Round Table Report: Next Steps for Childhood Dementia Care in Western Australia

July 2025

A Childhood Dementia Initiative report

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Executive Summary

This report summarises the outcomes of the Round Table on "Next Steps for Childhood Dementia Care in Western Australia," which brought together key stakeholders in health, disability, research, education, and funding sectors to address the critical issues facing children with childhood dementia and their families in WA. The consultation aimed to build consensus on these issues and develop prioritised recommendations for meaningful change.

The Round Table identified five key priority areas for action:

1. Care coordination and system navigation
2. Professional and public awareness of childhood dementia terminology
3. NDIS responsiveness and funding pathways
4. Research opportunities
5. Supporting diverse communities

For the top three priority areas, stakeholders identified the current challenges, desired future state, and specific recommendations for improvement. Key themes that emerged across multiple priority areas included the need for:

- Cross-sector collaboration and integration
- Consistent terminology and language
- Proactive rather than reactive approaches
- Reduced administrative burden on families
- Equitable access for all communities, including those in remote areas
- Family-centred and personalised support
- System navigation support throughout the journey

This report outlines the discussions that took place, analyses the opportunities identified, and presents comprehensive recommendations for improving care and support for children with childhood dementia and their families in Western Australia.

Background and Context

Dementia is usually only associated with older adults. Tragically, hundreds of thousands of children across the world suffer from dementia. It's caused by more than 100 life-limiting neurodegenerative disorders, many of which are not yet understood.

In Australia, a baby is born every 2 days with a childhood dementia disorder from which they will die, most likely before their 18th birthday. Before they die, they live with chronic, increasingly severe symptoms. Childhood dementia causes a similar number of deaths in Australia to childhood cancer for patients aged 0-14 years. Yet most health professionals are unaware of childhood dementia. Correspondingly, finding care and support is extremely difficult for families. Additionally, research is scant and there are no cures or treatments.

The Round Table was organised in response to insights gathered from families in Western Australia through previous consultations, documented in the pre-reading materials 'Childhood Dementia: Family experiences in Western Australia' published in July 2024 and 'What Matters Most: Priority Actions' published in January 2025. The event aimed to harness the expertise of professionals across various sectors to shape meaningful change.

Methodology

The Round Table was conducted at The Wonil Hotel in Crawley, WA on 25th March 2025 and followed a structured format:

1. Welcome and framing
2. Issues consensus building
3. Recommendations development
4. Shared understanding and refinement
5. Close and next steps

Participants were asked to review pre-reading materials and consider priority issues based on these readings and their professional experience. The discussion followed a consensus-building approach, with participants working in small groups and then sharing insights with the whole group.

Key Issues Identified

1. Care Coordination and System Navigation

Participants emphasised the critical need for coordinated care starting from diagnosis. As one participant noted:

> "These families have had a child who they believed was a very well child. Symptoms have started happening. They get a diagnosis. I think families, from that moment, are grieving. All of a sudden, they're having to deal with a system that they never thought they would have to deal with in their lives, they don't know how it all works. I think having care coordination right from diagnosis to help navigate parents through the system would reduce a lot of stress and anxiety for these families."

The discussion highlighted several key concerns about care coordination:

- The trauma of families having to repeatedly tell their stories to different providers.
- Unclear roles and responsibilities within and between service teams.
- The need for a dedicated system navigator to 'allow the parent to be a parent'.
- The value of patient passports and digital solutions to reduce repetition.
- Questions about where care coordination should be situated (hospital vs.community).
- Concerns about transitions to adult services and gaps in care after age 16.
- The need for cross-sector models of care that address 'whole of life' needs.

As participants discussed:

> "The ideal is having a system navigator, a centralised person that allows the parent to be a parent and they know they've got a dedicated team that they can talk to and know they'll get the answers."

The discussion also explored potential models for care coordination:

> "The McGrath breast care nurse model... they sit in health,a but they actually traverse... maybe the family doesn't need to be within the health or government hospital sector at that stage, but they can be supported in allied health therapy, even play groups, even peer support, all this other stuff."

Participants emphasised that care coordination should be cross-sectoral in nature:

> "The Rare Care Centre, we do a cross sector model, so we're not just in health... it affects the whole of life. And so having that navigator system be cross sector is important. It

> may be that the family's navigator is medical, but that medical person is a part of a team that consists of representatives from every sector that is involved with the child's life, education, NDIS, welfare, GP, the whole shebang, mental health."

2. Professional and Public Awareness of Childhood Dementia

A significant barrier identified was the lack of awareness and understanding of childhood dementia terminology among healthcare professionals and the public. This was highlighted as a "red flag" by participants:

> "Professional and public awareness and understanding of the terminology, of what it entails, of what it includes, has to be a priority. Some people on our table weren't aware that these conditions that we've experienced fall under that term. So it was unfamiliar terminology, which is already a red flag."

A healthcare professional with 30 years of experience noted:

> "I have come across a child being referred to as having childhood dementia once in my career, and that was when I first started out in my career, 30 years ago... We never used that terminology. And I would suspect over 90% of the children that were accessing hospice at that time had childhood dementia. They were labelled as 'too hard to manage' because of their behavioural issues."

Participants organised their recommendations for normalising terminology into three key areas:

1. **Community awareness:**
    - Increasing presence in media.
    - Creating forums in public spaces.
    - Linking to global awareness days.
    - Leveraging the success of adult dementia awareness.
    - Publishing articles in various media forms.

2. **Professional awareness:**
    - Integrating training in educational environments.
    - Hosting seminars and workshops.
    - Training across all levels of care (medical, nursing, allied health).
    - Education for school psychologists who may see early signs.
    - Upskilling rural and remote professionals.

3. **Government and systems level:**
    - Advocating for government support for childhood dementia care.
    - Creating a registry in WA with clear roles and responsibilities.
    - Implementing professional development requirements for all relevant roles.
    - Including childhood dementia education in onboarding processes.

As one participant noted regarding the value of consistent terminology:

> "It's about branding the experience. And I think that's where the childhood dementia, labelling the terminology, the language, is going to improve the experience. Knowledge can be associated with the grouping, rather than the 9000 long acronym names."

The group also discussed the importance of addressing the terminology gap in educational settings:

> "Access to information and support in schools is needed, because currently the struggle is that there is no box that they fit… and it is difficult to understand some of the behavioural implications, and certainly physical access implications of the disease."

3. NDIS Responsiveness and Funding

Participants identified significant issues with NDIS funding and responsiveness, particularly the need for proactive rather than reactive approaches:

> "How can we be proactive for their funding as they decline? With these children we can't wait for the decline and then request the equipment, it takes weeks and in that time there will be further decline. We need to be proactive to get equipment and help that they need."

Specific NDIS challenges discussed included:

- The burden on families to navigate complex NDIS supports.
- Lack of standardised evidence requirements for accessing funding.
- Issues with diagnostic criteria and age transitions.
- The need for simplified application processes.
- Challenges regarding frequent reassessments and evidence requirements.

As one participant noted:

> "The NDIS accepts Global Developmental Delay under the age of six, but by the age of seven, you need to have an intellectual disability diagnosis, which obviously a lot of these children would meet that diagnosis, but there's quite a lot of work that has to happen in

> terms of getting that assessment and that diagnosis, and that, in turn, puts a lot of pressure on their health system to have that available. And it's also happening at a transition point at school, and it also really affects school funding."

Participants also emphasised the importance of recognising parent reports as valid evidence:

> "We don't need an OT report to tell me that they're not sleeping at night. The parents will tell us that. So it's starting to bring that in... we need to listen to what our families are telling us, and that's what we need to shift - that parent reporting is absolutely as valid as professional reports."

The need for 'standardising buzz words that will activate support and funding' was highlighted, along with the importance of prioritising approval and creating predictive or proactive planning policies for children with childhood dementia.

4. Research Opportunities

Participants from the research sector identified potential opportunities for focused research:

> "We've got what's called centres of research excellence, funded through NHMRC, and I had a quick look. It doesn't look like there's a Childhood Dementia Centre of Research Excellence. I think a takeaway message, at least for the dementia sector, could be that we would be happy to lead what that might look like, put it together and then partner."

Key points included:

- Creating a dedicated Centre of Research Excellence for childhood dementia.
- Opportunities for both biological and qualitative research.
- Partnership potential between existing research centers, Childhood Dementia Initiatives and sector experts.

5. Supporting Diverse Communities

Participants emphasised the importance of equitable access to support for diverse communities:

> "Identifying our First Nation families, refugees and those with English as a second language from the beginning and figuring out how we can help them right from the beginning so their experience is the same as everyone else is important."

The role of spiritual and cultural beliefs was highlighted as crucial in how families receive and process information:

> “Spiritual beliefs really impact on how the family receives information and how they process information. It’s interesting because doing the bereavement work, you assume, because you have a cultural understanding, you also have a religious understanding. And it’s both very, very different and very, very important.”

Participants noted that First Nation families are overrepresented in rare disease cases but have reduced access to care coordination and supports:

> “When we were talking initially about First Nation families, they’re actually over represented in the rare disease space. I can’t comment on childhood dementia cases, but just in general, they are over represented, and of course, their access to care and coordination and support are very low.”

The discussion included the need for specialised approaches in remote areas such as the Pilbara, with suggestions to integrate childhood dementia awareness into existing regional initiatives and to engage with key stakeholders in education:

> “I also happen to oversee the Pilbara and staff in the Pilbara, so the work that we do together will be really important with those lead school psychologists, and to bring the chief psychologist of both Catholic education and the Department of Education along with us.”

Opportunities and Recommendations

Participants elected to explore three of the key issues identified to build a desired future state and recommendations on how to achieve this.

1. Integrated Care Coordination Model

Recommendation: Develop and implement a specialised cross-sector care coordination model for children with childhood dementia and their families.

Current state: Families navigate complex systems without adequate support, creating stress and barriers to accessing appropriate care. They often have to repeatedly tell their stories to different providers, causing re-traumatisation.

Desired state: A dedicated cross-sector care coordinator is assigned to each family from diagnosis, enabling parents to 'be parents' rather than full-time care coordinators. This navigator would:

- Support navigation across health, disability, education, and mental health systems.
- Coordinate communication between different service providers.
- Implement patient passports or digital solutions to reduce story repetition.
- Provide proactive planning for changing needs.
- Follow the child and family across their entire journey, including transition to adult services.

Key stakeholders: Health Department, NDIS, paediatric hospitals, family advocacy organisations, education sector, mental health services, existing community organisations with navigation expertise, philanthropic funders, WACHS (for regional/remote implementation).

Timeline considerations: Pilot program could be implemented within 12 months, with evaluation at 24 months.

Expected impact for families: Reduced stress, improved access to services, better preparation for changes in condition, more coordinated care, and ability to focus on family life rather than system navigation.

Required investment/resources: Funding for specialised care coordinator positions, training programs, coordination systems, and digital tools. Potential for partnership with existing not-for-profit organisations or philanthropic funding sources.

Success measures: Family satisfaction, reduced hospital admissions, timely access to equipment and services, improved quality of life measures, reduced family stress, and clear national standards for care coordination.

Implementation considerations:

- Care coordination should be community-based rather than hospital-centred.
- Models such as the McGrath breast care nurse approach could be adapted.
- Support should continue beyond age 16 to address transition gaps.
- Standards for quality care coordination should be developed.
- A cross-sector approach should be employed to address 'whole of life' needs.

2. Awareness and Terminology Initiative

Recommendation: Launch a comprehensive, multi-level campaign to normalise the terminology of 'childhood dementia' among medical professionals, educators, broader community, and government systems.

Current state: Limited recognition of the term 'childhood dementia' creates barriers to appropriate care, funding, and support. Healthcare professionals rarely use this terminology, leading to fragmented care and difficulties for families in accessing appropriate services.

Desired state: Widespread acceptance and understanding of childhood dementia as a recognised condition across health, disability, education, and government sectors, with three levels of implementation:

1. **Community level:**
    - Increased media presence and public forums.
    - Connection to global awareness days.
    - Integration with adult dementia awareness campaigns.
    - Publications across diverse media channels.
2. **Professional level:**
    - Integration into training environments and curriculums.
    - Regular seminars and workshops.
    - Training across all healthcare disciplines.
    - Specific education for school psychologists and educators.
    - Upskilling programs for rural and remote professionals.
3. **Systems level:**
    - Government recognition of childhood dementia.
    - Creation of a WA registry with national connections.

  - Mandatory professional development for relevant roles.
  - Integration into onboarding processes for all relevant services.

Key stakeholders: Medical schools, healthcare providers, professional associations, funding bodies, advocacy organisations, media outlets, government departments, education providers, school psychology services.

Timeline considerations: Development of educational materials within 6 months, integration into medical curriculums within 18 months, public awareness campaign within 12 months.

Expected impact for families:

- Families are met with clinicians familiar with the term, reducing their burden to educate providers.
- Faster recognition of conditions and appropriate referrals.
- Improved access to appropriate services and funding.
- Reduced need to continually explain their child's condition.
- Enhanced connection to other families with similar experiences.

Required investment/resources: Funding for educational materials, professional development programs, advocacy campaigns, registry development, and media initiatives.

Success measures:

- Increased use of terminology in medical settings.
- Creation of common marketing and branding around childhood dementia.
- Integration into education at a foundational level.
- Improved recognition in funding applications.
- Reduced time to appropriate referrals.
- Establishment of a functional registry.

3. NDIS Pathway Development

Recommendation: Establish a specific NDIS pathway for childhood dementia that recognises the progressive nature of these conditions, enables proactive funding allocations, and simplifies application and review processes.

Current state:

- Reactive funding model that often provides necessary equipment and support after decline has occurred.
- Families face significant burden navigating complex NDIS supports.

- Lack of standardised evidence requirements and application processes.
- Problematic age transition points (particularly at age 7) requiring new evidence.
- Frequent reassessments and requirements for professional reports that may be unnecessary.
- Limited recognition of parent reports as valid evidence.
- Lack of prioritisation for children with degenerative conditions.

Desired state:

- Recognition of childhood dementia as a specific category within NDIS frameworks.
- Anticipatory funding based on predicted decline and needs.
- Streamlined application processes with clear guidelines and checklists.
- Standardised templates for diagnostic and functional capacity reports.
- Recognition of previous assessments to reduce reassessment burden.
- Prioritisation markers for children with degenerative conditions.
- Acceptance of parent reports as valid evidence.
- Webinar sessions and clear instructions for families.
- Better connections with Early Childhood partners like Wanslea

Key stakeholders: NDIS, Early Childhood partners, advocacy organisations, healthcare providers specialising in childhood dementia, families, support coordinators.

Timeline considerations: Proposal development within 6 months, pilot implementation within 12 months.

Expected impact for families:

- Timely access to equipment and support.
- Reduced stress during periods of decline.
- Improved quality of life.
- Reduced administrative burden.
- Less time spent on repeated assessments.
- Better coordination with educational funding needs.

Required investment/resources:

- Policy development.
- Training for NDIS planners.
- Predictive planning tools.
- Standardised templates and checklists.
- Educational resources for families and providers.

Success measures:

- Reduction in time between identified need and support provision.
- Family satisfaction with NDIS processes.
- Reduced number of appeals and reviews.
- Decreased assessment burden on families and healthcare system.
- Increased proactive equipment provision.

Next Steps and Conclusion

The Round Table on Next Steps for Childhood Dementia Care in Western Australia brought together valuable expertise and perspectives from across health, disability, research, education, and funding sectors. The discussions resulted in three key priority areas and actionable recommendations: integrated care coordination, NDIS pathway development, and awareness and terminology initiatives.

Our immediate next steps focus on securing commitments from key stakeholders to lead specific initiatives and establishing timelines and accountability measures for recommendations. Critical actions include:

- Engaging with government representatives including the NDIS leaders to advance NDIS pathway improvements, which require a national approach given the scheme's federal structure.
- For integrated care coordination, CDI will develop a WA pilot program to test and refine care coordination models specifically for childhood dementia.
- The awareness and terminology initiatives will combine national resource development with sector-led responsibility for implementation and uptake.
- CDI will also approach philanthropic organisations to fund pilot programs and other WA-specific initiatives.

The discussions highlighted the complexity of challenges facing children with childhood dementia and their families, but also identified significant opportunities for system improvement and collaboration. The recognition of language and branding as critical tools emerged as a key insight, with participants noting that 'childhood dementia' terminology will improve experiences within the health system.

As noted by one participant: "This is the year for delivery." The genuine engagement and collaboration evident throughout the Round Table provides a strong foundation for implementing these recommendations. With stakeholders demonstrating exceptional commitment to working across traditional sector boundaries, there is significant potential for meaningful change that will improve lives of children with childhood dementia and their families in Western Australia.

As one stakeholder summarised: "Every time I come away from these things, you just see so many opportunities where we can make change." This sentiment captures the energy and determination to transform systems and create lasting, positive impact for this vulnerable group of children and their families across Western Australia.