Childhood Dementia

Childhood Dementia Care and Support Landscape

What Matters Most Report: Integrating the lived experience and health professional perspectives in childhood dementia

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Executive Summary: What Matters Most Report

Childhood Dementia Care and Support Landscape Integration Study

This report, commissioned by Childhood Dementia Initiative (CDI) with funding from the Department of Health, integrates findings from the ***Pathways Toward Report***, which identified ten key domains for childhood dementia care through healthcare professional consultation, with new research examining the lived experiences of families affected by childhood dementia. The study validates and extends the original findings through parent perspectives, creating a comprehensive view of care needs and priorities. The research, conducted through nine focus groups incorporating seventeen parents at various stages of their childhood dementia experience, reveals critical insights into the current care landscape and identifies priority areas for system improvement.

Integration with *Pathway Towards Report*

The study builds upon ten priority domains identified in the ***Pathway Towards Report***:

1. Care Coordination
2. Research
3. Diagnostic Pathways
4. Health Services
5. Healthcare Professional Awareness and Training
6. Palliative Care
7. Hospice and Respite Care
8. Psychosocial Support
9. Education Support for Children
10. NDIS and Disability Support

Key themes from parent experiences

Through focus group discussions centred on these domains, the study identified several overarching themes that characterise the lived experience of families:

Intense care burden: Some children with childhood dementia will experience a short yet devastating deterioration requiring intense care from diagnosis to end of life. Others experience regression for up to decades, creating unique challenges for sustaining care and family stability. Mothers hold the greater proportion of caregiving responsibilities.

Complex journey and system management: Parents face the continuous challenge of navigating multiple care and support systems, including healthcare, education, and disability services, while managing their child's progressive condition.

Whole family impact: The effects of childhood dementia extend beyond the affected child, significantly impacting parents, siblings, and extended family members.

Quality of life focus: Parents emphasise the importance of maximising their child's quality of life rather than solely pursuing curative treatments.

What Matters Most: Priority Actions

Five priority actions were identified by focus group participants. These were extracted via a) a targeted focus group question, and b) the emphasis that arose in the thematic analysis.

1. Establish dedicated care coordination

- Transform how families navigate healthcare and support systems
- Create efficient pathways to access services
- Reduce administrative burden on families

2. Advance healthcare professional education

- Develop specialised childhood dementia training
- Create quick-reference clinical resources
- Establish networks of informed specialists

3. Strengthen family support networks

- Implement comprehensive psycho-social support from diagnosis through bereavement
- Establish peer support networks
- Provide targeted support for siblings and extended family

4. Integrate a palliative approach from diagnosis

- Offer palliative care services from early stages
- Enhance quality of life through trusted and coordinated care
- Enable empathic conversations around end-of-life care planning

5. Enhance NDIS responsiveness

- Create accessible and responsive pathways tailored for childhood dementia
- Streamline approval and review processes
- Implement flexible, anticipatory funding

Implementation considerations

The report identifies several critical areas requiring attention for successful implementation:

- Development of specialised training programs for healthcare providers and support workers
- Creation of integrated care pathways across different service sectors
- Specialised care coordination from psychosocial care professionals
- Establishment of clear communication between various care providers and across sectors
- Integration of proactive care, supports and equipment through NDIS

Conclusions

The findings emphasise the need for a coordinated, family-centred approach to childhood dementia care that acknowledges the progressive nature of the condition and its impact on the entire family unit. Parents and families need to have all these priorities addressed to be able to perform a complex, informal caregiving role, while enabling a focus on nurturing the parent/child relationship, including parenting the siblings of impacted children. Parents also need support to be able to function in other critical relationships and roles (e.g. employment). This is particularly relevant for mothers who hold the main caregiver role and are most impacted by this change in life role. Immediate attention to the identified priority areas could significantly improve outcomes for affected children and their families.

The report validates the domains identified in the ***Pathway Towards Report*** while providing crucial lived experience perspectives that deepen understanding of implementation requirements. Care coordination emerges as the most immediate opportunity for positive impact, with parents emphasising that ‘even if you can't fix anything else overnight, at least if you've got someone who knows what's out there...they can point you in the direction of what is available.’ The findings suggest that implementing these recommendations would require a nationally coordinated approach to ensure consistent standards of care and equity of access.

What Matters Most: Priority Actions

Care coordination is the quickest win... because even if you can't fix anything else overnight, at least if you've got someone who knows what's out there... they can point you in the direction of what is available. [FG3.1]

1. Establish dedicated care coordination

Impact: Transforms how families navigate healthcare and support systems

- Create efficient pathways to access services
- Free parents to focus on caregiving and maintaining parent/child relationships
- Reduce administrative burden

2. Advance healthcare professional education

Impact: Creates an informed and responsive healthcare community

- Develop specialised childhood dementia training
- Create quick-reference clinical resources
- Establish networks of informed specialists

3. Strengthen family support networks

Impact: Enhances resilience and well-being for the entire family unit

- Implement psycho-social support from diagnosis through to bereavement
- Establish peer support networks
- Provide targeted support for siblings and extended family

4. Integrate a palliative approach from diagnosis

Impact: Ensures comprehensive support throughout the childhood dementia experience

- Offer palliative care services from early stages
- Enhance quality of life through trusted and coordinated care
- Enable empathic conversations around end-of-life care planning

5. Enhance NDIS responsiveness

Impact: Creates pathways tailored for paediatric neurodegenerative conditions

- Streamline approval processes for childhood dementia
- Implement flexible, anticipatory funding
- Ensure proactive equipment and support provision

1. Introduction

1.1 Background

Childhood dementia encompasses a group of rare genetic conditions that cause progressive cognitive and physical decline in children, profoundly impacting their quality of life and placing significant demands on families and health and social care systems. These conditions are usually identified from infancy into childhood and progression can take months or years, with periods of rapid regression and decline creating unique challenges for care delivery and family support.

Childhood Dementia Initiative (CDI) has undertaken a systematic approach to understanding and improving care for affected children and their families. In 2024, CDI commissioned *HealthConsult* to conduct stakeholder consultations with healthcare professionals across Australia, resulting in the ***Pathway Towards Report***. This initial research identified ten domains for a comprehensive model of care:

1. Care Coordination
2. Research
3. Diagnostic Pathways
4. Health Services
5. Healthcare Professional Awareness and Training
6. Palliative Care
7. Hospice and Respite Care
8. Psychosocial Support
9. Education Support for Children
10. NDIS and Disability Support

While this professional perspective provided valuable insights, CDI recognised the importance of integrating the lived experience into the development of care models. This recognition led to CDI commissioning *Collaboraide* (Principal, Dr Leigh Donovan) to design and deliver the ***What Matters Most*** project, which seeks to validate and extend the original findings through direct engagement with families affected by childhood dementia.

The project specifically aims to:

- Validate the ten priority domains identified in the ***Pathway Towards Report*** through the lens of lived experience
- Identify gaps or discrepancies between professional and family perspectives
- Understand the practical implications of implementing care improvements
- Capture the nuanced reality of navigating multiple care systems over extended periods
- Document the impact of childhood dementia on the entire family unit

This integrated approach acknowledges that effective care models must balance professional expertise with the context expertise gained through lived experience. By combining these perspectives, CDI seeks to develop comprehensive, family-centred solutions that address both the clinical and psychosocial needs of affected children and their families.

The findings from this research will inform policy recommendations, service design, and resource allocation to better support the 1400 people in Australia estimated to be living with childhood dementia (over 70% of which are children) and their families. This work represents a crucial step toward CDI's broader mission of improving outcomes and quality of life for all those affected by childhood dementia.

1.2 Project methodology

Childhood Dementia Initiative is deeply committed to responding to, and being led by, the lived experience of children living with dementia and their families. At the presentation of the ***HealthConsult CDI Pathways Toward Report***[1], the next critical step was to consolidate and validate healthcare professional perspectives, through integration of the lived experience.

A series of focus groups were designed, each targeting parents[2] who represent various stages of the childhood dementia experience:

- Parents of newly diagnosed children
- Long term carers of children with dementia
- Parents of children who were in the process of, or had transitioned to adult services
- Newly bereaved parents
- Parents of children who died in infancy (0-2 years)
- Long term bereaved

Parents aligned with the CDI Parent Advocacy Group were contacted by direct email and phone, inviting their participation. With their consent, a Focus Group Preparation Guide (Appendix A) was disseminated, outlining a series of five questions linked to the findings of the original ***Pathway Towards Report***. Seventeen parents consented to participating in this project (fourteen mothers/three fathers).

Nine focus groups, incorporating these seventeen parents representing the named stages above, were delivered and co-facilitated by the project team (external consultant *Collaboraide* and CDI team members). A running sheet was prepared based on the questions disseminated within the Focus Group Preparation Guide (Appendix B). Parents were invited to consent to recording of each focus group to allow for transcription through Otter.ai.

The steps of thematic analysis were observed[3] whereby each transcription was analysed for macro and micro themes: a) integrated with the ten care and support themes from the ***Pathway Towards Report***, and b) highlighting additional nuances and themes to complement the original report. At conclusion of the thematic analysis, a draft of key themes was disseminated to the CDI project team for review. The revised version was then disseminated to focus group participants for member checking and feedback from parents was integrated within this final report.

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[1] HealthConsult (2024), *Childhood Dementia Care and Support Landscape*, Pathway Toward Report

[2] We acknowledge the many parenting roles of focus group participants including biological parent, foster parent, adopted parent, kin parent. For the purposes of this report, the term parent represents all these domains.

[3] Braun, V., & Clarke, V. (2014). What can “thematic analysis” offer health and wellbeing researchers? *International journal of qualitative studies on health and well-being*, *9*(1), 26152.

Qualitative methodological approaches see a cohort of voices participate, that may not fully represent the majority. Limitations of this report are that the findings are based on a proactive group of parents who may not represent the global experience of childhood dementia. Of the seventeen parent participants, fourteen of these were mothers, already acknowledged as carrying the majority of caregiving responsibilities in families. Given this, the voice and experience of fathers is under-represented. Further, all parents participating in the focus groups are either caring for children some years following diagnosis, or bereaved. Therefore, this report does not present a longitudinal perspective of the childhood dementia experience from the point of diagnosis. As such, *Chapter 7, Research* may not accurately reflect the ultimate desire of all parents to find a cure for their child.

1.4 Structure of this report

Focus group participants were invited to consider the ten priorities for childhood dementia care within the ***Pathway Towards Report*** and identify what is working well, where the service or system could be improved, and where gaps in the service or system exist. Chapters 3 to 9 (Clinical Management Services) and 10 to 12 (Emotional and other support services) present a thematic analysis in response to these questions, with associated recommendations from parents and a guide for future considerations.

However, parents also identified nuances of their lived experience presented in **Chapter 2** that should be considered and integrated when reviewing their response to the ten priorities presented in Chapters 3 to 12.

Chapters 3 to 9 present the six priorities within Clinical Management Services:

- Chapter 3: Diagnostic pathways
- Chapter 4: Healthcare professional awareness and training
- Chapter 5: Care coordination
- Chapter 6: Health services
- Chapter 7: Research
- Chapter 8: Palliative care
- Chapter 9: Hospice and respite care

Chapters 10 to 12 present the three priorities within Emotional and Other Support Services:

- Chapter 10: Psychosocial support
- Chapter 11: Education support
- Chapter 12: NDIS and disability support

Each Chapter is framed as follows:

- **The lived reality for parents**
- **Recommendations from parents**

Chapter 13 presents conclusions and the **top five priorities** for children with dementia and their families.

Appendices A and B incorporate additional items referenced throughout the report to support methodological rigor.

2. Nuances of the child and parent experience: an integrated lens

Thematic analysis of focus group data moved beyond identification of themes in response to the ***Pathway Towards Report***. Seven additional themes, as presented below, share a deeper and more nuanced experience for children with dementia and their families, that must be integrated when considering and attending to the ten domains (clinical management services and emotional support and other support services) and priority actions (page 8).

2.1 Integration of the ten identified themes

It's such a complex question and there's no one answer. [FG1.1]

Parents stressed the overlapping nature of domains due to the complexity of their child's condition and stressed the domains should not be explored in isolation. The ***Pathway Towards Report*** and ***What Matters Most*** demonstrate instances where overlapping experiences exist, and integrated care and support services are required.

2.2 The journey of adaptation

What is particularly hard with these kids is that the goal posts constantly change. So, it could be working well for a short time and then not work well. [FG2.1]

Parents acknowledged that due to the regressive nature of childhood dementia, their child's needs and care and support required change in relation to the stage of their condition. What they present as a priority today may change as their child moves through another stage of regression, where 'goal posts constantly change'. This isn't a linear journey - it requires constant flexibility and redefinition of what success or progress looks like.

2.3 Caring for the whole child

There's no holistic view or consideration of the child. Typically, the mum is the only person who's looking at the holistic needs of the child. Everybody else is looking at a small part of the child, and nothing is done in a synchronised way. [FG4.1]

Parents described a complex system of care and support around their child and family. This saw connections throughout multiple macro systems including health, disability, education; and within each of these systems multiple micro connections with teams, departments, specialists and individuals, all focused on a certain aspect of their child. Consequently, parents expressed concern that there is no single overarching lens that observes the whole child. When reviewing the ten themes in Chapters 3 to 12, parents urge consideration of connection points that see the child as the focus, with systems and services radiating care around the child.

2.4 Quality of life

Where he was up to in his diagnosis, there wasn't anything that's going to save him. It was better spent giving him the best quality of life we could rather than trying to pursue a cure or a treatment. [FG3.1]

Parents described in explicit and implicit forms the extent of suffering they witnessed for their child, and therefore, their entire family. For some, they shared a level of pragmatism about their child’s present and future, with a necessary and learned focus on their child’s comfort and quality of life. Parents described a yearning for sufficient care and support for their child and family to temper the suffering experienced throughout the child’s life and beyond the death of the child.

2.5 Family unity and collective suffering

What matters most to me is keeping our family together and finding the support that helps us support each other. [FG2.2]

While parents described a necessary focus on their child affected by dementia, they expressed frustration at the lack of care and attention provided to the whole family, as well as failed attempts at seeking and accessing practical and emotional support. Multiple themes within Chapters 3 to 12 demonstrate the significant isolation experienced by parents, particularly mothers who hold the main caregiving role, from the point of attempting to gain a diagnosis for their child, through post diagnosis and throughout the multiple regressive stages, and continuing at their child’s end of life and their family's bereavement. The concertina impact of this acute focus on the child living with dementia, is significant for siblings. This collective impact on the whole family goes unacknowledged. Parents advocate for a whole family response from care and support systems that radiates from their child to siblings, parents, grandparents and extended family.

2.6 The intense nature of care

Being able to have that support system there I do think it would have helped me and his dad a lot, because you're constantly stressed. We were having to take it in turns staying up overnight where we both worked full time, so we were getting cranky at each other. Whereas if you just had that extra support when you needed it instead of waiting…’ [FG6.1]

The experience of childhood dementia is unique for each child, depending on their diagnosis. Some children experience an acute shorter trajectory of declining health; others experience much longer trajectories spanning decades. This creates unique challenges around sustaining care, maintaining family stability, and ‘shaping that journey’ to make it meaningful over the intensity of a dynamic care trajectory. This experience becomes protracted when more than one child in a family is diagnosed with childhood dementia. Care and support systems by necessity are required to adjust and adapt to this dynamic care experience.

2.7 Parental role complexity

The irony being we're disempowered, and yet everything falls on our shoulders, we're responsible for everything, including medicine management, retelling and retelling and retelling the story. [FG4.1]

Parents find themselves in a paradoxical position - simultaneously ‘disempowered’ within the medical system while bearing ultimate responsibility for everything from ‘medicine management’ to constantly retelling their child's story to new providers. Parents describe needing a balance in parental expertise being acknowledged yet requiring the professional expertise of a broad team to maximise the quality of life for their child and family.

3. Diagnostic Pathways

3.1 Lived reality

The diagnostic stage for [our daughter] started when she was nine months old... By the time she was 18 months old, we were like pushing for something's not right. She's not even sitting up by herself yet. [FG7.1]

Parents described a range of experiences in the trajectory toward their child's diagnosis, some experiencing a proactive diagnosis, however **most describing months, and sometimes years of advocating for their concerns to be heard.** Several parents described **feeling dismissed by health professionals** including GP's, paediatricians, child health clinics and specialists. At worst, parents described **being labelled a neurotic parent**. **Referrals for genetic counselling were spasmodic.** For those able to access a referral, the experiences were varied, with **some parents describing a lack of empathy** around when and how to deliver news of a devastating life limiting condition for a child and in some instances, more than one child (see *Chapter 4. Health Professional Awareness and Training*). Many parents described when finally receiving a diagnosis, **feeling completely abandoned without any guidance as to 'what next'.**

3.2 Recommendations from parents

I brought it up in the first meeting with [the child's hospital], could we have another child? Because that was a huge thing for me. I had to have another one. All our questions were answered. We were well informed from that perspective. [FG3.1]

Parents advocated for **screening** to include testing for childhood dementia conditions, ensuring **early diagnosis and potentially life changing interventions** that could positively change the health trajectory for their child. One parent described a general lack of public awareness about the very rare conditions that fall under the childhood dementia umbrella, believing that when standard screening throughout her pregnancy was clear, it meant she was carrying a healthy child. **Increased awareness provided at the stage of pregnancy planning** may provide a more informed perspective for prospective parents, with some parents **advocating for additional screening for risk of childhood dementia conditions prior to pregnancy (carrier screening).** Several parents advocated for **enhanced education, knowledge and awareness of symptoms** of childhood dementia conditions for professionals working at significant touchpoints for infants and children (e.g. child health clinics, GP's, paediatricians, childcare centres, early childhood educators), with responsive follow up protocols when concerns are identified. At diagnosis, most parents requested an opportunity for **immediate connection with support and resources, and patient-led organisations related to their child's condition**. While some parents reported positive experiences of genetic counselling, others recommended **improved professional training** to ensure a more **sensitive and empathic** approach when delivering difficult news. Parents also felt diagnosis was the time to be **introduced to a care coordinator** who could support them as they **navigate their way through the myriad care and support systems** that their child required. Some parents also suggested **opportunities to be connected to a peer at the point of diagnosis or early in**

their child’s health trajectory, to gain an intimate understanding and support from another parent experienced in caring for a child living with dementia.

4. Healthcare Professional Awareness and Training

4.1 Lived reality

I think my child's diagnosis is about one, one to two per million... the problem is, there's an unbelievable lack of expertise, given the rarity. [FG1.1]

Parents attributed a **protracted delay** in their child's diagnosis to a lack of expertise of health professionals in rare genetic diseases, specifically childhood dementia conditions. Some described empathy for health professionals not expecting them to know everything about every diagnosis, however, were dismayed at the apparent **lack of proactive activity** around sourcing education and guidance to improve their capacity to support children and families. As a result, **several parents resorted to sourcing medical guidance from other parents caring for a child with a similar condition,** for example, 'how did you manage seizures when they commenced'. As described in *Chapter 3. Diagnostic Pathways*, **parents experienced a sense of feeling disempowered** in the health system and by health professionals from the point of raising concerns regarding their child's poor development or apparent regression prior to diagnosis. This experience continued for many parents as they undertook their own research and became 'the experts' regarding their child's condition. **Parents described the contrast of becoming the experts** in their child's rare condition and the needs of their child, alongside the **exhaustion** of health professionals having this expectation of them.

4.2 Recommendations from parents

If we have one central place to put all this information in... health professionals can go back to that place, find similar conditions or similar kids with the similar symptoms. [FG5.1]

Several parents acknowledged the limitations for health professionals in having specialist knowledge in their child's rare condition. Several mechanisms were shared that have the potential to enhance the knowledge base of health professionals, for example, a **central repository or database** that holds details of childhood dementia conditions and symptoms which could potentially reduce lengthy diagnostic pathways and provide additional details of the child's potential trajectory. This central repository would need to be continually updated as new knowledge grows. Many parents described becoming proactive in seeking knowledge of their children's rare condition from interstate or overseas and expressed confusion around the reluctance of health professionals in doing the same. Some parents urged **health professionals to form collegiate relationships with specialist clinicians both in Australia and internationally,** to relieve the burden of having to feel an expert in every form of childhood dementia. One parent shared a **training and workshop model** based in Norway where specialists provide outreach education to local care providers. Parents also acknowledged that **education in childhood dementia conditions needs to be extended to all health professionals** (e.g. medical, nursing, allied health). See *Chapter 11. Education support* for an extension of this recommendation within the childcare and education sector. Some parents suggested **integration of parents with a lived experience in education and**

training, ensuring direct exposure for professionals who may have never met a child living with dementia.

5. Care Coordination

5.1 Lived reality

Then you become this Operations Manager for your child, you quit work, be an operations manager, try and figure it out all for yourself, while losing your mind because you're so exhausted and so distressed with no support. [FG1.2]

As described in *Chapter 3. Diagnostic Pathways*, most parents described receiving a diagnosis for their child without any **proactive guidance around the pathway forward**. All parents described entering a new world with very little experience and information around what was and would be required to support their child into the future. Some parents described **not being able to access the care and support they need**. Others shared **concerns around delays in accessing the support their child and their family needed**. Parents described becoming the **'operations manager'** for their child and having to educate themselves around their child's needs and where to access the appropriate support from a range of sectors including health, disability (NDIS) and education, with **poor communication and integration between these sectors.** Most parents described their child's trajectory extending into years with a **significant logistic, emotional, physical, familial and financial burden** of coordinating the extensive network of care and support that enabled the best quality of life for their child and their family, while still providing daily care and support and monitoring for any changes. Given the greater proportion of parents represented in this report were mothers, this report sees **the burden of coordination of care currently lying with mothers**. The **isolation described by parents was significant**, with some expressing confusion that there was no central service or support person who routinely and proactively 'checked in'.

5.2 Recommendations from parents

And that's where this notion, I suspect, of a care coordinator, could straddle, you know, multiple different services and a lifespan transitions, so that there's a distinct person traveling with you the entire way. [FG1.1]

Parents described a **single dedicated care coordinator** as potentially transformative. Parents indicated the following considerations in the development of this role.

A health or social care professional:

- That is **educated and knowledgeable** about childhood dementia conditions. This allows for a proactive response in supporting parents in what to anticipate for their child as their condition changes over time.

- Who **spans the multiple systems children access for care and support** including health, disability (NDIS) and education, and who **enables cross service communication**. Such a role would cast a broad lens around the ‘whole child’.
- Who **wears a family systems lens**, acknowledging each family member as a necessary part of the child’s life, requiring their own care and support, and understanding that the family unit includes parents, siblings, grandparents and other important people in the family’s life.
- Who walks alongside families **through the various transitions for their child to enable a trusted relationship to develop over time**. Transitions range from diagnosis, throughout a child’s life, end of life and bereavement following the death of a child.

Given the frequency of contact with health systems and the multiple specialists and teams children are connected with, a number of parents recommended **this role could sit within the hospital setting** (See *6. Health Services*), to proactively coordinate appointments and be the conduit for streamlined information management. Long-term funding and position stability are also vital to enable relationship building over extended periods.

6. Health Services

6.1 Lived reality

There is no team. They love to say the word team. There is no bloody team. There are individuals in different clinics. [FG1.1]

From first contact with health services, often at the time of advocating for attention to their child's pre-diagnosis, parents perceived the **lack of a team approach** and **little empathy in response to the emotional trauma of their child receiving a life limiting diagnosis**. Prior to diagnosis several children had already been tentatively diagnosed with conditions such as developmental delay, autism, and in one case a childhood cancer, meaning connections into a variety of health professionals and health clinics. Following diagnosis, and given the complexity of their child's needs, parents described multiple teams involved in their child's care, with **poor communication and integration between the teams.** Many parents described **extremely long wait times for specialist appointments,** despite the urgency of care required for their child. The impact of this saw their child and their own lives continually **led by the expectations of health services**. Life revolved around **fragmented medical appointments,** impacting the child's quality of life and parent's capacity to engage meaningfully in employment, seeing many parents withdrawing from the workforce to become their child's full-time carer (see *Chapter 10. Psycho-social Impacts*). Given the frequency of admission, parents expressed **frustration at having to routinely present to Emergency Departments where again and again they had to tell their story, educate health professionals around their child's diagnosis and needs, and in many instances, suffer significant wait times.** The transition from paediatrics to adult health services, where relevant, was something parents feared given their child developmentally remained 'a child' in an adult's body. Several parents described frustration at their child entering the adult health system and a renewed sense of having to **source and re-establish relationships with a new suite of health professionals.**

6.2 Recommendations from parents

It's like, once you get there [the hospital], that you have the VIP service, people meeting you and helping you and understanding your needs. [FG4.1]

Parents recommended **increased awareness of childhood dementia** conditions and the emotional impact for parents when receiving this diagnosis, calling for **heightened sensitivity and empathy from health professionals.** Parents expressed a desire for a **dedicated hospital ward** with specialist teams that are focused on **children with complex needs.** One parent suggested a form of **VIP service** whereby an alert is attached to their child's medical record that triggers an automatic response within the Emergency Department. This VIP service could also form the **single point of contact for urgent issues**. As per recommendations in *Chapter 5. Care Coordination*, integration of a **single dedicated care coordinator based within the hospital** may have the capacity to take on the role of advocate and liaison with multiple care teams, streamline appointments, and work proactively to ensure the health service is responsive to the specific requirements of each child. Parents articulated the need for **clinical advocates within health systems** who can 'fight for their child' to reduce waiting times for specialist referrals and appointments, and ensure **proactive rather than reactive care and support,** particularly regarding disease progression. Parents suggested using **clinic visits as opportunities for peer support** (see *Chapter 10: Psycho-social Support)*. Some parents whose child’s care trajectory extended beyond paediatric care, also noted that the current logistic and emotional complexities of their transition from paediatric to adult health settings could be eased by a **dedicated care coordinator** based in each setting.

7. Research

7.1 Lived reality

Newborn screening is something that... actually has a chance to give them a life of decades if they have a transplant before any symptoms start. [FG3.1]

When inviting parents to describe research as a priority area, some parents stated their number one 'dream' would be a cure for their child and felt the **ultimate priority should be research into curative treatments.** However, all were realistic that this expectation may not translate into a cure for their child, in their lifetime. Most parents spoke to this theme in terms of benefits to children in the future, including the integration of **newborn screening** for childhood dementia conditions that could see a child receive an early diagnosis and proactive medical response to their care. Some parents described their child **accessing clinical trials** however this meant regular interstate travel, family disruption and financial distress. The cost involved in accessing targeted pharmaceuticals was significant, with several parents describing the lengths they went to in sourcing and spending tens of thousands of dollars. One parent described collective concerns around the impact of anaesthesia on children with dementia and advocated for **research into the specific impacts of standard procedures** for children with childhood dementia.

7.2 Recommendations from parents

The Holy Grail would be like a treatment...[FG2.1]

Several parents described **access to curative treatment or treatment to delay disease progression and reduce complex symptoms as being their ultimate goal**. However, the majority emphasised that while research is important, their immediate needs around coordination and support are more pressing for day-to-day life. Some parents whose children are currently involved in clinical trials suggested **decentralised models to reduce the logistical and financial burden of travel to treatment centres interstate**. As noted on page 10, a complete longitudinal approach is not incorporated within this report as most children are some years post diagnosis, and parents were focused on the 'here and now' rather than 'what could have been'. Parents called for the **integration of childhood dementia screening into rapid screening programs,** to allow early access to treatments and emerging therapies.

8. Palliative Care

8.1 Lived reality

Don't wait until my child is literally dying or really, really sick to introduce a bunch of strangers into my life. It should be done now. So, we have rapport, a relationship. [FG1.1]

Overall parents described the need for **improved understanding** about palliative care. One parent advocated for **integration of palliative care at the point of their child's diagnosis,** while others, often due to misconceptions, were **fearful** about the reality of what this meant in terms of their child's life limiting condition. Several parents whose child was connected to palliative care described a sense of **comfort in being connected to a team that could support them through difficult decision making and end of life care plans**. When listening to the diversity of parent experiences, it became evident that **approaches to referrals differed according to health professional awareness and training, and between and within state based paediatric palliative care services.** Some services accepted referrals early in a child's care trajectory, while others resisted such referrals. Some families reported different experiences with palliative care teams despite being in the same state and accessing care from the same treating doctors.

8.2 Recommendations from parents

I've done her end-of-life plan with palliative care. I do feel good about that, a little bit of weight lifted off my shoulders. [FG1.2]

Given parent perceptions that palliative care is focused on end of life, parents suggested **improved education for health providers to emphasise that a palliative approach can improve quality of life.** Some parents urged health professionals to **integrate conversations regarding palliative care earlier in their child's health trajectory, suggesting improved education and awareness of palliative care for referrers**. One parent suggested **palliative care should be introduced at the time of diagnosis with a focus on improving quality of life for their child and family**, although acknowledging how confronting this may be. While some parents originally resisted the idea of this transition, once a referral had been made, they could see the **benefits of coordinated and streamlined care, building rapport and trusted relationships early in their child's health trajectory, skilled conversations about advanced care planning, and guidance and support throughout their child's end of life.** Parents felt confronted within the focus groups hearing that some children and families had experienced an early and smooth transition to palliative care, yet due to differing clinical approaches, other children and families, even within the same states, had not had referrals accepted. Parents urged for a **national consensus around the integration of palliative care** for children who had a life limiting childhood dementia condition. All families asked for consideration of **emotional support when transitioning to palliative care.** Parents described a range of medical specialities supporting their child and suggested **palliative care develop an interface with each of their child's specialist providers.** Others called for a palliative approach to care whereby their **child's primary healthcare team integrated the philosophy of palliative care** (for example, high level communication skills around advanced care planning and end of life conversations).

9. Hospice and Respite Care

9.1 Lived reality

It's great for kids that are very medically unwell and don't move around a lot, but the kids with a lot of the childhood dementias, they're hyperactive, and they've got behavioural issues. [FG2.1]

As referenced in *Chapter 8. Palliative Care* **hospices differ in their approach to the timing of referrals from children living with dementia**. Several parents described a desire for their child and family to access hospice care, yet were told **the hospices were not able to accommodate their child(ren) due to insufficient resourcing, and physical environments that were not fit-for-purpose.**. Some parents expressed concerns around the level of support their child routinely required at home, that may not be able to be met in the hospice setting. Some parents described their **child's care needs being the factor that meant a referral would not be accepted due to the level of staffing required,** and the consequent impact of their child's behaviour for other guests. Some parents resisted the concept of allowing their child to be cared for by an unfamiliar person in an unfamiliar environment. This appeared to be a particular issue for children with dementia where parents shared that **consistency in carers and the environment is critical to avoid escalation of behaviour**. One parent described her own **trust concerns** at allowing someone else to care for her non-verbal child as she had been the main carer for so many years.

9.2 Recommendations from parents

No one explained to us it's a place where you can have respite, where your family is gonna [sic] be surrounded by other families, where you gonna [sic] be a normal person. [FG3.1]

Parents described comfort at the idea of hospice respite care for their child, however stressed the need for **improved models of hospice care** that cater for the behavioural characteristics of children with dementia. Parents suggested **improved education for hospice staff** to enhance their understanding of the complexities of childhood dementia, such as behaviour and the associated need for consistency and familiarity of staff. Some parents suggested that if hospices could create a safe and supported environment for their child, they would readily access much needed respite. As per feedback regarding palliative care, parents urged **information about hospice and respite care to be delivered to parents early in their child's care trajectory,** to allow for the building of trusted and familiar relationships between staff and families in preparation for the option of hospice care for their child's end of life. Parents expressed a wish for their **child to feel understood and welcomed in hospices**, suggesting integration of a **dementia friendly approach**. Parents suggested this could include **safe spaces for their child and training for staff in the experience of childhood dementia** and how to manage associated behaviours. As described in *Chapter 6, Health Services*, parents articulated a need for **coordinated care between NDIS support workers who could provide additional familiar support** when children were admitted for hospice and respite care.

10. Psychosocial Support

10.1 Lived reality

It puts a hell of a strain on your family. It puts a lot of strain on your marriage, and it's something that you really probably need the time to then be able to focus on yourselves. [FG5.1]

Overwhelmingly parents described **extreme psycho-social issues** in relation to the diagnosis of their child's life limiting condition and ongoing care needs, that heightened in intensity as their child regressed. This was particularly prevalent for **mothers who hold the main caregiving role** in the lives of children living with dementia. Living in the knowledge that your child will die means an **anticipatory grief that parents live with constantly**, often extending for years, sometimes decades. The greater proportion of parents described **significant unmet psycho-social needs** from the point of diagnosis and assumed they would be able to access specialist counselling to support emotional and psychological functioning, yet felt let down when this was not provided. Parents described a sense of their **child with dementia becoming the necessary focus of their life** and their family's life, which had repercussions for parent/marital relationships and a consequent **impact for siblings when their sick brother or sister required significant attention.** Most parents participating in focus groups were mothers, with many describing a **loss of identity** as their lives became consumed by caring responsibilities. For some parents the caring responsibilities were so significant that **both parents withdrew from the workforce,** meaning significant **financial strain**. Some parents described the associated **physical toll of caregiving** as causing their own health issues. The combination of these stressors then resulted in a **mutual withdrawal from natural extended family and friendship networks.** Parents described an initial period of proactive support from this network, however as their child's life extended and care needs increased, this **natural support network waned**, leaving them **extremely isolated and socially disconnected.** Some parents described a **new social network evolving,** comprising health and social care professionals, support workers, and other parents of children with a rare health condition and/or disability. This replacement network then suffered following the death of their child when the professional carers withdrew and their own lives became removed from the disability sector, only enhancing a sense of disconnect from any form of social network.

10.2 Recommendations from parents

Psychological support probably. I'm obviously his primary caregiver. But if I'm not doing okay mentally, then that doesn't look good for anybody. [FG1.1]

All parents recommended the introduction of **specialist psycho-social support** at the point of their child's diagnosis for the whole **family unit**. They encouraged **consistency in this role** throughout their child's care trajectory to **allow for trusted relationships to develop** and avoid having to repeat their story again and again (see *Chapter 5: Care Coordination*). Parents believed these specialist support roles should be **social workers or psychologists, who have training in childhood dementia** and an understanding of the complexities of these conditions, the longevity of caring by parents, and the associated loss, grief and trauma of the intense care burden of caring for a dying child (see *Chapter 4: Health Professional Awareness and*

Training). Parents described the need for a **multi-pronged focus on the emotional, social, financial and existential impacts** of caring for a child with dementia, including practical support such as **financial assistance for medical costs and equipment, support for maintaining employment while caregiving, help with coordination of care systems and long-term care planning assistance** (see *Chapter 5: Care Coordination*). Parents suggested **proactive psychoeducation** regarding the impact of caring, **anticipatory grief and chronic sorrow**, and **marriage/relationship counselling. Parents caring for other children described a need for support services for siblings,** who become disenfranchised in the family due to their sibling's care needs. One parent described the benefits of **peer-to-peer support for her impacted child's sibling,** allowing them the opportunity to normalise their experience with another sibling. Many parents described comfort in meeting a peer with a similar experience of caring for a child with dementia and called for **facilitated peer to peer support programs**. Some parents suggested the **introduction of a peer at the point of their child's diagnosis** to alleviate the immense sense of confusion and isolation when entering this unfamiliar world of childhood dementia. Maintaining social connections in their natural community is important for families, with many parents expressing a desire for their **social networks to gain improved understanding of their experience and remain in their lives long term.** In response to the withdrawal of their natural friendship networks, parents called for **broader public awareness raising regarding childhood dementia that could enable natural support networks to be maintained long term** and reduce their ever-present sense of social isolation. Establishing **strong social connections for families throughout their child's life** could mean stronger social connections following the death of their child. Many parents described a need for **access to ongoing specialist psycho-social support in bereavement for the whole family.** Again, parents stressed the need for **bereavement support from professionals well versed in the experience and impact of childhood dementia.** Some parents recommended **transitional support from familiar health and social care professionals into bereavement** to ensure ongoing care following the death of their child.

11. Education Support

11.1 Lived reality

The education possibilities are very limited... even though they they're not going to become a lawyer or a doctor, but like, they could still learn things, and it's more about quality, their quality of life and engagement. [FG2.1]

Parents described accessing **childcare and education opportunities for their child as meeting multiple needs**: a sense that their child was learning in some form as is natural and necessary for a child, connection with their peers, and respite to allow parents to maintain employment and care for other children. However, accessing education was fraught with challenges. Regardless of their child's future potential, all parents described a desire for their child **to access education and a school environment to enhance their quality of life and provide engagement with children their own age**. However, parents described systemic barriers to realising this vision including a **lack of understanding from staff** as to how to understand and respond to the needs of children with dementia, **finding appropriate settings** where their child who is not progressing developmentally as their peers yet are chronologically of similar age, or **environments that are physically accessible** for their child. For older children, parents then described the **complexities of their child transitioning to high school**, when developmentally they had regressed and were the developmental age of a much younger child.

11.2 Recommendations from parents

One thing that we saw at the daycare where he was, where he had the good teachers, they would talk to the kids about what was going on. They didn't explain the full story, but they explained that his brain works a little bit differently. [FG6.1]

Parents described a need for **better guidance for families navigating educational choices for their child, including times of transition** between early childhood care to primary school and again at the transition into high school. Given most children are diagnosed with dementia from infancy, parents described a need for **specialised training for staff on the experience and needs of children living with dementia across the spectrum of early childhood education, primary and high schooling**. Most parents advocated for access to education in order to attend to their child's physical and cognitive needs, to improve social integration with peers, to normalise their experience of childhood and/or adolescence, and consequently to improve quality of life. Parents encouraged **inclusive education programs for children** at all education touchpoints and **flexible enrolment options between mainstream and special education schools**. Parents called for an **increase in physical accessibility** in all school settings, and the creation of **learning spaces that are safe**. Given the vulnerability of children with dementia, many of whom are non-verbal, parents recommended **improved communication protocols between staff and families** such as transparent daily communication logs between school and families, and **stronger oversight and accountability measures** to ensure their child's safety.

12. NDIS and Disability Support

12.1 Lived reality

We got told [by an NDIS support coordinator] when he was four that the research says there's no benefits of him doing therapy as he's a child with a degenerative condition. So, they took away all of his therapy funding. [FG6.1]

Parents experiencing a new diagnosis of childhood dementia expressed immense **confusion in how to navigate NDIS with no access to an identified support person or mentor**. Overwhelmingly parents described the **NDIS as not being cognisant or responsive to the experience of children** who, because of dementia, will regress over time. Many parents described significant **barriers to accessing appropriate and timely support** given a system they believe is focused on maintaining and building skills. This lack of understanding inhibits timely assessments and responses to requests for necessary equipment and home modifications, and requires constant advocacy within a **system that fails to understand the impact of therapy for children with degenerative conditions.** This lack of understanding extended to **support workers who were often not trained** specifically in caring for children with dementia, meaning parents yet again become the education source. The impact of poor access to and response from the NDIS elevated parents' experiences **of becoming the 'operations manager'** (see *Chapter 5: Care Coordination*) and continual advocate to ensure their child received the care and support required. The impact of this for parents is extreme, with many parents describing the **logistical and emotional burden,** given the time invested into undertaking a role that the NDIS is established for.

12.2 Recommendations from parents

Maybe it should be set up where it doesn't really matter if the planner or coordinator is in Western Australia, but that they're dealing with lots of kids with the same groups of conditions. [FG2.1]

Parents suggested the most significant impact within the NDIS would be **enhanced education of NDIS service providers.** Parents repeatedly described a lack of understanding about regression in childhood dementia and suggested **cross sector training** to expand knowledge and awareness of childhood dementia conditions beyond healthcare (see *Chapter 4: Health Professional Awareness and Training*). Given the volatility of their child's condition, parents called for a predictive **needs assessment** that anticipates the child's needs in advance to avoid delays in equipment and increased care supports, together with **fast-track approvals**. Several parents called for NDIS funded support workers to be able to **follow their child through regular hospital admissions**, to ensure continuity of one-on-one support. Given the many rare diseases that fall under the childhood dementia umbrella, and geographical disparity of children and families in Australia, parents suggested an **expertise based, rather than geographic based NDIS planner and coordinator.** This type of specialist model could enable **proactive and anticipatory support planning, timely access to equipment and other supports,** as well as reducing current stressors described by parents. Given the over 100 childhood dementia conditions, parents suggested a **virtual consultation model,** where NDIS expertise in Australia was accessed remotely by families.

13. Conclusion and future directions

This report represents the experiences of seventeen parents currently caring for a child or children living with dementia, and bereaved parents. The report aligns with the ten priority domains presented in the ***Pathway Towards Report*** highlighting the systemic challenges facing children living with dementia and their families.

These include, **complex and delayed diagnostic pathways** (Chapter 3), a **lack of healthcare professional specialist knowledge of childhood dementia** contributing to delays in diagnosis and guidance around the pathway forward (Chapter 4), the **burden of becoming 'operations manager' for their child** across their lifespan and healthcare trajectory (Chapter 5), and **fragmented health services with poor communication and integration between the myriad teams** caring for children with complex needs (Chapter 6). All parents advocated for attention to **curative treatments and the potential for screening to activate an early diagnosis** and clinical response (Chapter 7). Parents expressed **confusion around the role of palliative care** particularly in terms of referral timeframes, and called for a **national consensus around the contribution palliative care can make to children with dementia and their families** (Chapter 8), describing similar experiences with hospice care with the added burden of **feeling their child was excluded due to the nuances of the childhood dementia experience** (Chapter 9).

The **psycho-social burden for children living with dementia and their families is extreme**, in part due to the significant care needs of the child, and from the perspective of parents, due to the **lack of a systemic response from the health, disability (NDIS) and education sectors** (Chapters 10, 11 and 12). Parents described a **significant caregiving burden**, with **mothers shouldering the greater proportion of caregiving roles**, and consequently a **shift in role and identity**. This then translated into **financial burden for families** and an **acute focus on the child with dementia, leaving siblings increasingly isolated** (Chapter 10). Parents described the **challenge of identifying and accessing appropriate education** for their child, yearning for them to **experience a sense of normalcy through engagement with peers** (Chapter 11). At every stage of their child's life, parents described a **series of challenges engaging with the NDIS,** from the point of diagnosis and **confusion of how to access this system**, to a **lack of a proactive response to the needs of their child**, and **poor understanding of regression in childhood dementia** (Chapter 12).

Based on these experiences of children living with dementia and their families, **five priority actions were identified** that have the potential to develop comprehensive, family-centred solutions that address both the clinical and psychosocial needs of affected children and their families. These include: **Priority One: Establish dedicated care coordination** to create efficient pathways which could transform how families navigate healthcare and support systems; **Priority Two: Advance healthcare professional expertise** through development of specialised childhood dementia training and networks of informed specialists; **Priority Three: Strengthen family support networks** where comprehensive psycho-social support is extended to all family members from diagnosis through to bereavement; **Priority Four: Integrate a palliative approach from diagnosis**, where appropriate palliative services are offered to children and families from the early stages post diagnosis and enhance quality of life for the whole family; and **Priority Five: Enhance NDIS responsiveness** to ensure accessible and responsive pathways tailored for childhood dementia, with streamlined approval and review processes.

In addition to these five priorities identified by families who are impacted, or have been impacted by childhood dementia, there needs to be an acute focus on childhood dementia research to reach the goal for curative treatments for all children living with dementia in Australia.

The integration of ***What Matters Most*** for children with dementia and their families, with findings from the ***Pathway Towards Report***, is critical in defining a nationally coordinated framework that addresses issues defined by families and health and social care professionals. Future considerations could include delivery of these reports to the health, disability (NDIS) and education sectors; development of a national working party led by Childhood Dementia Initiative and comprised of representatives from each sector and parent advocates, to ensure a coordinated approach to systemic change.

Appendix A

Childhood Dementia Initiative

What Matters Most: Lived Experience Focus Group Invitation

Background

2024 has seen Childhood Dementia Initiative (CDI) and their consultancy partners undertake a range of projects, gathering evidence to articulate what needs to be considered and included in a **best practice model of care for children living with dementia and their families in Australia**. This evidence clarifies what is working well, what is missing, and what change would make the most impact to improve quality of life for children and their families.

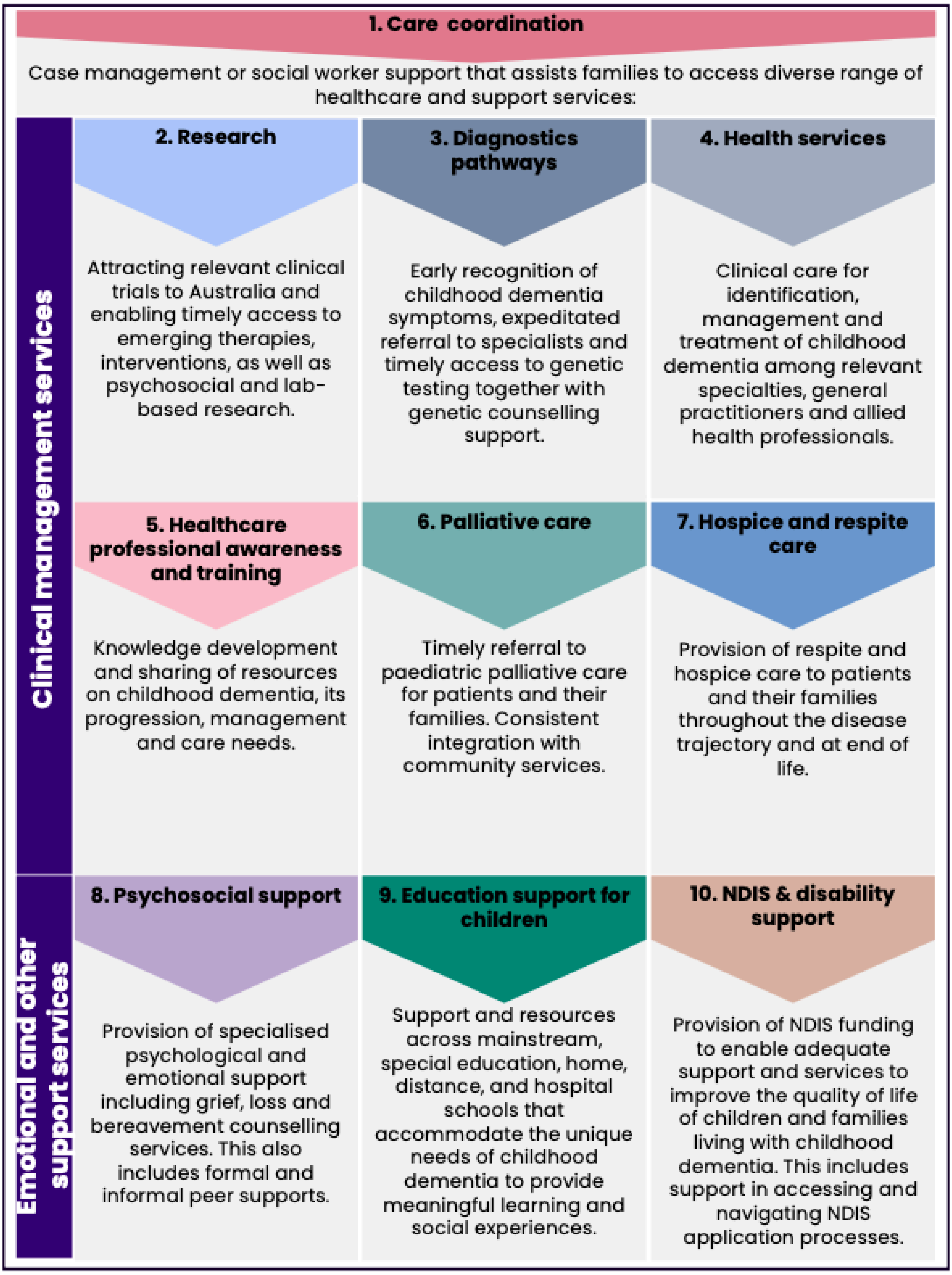
A key project was delivered by HealthConsult who were engaged to undertake a stakeholder consultation process with health and social care professionals throughout Australia, to explore their experience and perceptions of current service provision for children and families like yours. In summary, ten domains were identified that these stakeholders believe should be considered and incorporated within a childhood dementia model of care:

1. Care Coordination
2. Research
3. Diagnostic Pathways
4. Health Services
5. Healthcare Professional Awareness and Training
6. Palliative Care
7. Hospice and Respite Care
8. Psychosocial Support
9. Education Support for Children
10. NDIS and Disability Support

See Figure One, page 2 for further details within each of these domains.

However, ***what matters most***, is what you as parents and carers have learned from the lived experience of caring for a child or children living with dementia, and for some, experiencing your child's end of life, death and your family's bereavement.

We are very grateful that you have accepted our invitation to join a small focus group delivered via Zoom (a virtual meeting platform), where through a facilitated conversation we hope to understand more fully what matters most to you and your family when considering the development of a model of care for childhood dementia in Australia. **This is your opportunity to participate in influencing long term change.**



1. Care coordination

Case management or social worker support that assists families to access diverse range of healthcare and support services:

Clinical management services

2. Research

Attracting relevant clinical trials to Australia and enabling timely access to emerging therapies, interventions, as well as psychosocial and lab-based research.

3. Diagnostics pathways

Early recognition of childhood dementia symptoms, expeditated referral to specialists and timely access to genetic testing together with genetic counselling support.

4. Health services

Clinical care for identification, management and treatment of childhood dementia among relevant specialties, general practitioners and allied health professionals.

5. Healthcare professional awareness and training

Knowledge development and sharing of resources on childhood dementia, its progression, management and care needs.

6. Palliative care

Timely referral to paediatric palliative care for patients and their families. Consistent integration with community services.

7. Hospice and respite care

Provision of respite and hospice care to patients and their families throughout the disease trajectory and at end of life.

Emotional and other support services

8. Psychosocial support

Provision of specialised psychological and emotional support including grief, loss and bereavement counselling services. This also includes formal and informal peer supports.

9. Education support for children

Support and resources across mainstream, special education, home, distance, and hospital schools that accommodate the unique needs of childhood dementia to provide meaningful learning and social experiences.

10. NDIS & disability support

Provision of NDIS funding to enable adequate support and services to improve the quality of life of children and families living with childhood dementia. This includes support in accessing and navigating NDIS application processes.

What will the focus group involve?

Some of you may have previously participated in a focus group with Childhood Dementia Initiative. A focus group is simply the name used to describe an opportunity to come together with two facilitators, who will guide a conversation between group members on a particular area of focus. In this instance, the focus will be **what matters most, and what do you feel would have the most impact, when considering a model of care for children living with dementia in Australia, and their families.**

Each focus group will be comprised of up to four parents or carers and run for 90 minutes. Focus groups will be recorded for transcription purposes to ensure we accurately translate your thoughts and experiences. Your consent will be sought prior to recording.

We commit to ensuring our availability to you as you journey with us through our collective advocacy. In the event you feel the need for additional support throughout this experience, we encourage you to contact Joanne Kershaw, Care and Quality of Life, CDI joanne@childhooddementia.org or 0449 007 217.

What will happen with the focus group findings?

CDI has engaged a consultant, Dr Leigh Donovan of Collaboraide to lead this project Leigh is a strong ally of CDI, social worker by profession, and has dedicated over twenty years of her vocational life to paediatric palliative care and bereavement care in Australia. She now works in a consultancy capacity in the palliative care and bereavement sector with a focus on elevating the voice of the lived experience within health, social care and community settings.

After the focus group, Leigh, in collaboration with CDI colleagues, will analyse the feedback to identify the main themes across the group, and where there may be differences based on each individual experience. Leigh will forward a draft of the report to all focus group participants *inviting you to review and ensure your comfort in how your voice and experience is represented.* This information will be used to prepare a report detailing the findings across all focus groups and shared with CDI.

Who is my contact person throughout this experience?

Please feel free to contact Ellie Da Ros, Program Manager – Care (CDI) with any additional questions you may have as a focus group participant:

Mobile: ellie@childhooddementia.org or 0410 014 028

What happens next?

Please find attached a **Focus Group Preparation Guide** we invite you to read and consider prior to participation in the focus group. The facilitators will guide you through these question prompts on the day.

With thanks

We acknowledge your commitment in taking time to share your experience and would like to express our gratitude for working alongside CDI to ***realise our vision to reach sustainable global health solutions for childhood dementia.*** We also honour those parents and carers that simply may not have the capacity to participate at this time.

Appendix B

Time	Function	Team Member
10mins	Introduction to facilitators Background to What Matters Most project	Ellie
5mins	Invitation for parents/carers to share their name, the name of their child they are representing, and where they are dialling in from today. What to expect today Safeguarding	Leigh
20mins	**Question One** When considering the ten priorities for childhood dementia care and support landscape (as referred to in the Pathway Toward Report) and the impact of these for you, your child and your family: 1) What is working well, 2) Where could the service or system be improved, and 3) Where do gaps in the service or system exist?	Leigh
10mins	**Question Two** What other challenges do you face with regards to accessing care and support services (reference circles of care model)	Leigh
10mins	**Question Three** Which systems or services pose the greatest challenge on the most regular basis?	Leigh
10mins	**Question Four** What differences would have the most impact for your child or children living with dementia?	Leigh
10mins	**Question Five** What differences would have the most impact for you and your family as you manage your child or children's care?	Leigh
5mins	**To summarise,** what are your top five priorities for care and support services you would like addressed.	Leigh
5mins	**Next steps** Transcription and thematic analysis Member checking – did we get it right? And when to expect this document for review Gratitude and keeping connected	Leigh Ellie