (NDIS, 2020a. p 5). The following questions require clarity:

- *Is it intended that there be a similar funding approach for the remaining 48,000 0–6-year-old and 37,000 7–14-year-old participants?*
- *Were the things learned from the tiered model of funding that was introduced for early childhood supports, and then withdrawn, during the transition to the NDIS considered?*
- *Will there be a pilot for this approach for children with ASD in order to carefully monitor and evaluate outcomes for children and their families?*

Finally, there are concerns about the indicative levels of funding that require clarity, including:

- *How will decisions be made by the NDIS planners about functional impact and subsequent indicative levels of funding for individual children with ASD?*

- *Are the indicative funding levels intended to align with levels of severity outlined in DSM-V diagnostic criteria for ASD? (American Psychiatric Association, 2013)*

The language used in the paper certainly alludes to an alignment between levels of funding and levels of severity. This is a pressing issue in part because of the proposed approach to independent assessments outlined in the ECEI Reset (NDIS, 2020a) and Independent Assessments Consultation (NDIS, 2020b) papers. Some of the key issues relevant to the tension between independent assessments and indicative levels of funding for children with ASD include:

- The suggested suite of assessments for young children were not designed for making funding decisions.
- Assessment of function requires multiple methods, sources, settings, and occasions (Bagnato et al., 2014; DEC, 2015; Hebbeler & Spiker, 2016).
- Child assessment requires respect for language and cultural differences (de Sam Lazaro, 2017; DEC, 2015). Cross-cultural validity has not been established for PEDI-CAT ASD.
- Given the chronic workforce shortage, it is unlikely that there are enough practitioners with the necessary skills and experience in working with children with ASD to support the proposed approach. Planners charged with the responsibility of making informed recommendations to the delegate require a high level of expertise.<sup>1</sup>

A clear rationale and transparency about the proposed approach that separates funding for children with ASD from other disability categories, and appears to put diagnosis ahead of function, is required. Information about how the approach interacts with independent assessments is also necessary.

## **1.2 A developmental approach for children with ASD**

NDIS policy reforms for people with ASD must reflect an understanding of the dynamic and unpredictable developmental trajectory and support needs of children, and the individual and changing resource needs of their families. Policy must address both children's immediate and short-term needs, as well as their long-term preparation and transition to adult life. Reforms should also recognise the needs of children and families entering disability services, and the importance of early identification of ASD, access to appropriate services and continuity of support. This is in recognition that ASD is a collective term for a group of neurodevelopmental conditions, and therefore by definition is developmental in nature, and that:

- ASD is a lifelong developmental condition and many people with ASD continue to face challenges throughout adulthood (Howlin, 2017; Magiati & Howlin, 2014)
- Although the behavioural features of ASD are generally present in the first years of life, they may not become apparent until later in life. The features of ASD vary in nature and level and change over time (Simonoff et al., 2019).
- ASD is not a static condition and there can be a pattern of functional improvement from childhood to adolescence and adulthood. ASD symptoms usually decline in quantity and intensity over time (Farley et al, 2018; Howlin & Magiati, 2017; Lord et al., 2020; Magiati & Howlin, 2014; Seltzer et al., 2003).

---

<sup>1</sup> Further issues related to Independent Assessments can be found in the Noah's Ark submission to the ECEI reset.

- Intellectual disability, medical conditions and mental health problems frequently co-occur with ASD (Amiet et al., 2008; Bradley, Summers, Wood & Bryson 2004; Fombonne, 2005; Gadow, DeVincent, Pomeroy & Azizian, 2004; Tuchman & Rapin, 2002; Tonge & Einfeld, 2003; Volkmar & Klin, 2005). These comorbid conditions, in conjunction with the core characteristics of ASD, can create significant barriers to a person's ability to function independently in their environment, with longer-term implications for functional abilities, participation, independence and wellbeing (Lord et al., 2020).
- The environments in which children engage and participate, and the interactions they have with others, become increasingly complex as they move from the secure base of family and home in the early years, to the demanding social environments of kindergarten, school, and community settings. The environments and people within them also change over time and need to make appropriate adjustments to support the diverse needs of individuals with ASD so they belong, participate, and contribute.

Good practice in the provision of services and supports for children with a disability, including those with ASD, has a dual focus:

- promoting the learning, development, well-being, participation, and independence of the child, and
- strengthening, preserving, and promoting the capacity, and supporting the wellbeing, of their family.

Not providing such support early and effectively can incur costs in several ways:

- Appropriate services and support early in life may ameliorate the impact of the core features of ASD and the person's ability to participate meaningfully in family, education, and community life.
- Appropriate and timely resources and support has been associated with reduced family and community burden (Johnson & Myers, 2007).
- The provision of appropriate interventions during childhood provides a significant opportunity to support early development, minimise disability, and maximise each child's strengths and opportunities over the long term (Whitehouse, 2017).
- Children 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.
- Lifetime costs for an individual with ASD in the USA have been reported over a decade ago as exceeding US \$1.2 million (Ganz, 2007; Shimabukuro, Grosse, & Rice, 2008). In the United Kingdom, the lifetime cost, after discounting, for someone with ASD and intellectual disability is estimated as exceeding £1.2 million, and for someone with ASD without intellectual disability is approximately £0.80 million (Knapp, Romeo, & Beecham, 2009).
- In 2015, the cost for carers of people with intellectual disability and/or ASD in Australia in lost income has been estimated at AU\$310 million, lost taxation of AU\$100 million and increased welfare payments of AU\$204 million (Schofield et al., 2019).

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

income for their parent/carers. The long-term support needs of people with ASD appears to be reflected in the current NDIS data which shows an increase in average annualised committed supports over time for individuals with ASD, from \$27,000 for children 0-6 years, to \$47,000 for 15-18 years with ASD. This figure steadily increases to \$150,000 for adults 55- 64 years (NDIS, 2021b). This increase in funding support is contrary to the notion that if supports are in place early in life the child will necessarily require less support over time.

With this knowledge of the dynamic and unpredictable developmental trajectory and support needs of children, Noah's Ark is concerned about further elements outlined in the consultation paper:

- The ASD consultation paper indicates that “Many children on the autism spectrum will benefit from Short Term Early Interventions (STEI) through our EC Partners and may never need to become participants of the Scheme” (NDIS 2021, p17). The quantifying indicator of ‘many’ appears to be suggesting that only few, or some, will be eligible for the Scheme. Given all that we know about the benefits of ECI for children with ASD, and the complexity of not knowing from the research what interventions work for which children, it is extraordinary that the proposed approach would be to provide STEI for ‘many’, rather than a ‘comprehensive family centred approach aligned with best practice’ that the Scheme’s broader ECEI approach intends for participants (NDIS, 2020a, p72).
- The simplistic approach of providing STEI through the EC Partners for ‘many’ children fails to recognise the complex problem of the ‘missing middle’ we are currently facing. The second tier of services required to support children with developmental needs who are not participants of the NDIS is missing.
- The paper indicates that “there may be a small number of children who require some further consideration due to other factors, for example, where they may have multiple disabilities or significant behaviours of concern” (NDIS, 2021a. p26). Given the significant percentage of children with ASD reported in the literature who have co-occurring intellectual disability, medical conditions, and mental health problems, (Amiet et al., 2008; Bradley, Summers, Wood & Bryson 2004; Fombonne, 2005; Gadaw, DeVincent, Pomeroy & Azizian, 2004; Tuchman & Rapin, 2002; Tonge & Einfeld, 2003; Volkmar & Klin, 2005), this ‘small number’ is likely to be an underestimation.
- The consultation paper provides indicative levels of funded supports that begin for children under seven years at \$4,000-\$8,000. Given that this proposal is for children with an ASD and functional needs that indicate eligibility for the Scheme, it is alarming that the level of funding is below what was previously provided through state based ECI prior to the NDIS, and current funding for Continuity of Support ECI which in Victoria is \$8709.
- Level 1 indicative levels of funded supports for children under seven years are also below the level of funding provided for early childhood supports during the transition to the NDIS in 2014, when there were three levels of funding. At that time, level 1 funding for ‘low needs’ was \$6,000-8,000 (NDIA, 2014).
- The indicative level of funding does not equate to the hours of support described in the tables. (NDIS, 2021 pp27-30). For example, level 1 funding for children 7-12 years is \$2,400-\$4,800 (NDIS, 2021. Table 3. p29). The corresponding supports described for this level equate to 28 hours of interventions, costing the family \$193.99 per hour, or \$5,431 (NDIS 2020d). This is clearly more than the highest amount of funding available for that level and a conservative estimate that has been based on a school visit being only one hour.

### 1.3 The role of families

Children are legally, functionally, and emotionally dependent on their families, and their wellbeing is profoundly entwined with family wellbeing. For families, good practices support quality of life and build parent capabilities during the difficult period starting from the identification of the child's developmental disability, seeking diagnosis, and the realisation of the potential implications of the condition and their ongoing role in raising their child.

The stressors experienced by the parents or carers of young children with ASD are in addition to the significant demands of raising any child. These stressors may include: the need 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. The impact of these stressors varies according to the experiences of parents, the size of family networks and the resources available to them. Stressors can reduce the ability of families to provide the essential developmental experiences needed by children to grow and learn successfully (Guralnick, 2018).

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 their contribution to social productivity as workers and taxpayers. (Australian Bureau of Statistics, 2012).
- Parenting a child with an ASD contributes to a higher incidence of parental stress and mental health problems and adversely impacts upon family functioning compared to parents of children with other disabilities (Dunn, Burbine, Bowers & Tantleff-Dunn, 2001; Yim, Moon, Rah & Lee, 1996; Tonge et al., 2006, Pisula, 2003; Schieve, Blumberg, Rice, Visser & Boyle, 2007), all of which have additional treatment costs to society.
- Children with developmental disabilities are more likely to be neglected or abused, with adverse effects upon their development and well-being and higher societal costs in the form of child protection and other services (Moore et al., 2015).
- 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 both personally, socially, and economically.

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

With this knowledge, Noah's Ark is concerned about several issues from the consultation paper:

- There is little recognition of the role of families in the child's life in the ASD consultation paper and parents are omitted from important components of the proposal. For example, the paper indicates "we are proposing four funding levels based on the functional capacity and assessment needs of a child, reflecting all we know at this stage" (NDIS, 2021, p24). This is at odds with good practice that recognises that the provision of services needs to respond to the child within the context of their family and endeavours to preserve, strengthen and promote family capacity as a focus of services and supports.

This necessarily includes inclusion of family goals in plans and the provision of funding to reach family outcomes.

- This issue of current processes not considering the needs of parents and carers have been highlighted in the ECEI Reset paper (Improvement area 6) and the Tune Review (Recommendation 12).

## 2. Overarching systemic problems

There are several overarching systemic issues that need to be addressed by the NDIS in order to meet the commitment to developing and supporting the capacity of individuals with a disability to participate in community life. Noah's Ark feels compelled to raise these issues once again as they underpin any proposed changes to the Scheme, such as those outlined in the interventions for children on the autism spectrum paper.

The following issues need to be addressed as a matter of urgency.

### 2.1 Child and family outcomes

It is a significant concern that in the section on disabilities in the Productivity Commissions' Report on Government Services which reports on outcomes for NDIS Participants, there are no reportable outcomes for children from 0-14 years. The report has measures for choice and control, social participation of people with disability and the use of mainstream services by people with disability. These are important measures. However, in each instance the data reported on is only for people with disabilities aged 15–64 years (Productivity Commission, 2020).

Transforming the experience of children and their families is essential to making long-term and enduring change. To measure participants' goals and outcomes across a range of domains, the NDIS needs outcome-based frameworks. Frameworks should be specific to the needs of the children, and to those of their families, and which track their development and participation across the life course.

In supporting a lifetime and outcomes-based approach to children and family outcomes, the NDIS needs:

- A specific outcomes framework that includes children and their families with a focus on inclusion and participation.
- Short- and long-term outcome measures which include dimensions such as functional independence, relationships, and participation in and contribution to the community.
- Data collection and review processes that underpin individual goal setting, planning, and child and family outcomes.
- Transparent and regular reporting on child and family outcomes.

### 2.3 An integrated service system

In championing an NDIS, the Productivity Commission called the services for people with disabilities underfunded, unfair, fragmented, and inefficient (Productivity Commission, 2020).

The NDIS has brought together payments for disability supports within one organisational structure. The NDIS has introduced vertical integration into funding for people with disabilities. Rather than funding changing at each transition point, and families having to seek new funding under different guidelines, there is now continuity of support. This is a major achievement.

In Australia, 211,259 children and young people (0-18 years of age) are NDIS participants. They now make up 49% of the total Australian NDIS participants. 16% of participants are aged 0-6 years. Of those young children, over 20,000, or 30% of 0–6-year-old participants, have a diagnosis of ASD (NDIS, 2021b).

The introduction of the NDIS has also provided greater resources to some children, although inequity remains a significant problem in the Scheme (NDIS, 2020a). However, the introduction of the vertical integration of funding for people with disabilities through the NDIS has also had a significant impact on children's horizontal integration into early childhood policies, systems, and services. Children with disabilities are now in a policy context dominated by concerns about adults. Children with disabilities have become disconnected from early childhood policy, its desired outcomes, its language, and its professional networks. This disconnect continues for school-aged children where, for example, different approaches and processes for state and federal funding have a negative impact on community inclusion. The opportunity for specialist and mainstream services to work together towards the benefit of the child through shared objectives and desired outcomes has been compromised by the lack of definition of outcomes for children, particularly in the NDIS, and a lack of collaboration between different levels of government (NDIS, 2020a; Productivity Commission, 2020).

Within the State/Territory policy framework, programs for children with disabilities were previously part of a continuum of services for families and children. Children with disabilities are no longer connected to the developing understanding of child development that engages other children and family services including child and maternal health, early childhood education, family services, child protection and community health. Children with disabilities are also disconnected from early childhood services and professional networks which have been strengthened over time (DET, 2009). The connection to the early childhood sector is critical to children and their families as it supports early identification of ASD, referrals to early childhood intervention, referrals between services, access to family services and it supports participation in children's services. For example, at a services level, the resources for preschool teachers to support children's inclusion, participation, and successful start to school was provided by State and Territory Early Childhood Intervention (ECI) services. In transitioning to the NDIS, young children with disability or developmental delay (including those with ASD) may have become better resourced, but arguably less understood and less supported. They are certainly not as well connected.

The NDIS has disrupted the connection between specialist and mainstream services, particularly for young children. A new policy framework that reinvigorates cooperation and coordination between mainstream services, community programs and supports provided through the NDIS is essential. This includes:

- Development of policies that articulate how state, territory and national government departments and community services can contribute to enhancing the opportunities and participation of children with a disability.
- A renewed focus on strengthening a system-wide process for implementing supports and services for young children where there are concerns about their development. This

second tier of services needs to fill the growing gap between mainstream early childhood services and the NDIS.

- A commitment to the participation and contribution of children with a disability in the same community activities, early childhood services and schools as their typically developing peers.

## **2.4 A strong and capable workforce**

The ECI sector is currently experiencing unprecedented workforce pressures. There is a chronic shortage of paediatric allied health practitioners and specialist teachers with the skills, knowledge, and experience to work effectively with children with a disability and their families. It has been recognised that services for young children with a disability already constitute a thin market. It is a thinner market when considering those who have experience working with young children with ASD and the necessary qualifications to deliver some of the specific evidence-based interventions that require additional training and assessment of competencies (e.g., Picture Exchange Communication System or Hanen’s More than Words) (Whitehouse et al., 2020).

The first standard proposed in the consultation paper for the delivery of autism interventions is that “the intervention is delivered by, or supported by, appropriately qualified and experienced professionals” (NDIS, 2021a, p14). This requires a ready and capable workforce. However, the development of the workforce for children does not appear to be a priority in the development of the NDIS.

There are two national workforce plans currently under development that are particularly relevant to the sectors workforce crisis. Firstly, the Joint Standing Committee on the NDIS Workforce Interim Report addresses the issues for the broader disability workforce for adults, but not the childhood sector (Australian Government, 2020). The NDIS workforce plan should include strategies that aim to attract, supply and retain ECI practitioners, including allied health practitioners and specialist teachers. Secondly, the Australian Children’s Education and Care Quality Authority (ACECQA) is attending to the associated issues in the early childhood sector through the 2021-2030 National Children’s Education and Care Workforce Strategy (ACECQA, 2021). This plan, which is currently in the consultation phase, is concerned with the absence of a national workforce strategy for early childhood educators, particularly teachers, to offer economies of scale and provide solutions at a system level. In its current iteration, the strategy does not address the issue of specialist early childhood educators required to build the capacity of the broader early childhood workforce in providing high quality inclusive environments, only the “micro-credentials” needed for educating and caring for children with additional needs (ACECQA, 2021 p12). As such, the workforce issues for children with developmental delay or disability are not being addressed by either of the relevant workforce plans that are under development. The workforce issues we are facing are complex and require a collaborative and long-term approach, coordinated through National and State/Territory bodies. Noah’s Ark urges the NDIS to ensure issues related to the sector working with children with developmental delay and disability are addressed in the upcoming National Workforce Plan and attention is drawn to the issue with the Australian Children’s Education and Care Quality Authority.

Furthermore, without the development of a workforce that is family centred and actively supports inclusion and participation in its practice, with a focus on capacity building, families will experience poor quality services. Families in rural and remote areas are particularly disadvantaged. A ready and capable professional workforce that includes both allied health

practitioners and specialist teachers with specific knowledge, skills, and experience in working with children is critical to the effectiveness of the NDIS to achieve outcomes that benefits participants. A workforce strategy that addresses the need for a comprehensive range of training options for those working in the ECI field across pre-service, in-service, and postgraduate training is critical. The strategy should be regularly reviewed to ensure it reflects emerging workforce issues and be based on a workforce census that provides comprehensive information about key workforce indicators.

The need for a capable ECI workforce has been addressed in part by the ECEI Reset recommendation to enhance compliance to the Practice Standards on EC Supports and increase awareness of best practice providers (Rec 6) (NDIS, 2020a). Data indicates that 80% of families of young children partly self-manage, fully self-manage or plan manage their funding and a choice to access non-registered providers (NDIS, 2020a, Exhibit 14, p48). Whilst non-registered providers are required to comply with the NDIS Code of Conduct, there are no further requirements in relation to the NDIS Practice Standards on Early Childhood Supports (NDIS, 2020). Our concern about the lack of mechanisms for ensuring compliance to quality practices is heightened due to the lack of accessible information provided for families on best practice to support them in making informed decisions. Noah's Ark has recommended in their submission to the ECEI reset that mandatory registration with the NDIS Commission for all early childhood providers and a requirement that self-managed and plan-managed participants use only registered providers. This will need to be supported by funded initiatives to develop a suitably trained workforce. This is critical given that the number of registered providers is falling, with 1,739 active providers for 0–6-year-old children with ASD in Oct-Dec 2020, compared to 4,263 providers for this group active since the beginning of the NDIS (NDIS, 2021).

## Recommendations

### Noah's Ark recommends that the NDIS:

- Implements funding models that are based on function, not disability type.
- Provides transparent information about how the proposed approach for children with ASD will impact on other children with a disability and interacts with independent assessments and the ECEI approach.
- Reflects in policy an understanding that good practice in the provision of services and supports for children with a disability, including those with ASD, has a dual focus:
  - promoting the learning, development, well-being, participation, and independence of the child, and
  - strengthening, preserving, and promoting the capacity, and supporting the wellbeing, of their family.
- Supports the development of a second tier of services for children with developmental needs who are not participants of the NDIS, in cooperation with State and Territory governments.

- Develops a specific outcomes framework for children and their families that recognises the importance of inclusion, functional independence, relationships, and children’s participation in family and community life.
- Develops a new policy framework and implementation plan to reinvigorate cooperation and coordination between mainstream services, community programs and supports provided through the NDIS.
- Supports the clarification of roles and responsibilities and the development of integrated policies and outcomes across various levels of government, and specialist and mainstream services, including a clearer, stronger, and more accountable agreement of responsibilities and integrated policies, plans, programs, and service systems.
- Develops a comprehensive approach to build a skilled workforce to work with children with disability or developmental delay and their families which is included in the upcoming National Workforce Plan.

## References

Amiet, C., Gourfinkel-An, I., Bouzamondo, A., Tordjman, S., Baulac, M., Lechat, P., Mottron, L., & Cohen, D. (2008). Epilepsy in autism is associated with intellectual disability and gender: Evidence from a meta-analysis. *Biological Psychiatry*, 64(7), 577-582.

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

Australian Children’s Education and Care Quality Authority. (2021). Consultation on a Ten Year National Children’s Education and Care Workforce Strategy (2021–30) Retrieved from: <https://www.acecqa.gov.au/national-workforce-strategy>

Australian Government (2013). NDIS Act. Retrieved from: <https://www.legislation.gov.au/Details/C2020C00392>

Australian Government (2020). Joint Standing Committee on the National Disability Insurance Scheme NDIS Workforce Interim Report. Retrieved from: [https://www.aph.gov.au/Parliamentary\\_Business/Committees/Joint/National\\_Disability\\_Insurance\\_Scheme/workforce/Interim\\_Report](https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/National_Disability_Insurance_Scheme/workforce/Interim_Report)

American Psychiatric Association (2013). *The Diagnostic and Statistical Manual of Mental Disorders*.

Bagnato, S. J., Goins, D. D., Pretti-Frontczak, K., & Neisworth, J. T. (2014). Authentic assessment as “best practice” for early childhood intervention: National consumer social validity research. *Topics in Early Childhood Special Education*, 34(2), 116-127.

de Sam Lazaro, S. L. (2017). The importance of authentic assessments in eligibility determination for infants and toddlers. *Journal of early intervention*, 39(2), 88-105.

Department of Education and Early Childhood Development. (2009). Victorian Early Years Learning and Development Framework For all Children from Birth to Eight Years. State of Victoria Retrieved from:  
<https://www.education.vic.gov.au/Documents/childhood/providers/health/veylframework.pdf>

Division of Early Childhood (2015). DEC Recommended Practices: Assessment.  
[https://d4ab05f7-6074-4ec9-998a-232c5d918236.filesusr.com/ugd/95f212\\_12c3bc4467b5415aa2e76e9fded1ab30.pdf](https://d4ab05f7-6074-4ec9-998a-232c5d918236.filesusr.com/ugd/95f212_12c3bc4467b5415aa2e76e9fded1ab30.pdf)

Farley, M., Cottle, K. J., Bilder, D., Viskochil, J., Coon, H., & McMahon, W. (2018). Mid-life social outcomes for a population-based sample of adults with ASD. *Autism Research*, 11(1), 142-152.

Fombonne, E. (2005). Epidemiology of Autistic Disorder and Other Pervasive Developmental Disorders. *Journal of Clinical Psychiatry*, 66, 3-8.

Gadow, K., DeVincent, C., Pomeroy, J., & Azizian, A. (2004). Psychiatric Symptoms in Preschool Children with PDD and Clinic and Comparison Samples. *Journal of Autism and Developmental Disorders*, 34,(4), 379-393.

Ganz, M. L. (2007). The lifetime distribution of the incremental societal costs of autism. *Archives of pediatrics & adolescent medicine*, 161(4), 343-349.

Guralnick, M. J. (2018). Effective early intervention. The Developmental Systems Approach. Baltimore, ML: Brookes Publishing.

Hebbeler, K., & Spiker, D. (2016). Supporting young children with disabilities. The future of children, 185-205.

Howlin, P. (2005). Outcomes in Autism Spectrum Disorders. In F. R. Volkmar, Paul, R., Klin, A., & Cohen, D. (Ed.), *Handbook of Autism and Pervasive Developmental Disorders*. New Jersey: John Wiley and Sons.

Howlin, P., Goode, P., Hutton, J., & Rutter, M. (2004). Adult outcome for children with autism. *Journal of Child Psychology and Psychiatry*, 45(2), 212-229.

Howlin, P., & Magiati, I. (2017). Autism spectrum disorder: Outcomes in adulthood. *Current Opinion in Psychiatry*, 30(2), 69-76.

Itzchak, E. B., & Zachor, D. A. (2011). Who benefits from early intervention in autism spectrum disorders?. *Research in Autism Spectrum Disorders*, 5(1), 345-350.

Johnson, C. P., & Myers, S. M. (2007). Identification and evaluation of children with autism spectrum disorders. *Pediatrics*, 120(5), 1183-1215.

Knapp, M., Romeo, R., & Beecham, J. (2009). Economic cost of autism in the UK. *Autism*, 13(3), 317-336.

Lord, C., McCauley, J. B., Pepa, L. A., Huerta, M., & Pickles, A. (2020). Work, living, and the pursuit of happiness: Vocational and psychosocial outcomes for young adults with autism. *Autism*, 24(7), 1691-1703.

Magiati I, Tay XW, Howlin P. Cognitive, language, social and behavioural outcomes in adults with autism spectrum disorders: A systematic review of longitudinal follow-up studies in adulthood. *Clinical Psychology Review*. 2014;34:73–86.

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

NDIA (2014). Support Clusters Definitions and Pricing for Victoria.

NDIS (2020). *ECEI Implementation Reset. Project Consultation Report*. Retrieved from: <https://www.ndis.gov.au/community/have-your-say/supporting-young-children-and-their-families-early-reach-their-full-potential>

NDIS (2020b). *Independent Assessment Framework*. Retrieved from: <https://www.ndis.gov.au/participants/independent-assessments/independent-assessment-framework>

NDIS (2020c). Planning Policy for Personalised Budgets and Plan Flexibility Consultation paper. Retrieved from: <https://www.ndis.gov.au/community/have-your-say/planning-policy-personalised-budgets-and-plan-flexibility>

NDIS (2020d). NDIS Price Guide 2020-2021. Retrieved from: <https://www.ndis.gov.au/providers/price-guides-and-pricing#ndis-price-guide-2020-21>

National Disability Insurance Scheme. (2021a). *Consultation paper: Interventions for children on the autism spectrum*. Retrieved from: <https://www.ndis.gov.au/community/have-your-say/interventions-children-autism-spectrum>

National Disability Insurance Scheme Website. (2021b). *Explore data*. Retrieved from: <https://data.ndis.gov.au/explore-data>

Productivity Commission (2020). *Report on Government Services*. Retrieved from: <https://www.pc.gov.au/research/ongoing/report-on-government-services/2020>

Seltzer, M. M., Krauss, M. W., Shattuck, P. T., Orsmond, G., Swe, A., & Lord, C. (2003). The Symptoms of Autism Spectrum Disorders in Adolescence and Adulthood. *Journal of Autism & Developmental Disorders*, 33(6), 565-581.

Shimabukuro, T. T., Grosse, S. D., & Rice, C. (2008). Medical expenditures for children with an autism spectrum disorder in a privately insured population. *Journal of autism and developmental disorders*, 38(3), 546-552.

Tonge, B. J., & Einfeld, S. L. (2003). Psychopathology and Intellectual Disability: The Australian Child to Adult Longitudinal Study. *Research in Mental Retardation*, 26, 61-91.

Tuchman, R., & Rapin, I. (2002). Epilepsy in Autism. *Lancet Neurology*, 1(6), 352-358.

Volkmar, F., & Klin, A. (2005). Issues in the Classification of Autism and Related Conditions. In F. Volkmar, Paul, R., Klin, A., & Cohen, D. (Ed.), *Handbook of Autism and Pervasive Developmental Disorders* (3rd ed., Vol. 1). New Jersey: John Wiley and Sons.

Whitehouse, A., Varcin, K., Waddington, H., Sulek, R., Bent, C., Ashburner, J., Eapen, V., Goodall, E., Hudry, K., Roberts, J., Silove, N., Trembath, D. *Interventions for children on the autism spectrum: A synthesis of research evidence*. Autism CRC, Brisbane, 2020