

# Interventions for Children on the Autism Spectrum

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**AASW**

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Australian Association  
of Social Workers

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# The Australian Association of Social Workers

The Australian Association of Social Workers (AASW) is the professional body representing more than 14,000 social workers throughout Australia. We set the benchmark for professional education and practice in social work, and advocate on matters of human rights, discrimination, and matters that influence people's quality of life.

## The social work profession

Social work is a tertiary qualified profession recognised internationally that pursues social justice and human rights. Social workers aim to enhance the quality of life of every member of society and empower them to develop their full potential. Principles of social justice, human rights, collective responsibility and respect for diversity are central to the profession, and are underpinned by theories of social work, social sciences, humanities and Indigenous knowledges. Professional social workers consider the relationship between biological, psychological, social and cultural factors and how they influence a person's health, wellbeing and development. Social workers work with individuals, families, groups and communities. They maintain a dual focus on improving human wellbeing; and identifying and addressing any external issues (known as systemic or structural issues) that detract from wellbeing, such as inequality, injustice and discrimination.

## Autism, neurodiversity and disability

The AASW welcomes the opportunity to make a submission to the NDIS on the Interventions for children on the autism spectrum consultation paper. We want to begin by recognising the importance of language and self-determination. As People with Disability Australia points out "non-disabled people need to be led by, respect and affirm each individual person with disability's choice

of language they use about themselves”.<sup>1</sup> While the AASW uses person-first language, as people should not be reduced to their disability, we also recognise the right of every person to use language that best reflects their experience and identity.

We also want to recognise the importance of understanding neurodiversity in relation to autism. Neurodiversity is the concept that humans don't come in a one-size-fits-all neurologically typical. Neurodiversity is seen as a movement by many towards more equal treatment and more widespread acceptance for those on the spectrum, and with disabilities in general.<sup>2</sup>

In our submission we will use the term 'people or children with autism', and in doing so we acknowledge that the term encompasses a wide range of experiences that are commonly reduced in society to narrow characteristics.

More broadly, social workers prioritise a holistic understanding of the person, seeing their disability as only one aspect of what makes them who they are. This view is driven by a deep belief in the intrinsic worth of all human beings and their inalienable right to dignity and self-determination. Drawing on the significant contribution of the self-advocacy movement, social workers understand that people with disability are a diverse group and have a wide range of experiences, abilities, impairments and potential for development.

Social workers adopt a person-in-environment approach that includes a focus on the structural and cultural factors that may negatively impact on an individual's abilities to engage with the social world. Social workers believe that all people, regardless of difference, have the right to be included in society and to have outcomes equal to other citizens. It is this understanding and commitment that social workers bring when working with people with disability.

## Social work and the NDIS

The AASW has welcomed the National Disability Insurance Scheme (NDIS). The values of “choice and control” that underpin the NDIS framework are consistent with the values and principles of self-determination and empowerment that have guided the social work profession for many decades. The AASW Code of Ethics aligns closely to the objectives and principles of the NDIS Act<sup>3</sup> and the UN Declaration on the Rights of Disabled Persons.<sup>4</sup> As social workers focus on enhancing quality of life and empowering people to full social and economic inclusion, the values, qualifications and skills that social workers bring are a match with the person-centred approach of the NDIS.

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<sup>1</sup> <https://pwd.org.au/resources/disability-info/language-guide/identity-vs-person/>

<sup>2</sup> <https://autismawarenesscentre.com/un-adopts-new-goals-disabilities/>

<sup>3</sup> <https://www.ndis.gov.au/about-us/operational-guidelines/overview-ndis-operational-guideline/overview-ndis-operational-guideline-about-ndis>

<sup>4</sup> <https://www.ohchr.org/EN/ProfessionalInterest/Pages/RightsOfDisabledPersons.aspx>

However, despite the NDIA's claim that their funding process builds the child's functional capacity using an approach that is strengths based, this process falls short of what social workers mean when they use that term. The assessment tools used by the NDIA are inherently deficit focused, where children with autism and their parents are repeatedly required to justify why their support needs should be met by the NDIA. The underlying rights-based principle of the NDIS should lead to an optimum experience for every participant resulting from their engagement with the NDIS. To achieve this, it is crucial that NDIS funding frameworks and best practice interventions for children on the autism spectrum are improved. The NDIS scheme undoubtedly holds potential, but it must respond better to the needs of children with autism and their families.

Social workers are present throughout the NDIS in a variety of roles, working as individuals or in organisations. Many of our members have made, or are making, the transition to being registered providers of early childhood intervention or therapeutic services. Many have extensive experience in assessment, planning and case management with people living with multi-faceted disabilities and are providing Coordination of Supports or Specialist Support Coordination. Social workers are also working in other roles within the NDIS including service development, planning, local area coordinators, supervisors and service coordinators. Social workers are well placed to consider and respond to this consultation process and the AASW welcomes the opportunity to contribute.

## Our submission

Our submission is based on the practice and lived experience of our members.

### **1. Which of these would you use to find information about choosing and accessing best practice interventions (or services) for children on the autism spectrum?**

- NDIS website
- NDIS Operational guidelines
- Participant decision making guides (not yet developed)
- My usual NDIS or NDIS partner contact
- Autism organisations or peak bodies
- None of these

### **2. Where else would you like to find information about accessing best practice interventions (or services) for children on the autism spectrum?**

Our members would like to see information about best practice interventions be more widely available to Autism organisations/peak bodies, the NDIS, GPs, Paediatricians, Psychiatrists, pre-school and schools in an effort to better arm the community with consistent and accurate information about the experience and needs of children on the autism spectrum, not just their families.

One of the biggest barriers to consistent, timely and best practice autism support is the misinformation across all sectors of Australian community, even the professional sectors that in many cases are the first point of contact. A recent newspaper article describes instances where bleach enemas, restrictive diets and potentially toxic pills are being sold as “therapies” for parents of children with autism.<sup>5</sup> Social workers have highlighted numerous experiences of working across professional groups who work with children with autism, who, from their reported responses, do not have accurate and current information about autism, in particular from a psychosocial perspective. This lack of widely available consistent, relevant and accurate information means these important (in gate-keeping roles) and influential professionals can compromise resources, that further reduce best practice and optimal outcomes.

Public misinformation accounts for potential trauma, especially in relation to stigma and discrimination. A balancing of what autism actually is, for the public’s benefit, would be useful to create more inclusive community cultures. Amaze’s survey of community attitudes revealed that while 85% of Australians have a personal connection with a person with autism, a mere 29% feel they understand how to support them and only 4% of people with autism and their families agree that the community understands how to support them.<sup>6</sup> Information on how the community can better support children with autism must be nationally-delivered, widespread and evidence-based to take the burden of education solely off children with autism and their families and distribute it among government, schools and the community.

### ***3. Holistic planning is a part of the proposed funding framework for early intervention for children on the autism spectrum. How can we help families to find and connect with other supports outside of NDIS?***

There is an urgent need for cohesion, collaboration and integration of services for planning to be holistic and this is currently not happening. AASW members’ experience, particularly those working as Accredited Mental Health Social Workers in the autism field, is that the current operation of the planning process is far from holistic. At present, the Australian system of support is fragmented, leading to poorly coordinated services that are not client-centred and contrary to best practice guidelines. Inconsistency in service delivery can be particularly destabilising for children on the autism spectrum, who struggle with change, anxiety or may have difficulties conveying their needs or frustrations. The current model has created ‘professional silos’ where medical, allied health and other workers practice independently of each other leading to poor overall service outcomes, particularly for those in lower socioeconomic and disadvantaged groups.

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<sup>5</sup> <https://www.theguardian.com/australia-news/2021/apr/18/false-hope-desperate-families-prey-to-nonsense-snake-oil-treatments-for-autism>

<sup>6</sup> <https://www.amaze.org.au/wp-content/uploads/2019/06/General-Understanding-Fast-Facts.pdf>

The AASW highlights two core areas of support for children with autism outside the NDIS, whose importance has been consistently reiterated by our members: families and schools. The support system currently does not adequately recognise the irreplaceable contribution that families provide to the lives of children with autism. We continue to see medicalised and individualised approaches to supports that fail to appreciate the strengths and needs of families. Our members' experience informs the opinion that utilising the strength of the enhanced parent-child connection is a profoundly valuable resource in assisting with skill development in self-regulation and social skills training for the children with autism. This includes assisting the parents to understand the specific presentation of their child's autism and how it manifests in day-to-day interactions. The NDIS can help families to connect with supports outside the NDIS by upskilling them to feel competent and empowered to engage in social contact that is both atypical and neural typical.

Schools are key institutions for children with autism and require greater resourcing and training to ensure that students and school staff understand autism, which in turn improves support for children with autism and their families. There needs to be greater incorporation of non-teaching professions in schools, like social workers, who can contribute their knowledge of social, emotional and developmental needs and how they can impact the child's learning if they are not met.

**4. Building from the Autism CRC research the paper outlines specific principles that the NDIS considers as early intervention best practice for young children on the autism spectrum. Is there anything you would like to add?**

No.

**5. Building from the Autism CRC research the consultation paper outlines specific standards that the NDIS considers as early intervention best practice for children on the autism spectrum. Is there anything you would like to add?**

The AASW supports the NDIS' creation of practice standards but believe that unless these standards are embedded into the National Quality Safeguards Commission guidelines/processes, the NDIS Code of Conduct and/or the NDIS Practice Standards, they will remain aspirational at best. Further information from the NDIS should unpack how these standards will inform decision-making regarding funding decisions, as NDIS delegates are permitted to adhere to the 'reasonable and necessary' criteria. While the recognition of these standards is a positive step forward, the Consultation paper falls short of detailing how such work will be effectively consolidated into a) the NDIS decision-making process; b) quality assurance activities of registered providers; and c) alignment against all other frameworks of the NDIS to ensure internal congruency. Until this information is provided or greater clarity is developed, the seven standards will have no real impact for change.

We recommend the inclusion of the following additional standard: *Decisions about 'reasonable and necessary' therapies and supports must be determined collaboratively.* The decision-making process must be person-centred and driven by core principles of self determination. Children with

autism and their families are best placed to make decisions about what supports they need to pursue their own goals. They should be brought into the decision-making process and not sidelined, reflective of the “choice and control” ethos of the NDIS.

**6. Do the case studies provided at Appendix one help you to understand what we mean by “reasonable and necessary”?**

The case studies have the effect of providing exposure for children with autism and their families to the uniquely diverse experiences and needs of people with autism, which is positive. Such exposure reiterates understanding that there is no one size that fits all, improving community understanding of the many ways a person with autism can present. The more examples that can be offered depicting real life circumstances associated with autism, the more professionals working with children with autism will recognise the diverse presentations of autism spectrum, ideally resulting in early identification and intervention for the child. Similarly, the more explicit the information, by way of case studies to exemplify, the better families will be able to recognise what their specific experience is and the more realistic their expectation of their child, themselves, and the supports that are made available to them will be.

However, AASW members highlight that ‘reasonable and necessary’ is inherently a subjective assessment. Our members’ experience is that each NDIS delegate operates from their own value system and this is brought into the funding determination allocation. Until there is a better system that includes considerations of risk and vulnerability when determining funding allocation, any positive impact from the case studies will remain superficial.

**7. Do you have any other feedback about how we explain “reasonable and necessary”?**

AASW members highlight problems with the way the NDIS uses ‘reasonable and necessary’ to sidestep funding for supports that are crucial for children with autism and their families. For example, section 34(e) of the National Disability Insurance Scheme Act 2013 (Cth) states, “the funding or provision of the support takes account of what is reasonable to expect families, carers, informal networks and the community to provide”. Our members disclose instances where this provision is being used by the NDIS to not fund respite for families, which was once funded through local government. Maintaining the viability of informal supports cannot be underestimated. If the NDIS is committed to delivering ‘holistic planning’, funding of respite must be included in a participant’s core support budget.

An ongoing concern for the AASW and the sector as a whole is how the NDIS communicates the supports it provides and the rights of participants, assuring that it is in an accessible language. The AASW acknowledges the NDIS Plan Explainer tool,<sup>7</sup> which has been updated frequently to account for the changing environment (including the ever-changing Covid-19 landscape), and encourages

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<sup>7</sup> <https://providerchoice.com.au/plan-explainer>



the NDIS to continue to create free tools to help participants understand what supports the NDIA considers to be 'reasonable and necessary' to provide clarity and consistency for children with autism and their families. Such tools should be co-designed using effective consultation and communication by government and services with parents, carers, families and people with autism (i.e. those with lived experience).

**8. Do Table 2 and Table 3 clearly explain the indicative levels of funded supports?**

Yes, this is explained clearly

**9. Do you have any other feedback about how we explain the indicative levels of funded supports?**

Each person with autism has their own unique circumstances, needs and experiences and as a result, we cannot fund autism generically. The NDIS is very clear that funding is based on the needs of the participant. AASW members recognise the high or medium/low area funding mechanism as a way of explaining the participants' needs to be addressed and intervention to be provided. However, the very notion of budget and funding levels informally suggests that the Scheme requires the child's needs to be fit into static categories, which is inherently difficult to achieve and results in subjective decisions. This is made more difficult for children with autism and their families when some therapies are hugely costly, such as Applied Behaviour Analysis (ABA), whilst others are not, leading to mismatched funding levels and support outcomes.

The indicative levels of funded supports are only applicable once a child with autism has been assessed and cleared to access NDIS funding. An issue repeatedly highlighted by AASW members is the long wait times for families to even enter into the NDIS, which must be addressed. This issue is exacerbated by the current iteration of the Early Child Early Intervention (ECEI) program, which has wait times that are unacceptable and can delay a child's access to diagnosis and the early intervention supports that flow from diagnosis. There is considerable evidence to suggest that early intervention support is key to improving the child's life outcomes, including enabling independence, and engagement in school, employment and the community. The AASW welcomes the NDIS' plan to reset the ECEI approach as a necessary step towards supporting children with autism and their families to reach their full potential.

**10. There may be situations where families or carers need extra NDIS supports such as during first plans, or where plans reduce in value due to the impact of mainstream services. What do we need to consider in those situations?**

The NDIS consultation paper, in the section titled "Outcomes focused - as capacity is built, professional supports reduce", describes the NDIS' intention to set foundations for children with autism through funding interventions, which should result in "reduced dependence" on professional supports later on in life. For this reason, the NDIS includes higher levels of funding in the child's first NDIS plan, as it recognises the importance of "early investment". What the NDIS misses here is that as children grow and develop, so does the demand for new skills. Investment in one year does not

mean that the budget should be reduced the next year. Taking a developmental approach to ages and stages in life should also imply that children will need new capacity building budgets to help acquire the skills they need to reflect age and stage of growth.

Funding for autism should not end with initial intervention but must be intimately tied to the needs of the child, incorporating what the child wants and the parental point of view as well. This will change throughout the life cycle, commencing in adolescence and continuing into early adulthood, for example, in pursuing education, broadening their social and community contacts, leaving the family home for the first time, pursuing employment or starting a family. The concept of 'early intervention' should refer to *early after diagnosis* and not just *early in life*, as adults with autism deserve the same opportunities for a good life as every other person. Commonwealth, state and local government services are required to meet the needs of people with autism at all life stages and not simply those required in early childhood.

**11. We want to support children and parents with implementing plans using the Autism CRC research and best practice. Are the questions in Section 8.2 helpful for parents and carers when selecting providers?**

Yes, these questions are helpful.

These questions are one way to empower parents and carers with tools to ensure services are evidence-based and delivered relying on best practice research and knowledge. However, these questions require providers to have strong outcome measurement tools to be able to answer them. Outcome tools are variable with providers and even if used, are at a research level, so require the planner/delegate (who might have no qualification or minimum qualifications) to interpret what it means and its implications for funding subsequent plans. If the NDIS is providing parents and carers with questions to assess the outcomes of services, it will be important for services to have outcome measurement tools to provide the answers, as they have significant implications for review meetings.

These questions may help parents and carers to feel independent and confident in decision-making for their children, which may facilitate collaboration with services and empower them to full economic and social inclusion. The questions communicate the message that any professional intervention must result in desirable shifts and changes for the whole family system. If this is not happening, the family should feel empowered to challenge this and to move on to another provider and should be assisted to do so. Service providers should be very explicit about what their service aims to do; the responsibility should not solely fall on parents to ask the right questions. Where parents feel they can ask questions and the provider can offer genuine answers supported by evidence, an effective and transparent working relationship may be fostered.

**12. What other guidance or tool do families need to feel confident to implement plans in line with the Autism CRC research and best practice?**

Many participants in the early intervention space of the NDIS do not get funding for a support coordinator. Those who provide Coordination of Supports or Specialist Support Coordination, such as social workers, are able to develop a relationship with a person that seeks to foster collaborative decision-making in assuring that services are well targeted and person/family-centred. Social workers in care coordination roles are able to build positive working relationships with a person in order to develop care plans that address their needs, strengths and goals. Support coordination is an important avenue to supporting families to feel confident to implement plans for their child in line with best practice and current research.

The AASW recommends the NDIS introduce clear guidelines on when Coordination of Supports and Specialist Support Coordination can be funded in a participants' plan and establish a procedure to indicate to planners when such supports are required. Where support coordination funding is included, the allocation must be sufficient to achieve meaningful improvements in participant outcomes. The NDIS should have clear guidelines for the amount of time that is needed for this role according to the needs of participants and the availability of services. Such actions would support families and carers of children with autism to make informed decisions about their plan, with a professional who is focused on the child's needs, strengths and goals.

Families would be further supported by the NDIS to confidently implement plans if they had funded access to respite. The AASW supports the Autism Family Support Association (AFSA) in their call for more to be done to support the family members and carers who look after individuals with autism, with many parents described as tired, "burnt out" and in need of more support.<sup>8</sup> Parents and families are an integral support for a child with autism; a lack of respite may result in families feeling overwhelmed and unable to cope in their caring role, and children with autism to miss out on the value and strength of family supports. The NDIS must ensure respite is consistently funded in a participant's core support budget.

***13. With regards to conflicts of interest, how can we support families and carers to feel confident to make decisions about what is in the best interests of the child and family?***

The NDIS can support families and carers to make decisions in their child and families' best interests by providing them with all the information necessary to support their child with autism. By doing so, families feel equipped to make the best decisions about who assesses, who treats and importantly, clarity around why (i.e. not simply based on who they are connected to). It is important for there to be boundaries between those who assess and those who support/provide interventions, as is important in all therapeutic contexts. If a participant receives multiple supports from one provider, then that provider should implement procedures to avoid and manage conflicts of interest.

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<sup>8</sup> [https://www.aph.gov.au/Parliamentary\\_Business/Committees/Senate/Autism/autism/Submissions](https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Autism/autism/Submissions)

The NDIS must ensure there is an effective system in place to manage (real or perceived) conflicts of interest. While the Quality Safeguards Commission currently holds the role of monitoring and investigating providers, members report that they have seen little evidence of enforcement in this area. There is a concern that quality of care can be compromised in the pursuit of profit and that complaint mechanisms need to be more accessible for NDIS workers and participants to ensure that they are empowered to make complaints. As of September 2020, just one fine had been issued and only one provider banned by the Quality Safeguards Commission despite more than 8000 complaints lodged in the two preceding years,<sup>9</sup> which may lead to questions about whether the Commission is effectively monitoring and prosecuting complaints.

The successful management of conflicts of interest should be a particularly live issue for the NDIS in light of recent concerns raised regarding evidence of independent assessment contractors not being subject to strict conflict of interest rules.<sup>10</sup> On this issue, Autism Awareness Australia chief executive Nicole Rogerson stressed the importance of conflicts being investigated to ensure that the “NDIS is serving individual Australians with disability and not just lining the coffers of multi-million dollar corporates”.<sup>11</sup>

Cases of fraud, where participants are persuaded to sign blank timesheets for services that are not being received, need thorough investigation and must be enforced to the full extent of the law. Further, enforcement actions such as banning orders, revoking and suspension of registration and the proposed strengthening of enforcement powers of the Commission for the most serious cases are welcomed. It is important that the Quality and Safeguards Commission make the details of providers and workers who have been banned publicly available in the NDIS Provider Register. People with disabilities, their supporters and providers can use the Register to check that people they are engaging to deliver NDIS services have not had a banning order against them.<sup>12</sup> It is crucial that these new strengthening powers of the Commission be adequately advertised to ensure that people providing NDIS services and participants are aware of these changes.

#### **14. Do you have any other feedback?**

Independent Assessments are not consistent with the ‘choice and control’ ethos of the NDIS and should not be used for children with autism. It is crucial that children seeking entry to, or continued funding by the NDIS have access to proper assessments conducted by qualified individuals and therapists who know the child. As we know, there is no ‘one-size-fits-all’ presentation of autism. To exclude the knowledge of allied health professionals who have previously worked with a child and their family will exclude important information from the assessment process. The AASW would be

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<sup>9</sup> <https://www.smh.com.au/politics/federal/disability-care-watchdog-has-issued-just-one-fine-despite-8000-complaints-20200916-p55w7q.html>

<sup>10</sup> <https://www.abc.net.au/news/2021-03-25/david-bowen-raises-concerns-on-ndis-independent-assessments/13271354>

<sup>11</sup> Ibid

<sup>12</sup> <https://ministers.dss.gov.au/media-releases/5876>

delighted to cooperate with the NDIA in a collaborative design process to come up with an alternative assessment process for the NDIS that is fair and consistent.

## Conclusion

As people with autism make up the largest proportion of NDIS participants by primary diagnosis (29% of all NDIS participants), interventions for children on the autism spectrum should attract significant attention from the NDIS. The AASW welcomes the opportunity to make a submission to the NDIS on the Interventions for children on the autism spectrum consultation paper and would warmly receive the possibility to discuss further any of the points raised.

*Submitted by and on behalf of the Australian Association of Social Workers*



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