The NDIS experience for Western Australian families affected by childhood dementia: Brick wall after brick wall

August 2025

A Childhood Dementia Initiative Report

childhood dementia INITIATIVE

This research and report was commissioned by the Childhood Dementia Initiative with funding from the Stan Perron Foundation.

We acknowledge the Aboriginal and Torres Strait Islander peoples as the First Australians and the Traditional Custodians of the lands on which this report was prepared.

We thank all the Western Australian families and individuals who provided their time and valuable insights for the preparation of this report. Their generosity, openness and determination to assist others by their involvement, despite the personal emotional toll, is greatly appreciated.

Childhood Dementia Initiative (2025). The NDIS experience for Western Australian families affected by childhood dementia: Brick wall after brick wall

https://www.childhooddementia.org/getasset/691WU0

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Executive summary

In Australia, a child is born every 3 days with a childhood dementia condition. Half of these children will not reach their 10th 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. As their needs escalate and change rapidly, these families are among the most intensive users of the National Disability Insurance Scheme (NDIS).

This report examines how Western Australian families navigate the NDIS, revealing systemic challenges that compound their already devastating circumstances. Western Australian families face unique challenges, including the transition from the previous state-based Disability Services Commission to the NDIS system, and geographic challenges of accessing specialist services in regional and remote areas.

This study identified 6 critical themes affecting Western Australian families:

1. Fundamental systemic barriers for degenerative conditions: The NDIS framework, designed for stable or improving conditions, fundamentally fails to accommodate the rapid, often unpredictable decline characteristic of childhood dementia. Western Australian families report that the transition from the more flexible state-based system has created additional challenges in accessing responsive support. The system's rigid planning cycles, fixed review timeframes, and focus on building capabilities cannot adapt to conditions where abilities are being relentlessly lost, often at an accelerated pace.

2. Lack of workforce understanding significantly impacts families: NDIA staff demonstrate minimal comprehension of childhood dementia, with families reporting fundamental misunderstandings of progressive conditions. This lack of understanding leads to inadequate support plans, delayed approvals, and forces families to repeatedly relive their child's decline through constant explanation and justification. Western Australian parents report that this burden is particularly acute when dealing with planners unfamiliar with the state's previous disability support system.

3. The overwhelming administrative burden: Western Australian families spend hours upon hours on NDIS paperwork and coordination, reducing precious time they could spend with their children. The process requires constant documentation of decline, creating significant psychological strain. For regional WA families, this burden is amplified by the need to coordinate with distant services and providers.

4. The lottery of care – inconsistent support: Access to appropriate care varies dramatically based on individual planners. Additionally, geography adds an extra layer of variability, with rural and regional Western Australian families facing particular challenges in accessing services and finding qualified support workers. The vast distances between population centres in WA create additional barriers to consistent care.

5. Equipment and modification challenges: The Battle for Essential Support: Families face extensive delays in accessing essential equipment, often waiting months or years for basic necessities. These delays create serious safety risks for both children and their carers, while equipment, when finally approved, may no longer meet the child's changed needs. WA families report particular difficulties finding approved providers for home modifications in regional areas.

6. Fighting on all fronts: The Failure to Align Support Systems: Critical gaps exist between the NDIS and other Western Australian support systems, particularly in managing hospitalisations and palliative care. The transition from state-based services has created additional coordination challenges unique to WA families.

These findings underscore the urgent need for systemic reform to better serve Western Australian families facing childhood dementia, ensuring their limited time together is spent on being a family rather than bureaucratic battles. The report highlights opportunities for collaboration between the NDIS and state-based services to create a more responsive and supportive system.

Introduction: childhood dementia in Western Australia

In Australia, a baby is born every 3 days with a childhood dementia condition–a devastating reality where half of these children will die before reaching their 10th birthday, and 70% will not survive to adulthood.[1] These short lives are characterised by relentless progression of disability, with children experiencing profound physical and cognitive decline that necessitates increasingly complex disability support. As their needs escalate and change rapidly, these families are among the most intensive users of the National Disability Insurance Scheme (NDIS).

Childhood dementia represents one of the most challenging and overlooked healthcare challenges in Australia. These genetic, progressive, and life-limiting conditions create a unique and heart-wrenching journey for families, who find themselves navigating a health and social care system fundamentally unprepared to support their children's complex and constantly changing needs.

As one Western Australian parent poignantly described, childhood dementia is like watching a child "slowly be unpicked until there's nothing left"–a cruel progression that strips away developmental milestones, abilities, and ultimately, life itself. For these families, every day of delay or administrative burden represents precious time lost.

In this already devastating landscape, Western Australian families face an additional challenge: the transition from the state-based Disability Services Commission to the national NDIS system. This transition has created further complications for families already navigating complex systems. Every family interviewed for this report expressed gratitude for the NDIS, acknowledging it as a world-leading disability support scheme that provides access to vital equipment and services they could never otherwise afford. However, in practice, accessing this support has become yet another battleground for families already fighting an overwhelming battle.

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[1] Elvidge KL, Christodoulou J, Farrar MA, et al. The collective burden of childhood dementia: a scoping review. *Brain J Neurol.* 2023;146(11):4446-4455. doi:10.1093/brain/awad242

Research methodology

This research employed a comprehensive methodology that placed Western Australian families with lived experience of childhood dementia at the heart of the investigative process. Recognising that families are the true experts in their children's experiences, the research design was collaboratively developed to ensure authentic and meaningful insights.

It incorporated multiple data collection methods:

1. In-depth interviews
    - Western Australian families participated in detailed interviews
    - Participants included parents with children at various stages of childhood dementia conditions
    - Interviews allowed for rich, narrative exploration of families' experiences
    - Both metropolitan Perth and regional/rural families were represented
2. Previous research analysis
    - Analysis of previous consultations with Western Australian families
    - Review of state-specific findings from broader national studies
    - Examination of Western Australian family perspectives from the "We Don't Fit" report and state-based consultations
3. Professional input
    - Insights from health professionals and service providers working with WA families
    - Perspectives on the transition from state-based services to NDIS

The research deliberately sought Western Australian participants from diverse backgrounds:

- Geographic representation (metropolitan Perth, regional, and rural areas)
- Socioeconomic backgrounds and family structures
- Diagnostic diversity (families with different childhood dementia conditions and varying stages of progression)
- Families with single and multiple children with childhood dementia

Data from interviews and prior research were analysed using:

- Thematic analysis to identify recurring patterns
- Comparative methodology to understand WA-specific challenges
- Lived experience validation to ensure authentic representation
- Analysis of Western Australian healthcare and support system interactions

The research approach recognised the sensitive nature of these discussions and the significant emotional burden that revisiting challenges can place on families already under extreme stress. Every effort was made to conduct interviews in a supportive, respectful manner that acknowledged the expertise of parents and caregivers while minimising additional trauma.

Key themes from Western Australian families' experiences

THEME 1: Fundamental systemic barriers for degenerative conditions

The NDIS framework is fundamentally misaligned with childhood dementia as it is designed for static or improving conditions rather than progressive decline, forcing Western Australian families to operate within an impossible model of goal setting and improvement.

The fundamental disconnect: a system not built for rapidly progressing conditions

Childhood dementia represents a cruel paradox that the NDIS framework is fundamentally unprepared to address. Where most disability support systems are designed around improvement, stabilisation, or long-term management, childhood dementia follows a relentless path of decline that defies traditional support models.

For Western Australian families, this misalignment has been particularly pronounced following the transition from the state-based system. Many parents found the previous state system ultimately more responsive to the needs of degenerative conditions and supporting parents' health and wellbeing:

“Back then, when my son got Global Developmental Delay, we had the Disability Services Commission in Western Australia... they actually were quite good with the other stuff. So we got funding for playground equipment. We got funding for me to join a gym as part of just my own psychological wellbeing... they covered a lot, and they actually were quite good."

One parent elaborated on the comprehensive nature of support under the previous WA system:

“Everyone was more supportive. They would give us more... The girls that I had through our therapy team, they were awesome. They were like family. You weren't a number, you weren't just anything. It was basically they helped in so many different ways. Gave us tips on little ways that we could get around the systems, or to be able to get cheaper medications, buying things online."

When progress isn’t a possibility

The NDIS’s focus on improvement and goal setting directly conflicts with degenerative conditions. This creates significant stress for families who must frame their needs within an unachievable model.

One Western Australian parent described this experience:

“We were forced to make inappropriate goals for him in the planning process. Goals he is unlikely to achieve. Goals that are achieved, he will lose. It is difficult to help NDIA representatives understand this."

Another parent highlighted the challenges of meeting standard expectations:

“They don't understand. And I don't think they understand that [my child] will never be independent, never. They're going to get worse and more dependent. So it doesn't work for us, this system of let's help everyone be as independent as they can, because that's not us, and that needs to be recognised."

The high cost of waiting

The urgent and unpredictable nature of the needs of children with degenerative conditions conflicts with the NDIS’s lengthy approval processes. The administrative approach creates life-altering consequences:

“By the time they look at your requests and knock you back for parts, then you have to redo it all again... And by then, we've already deteriorated even more. So then your needs become even more. It's a roller coaster that does not stop."

A Western Australian parent shared their experience with ongoing delays:

“We've been fighting this now for you... well, 3 years, 4 years, and having to resubmit, resubmit, and we've just resubmitted again, just to try and get the bathroom modified for [my child], but they just keep knocking you back, knocking you back and saying that it's she does qualify for this, when health professionals say she does."

Another parent described how they’ve spent years waiting for home modifications:

“We're literally at the base level, even though it's been in the pipeline for months, like we're waiting for the approval for the complex home OT team to do their review to then put in what we actually need. So we're, like, right at the very beginning baseline, and you know, that takes 12 months, and then you got another 12 months to get

everything approved through the OT after that. And then, you know, 2 to 3 years later, we're finally getting home modifications done."

THEME 2: Lack of workforce understanding significantly impacts families

The reported lack of understanding and empathy about childhood dementia among NDIA staff creates significant barriers for Western Australian families. Families are forced to constantly explain and educate about their child's condition.

"We don't have that permanent person that we can talk to, like we have to just send an email to the NDIS, like the main email, and then wait for a response, but we might not get a response for a little while."

A parent described how the Local Area Coordinator (LAC) demonstrated a fundamental misunderstanding of their child's condition:

"I got sent a report, and it had a diagnosis of Cornelia de Lang syndrome. So I got in touch. It's not Cornelia de Lange syndrome, it's [correct syndrome]. Can you change this? 'No, we can't change it now. It's in the system, but I'll write a note on his file saying that it's [correct syndrome].' I'm not kidding."

The complexity of multiple children with dementia

An additional issue is the failure or inability of the system to recognise the exponential loading of families who have more than one child with dementia:

"The NDIS doesn't cope when you have 2 kids in the family."

The emotional toll of repeated justification

Families become unwilling performers in a system that demands they continuously prove their child's deterioration. One Western Australian parent captured the emotional exhaustion of this repetitive process:

"I have to dwell on the terrible, awful, heartbreaking parts about my child, and that's in terms of everything. So I have to dwell on his disability. I have to dwell on his behavior challenges, and I really have to paint the picture of how shit everything is,

and none of it's a lie, but it's when you're completely focused on those awful, awful parts of your life, the psychological impact that has on you as a parent is quite profound."

Psychological impact of repeated storytelling

The administrative process becomes a persistent source of psychological distress, contributing to emotional exhaustion and potentially leading to secondary trauma as families are repeatedly forced to focus on their child's deterioration:

"Have to pour out my complete heart and soul and describe every utterly devastating part of my life. I feel guilty and depressed writing it. It leaves me feeling an emotionally exhausted basket case."

Cumulative trauma

Ultimately, the result of this barrage is that families lose faith in the system and the professional relationships become adversarial:

"It's beyond my levels of comprehension and sanity dealing with the NDIS. I have to laugh, or I would be an absolute wreck."

THEME 3: The overwhelming administrative burden

The administrative burden imposed by the NDIS transcends mere paperwork–it becomes an all-consuming occupation of emotional and psychological warfare, further burdening Western Australian families already stretched to their absolute limits.

"The reports, it costs a lot of money in terms of your therapy money, they will charge you for every hour that they do administrative work...I mean they are hugely, huge, long reports."

The additional trauma of constant documentation

As well as the administrative load, each document becomes a painful dissection of a child's declining capabilities:

“A Day in the Life of [my child]. This document reads like a timeline of an average day in my household. Again, it is very difficult to read and I feel guilt and shame. I feel terrible that my child who I love is having all of their flaws and shortcomings exposed and focused on."

The financial burden of proving changing needs

The financial cost of documentation adds another layer of difficulty and creates additional barriers:

“It's like thousands of dollars to gett these reports. They come and see me for, you know, an hour, and then they charge $500 for that service, and then they go and write this report, and it's so many hours and it's $2000."

Fear of “getting it wrong”

Western Australian parents consistently spoke of living in a ”constant state of fear” when dealing with the NDIS:

“We are treated like we are the criminals."

A parent elaborated on this fear:

“You feel judged. You feel really judged like your delegate, or whoever is sitting in their ivory tower is making a judgment on you and your life and whether you're telling the truth or not. They've got all the power we have none."

Transition from previous WA system

The transition from the Western Australian Disability Services Commission to the NDIS has created additional administrative challenges:

“When NDIS was coming in, I attended a few meetings, and I walked out still not understanding how any of this was going to work and what I had to do."

One parent reflected on what was lost in the transition:

“There used to be a scheme that you could go as families and the parents would be able to go off for a retreat to have time away. But now there's, there's nothing. There's nothing at all offered to you. It's everything about time and dollars, you're on a time schedule because you're charged by the hour and or by each kilometre."

THEME 4: The lottery of care – inconsistent support

Support for childhood dementia families resembles a high-stakes game of chance, where the quality of support depends on an individual coordinator's understanding, empathy, and expertise.

"It comes down to the NDIS person you get... it's the roll of the dice."

A Western Australian parent described the variability in their experience:

"We've had a few families talk about almost feeling like they're doing something wrong. I am certain that there will be people that do dodge the system, without a doubt, like with anything, but then legitimate families are just trying to get to what they need to get through. You literally are drilled about every single little thing."

The expertise vacuum lottery

Western Australian families encountered a stark reality: most support coordinators had minimal understanding of childhood dementia and how to navigate the system:

"I've never, ever, in all of the meetings I've had with the NDIS, had someone who was familiar with not only [the specific condition], but with childhood dementia, never, ever."

Another parent experienced complete misunderstanding of their child's condition:

"I key lock my door, my front door. I have to because and I have to hide my keys because he has gotten out before, and he has been lost before. He's literally been out of my street and around the corner and at the back of a house... When I'm asking for a seat belt on a disability dedicated stroller, they're questioning whether that's a restrictive practice. He's a child who runs, who will bugger off, you know, get out of seats and stuff, and he's lost, and if that stroller flips and falls, he can't catch his fall and smashes his face. But apparently, that's a restrictive practice. It's absolute nonsense."

Additional challenges for regional and rural families

Western Australian families in regional areas face additional barriers, particularly limited options for appropriate local providers:

"Being in regional [Western Australia], there is no one, there's no companies at all who will help. My daughter's case is too challenging."

One parent shared their struggles with finding allied health providers in regional WA:

“We went months and months without a speech [therapist]. We've had multiple changes to the team. People have come and gone in the last, like, just over a year since we've moved down here, we had a more solid team in [regional town], which is in the middle of nowhere in the Pilbara than what we have down here in one of the sort of, what would you say, second biggest regional city in, you know, WA. So that was a big eye opener for me."

THEME 5: Equipment and modification challenges – the battle for essential support

Every Western Australian family interviewed had struggled to access appropriate equipment in a timely manner for their child, some fighting for basics and waiting months or years.

“You can't wait 6 to 12 months without a wheelchair when you've got a child that can't walk."

A WA parent described the process:

“We put in an application to upgrade our travel wheelchair... because she'd outgrown the basic level one that we'd had prior to that. It had also been across to the states and back many times, and was worse for wear. And we put in an urgent request 6 months before we were flying, because we did it as soon as we got back from the last trip, and still, we left for the next trip 6 months later, and it still hadn't come through and been processed. And I think it was like a month or 2 after we returned from that trip. So I think all up, it took 7 to 8 months to get that travel wheelchair."

The dehumanising battle for basic necessities

Families reported feeling like they were undertaking a constant battle, asking for equipment or home modifications:

“We've been fighting this now for 3 years, 4 years, and having to resubmit, resubmit, and we've just resubmitted again, just to try and get the bathroom modified... they just keep knocking you back."

There is also fear for the physical safety of their child and themselves without access to the right equipment:

“Do you want me to show you the bruises? Do you want me to show you the holes in the walls where she literally grabbed at the towel rail in the bathroom as a grab rail and pulled it off the wall?"

A parent shared their fears about waiting for essential home modifications:

“So we're sort of getting to that point again now where there's some mods that need to be done in the house, which is fine, it's all gone through the system. It's taking a very long time, but [our child] is not getting any lighter either. Our backs aren't getting any better, so we're tending to lift a lot, and even our carers that are here now, we risk losing them potentially, because they can't handle the load of lifting her. And they're just saying, unfortunately, it's too much for us."

The hidden costs

Beyond the visible challenges of equipment delays, Western Australian families bear numerous unseen burdens:

“I am just trying to keep my family together."

A parent explained the impossible tradeoffs they face:

“I think what they want is to wear you down."

THEME 6: Fighting on all fronts – the failure to align support systems

The intersection between the NDIS and other Western Australian systems, such as health, is a minefield of overlapping needs and gaping holes.

A parent described their nightmare with coordinating services:

“I had to get back into the hospital system with a few things, because we had nobody caring for us. But then, because they're under NDIS, we had to get special permission from the hospital for them to even see us as well, because you're under that NDIS banner. So that was a whole other issue in itself."

Hospitalisation

Western Australian families face particular challenges during what can be frequent hospitalisations, including coordination between hospital systems and NDIS supports, and accessing appropriate care when hospitalised. These challenges are especially acute for families who must travel long distances to access specialist medical care.

Transition from WA Disability services to NDIS

The transition from the Western Australian state-based system to the NDIS has created particular challenges. One parent lamented what was lost in the transition:

“So we had something in place, being in Western Australia, and I actually formed a really close relationship with my speech therapist, because at the time, I didn't know what the hell was going on with my kid, and she was in my house every week."

A mother described how the previous system in WA better supported the entire family:

“Disability Services, our area coordinator and all of them and our therapy team, they would come to my case conferences at school, just to, you know, fight the department for [my child's] aid time. They would help you with medication, to find things that were cheaper. They would tell us things. They would tell us about little retreats that you could go on as parents, to get away for a bit. You don't get nothing now."

Palliative care

Due to the lack of curative treatments for childhood dementia, all care from the point of diagnosis is palliative in nature. The topic of palliative care was particularly fraught for Western Australian families:

“NDIS doesn't seem to understand the difference between palliative care and end of life."

One parent shared their reluctance to use the term with NDIS:

“I haven't used that term [palliative care], I haven't even set anything concrete there either. I've not used those terms.”

Next steps

As next steps, Childhood Dementia Initiative will be developing comprehensive recommendations based on the findings of this report and working collaboratively with the NDIS to drive improvements. This collaborative approach will aim to create meaningful system change that recognises the unique needs of children with dementia and their families.

Through ongoing consultation with affected families, health professionals, and NDIS representatives, Childhood Dementia Initiative is committed to developing practical solutions that can be implemented to improve the lived experience of Western Australian families navigating this challenging journey.

The initiative will continue to advocate for consistent, appropriate support that acknowledges the progressive nature of childhood dementia conditions and the urgent need for responsive, compassionate systems that truly support affected children and their families.