Exploring the issues series

Childhood Dementia: Family experiences in Queensland

May 2025

A Childhood Dementia Initiative report

childhood dementia INITIATIVE

Childhood Dementia Initiative (2025). Childhood Dementia: Family experiences in Queensland

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Acknowledgments

In the spirit of reconciliation, Childhood Dementia Initiative acknowledges the Traditional Custodians of Country throughout Australia and their connections to land, sea and community. We specifically acknowledge that this Long Table was held on Meanjin, the lands of the Jagera and Turrbal people.

Childhood Dementia Initiative acknowledges the voices of families as central to improving awareness and understanding of childhood dementia and to creating change.

We thank the James Frizelle Charitable Foundation for making this event possible.

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Executive summary

Dementia is usually only associated with older adults. Tragically, hundreds of thousands of children across the world living with dementia, caused by more than 100 life-limiting cognitive decline conditions, many of which are not yet understood. In Australia, a baby is born every 2 days with a childhood dementia condition from which they will die, most likely before their 18th birthday. Yet most health professionals remain unaware of childhood dementia, and finding care and support is extremely difficult for families. Research is scant and there are currently no cures or treatments.

Childhood Dementia Initiative (CDI) was formed in 2020 to transform this situation. In May 2025, CDI conducted a participatory research event in Brisbane – the Long Table – bringing together parents and family members of children living with dementia conditions in Queensland. Families discussed their experiences of the health and disability support system, while stakeholders from those systems listened. This report provides a thematic analysis of the discussion, with the intent that it be used as a basis for future improvements.

Key findings

The trauma of diagnosis and professional knowledge gaps

Families consistently described profoundly traumatic diagnosis experiences that created lasting damage to their trust in the health system.

- Diagnoses were often delivered without preparation, support, or follow-up, in stark contrast to the wraparound care given for other life-limiting childhood conditions.
- Parents frequently held more detailed knowledge of their child's condition than the professionals treating them, creating a recurring gap in care.

Pain recognition, medical trauma and discriminatory attitudes

Healthcare professionals often failed to recognise or treat pain appropriately, based on misconceptions about how children with dementia experience it.

- Some families described discriminatory attitudes that revealed a devaluation of their child's life relative to other patients.

Systemic failures within the NDIS

The NDIS created significant bureaucratic burden for families, at a time when they could least afford it.

- Delays in accessing essential equipment, and processes that questioned legitimate medical needs, added stress during children's limited lifespans.

The impact on the whole family

The effects of a child's diagnosis extended well beyond the child themselves, disrupting entire family systems.

- Siblings experienced significant distress with little acknowledgement or support, and many families experienced relationship breakdown and profound social isolation.

Living with ongoing loss, anticipatory grief and forced resilience

Families described the challenge of grieving a child who is still alive, while trying to maintain hope and a normal family life.

- Many families developed skills and resilience they never expected to need, often channelling this into advocacy for others.

Insights from bereaved parents

Bereaved parents described long-term psychological impacts that persisted well beyond their child's death.

- Many continued to support other families navigating similar journeys, carrying the ongoing emotional burden of doing so alongside their own grief.

Background

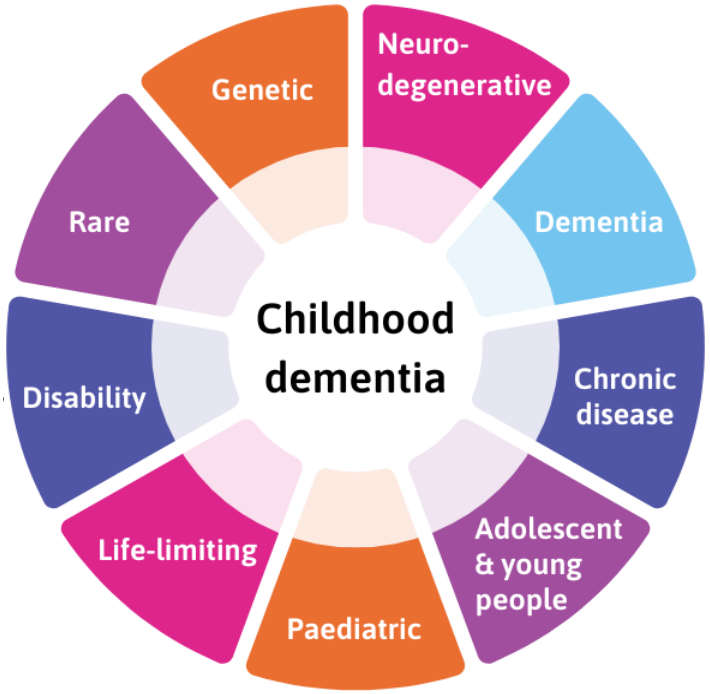
This report explores family experiences of the health and disability support system for children with dementia in Queensland. Through their voices, Childhood Dementia Initiative seeks to communicate how families interact with these systems, and to provide a basis for future improvements.

Childhood dementia is uniquely devastating and severely under-recognised. The condition is unknown to most people, including health professionals. As such, there are tremendous unmet needs in treatment, research and psychosocial support.

Childhood Dementia Initiative commends the professional stakeholders who participated in the research outlined in this report, and their commitment to addressing the needs of families enduring this disease.

About Childhood Dementia

A baby is born every 2 days in Australia with a childhood dementia condition from which they will die. Sadly, 50% of these children will die before their 10th birthday and 70% of them before they reach adulthood[3]. Childhood dementia causes 91 deaths in Australia every year. This is a similar number to deaths from childhood cancer for patients aged 0-14 years[2].



Childhood dementia is caused by 100+ cognitive decline genetic conditions. These conditions have recently been grouped to define this unique and under-recognised cohort. The specific attributes of childhood dementia and the lack of a coordinated approach means the children with dementia face a uniquely devastating situation in the Australian health system:

- There are no cures for childhood dementia and it is life-limiting for all affected children.
- Children experience chronic, increasingly severe symptoms and their intellectual and physical disabilities progress until they die prematurely. Children living with confusion, distress, unhappiness and pain. The complex childhood dementia conditions can also cause seizures, loss of vision and hearing, and problems with bones, joints and cardiovascular, respiratory, or digestive systems.
- Due to the lack of awareness, disability, health and education systems don't cater for the unique needs of children with dementia. This results in heightened carer responsibilities for families. The psychosocial challenges they face are broad, encompassing physical, economic, social, emotional and psychological implications[5].

- Children with dementia are often excluded from essential services due to their dementia symptoms.
- The challenges facing children with dementia are not currently addressed by any national dementia policies globally.
- There is, and has always been, a complete inequity and underinvestment in research. This has resulted in no notable improvement in survivorship for children with dementia[6].
- Childhood dementia conditions are individually rare. Families report struggling to get diagnoses[45] and can subsequently go on to have more than one child without knowing about their genetic risk.

The challenges described by families in this report accumulate and are exponential when there are multiple children with dementia in a family. Given the genetic nature of childhood dementia, this is not uncommon.

Methodology

This report summarises key insights that emerged during a participatory research event in Brisbane – The Brisbane Long Table – held in May 2025. The Long Table was developed and hosted by CDI, with this event held as part of CDI's national programme of Long Table events, following the earlier event in Western Australia.

Parents and family members of children with dementia discussed their experiences of health, disability and support systems in Queensland, while stakeholders from those systems and related services listened in silence. The discussion was recorded and transcribed. A thematic analysis of the transcripts was used to generate this report.

For more information on the Long Table methodology, see the Appendix.

Key issues

1. The trauma of diagnosis and professional knowledge gaps

Queensland families consistently described their diagnosis experience as profoundly traumatic, in ways that shaped their trust in the health system for years afterward. One mother, alone in hospital while feeding her daughter breakfast, had a paediatrician walk in and deliver the news matter-of-factly before leaving the room; other professionals then began arriving with equipment lists and surgical schedules. No partner was present, and no social worker or preparation had been offered.

> *"Yep, so your child is positive for CLN2. And also, she has a life expectancy of 8–10 years... It's a terminal diagnosis."*

This pattern held across decades. One family was called to an unprepared meeting on a Friday evening, where a consultant grabbed the nearest available room and asked a random nurse walking past to witness the conversation. There was no emotional or psychological support offered as they were told their newborn had a fatal disease with no cure and was unlikely to live three months. A decade before that, another family received their son's diagnosis when a specialist admitted she didn't know much about the condition, having printed information from the internet, before telling them to prepare for him to die.

These experiences created lasting damage that extended well beyond the moment of diagnosis, affecting every subsequent interaction with the health system. Families described losing trust in medical professionals and feeling abandoned at their most vulnerable moment, while having to process their child's condition and make critical care decisions at the same time. The impact was not contained to parents: siblings witnessed the aftermath, extended family struggled to understand what had happened, and families found themselves needing to advocate for their children immediately, while still absorbing the shock of the diagnosis itself.

Families drew a stark contrast with how other life-limiting paediatric conditions were handled. One parent, whose nephew died of cancer, described the wraparound support her brother and sister-in-law received:

> *"There was a social worker, there were people in the room. There was the paediatrician, there's the oncologist, there was a head person from the hospital. There were all these support people. They were given a Red Kite [resources] bag. They were given food vouchers. They were given free parking."*

For families receiving a childhood dementia diagnosis, the experience was starkly different. As one parent put it:

> *"I was just, I didn't get a piece of paper. I was just told, "your kid's gonna die," and it's like, cheers."*

Alongside the trauma of diagnosis, families described an ongoing pattern in which healthcare professionals openly acknowledged that parents knew more about their child's condition than the treating medical team. The phrase "you know more than we do" became a recurring refrain families heard from specialists, emergency department doctors, social workers and support staff.

Emergency departments emerged as a particularly difficult setting, with staff often unprepared to treat children with childhood dementia conditions. One mother described waiting seven hours before an ED doctor asked what had brought them in that day, despite her child's complex medical file being available on record.

> *"They need to walk back out there, go read her file, and then come back in here and ask me how I am tonight."*

Families found themselves becoming medical experts by necessity – researching complex conditions, connecting with international specialists, and holding more detailed knowledge than the professionals treating their child. Parents described giving doctors printouts and contact information for international experts because local clinicians had reached the limits of what they knew, and found themselves repeatedly educating new professionals, often while their children were acutely unwell and needed immediate care.

This created a particular contradiction: professionals would acknowledge parents' expertise in principle while dismissing it in practice.

> *"You know they are saying, "you're the expert", but at the same time, they don't listen to you... it's a bit contradictory, really."*

The most serious consequence of this gap in professional knowledge was false suspicion of child abuse, when medical professionals could not account for the presentation of an unfamiliar condition. Multiple families described being accused of child abuse when their children presented with injuries or symptoms that resulted from their condition. One family had child safety services involved, with the record of that involvement remaining on file years later, unable to be removed.

2. Pain recognition, medical trauma and discriminatory attitudes

A significant pattern to emerge was the systematic failure to recognise, assess and appropriately treat pain in children with childhood dementia, based on misconceptions about how these children experience and remember pain. In one of the most serious examples, a child split his head open and required emergency treatment. Despite the parent explaining the child's condition and why he would not show a typical pain response, the doctor left the room, returned and put four staples in his head without warning or preparation.

> *"Don't worry, he'll forget in five seconds."*

The child was not given any pain relief, numbing, or preparation for a procedure that would be considered traumatic for any patient. This reflected a broader pattern: parents described healthcare professionals operating on the belief that children with dementia do not experience pain the same way as other children, or that memory impairment makes pain management unnecessary.

> *"My child will recognise when he first hurts himself, but after like a minute or two, it's like he... forgets that he's hurt himself."*

Rather than prompting a different approach to pain assessment, this was instead used to justify inadequate pain management.

Families also described specific instances of discriminatory attitudes among healthcare professionals, which revealed a devaluation of children with dementia relative to other patients. One specialist recommended a particular medication not for medical reasons, but so that the family could manage without the child needing to be present.

> *"That's so you can put him in the corner with a blanket over him, and you can get on with your life."*

Another specialist told parents they had been "scammed" by receiving care, and reminisced – in front of the child – about a time when families could:

> *"just turn up, drop your kid off at a home [an institution] and drive away and get on with your lives."*

Families also described healthcare professionals referencing the historical institutionalisation of children living with disabilities as though it had been preferable to current family-centred care.

Families discovered that resources available to children with other life-limiting conditions were not extended to those with childhood dementia. Hospital quilts donated for children were reserved for the oncology department, while children with dementia were told they were not eligible, despite having terminal conditions.

Healthcare professionals also routinely questioned whether children with dementia deserved the same level of medical intervention as other patients, including during pre-surgical consultations, in ways families said would not occur for other conditions. One specialist, looking at a child in a wheelchair, asked:

> *"How much does she use her legs anyway?"*

3. Systemic failures within the NDIS

The NDIS created significant bureaucratic challenges for families, made more acute by the time-limited nature of childhood dementia conditions. One of the most difficult aspects was delay in accessing essential equipment during children's limited lifespans. Families described waiting nine months for an adapted pram for a child whose condition carried an average lifespan of eight years.

> *"You're wasting my time. I want to, like, I want these things, to go out and take him for a walk and enjoy life."*

These delays were not simply an inconvenience; families described them as a loss of opportunities for family experiences, quality time and basic dignity during the time they had left. NDIS processes also required families to take on an administrative role on top of full-time caregiving, managing complex requirements that consumed time and energy needed elsewhere.

> *"I feel like I am his personal assistant. I need five of me to do what I need to do. It's so overwhelming."*

Families also described NDIS assessors questioning legitimate medical procedures and equipment needs. When one child underwent PEG (feeding tube) surgery, the assessor questioned whether the procedure had actually taken place, despite a letter from the specialist and supporting nursing documentation being provided.

This combination of complex requirements and inconsistent decision-making created ongoing anxiety about the possibility of an audit, even for families who had followed proper process.

> *"This fear of if you're going to be audited."*

Families also described the requirement to re-confirm a diagnosis annually for conditions that are, by definition, degenerative and permanent. One parent summarised the position this placed families in:

> *"Something almost as inhuman as an insurance scheme that says once a year you've got to re-diagnose your child for the same condition, who's not going away."*

4. The impact on the whole family

Impact extended far beyond the affected child, disrupting entire family systems, with healthcare focusing almost exclusively on the diagnosed child while overlooking the effects on others. Non-diagnosed siblings experienced significant distress witnessing their sibling's progressive decline, yet parents described no support services being available to address their needs – including from mental health professionals who dismissed sibling needs as beyond their remit.

> *"We don't know how to help her. She's too young. She doesn't understand what's going on."*

This dismissal occurred despite clear evidence that siblings understood far more than professionals assumed, with young children asking their parents whether the doctors had fixed their sibling yet.

> *"Mum, have the doctors fixed [sibling with dementia condition] yet? Have they helped him yet?"*

Siblings were excluded from support at an age when they were already old enough to be aware of what was happening in their family. The intensive needs of the child with dementia consumed family resources, leaving siblings with reduced parental attention and fewer opportunities for ordinary childhood activities, and struggling to understand why their sibling had access to specialised equipment and support that they did not.

The stress of caring for a child with a dementia condition contributed to high rates of relationship breakdown, with many families experiencing separation or divorce as different coping strategies and caregiving approaches led to conflict.

> *"My mental health really, really suffered. It ended up that my husband and I separated for 18 months."*

Families also described profound social isolation, as friends and extended family struggled to comprehend the reality of a child's terminal illness. The pattern of friendship loss was both systematic and sustained, with close relationships disappearing after diagnosis. Families described people they had thought were close friends subsequently blocking or avoiding contact through social media, in one case:

> *"literally just wiped me off the face of the earth."*

Maintaining the relationships that did remain required families to conceal the true extent of their child's condition and their own emotional distress, to avoid making others uncomfortable – an ongoing emotional labour on top of caregiving itself. As personal friendships disappeared, families described becoming increasingly dependent on relationships with healthcare providers and support workers for human connection, despite knowing these relationships were temporary and bounded by their child's care.

> *"My biggest fear is that when my child passes... I'm good friends now for the nurses at the hospital, when she passes, who am I? Yeah, what do I become? I'm not gonna be at the hospital every week... all my friends are gone."*

Families described being unable to share the full reality of their daily experience without causing discomfort or shutting down conversation, leaving them to process much of it alone.

5. Living with ongoing loss, anticipatory grief and forced resilience

Queensland families described the challenge of grieving their children while still caring for them daily, living with constant awareness that death was inevitable while trying to maintain hope and a normal family life. Unlike other life-limiting conditions with more predictable trajectories, childhood dementia left families with ongoing uncertainty about timeline and progression, making planning difficult and decisions agonising – whether to spend cautiously in case years of care lay ahead, or make the most of time that might be short.

> *"this anxiety that you have all day and all night... you're laying in bed that noise that you hear, you think, oh, better get up and check in. You know, this goes on the whole time."*

Parents described a daily ritual of confirming their children had survived each night, creating a cycle of relief and dread that began fresh every morning. Waking to silence carried the fear of loss; waking to noise confirmed survival but came at the cost of interrupted sleep.

> *"I wake up every day, if my child's voice wakes me up, I wake up cranky because I haven't had enough sleep. And if her voice doesn't wake me up, I don't want to get out of bed because she hasn't, she hasn't survived the night."*

Families also had to engage in practical planning for their children's deaths while still providing hope-filled daily care, including conversations about organ donation, funeral arrangements and end-of-life preferences that healthy families never need to have. When one parent tried to raise organ donation, they were told by medical professionals:

> *"you don't have to think about that now."*

"Why not?", the parent responded. The reality of a terminal condition required this planning, even when professionals were uncomfortable acknowledging it – and having these conversations with a spouse added its own relationship strain.

Even after a child's death, the anxiety developed during their illness did not simply end.

> *"that anxiety is still there, but it's you can't do anything with it, because can't get up and check them in the night."*

The hyper-vigilance and habits developed during care giving persisted after bereavement, contributing to ongoing trauma symptoms and adjustment difficulties. Families also described a form of "grief policing" – social pressure to moderate the expression of anticipatory grief from others uncomfortable hearing about a child's prognosis or future planning – which added a further layer of isolation on top of the grief itself.

Despite these systemic failures, families also described extraordinary resilience and transformation, developed through necessity rather than choice.

> *"I went from being a very meek and mild person that would never have challenged a medical person... I've had to learn the very hard way, and I'm now an absolutely fierce advocate."*

This transformation, while it gave families new skills and confidence, came at real personal cost, developed under extreme stress while still managing complex caregiving responsibilities. Many channelled their experience into advocacy for systemic change, driven by the wish to prevent other families from experiencing the same harm.

> *"I'm not here to point fingers or even rehash my anger... but really being here to be part of meaningful change... it happened 16 years ago, but it's still happening."*

6. Insights from bereaved parents

The Long Table included bereaved parents whose children had died with childhood dementia, providing insight into longer-term impacts and challenges that continue after a child's death.

Bereaved parents often found themselves supporting newly diagnosed families, drawing on the expertise and advocacy skills they had developed. This role carried its own burden: some parents' current work supporting families with palliative conditions meant they continued to encounter the same system failures that had traumatised their own family years earlier.

> *"I guess I suffered from post traumatic stress... something that hadn't bothered me before, all of a sudden, became a big issue that I couldn't deal with."*

Bereaved parents also described the emotional labour of keeping others comfortable during their children's illnesses, often at the cost of their own authentic emotional processing.

> *"I wanted to kept it very light the whole time... I took a photo of that x ray and sent it to my sister, who's in the medical profession, and with the comment, so, is this a photo or is this a clip from a movie Alien, or is this a photo of Thomas's X ray? Right? Just to try and keep everybody out of that dump."*

The necessity of staying strong during their children's illnesses meant that many parents delayed processing their own trauma until after bereavement, which often intensified grief and complicated adjustment to life after loss.

> *"I wasn't sure the burden that took on me, but once, it was all over, and Thomas passed a few months later, I guess I suffered from post traumatic stress... I looked back on some of those things and thought, Oh, God, Did I really say that at that time."*

Bereaved parents also described a profound sense of identity loss after their children's deaths, particularly where their primary social connections had been through healthcare settings and support services. The end of medical appointments and treatment schedules left parents without the professional relationships that had become their primary social connections.

"You're in no club, not important at the hospital anymore... the lady on the bus that cares for them on the bus to school. You know that you saw every day... it was this whole what had become your social network... it suddenly goes."

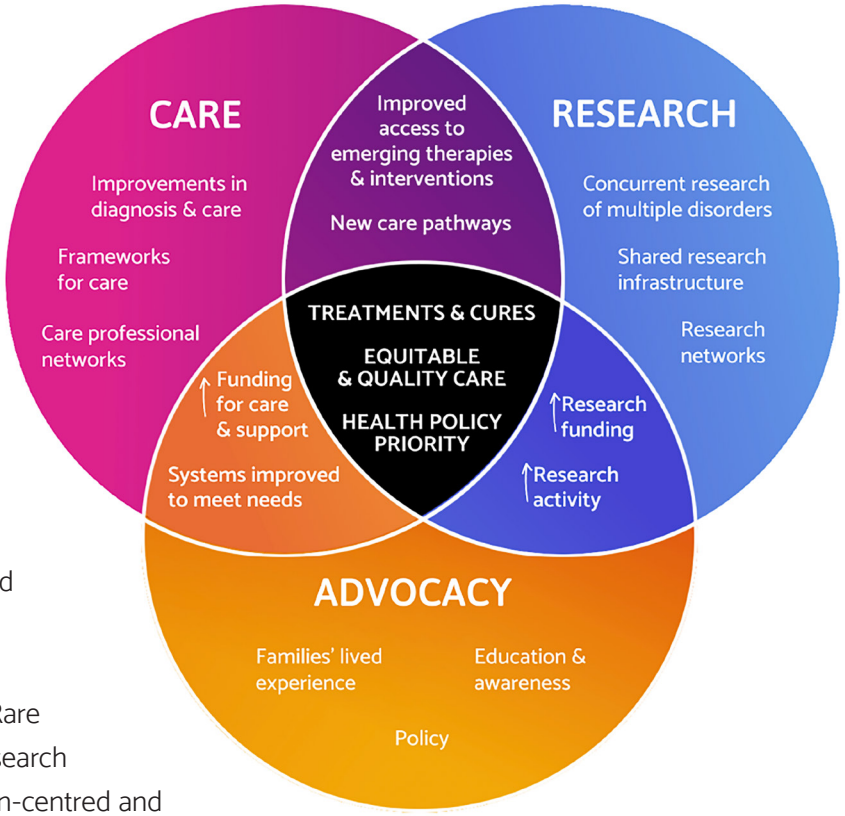
Bereaved parents also observed patterns of gendered caregiver burden, with mothers typically remaining as primary caregivers while fathers withdrew or disappeared entirely – a dynamic that shaped family structures well beyond the illness itself, often leaving mothers as sole carers both during their child's life and after bereavement.

"It's very female dominated. The guys tend to sort of either back away or disappear altogether. I've been surprised how many singles that people are dealing with these types of enormous issues."

Childhood Dementia Initiative

Childhood Dementia Initiative is driving world-first action for every child with dementia, bringing all the genetic conditions that cause dementia in childhood together under a single umbrella.

Framework for Childhood Dementia Systems Change



Childhood Dementia Initiative works to ensure that Australian children and their families can access the treatments and support they need. This will change the lives of thousands of Australians now as well as the lives of future generations. Childhood Dementia Initiative's work is informed by the Framework for Childhood Dementia Systems Change and underpinned by the key principles of evidence, people and co-design. The framework aligns with the National Strategic Action Plan for Rare Diseases, which recognises the need for research into rare diseases to be collaborative, person-centred and systematically address gaps.

Established in 2020, Childhood Dementia Initiative drives vital change by:

- Building evidence that is validated by families, experts and empirical data.
- Building networks. We bring cross-disciplinary experts together to enable change. This includes families, researchers, health professionals and service providers, and policymakers.
- Enabling partnerships, collaborations and co-design. This ensures sustainable, effective solutions are implemented.
- Advocating for enablers. This includes investment, policy and practice changes, as well as greater awareness. Shifts in funding, policy and awareness are already having an impact.

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Appendix 1 - The Long Table Methodology

What is The Long Table?

The Long Table is a format for discussion that uses the setting of a table conversation as a means to generate public discussion and new knowledge. Conceived in 2003 by Lois Weaver in response to the divided nature of conventional panel discussions, the Long Table allows voices to be heard equally, disrupting hierarchical notions of "expertise".[7]

The Long Table has been used at institutions and festivals worldwide, inviting hundreds of people to sit and share their views and experiences on a myriad of topics.

Brisbane Long Table Adaptations

For the Brisbane Long Table, the methodology was adapted to centre family voices while ensuring stakeholders could listen without interruption:

- **Family-centred conversation:** Only families affected by childhood dementia spoke at the table
- **Stakeholder listening:** Healthcare professionals, researchers, and policymakers listened from surrounding seats
- **No interruption policy:** Stakeholders observed without questions or professional input
- **Recording for analysis:** The discussion was recorded to enable thematic analysis and report generation

Participants

The Brisbane Long Table included families representing diverse experiences across Queensland, including those from metropolitan Brisbane, Gold Coast and regional areas. Stakeholders represented health services, disability support, education, research, and policy sectors.

Appendix 2: Long Table Etiquette Guide

This is a collaboration of conversation and discussion about childhood dementia.

Anyone seated at the table is an expert in their child, their family and their experiences of childhood dementia.

- Family voice and experience is the only course.
- No one will moderate.
- But a host may assist you.
- It is a democracy and everyone shall be heard.
- To participate, simply take an empty seat at the table.
- If you leave the table you can come back again and again.
- Feel free to write your comments on the tablecloth.
- There can be silence.
- There might be awkwardness.
- There might be sadness or tears.
- There could be laughter.
- There is an end, but no conclusion.

We respectfully acknowledge that this Long Table was held on Meanjin, the lands of the Jagera and Turrbal people and pay our respects to Elders past and present.

We thank the James Frizelle Charitable Foundation for making this event possible.

Long Table Spectator Etiquette Guide

As a spectator, you are invited to watch, observe and participate through deep listening to the discussion and conversation at the Long Table.

The people at the table are parents and family members of children with dementia conditions. They are experts in their child, their child's condition, their family and their experiences of the health and disability support system. There is no question-and-answer segment or time to ask questions during the Long Table.

A long table was set with a white tablecloth and marker pens, to help document the conversation and produce a physical record of the event, with surrounding chairs for spectators placed around the Long Table.

Appendix 2

Long Table participant etiquette guide

Etiquette

The Long Table: Exploring the Issues in Health for Childhood Dementia

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It is a democracy and everyone shall be heard.

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Long Table spectator etiquette

Coming to the Long Table

What is a Long Table?

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The Long Table has been set at institutions and festivals worldwide, and invited hundreds of people to sit and share their views and experiences on a myriad of topics.

What to expect

Setting the table
The Long Table is an event; people participating in the discussion have been invited to be seated at the table, and people have been invited to spectate by watching and listening from seating outside of the table.

A Long Table
A long table will be set with a white tablecloth and marker pens to help document the conversation and produce a physical record of the event.

Surrounding chairs for spectators will be placed around the Long Table.

A host and etiquette
The Table will moderate itself, and there is no need for anyone to 'tie up loose ends' at the end. However, a host can ensure everyone follows Long Table etiquette and close the conversation at the set time.

Your role

As a spectator, you are invited to watch, observe and participate through deep listening to the discussion and conversation at the Long Table.

The people at the table are parents and family members of children with dementia conditions. They are experts in their child, their child's condition, their family and their experiences of the health and disability support system. There is no question-and-answer segment or time to ask questions during the Long Table.

A long table was set with a white tablecloth and marker pens, to help document the conversation and produce a physical record of the event, with surrounding chairs for spectators placed around the Long Table.

1

Schedule

Arrival 9.30 am

Introductions 9.45 am

The Long Table commences at 10.00 am

Lunch will be served from 12.15 pm

Finish 1.00 pm

We respectfully acknowledge that this Long Table was held on Meanjin, the lands of the Jagera and Turrbar people and pay our respects to Elders past and present.

We thank the James Frizelle Charitable Foundation for making this event possible.