

Childhood dementia and the National Disability Insurance Scheme (NDIS)

Right now, in Australia, there are an estimated 2,300 children and young people suffering from dementia. Their quality of life is extremely poor, the burden on their loved ones who care for them is immense, and their needs are not currently met by health and social systems¹. Families report that while the NDIS is vital, the progressive needs of their child(ren) are not understood or accommodated and they are constantly “battling”, building and defending their case for support.

Appointment of specialist advisors for children with dementia should be the first step to improving the access to the NDIS for children with dementia. This would lead not only to better outcomes for the children but efficiencies for the NDIA. Such an approach would be consistent with the Minister’s address to the Press Club on 18 April².

Better outcomes would result from:

- consistent, appropriate application of NDIS structures to this cohort;
- comprehensive understanding of and expertise in childhood dementia, its prognosis, unique challenges and the progressive needs associated with it; and
- an identified point of contact which would not simply result in referral from generalist contacts.

Efficiencies would result from:

- avoidance fruitless calls to generalised planning services;
- accelerated reviews when increased supports are required mid-plan due to disease progression;
- prevention of the withdrawal of necessary supports and enabling the continuity of engaged providers;
- minimising the requirement for repeated full functional assessments from allied health professionals to provide evidence of their diagnosis and ongoing support needs;
- allowing for plan reviews to be synchronised when there is more than one child with a dementia disorder in a household; and
- allowing the self-management of all aspects of plans, including Specialist Support Coordination, and providing adequate funding for the associated administrative process.

The end result would be person centred planning and avoidance of resource wastage.

¹ Donnell M, Elvidge K, Hilton G. State of Childhood Dementia 2022. <https://www.childhooddementia.org/state-of-childhood-dementia>

² Shorten B. April 18 2023. Address to the National Press Club. <https://ministers.dss.gov.au/speeches/10911>

Childhood Dementia Background

There are an estimated 2,300 Australian children living with a childhood dementia disorder that results in global neurodegeneration and progressive loss of skills. A child with a dementia disorder will progress from mild to severe disability before prematurely dying. Around 75% of these children will die before they turn 18.

There are [70+ genetic disorders](#) that cause dementia in childhood, the majority of which present in early childhood, with children initially displaying developmental delay and learning difficulties, followed by regression of global function. One of the hallmark characteristics of childhood dementia is enduring and progressive loss of previously acquired developmental skills, in contrast to static or transient loss³⁴. The trajectory of childhood dementia classically proceeds in line with normal development for a time then decelerates and ultimately regresses.

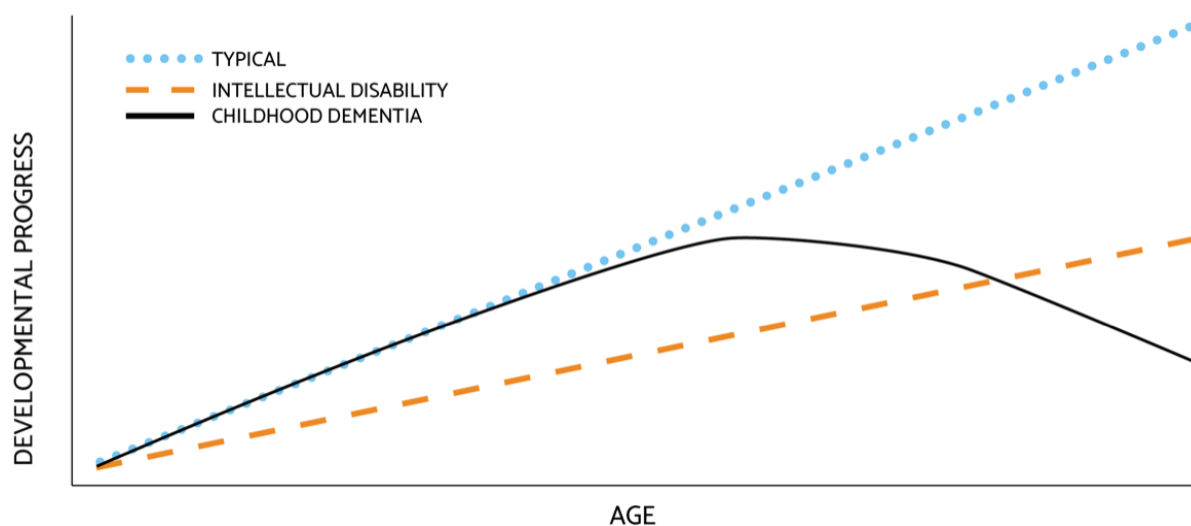


Figure 1: Developmental trajectories of individuals with typical development, intellectual disability and childhood dementia. (adapted from Haugen et al, 2019).

During their short lives children with dementia will have severe symptoms, high complex care needs, and poor quality of life. Emerging evidence⁵⁶ indicates that the burden on caregivers for a child with dementia is severe and that health and social systems do not effectively meet their needs.

³ Nunn K, Williams K, Ouvrier R. 2021. The Australian Childhood Dementia Study. *European Child & Adolescent Psychiatry*

⁴ Verity C, Baker E, Maunder P, Pal S, Winstone AM. 2021. Differential diagnosis of progressive intellectual and neurological deterioration in children. *Developmental Medicine & Child Neurology*.

⁵ Nevin SM, McGill BC, Kelada L, Hilton G, Maack M, Elvidge KL, Farrar M, Baynam G, Katz NT, Donovan L, Grattan S, Signorelli C, Bhattacharya K, Nunn K, & Wakefield CE. 2022. The psychosocial impact of childhood dementia on children and their parents: A systematic review' (under review)

⁶ Childhood Dementia Initiative. 2021. Childhood Dementia Matters: Key issues and comments from the consumer roundtable hosted by Palliative Care Australia and the Childhood Dementia Initiative on 24 Nov 2021. <https://www.childhooddementia.org/getasset/H55HQ6>

NDIS is essential for children with dementia

Equity demands that all Australians should be able to access appropriate and effective care and support services that reflect their needs and in settings that are appropriate to their age.

Families impacted by childhood dementia report that NDIS packages provide essential support, but are universally challenging to access and manage.

Support needs typically increase over time, but the pace, sequence and depth of these needs are unique to the individual child. There is no clear, consistent timeline for what will be needed when.

“The NDIS is brilliant and when you get funding you need it can transform your ability to care for your child but in order to get to that point there is so much you need to do to educate and advocate and not just once...this will happen every review...and often more than once a year”

Mother of a child with dementia

Regression in skills and abilities can sometimes occur quite slowly over a number of years, and at other times there may be periods of steep regression that result in many additional acute care needs. The focus of NDIS support for children with dementia is on quality of life for the child and typically includes ensuring the safety of the child at home and in the community, support and therapy to maintain skills for as long as possible, support workers to assist with daily living, and associated equipment as the child's care needs become more complex.

Challenges in access

Families universally report significant challenges in accessing what they need through the NDIS with many parents describing the experience as a ‘constant fight’ while they are simultaneously managing day to day family life and the chronic grief that accompanies a deteriorating child⁷.

The lack of knowledge and understanding of childhood dementia amongst National Disability Insurance Agency (NDIA) staff, particularly in relation to the regressive nature of the childhood dementia disorders. This necessitates a high level of repeated individual advocacy be undertaken by

“The dementia symptoms were causing severe behavioural and psychological issues. We needed a wheelchair just to get out the house and keep everyone safe. But we were told that was just challenging behaviour, and our ‘parental responsibility’. They couldn’t see that it was as a result of the dementia. And it meant we couldn’t even get out to the shops or to bring the kids to the playground”

Mother of 2 children with dementia

families. This often means longer, more complex negotiations to gain access to the required supports, and inconsistent assessment and funding decisions. Each review requires families to retell their story and start from the beginning in educating the allocated case worker on their child's condition, prognosis and increasing needs.

Some families report being left feeling deeply upset due to the unsympathetic, insensitive and offensive language and approach demonstrated by NDIA staff who did not understand their circumstance.

⁷ Nous Group. 2023. *The lived experience of families affected by childhood dementia and their interactions with care and support services.* [Http://childhooddementia.org/we-dont-fit](http://childhooddementia.org/we-dont-fit)

In addition, the onerous and inflexible NDIS assessment process makes it difficult to plan ahead. Support needs increase, rather than decrease, over time and families know that as their child's condition deteriorates additional supports will be required, but they are not able to seek or secure these supports until the regression has occurred. Often the subsequent wait times for review and acquisition of necessary supports means that a child is without essential items which severely impacts quality of life. In addition, In a recent study, parents highlighted the importance of continuity of disability support workers, which is often a challenge to achieve.

Childhood dementia disorders are generally poorly understood in the broader community and health and disability settings, so families face a range of interlocking issues in obtaining appropriate care for their children. This includes capability, knowledge and continuity of resources across all aspects of the care team, from support coordinators, to disability support workers, and allied health professionals. This challenge has prompted some families to self-manage their NDIS plans adding significant administrative burden.

Opportunities for the NDIS to improve support for children with dementia

Specialist childhood dementia team

Appointing a specialist childhood dementia team within the NDIA would enable consistent, appropriate application of NDIS structures to this cohort. Comprehensive understanding of and expertise in childhood dementia, its prognosis, unique challenges and the progressive needs associated with it, are essential.

Guiding principles

Establishing guiding principles for how plans relating to participants with childhood dementia disorders should be managed would not only reduce the burden on families and more appropriately meet the needs of the participant, but also reduce the administrative load on the NDIA. Such principles may include, but not be limited to:

- accelerated reviews when increased supports are required mid-plan due to disease progression;
- avoiding the withdrawal of necessary supports and enabling the continuity of engaged providers;
- minimising the requirement for repeated full functional assessments from allied health professionals to provide evidence of their diagnosis and ongoing support needs;
- allowing for plan reviews to be synchronised when there is more than one child with a dementia disorder in a household;
- allowing the self-management of all aspects of plans, including Specialist Support Coordination, and providing adequate funding for the associated administrative process.