

Submission to the National Disability Insurance Scheme (NDIS) Act Review and Participant Service Guarantee (Tune Review)

Neurodevelopmental and Behavioural Society of Australasia (NBPSA)

The NBPSA

The Neurodevelopmental and Behavioural Paediatric Society of Australasia (NBPSA) is a membership organisation for doctors who work with children, and their families, who have problems impacting development and behaviour.

Established in 2012 the NBPSA includes over 500 paediatricians, paediatric neurologists, psychiatrists, general practitioners, career medical officers and specialist physician trainees. The Society represents doctors who have a specialist interest in working with children with neurodevelopmental and behavioural challenges with members responsible for diagnosing the majority of children with Autism in Australia.

As an affiliate of the Royal Australasian College of Physicians, the NBPSA provides the highest level of physician expertise in caring for children with neurodevelopmental and behavioural conditions. The Society runs professional seminars and conferences for members and allied health professionals working in neurodevelopmental and behavioural paediatrics and works to promote the most up to date clinical practice across Australasia.

Having no single diagnostic focus ensures that the Society provides individuals, organisations and governments with impartial, consensus medical advice on the complex array of behaviours, assessments, diseases and interventions in neurodevelopmental and behavioural (NDB) paediatrics. This submission outlines how the NDIS can better support the special needs of children with NDB challenges.

Recommendations

The NBPSA is keen to work with the Department of Social Security and the National Disability Insurance Agency (NDIA) and other government agencies to ensure the NDIS maximises the opportunity for children to be the best they can be and to reduce the impact of disability during transition to adulthood.

To achieve this, a new Child and Family Developmental Framework is required to recognise that support needs change over time and to ensure the NDIS is responsive and agile to these changes.

Families and clinicians need less red tape in decision making, a re-focus on local support networks and a transparent set of standards and competencies for planners. A new funding approach is also required that better aligns supports to functional needs and allow entry and exit over time with the long-term goal of successful adult transition.

Families with young children and at-risk individuals or populations require key workers to help them manage childhood behavioural problems and to advocate on their behalf through periods of stress and transition. Paediatricians who specialise in neurodevelopmental and behavioural paediatrics could help ensure appropriate services are funded after initial diagnosis, and on regular review.

Finally, government agencies need to work together as part of Action Networks at a state and local level to better support children and families in times of urgent need.

NBPSA Recommendations

The NBPSA recommends

1. A new Child and Family Developmental Framework that:
 - a) aligns NDIS supports to a child's functional and care needs. The Framework should allow for initial access based on need (not diagnosis) with potential for agile escalation and de-escalation of supports across periods of stress and key transitions, such as from childhood to adolescence and then to independent living
 - b) supports early intervention for families of very young children by providing families with a Key Worker who can build the family's capacity to support their child's development and manage resources for necessary activities including case conferences, travel to home and childcare.
2. Development of a joint Health Agency and NDIA approach to support the Framework including:
 - a) local Action Networks for responsive, agile management of children in urgent need
 - b) timely access for children with NDB conditions and disabilities
 - c) addressing the interface issues between the NDIS and neurodevelopmental-behavioural services within Health and in particular establishing a coordinated approach to assessment and review of a child's needs
 - d) promoting consistency across policy frameworks for assessments and data collection with development of valid and reliable measurements to evaluate the outcomes of NDIS and Health funded interventions and support plans
 - e) development of a transparent set of standards and competencies for planners and service providers.
3. Enhanced support for families where risk factors impact in terms of parental capacity to advocate for their child's needs. This includes at risk populations (e.g. CALD, ATSI, rural remote, out of home care) as well as families with individual risk factors (e.g. parental mental health, poor health literacy, financial adversity).
4. Development of a sustainable provider market that includes;
 - a) quality certification and standards of service for children and families with neurodevelopmental-behavioural concerns
 - b) removal of financial incentives that link assessment services and therapeutic interventions, particularly where there is no evidence of therapeutic efficacy
 - c) active management of the location and colocation of medical and allied health services to improve access for those in rural and regional areas.
5. Development of key performance indicators for any agreed NDIA principle with an action research approach taken to ongoing monitoring of performance.

Children and the NDIS: time for a new approach

Diagnoses as a gateway

The NBPSA does not support diagnoses as a gateway to the NDIS.

Neurodevelopmental and behavioural diagnoses often overlap and interact and for many children an accurate diagnosis may not be clear, or possible, early in their life course. A much better approach is a functional and care needs-based approach.

It is typical that neurodevelopmental and behavioural conditions lie on a spectrum. A child at one end of the spectrum may need no support or minimal supports to reach their potential while another child, with the same condition, may have complex problems that require lifelong care.

There are unintended consequences arising from the current system where complexity and severity creep has led families to focus on, and emphasise, their child's worst day rather than their best day just to meet NDIS access requirements. Currently, a diagnosis of Autism Spectrum Disorder (ASD) Level 2 or 3 acts as a gateway to the NDIS. When families are turned down for NDIS support because their child has a Level 1 Autism diagnosis (defined in the DSM 5 as 'requiring support') their only option is to focus on the child's worst behaviour and try to qualify for a higher level of disability as early as possible.

Further, for a child with Autism Spectrum Disorder who has access to NDIS, their support needs may escalate as they go through puberty. Unfortunately, despite being foreseeable, this escalation may not be funded due to their previously documented ASD Level. There are similar increased difficulties in adolescence and at other times of transition for children affected by Foetal Alcohol Syndrome Disorder and many other complex neurodevelopmental disorders.

A focus on diagnosed disability is also at odds with the opportunity for short bursts of early intervention at critical developmental stages, with the aim of preventing considerable future disability. NDIS planners need to be 'developmental disability aware' so that support and care of children with broader neurodevelopmental challenges can be planned and interventions coordinated with health and other service providers, particularly in situations where the diagnosis is uncertain or yet to be determined.

A new Child and Family Developmental Framework

Adults with disability often have fixed disorders and predictable trajectories. It is often impossible to put this lens on a child who will have fluctuating support needs across the predictable transition times from infancy through to adulthood.

Children with neurodevelopmental and behavioural challenges have disabilities arising from complex, brain-based medical conditions. These conditions can change rapidly as a child develops: the child's support needs may also change significantly through various stages of learning and development.

The original design of the NDIS did not consider the special needs of children. While the Early Childhood Early Intervention (ECEI) approach was a well-intended attempt to address this oversight, it has proved not to be fit for purpose.

A new Child and Family Developmental Framework is needed to provide access to baseline NDIS supports with intermittent escalation of support at times of stress or transition. This needs to continue to be available through childhood and adolescence, rather than stopping at 6 years 11 months, with increasing family and young person autonomy (choice and control) aligning with the level of supports provided over time.

Getting it right early can make a big difference to a child's development and a family's ability to cope. For children with NDB conditions there is a significant opportunity for the NDIS to help reduce the overall level of adult disability as well as providing support for those needing lifelong care.

NDIA and Agencies: an opportunity for collaboration

There is a need to establish stronger connections between the NDIS and related government agencies.

Prior to transfer of state and territory disability services and funding to the Commonwealth, local disability networks supported good communication and action for children in immediate need, particularly those at risk of harm. An unintended consequence of implementation of the NDIS has been the erosion of these networks and reinforcement of government silos. **The result has been that families are now expected to bring everything together and they are getting lost.**

Cross agency networks are critical to good care. For example, a review found that nine in ten Western Australian youth detainees had a severe neurodisabilityⁱ. Children with psychosocial conditions and complex neurodevelopmental and behavioural challenges require specialised collaborative care and review. An approach is needed that facilitates NDIS, Health, Education, Justice and other programs working in an efficient and coordinated manner to support children and families. Connecting the dots to reduce psycho-social adversity is likely to reduce functional impairment. For example, a family who has a house and food and mental health supports is less likely to be overwhelmed by, and more likely to better manage, their Autistic or intellectually disabled child's tantrums.

These complex interactions and constant changes present unique challenges for the child and their families, clinicians, educators and disability planners. Each person experiences the opportunities presented through their developmental years just once in their lifetime. Yet there is no coherent policy environment that allows experts across health, education, justice and disability to share their expertise, collect common data or evaluate and measure common intervention strategies.

In addition, the growing pre-occupation with diagnosis across non-health agencies diverted attention from carefully, considered functional and needs-based assessment. A multi-agency approach is required to ensure informative, clinically valid and consistent assessment approaches are undertaken across agencies. Over time, this would be expected to improve coordination of care planning and the evaluation of outcomes for future system improvements.

This siloed policy environment has exacerbated the frustrations experienced by carers, families and adults who have grown up with NDB challenges. It also reduces capacity for finding, or building the evidence needed to inform, sensible solutions.

Reducing disadvantage

The Adverse Childhood Experiences (ACE) study shows a positive relationship between a history of exposure to childhood/household trauma and multiple risk factors for several of the leading causes of death in adults.ⁱⁱ

To help address this there is a need to consider the impact of parental mental health, poor health literacy, financial adversity and other risk factors in terms of parental capacity to advocate for their child's, and their own needs. **Consideration is required at all stages: initially; on review of the NDIS plan each 12 months, and for acute deteriorations.** Paediatricians who specialise in neurodevelopmental and behavioural paediatrics could help ensure appropriate services are funded after initial diagnosis, and on regular review.

Location of services and colocation of medical and allied health services is also important to families, with the need to consider those in rural and regional areas and those in low socioeconomic areas at

a disadvantage in terms of access. Anecdotal evidence suggests that application of the NDIS in rural and regional areas has led to an increase in private allied health services at the expense of publicly available services. There is a need to ensure that affordable access to paediatric trained allied health is readily available for both diagnosis and ongoing therapy.

The siloed, single agency approach to developing the provider market has only further dispersed already scarce allied health resources. It has also diluted capacity to manage quality and credentialing and made the task of coordinating these complex, multi-disciplinary services even more difficult.

Standards and Outcomes

During the development of the National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorder in Australia, the NBPSA stressed that any assessment of autism concerns must be undertaken within the context of a broader neurodevelopmental, behavioural diagnostic and functional assessment. Further, the Society advocated for clinicians who do assessments to have a clear set of competencies that inform their suitability to do this type of work. While the former recommendation was incorporated into the guidelines, the latter has yet to be addressed.

Families have reported that NDIS planners do not want a doctor's view, preferring to concentrate on what the families say they need. While this input is critical to the process, some families struggle to understand the context of disability and likely trajectory for their child. The treating clinician is in a far better position to advise on the potential and timing for escalation and de-escalation of any needed supports.

NDIA planners also need a transparent set of standards, competencies and frameworks in order to reduce any unwarranted variation and to allow for evaluation of their outcomes.

Having an expert who has a known set of competencies carry out a functional assessment by getting to know a child and family is likely to be a much more valid and reliable system than using a tool that a non-expert administers to generate a number or a score.

Performance Monitoring: action research

The inclusion of suggested Principles for NDIA Service Standards is welcome and the NBPSA supports the Royal Australasian College of Physician's submission on potential inclusions.

For children the key is how well a team-based approach is adopted, both during NDIA interaction with government agencies and at a participant level with treating clinicians. The value of medical and allied health interventions should also be acknowledged and supported.

Critical to introduction of any principles or standards is **ongoing monitoring and timely adjustment when issues arise**. The NBPSA suggest an action research approach is taken, with researchers working alongside families, planners and clinicians to gather evidence of levels of performance (perceived and real) with improvements progressively implemented.

ⁱ [Bower C, Watkins RE, Mutch RC, et al. Fetal alcohol spectrum disorder and youth justice: a prevalence study among young people sentenced to detention in Western Australia. *BMJ Open* 2018;8:e019605. doi:10.1136/bmjopen-2017-019605](#) accessed 3 November 2019 3pm

ⁱⁱ [Felitti V, Anda R et al Relationship of Childhood Abuse and Household Dysfunction to Many of the Leading Causes of Death in Adults. *The Adverse Childhood Experiences \(ACE\) Study, American Journal of Preventive Medicine, May 1998, Vol 14, Issue 4, Pages 245-258*](#) accessed 31 October 2019 5.30pm.