childhood
dementia
INITIATIVE

NDIS: A System Failing Those Most Vulnerable

Background

In Australia, a child is born every three days with a condition that will lead to dementia in childhood. There are no treatments or cures available to these children and all face a limited life expectancy: half will not reach their tenth birthday, and 70% will not survive to adulthood.

These short lives are characterised by relentless progression of disability, with children experiencing profound physical and cognitive decline that necessitates increasingly complex disability support.

At any one time, there are an estimated 1,500 children living with dementia in Australia.

Since inception in 2020, Childhood Dementia Initiative has undertaken extensive consultation with the community of families who have a child (or children) with a childhood dementia condition or are bereaved. Through these consultations, the National Disability Insurance Scheme (NDIS) has consistently been highlighted as a system that is essential but universally challenging to access and manage.

To better understand the experiences of these families and the corresponding failings of this critical system, Childhood Dementia Initiative commissioned a study that resulted in the "*Brick wall after brick wall: The NDIS Experience for Childhood Dementia Families*" report.

The Problem

The stories within the report '*Brick wall after brick wall*' are not just bureaucratic challenges – they are human tragedies unfolding in real-time. For families navigating childhood dementia, every moment is precious, and every administrative barrier represents stolen moments of connection, joy, and love.

The National Disability Insurance Scheme, designed as a beacon of support, has become an additional battleground for families already fighting an impossible fight. A child born with a childhood dementia condition faces a cruel reality: no access to treatments, grossly inadequate care and support, and a severely shortened lifespan. In this heart-wrenching landscape, the NDIS - a critical service - becomes another obstacle.

The systemic failures revealed in this research are profound and multifaceted. It reveals:

- The NDIS is designed for stable or improving conditions and fundamentally fails to accommodate the often rapid decline characteristic of childhood dementia;
- A workforce that demonstrates minimal comprehension of childhood dementia, with 90% of families reporting critical misunderstanding of these progressive conditions;
- Complex administrative processes that not only demand time-consuming coordination, thus reducing precious time with their children, but also re-traumatises them by forcing them to continually document their child's deterioration; and
- Significant delays in the provision of essential supports, including equipment and home modifications, where participants often wait months or years for approval - time children with dementia simply do not have.

These are not mere administrative shortcomings. They represent a fundamental failure of empathy, understanding, and human-centered design.

The cost is immeasurable. Families are losing not just support hours, but precious moments with their children. Parents are becoming full-time administrators instead of caregivers. Siblings are neglected. The entire family ecosystem is destabilised by a system that should be providing support.

The Solution

Childhood Dementia Initiative is calling on the NDIS to implement a **specialist pathway** for childhood dementia that recognises the unique, non-linear trajectory of these progressively declining conditions. This includes:

1. Developing a **specialised NDIS workforce** for childhood dementia;
2. Enabling **predictive planning** to anticipate and accommodate known disability progression trajectories and streamline processes to reduce administrative burden; and
3. Streamlining **rapid-response review processes** for urgent changes in support needs across all areas including core, capacity building, assistive technology and home modifications.

As one parent poignantly said: "*We are all human too... We never asked for it... We just want something simple and easy for her as long as possible. Just nothing too dramatic, just to make life a little more simpler.*"

A specialist pathway would enable the NDIS to fulfill the principles outlined in the NDIS Participant Service Charter for children with dementia by offering a service that is transparent, responsive, respectful, empowering, and connected.

This is not just a call for administrative adjustment, but a necessary change to ensure equitable, responsive disability support for children with the most complex and urgent needs.

Delay compromises the quality of life for children and families already facing extraordinary challenges. The time to implement meaningful change is now.

Specialist Pathway Elements

Children with degenerative conditions require a fundamentally different approach than those with stable or improving conditions. A dedicated pathway would acknowledge the unique trajectory of childhood dementia and provide appropriate, timely support.

"We only have a short time with our kids... As families, we need to be spending quality time with our families, not spending it creating evidence and fighting ridiculous decisions because the planners and systems don't have the right training and understanding." - Mother of a child with dementia

1. Specialised NDIS workforce for childhood dementia

The profound lack of understanding about childhood dementia among NDIS staff creates significant barriers for families. Developing expertise within the NDIS would dramatically improve outcomes.

Key implementation components:

- Establish a dedicated team within the NDIS with expertise in childhood dementia conditions
- Provide comprehensive childhood dementia training programs for all NDIS staff who might interact with these families
- Develop trauma-informed practices that recognise the emotional toll of repeatedly documenting decline and justifying reasonable and necessary supports
- Create consistent decision-making frameworks that ensure equity regardless of planner or location

"I think what I would really love is almost like specialist teams within the NDIA that know directly what childhood dementia is, and so you don't have to spend the whole time explaining it." - Mother of child with dementia

2. Predictive planning and streamlined administrative processes

The NDIS fundamentally fails to accommodate the predictable decline of childhood dementia, forcing families to wait for deterioration before beginning the often complex and drawn out process required to access essential support.

Furthermore, the overwhelming administrative workload placed on families takes precious time away from their children and creates significant psychological strain.

Key implementation components:

- Develop mechanisms for proactive planning based on predicted disease progression rather than waiting for the expected critically reduced function to present before addressing;
- Reduce administrative burden through simplified processes that don't require repeated justification of degenerative conditions;
- Design flexible funding models that can adapt to rapidly changing needs without triggering full review processes;
- Prioritise early intervention and capacity building, recognising that timely, intensive support can significantly extend the maintenance of skills and improve quality of life throughout the progression; and
- Implement anticipatory approvals based on predicted disease progression.

"The administrative workload leaves no time for me to be a parent. I'm just managing paperwork." - Mother of two children with dementia

3. Rapid response review processes

The delays in accessing essential supports, including equipment, represent one of the most critical failures of the current system, with profound impacts on quality of life and safety.

Key implementation components:

- Create mechanisms for rapid reassessment and streamlined approval pathways when support needs for children with dementia change unexpectedly;
- Improve flexibility of funding utilisation to enable participants to manage rapidly changing needs;
- Establish equipment loan programs for urgent needs while formal approvals are processed; and
- Develop flexible approaches for rural and regional families facing provider shortages.

"By the time they approve a wheelchair, my child might have lost the ability to even be positioned in it. Each month of delay is a month of my child's limited life that we can never recover." - Mother of child with dementia