Childhood Dementia Initiative

Submission to the Public Consultation Paper for the National Dementia Action Plan

January 2023

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Executive Summary

Childhood Dementia Initiative welcomes the opportunity to respond to the proposed National Dementia Action Plan (Action Plan) as outlined in the Public Consultation Paper (Australian Government, Department of Health and Aged Care, 2022).

To be truly inclusive and respond to the real needs of Australia's dementia population, **the final Action Plan must acknowledge and address that dementia is experienced at all ages, including childhood.** Children with dementia are a high-needs and neglected sub-population of people with dementia. They experience the same progressive loss of skills and neurodegeneration as adults with dementia. However, they are largely excluded from dementia support services and policy responses.

Children are not sufficiently recognised in the proposed National Dementia Action Plan (Action Plan). The Action Plan must include, prioritise and respond to children with dementia in order to address the severe inequity of access to care and support, and the systemic neglect and discrimination they and their families currently experience.

Critically, children should be identified as a priority population in the proposed Action Plan. Approximately one child in every 2,800 is born in Australia with a genetic condition that causes dementia in childhood. In the absence of treatments, they inevitably will develop dementia. They face great inequity in access due to the severely limited availability of appropriate support services. Additionally, the symptoms of their dementia can result in their exclusion from existing general paediatric support services.

Addressing discrimination and stigma experienced by all people with dementia is essential. **The heightened and systemic discrimination experienced by children with dementia and their families, however, must be addressed.** Their inclusion in the Action Plan is key to achieving this.

Provided children are definitively addressed, Childhood Dementia Initiative is aligned in principle with the objectives and immediate priorities proposed in the Action Plan. However, detailed responses to each section are outlined in this document.

It is important that provision is made for the Action Plan to respond to evolving research and immediately translate it into care and support practices. Additionally, **an analysis of the appropriateness and accessibility of current services and programs available to adults that could be extended to children should be prioritised and incorporated into the Implementation Blueprints.** Other key activities that should be incorporated into the first Blueprint include workforce capability development specifically focused on childhood dementia and the inclusion of children in key dementia datasets.

Data collection, monitoring, reporting and governance all need to incorporate children and it is essential that the Action Plan's governance structure include representation of children with dementia.

Introduction

While dementia is usually associated with older people, children also suffer from dementia-causing disorders, resulting in neurodegeneration and progressive loss of skills. These disorders lead to severe symptoms, high care needs, extended chronic grief, and poor quality of life for children and their families. Less than 5% of the disorders that cause childhood dementia have effective treatments, and 75% of affected children will die before they turn 18 (Tilden et al., 2020).

Given that dementia affects Australians at many different points – from childhood to old age – this impact across the life course should be recognised in policy-making, program development and service delivery.

Equity demands that all Australians should be able to access appropriate and effective diagnosis, care and services that reflect their needs and in settings that are appropriate to their age.

At present, 2,300 Australian children are suffering and slowly dying from dementia. These children do not have access to appropriate care or therapies that might help them. It is not a large population but it is underserved, largely unrecognised and almost entirely ignored, not just in Australia but globally.

It is not only these children who are impacted by their dementia. Parents, siblings, extended families, and friends are all affected by the experience of a child living with dementia and given the genetic nature of childhood dementia, many families have more than one child living with the condition. Nearly 9,000 Australians are estimated to share a household with a child living with dementia. This impacts their capacity to work, socialise and many other elements of their lives.

The proposed National Dementia Action Plan (Action Plan), as outlined in the Public Consultation Paper (Australian Government, Department of Health and Aged Care, 2022), does not adequately address this situation or the inequitable position that children with dementia and their families currently face.

Development of the Action Plan provides the opportunity to recognise this neglected and ignored population, support children with dementia and their families and firmly position Australia as a global leader in this area. It also offers the opportunity to put in place clear steps that will help end the discrimination faced on a daily basis by this group of vulnerable Australians.

This response to the Public Consultation Paper by the Childhood Dementia Initiative:

- Provides overarching feedback regarding the current proposed Action Plan;
- Considers the Proposed Objectives as they relate to children; and
- Comments on the Immediate Priorities, what Childhood Dementia Initiative is already doing about these, and why and how the needs of children might be better captured or reflected within these.

Importantly, throughout this response, we outline how children with dementia and their families might be better recognised and supported by the Action Plan.

Overarching feedback on the proposed Action Plan

Children are a critically important sub-population of people with dementia. Not only does childhood dementia have a tragic and life-limiting impact on children and their families, it also has an estimated cost of $389 million every year to the Australian economy (Tilden et al., 2020).

Children are not sufficiently recognised in the proposed Action Plan

The proposed Action Plan does not sufficiently note the experiences, challenges and barriers to services, diagnosis and support that children with dementia and their families face. This is not unexpected – not a single national policy or action plan globally currently recognises childhood dementia – but it is not good enough.

Most of the references to children in the proposed Action Plan relate to the children of adults living with dementia, not as children with dementia. Children living with dementia are recognised on page 45, and there is a small reference to having counselling support for children on page 46, but it is unclear whether the services are to be delivered to children with dementia or children of people experiencing younger onset dementia. Children living with dementia, their experiences and those of their parents are largely ignored.

Childhood Dementia Initiative supports the principles and objectives outlined on page 13 of the Action Plan. These are meaningful to all people who have dementia, no matter their life stage. However, nuance and detail are needed to ensure that these principles are addressed at each point of people's life course.

In addition to principles and objectives, the full life course of people living with dementia must be reflected throughout the final Action Plan, including the implementation blueprints, monitoring, reporting and governance of the Action Plan and in all infographics, diagrams, pictures and in statistics. This includes children.

Children should be identified as a priority population

The proposed Action Plan identifies a number of groups as being 'at higher risk of developing dementia or facing barriers to equitable access' (Australian Government, Department of Health and Aged Care, 2022:9). Children with dementia clearly meet these criteria:

- There are very limited dementia services currently available or appropriate for children with dementia.
- Established general paediatric services (e.g. disability and palliative care services) do not fully meet the needs of children with dementia. Additionally, families report children being

excluded from services due to their dementia symptoms, such as behavioural and psychological symptoms of dementia (BPSD) (Nous Group, 2023).

- Every year in Australia, an estimated 129 children (1 in 2,800 births) (Tilden et al., 2020) are born with a genetic condition that causes dementia in childhood. In the absence of treatments, they are not just at higher risk of developing dementia, they inevitably will. It is also important to note that due to the genetic causes of childhood dementia, it is not uncommon for a family to have multiple diagnosed children. This results in an even greater impact on their family and compounding unmet needs.

Children with dementia undoubtedly face barriers to equitable access and should be recognised as such in the final Action Plan. While they are a small population within the dementia community, given their young age, the impact of their dementia is significant. The Years of Life Lost are estimated to be over 1,000 every year in Australia and the Years of Life lost due to Disability to be approximately 450 (Tilden et al., 2020). The loss of opportunities and experiences as well as the loss faced by their families is, of course, immeasurable.

Despite this impact, children with dementia are not recognised in policy, clinical or care settings. Their needs are underserviced, and they and their families struggle to access care and services in a timely manner and in age-appropriate settings. This lack of equity is unacceptable in modern Australia.

Recognising that children suffer from dementia is necessary to help ensure that due and appropriate attention is given to their needs. This recognition is essential to driving change in services, clinical practice, and how these children and their families are viewed and treated.

While not sufficient in and of itself, naming children as a clear population within this document would act to elevate awareness of childhood dementia and support work already being undertaken to raise awareness of this condition with healthcare and education professionals and within the community more generally.

Intersections with other priority populations

Accessing care and services for children with dementia is challenging regardless of where in Australia families live. Living in regional, rural or remote Australia exacerbates these challenges immensely, particularly in accessing respite care. As such, there are significant overlaps with the challenges faced by adults with dementia living in those areas.

This again points to the need to take a life course approach to dementia. There are undoubtedly lessons across populations, research programs and service delivery that should be leveraged to deliver better care and support for all people living with dementia regardless of their age and location. The strong intersections between priority groups are recognised within the proposed Action Plan (page 9). Capturing the potential benefits of this life course approach is another reason that children should be included within the priority populations.

Systemic discrimination against children must be acknowledged

Currently, children living with dementia and their families experience significant discrimination. While it is important to recognise and call out the discrimination and stigma experienced by all people with dementia, it needs to be recognised that, within the dementia population, a subset of it – children – experience even more extreme discrimination.

This is evident not only within the healthcare system but across other systems with which children interact. For example, while 50% of NDIS participants are children, they receive only 8% of total NDIS funding (Shorten, 2022). This funding imbalance reflects the significant burden that falls on families. Many parents of children with dementia are told that there is a 'natural parenting role' that they should perform before seeking to access services to support their children. This is simply not an experience reported by other groups of carers within the dementia community.

Likewise, parents of children with dementia frequently find that the behavioural and psychological symptom of dementia (BPSD), which is recognised within the adult population, is generally perceived as poor childhood behaviour or parenting (Childhood Dementia Initiative, 2022). This leads to further exclusion and discrimination, including from the very systems and services they require. In the childhood dementia population, reversing these misconceptions is reportedly difficult. This is likely due to a lack of awareness of the condition (Nous Group, 2023).

As highlighted below, discrimination against children also occurs in the collection of dementia data – even the Australian Institute of Health and Welfare fails to include them – and in many research projects.

If key actions to address the needs of children with dementia and their families are not identified and implemented via the proposed Action Plan, it risks not only the opportunity to address discrimination, but further exacerbation of systemic discrimination against this vulnerable subset of the dementia population.

Immediate Priorities

Childhood Dementia Initiative generally supports the immediate priorities for the first three years of the proposed Action Plan although the needs of children must be definitively addressed. This includes making children with dementia a priority population and putting in place projects to analyse the appropriateness and accessibility of current services and programs provided to adults that are not available to children but might be adjusted or adapted so that access might be extended to them and the gaps that then remain. This would enable solutions to resolve these gaps identified and progressed.

Childhood Dementia Initiative has undertaken a great deal of work in relation to the identified priorities – as outlined in Appendix – and has more work underway that will continue to contribute to these during the years 2023 to 2026.

It is not appropriate however that all this policy, data gathering and professional education for a subset of the dementia population be undertaken solely by a patient advocacy organisation, even with a degree of support from Government. Childhood Dementia Initiative looks forward to working more closely with and contributing to other organisations responsible for dementia more broadly going forward. This includes the Australian Federal Department of Health, the National Centre for Monitoring Dementia, the Australian Institute of Health and Welfare and others. Childhood Dementia Initiative already has close working relationships with other patient groups and intends continuing the partnerships and work initiated with them.

In addition to these observations and the work currently underway, it is critical that provision is made within the final Action Plan to be responsive to outcomes of research and other work as it evolves. This is particularly important as research will be both undertaken and published during the 2023 to 2026 period that identifies best practice. Any such evidence should be utilised immediately and translated into care and support practices without delay.

Proposed Objectives

Childhood Dementia Initiative has the following comments on the Action Plan's proposed objectives as follows:

Objective 1: Tackling stigma and discrimination

There is no doubt that broader awareness of dementia is needed to help tackle the stigma and discrimination experienced by people living with dementia, regardless of their age. At the same time, awareness of childhood dementia is significantly lower than that of adult dementia. Additional attention is required to address this knowledge gap.

Dementia awareness needs to be considered with an inclusive lens that acknowledges dementia is experienced across the life course, from childhood to adulthood and by older people.

There are specific issues that parents report when raising a child with dementia. In the health, care and education systems and community more broadly, dementia in children is not well understood. Many children with dementia are perceived as 'difficult' or badly behaved. While it is recognised that changes in behaviour can be associated with dementia in adults, this is not similarly acknowledged in children. Parents report their parenting being called into question (Childhood Dementia Initiative, 2022:6) and the resultant behavioural and psychological symptoms of dementia (BPSD) can lead to children being excluded from school and other activities. Addressing stigma and discrimination needs to occur for these children, not simply in the health and care systems, but also in the education system.

To help address stigma and discrimination against children with dementia, the following actions should be taken and included within the Action Plan:

- Enable equitable access to dementia services regardless of life stage. There are currently many established dementia support services for adults, for example the National Dementia Support Program, that are not available to children.
- Assess existing dementia services and their ability to meet the needs of children and families and, where possible, adapt and extend services to accommodate this subset of the dementia population.
- Identify and ringfence funds for services for children in order to specifically address the current discrimination and barriers to equitable access experienced by them and their families.
- Continue to build capacity of relevant professionals through the current childhood dementia education program funded and endorsed by the Australian Federal Department of Health.

Objective 2: Minimising risk, delaying onset and progression

Early diagnosis is not only critical for the delivery of equitable and quality care, it also plays a key role in the development of much needed therapeutic interventions for children with dementia. The window of time where therapeutic intervention might be most effective is largely unknown for the childhood dementia disorders. Emerging evidence from clinical trials indicates, however, that in many cases if a child is presenting with symptoms significant enough to lead to diagnosis, it may be too late (Sevin & Devia, 2021).

This presents a tragic dichotomy for the development of treatments and cures for children living with dementia. If pre or early symptomatic children cannot be identified to participate in clinical trials, demonstration that a particular intervention is effective is impossible which results in therapeutics not being available for children with these conditions.

Expanding and improving newborn screening programs and rapid diagnosis pathways for childhood dementia disorders would make great strides towards breaking this tragic predicament.

Early diagnosis would also provide reproductive confidence for families both within the immediate family of an affected child as well as their broader family.

Objective 3: Improving dementia diagnosis and post-diagnostic care and support

Diagnosis

Parents report a diagnostic odyssey that can extend for years (Nous Group, 2023). As parents express concern around a growing range of symptoms with health professionals, they are often dismissed as 'neurotic' (Nous Group, 2023; Childhood Dementia Initiative, 2022). To improve the diagnosis of childhood dementia, more health and social care professionals need to be trained to recognise it with a focus on natural touch points throughout an infant and child's developmental stages. This includes General Practitioners (GPs), childhood nurses, early childhood educators and paediatricians.

Parents regularly report a lack of awareness of childhood dementia by GPs and, given that this group is the first point of contact for many primary care issues, dementia education of GPs should be prioritised. This is particularly important given that many parents report that they are often not listened to when they initially raise concerns about their children's progress or lack thereof or other symptoms (Nous Group, 2023). Mothers, in particular, report that their concerns are downplayed or ignored and that they face 'medical misogyny' when dealing with GPs and other healthcare professionals on behalf of their children (Nous Group, 2023).

Childhood and maternal nurses are often a key touchpoint for many parents at the time their children are beginning to show early signs of dementia. Parents report (Nous Group, 2023) that these professionals are often extremely proactive. Therefore, training should be delivered to make childhood and maternal nurses more aware of the symptoms and signs of childhood dementia.

In terms of other medical professionals, paediatricians are among the specialist medical groups that should be trained in and targeted for awareness and diagnosis of dementia. Additionally, raising awareness among the paediatric and adolescent health and care workforce should be prioritised.

Early childhood educators are also a key touchpoint for recognising children's developmental delays, which can begin the pathway to diagnosis. Supporting this group to better understand and identify the symptoms of childhood dementia would prove valuable.

Fundamentally though, broad awareness of childhood dementia is required across health, disability and education settings to support early diagnosis and ongoing responsive care for children with dementia. In addition, those working with children with dementia need a deep understanding of family needs, emerging research and changing policy and practice. Workforce education must be embedded in systems and structures to ensure ongoing sustainable change.

Post-diagnostic care and support

There is a clear need for an evidence-informed approach to nationally consistent dementia care pathways appropriate to all life stages. This will not only help ensure that children receive appropriate care at the right time, and parents get the support they need, it will also generate a more accepting, inclusive and proactive health and care environment for children with dementia.

Following diagnosis of childhood dementia, parents report feeling adrift without clear diagnostic information or prognosis for their child. Some parents report that it was not made clear their child's diagnosis was terminal until they 'Googled it' (Nous Group, 2023).

Adjustment to the diagnosis of a child's terminal condition is fraught for parents (Brouwer et al., 2021) (Nous Group, 2023). Immediate, effective post-diagnostic support should include not simply clinical and allied health support but also specialist psychosocial support given the significant psychosocial challenges experienced by children with dementia and their families as noted above.

Extending support into the education sphere is also important. Children with dementia have the right to develop their personality, talents and mental and physical abilities to their fullest potential (United Nations, 1989). Childhood Dementia Initiative notes the extensive support and focus given to helping adults with early onset dementia maintain their working life and associated routines. This approach should be extended to children with dementia as a means to support them to continue to play and learn within the education system post-diagnosis and to potentially delay progression.

Objective 4: Improving treatment, coordination and support along the dementia journey

To improve treatment, coordination and support for children along their dementia journey, the various systems with which they and their parents interact need to be recognised in the Action Plan. These include, education, the National Disability Insurance Scheme (NDIS) and specialist paediatric palliative care. These additional areas are frequently not recognised. For example, the diagram on page 39 of the proposed Action Plan does not include either education or the NDIS and palliative care is defined only for the end of life process, rather than for improving quality of life as is appropriate in the paediatric setting..

The challenges of having more than one child with dementia, as many families do, should be recognised in terms of coordination and support to children and their families. Increased coordination of care and support would, in this instance, not only relieve some of the burden on families but also increase the efficiency of service provision.

Interaction with the NDIS

Particular challenges exist in relation to children living with dementia and the NDIS. Parents report issues in gaining knowledge of NDIS referral pathways and systems following their child's diagnosis and at ongoing points of deterioration (Nous Group, 2023). Special guidance is required at this time of immense confusion and suffering as parents grapple with their child's increasing support needs.

According to Bruce Bonyhady, founding Chair of the National Disability Insurance Agency (NDIA), the NDIS has built into it 'an incentive to make short-term investment in participants aimed at increasing their independence and participation in the community and the workforce in the hope of reducing long-term costs' (Buckmaster, 2016). This mindset governs much of its decision-making. As a result, the NDIS is not well-positioned to address the needs of children who are progressively losing skills and abilities rather than building and improving them. Regression is simply not understood within the NDIS. Yet maintaining skills, and support to do so, is critical for this cohort. Workforce capacity development across the NDIS is required to appropriately accommodate and meet the needs of children with dementia and their families.

The timeliness of NDIS service has also proven to be an issue. Several families have reported that equipment deemed as necessary has arrived after their child died, causing additional and unnecessary distress and frustration (Nous Group, 2023).

Lack of NDIA staff knowledge and understanding of dementia significantly affects the quality of assessment and care received by children with dementia and their families. Families have to repeatedly explain their child's condition, are refused reasonable requests, experience inconsistent decision making and psychological impacts due to the constant 'battle' they face to access necessary supports (Childhood Dementia Initiative, 2021).

These challenges are exacerbated for families with more than one child living with dementia. NDIS planning is often not designed to accommodate multiple family members with similar needs. As result, plan timings are often misaligned, as are services that are needed and could be utilised by more than one child.

Dementia services for children

There are very limited dementia services currently available or appropriate for children. Dementia services, both established and emerging, should consider the full life course of dementia, including children, and how they might provide services to them. This applies across the board, from major service providers to local councils and Dementia Friends. There is emerging evidence that services established for the adult dementia population can be effectively extended to children with dementia. One such example is the recent successful delivery of behaviour support services by Dementia Support Australia (HammondCare).

Childhood Dementia Initiative recognises that the profound and deeply concerning impact of the inequitable, inappropriate and disparate care on children with dementia and their families, requires a comprehensive, evidence-based and urgent response. An analysis of the appropriateness and accessibility of current services and programs available to adults should be undertaken to determine those that might be adapted and extended to meet the needs of children with dementia.

Currently, for example, the Dementia Behaviour Management Advisory Service builds the capacity of aged care workers to care for people with dementia but does not provide similar support to those working with children. Funding should be ringfenced to extend this service and build the capacity of health and care workers working with children.

Palliative and end of life care

Childhood Dementia Initiative notes in relation to this Objective that there is no recognition in the proposed Action plan of the need for children to receive immediate referral upon diagnosis to specialised paediatric palliative care. In fact, there is no mention of children in relation to palliative care or other services at all and no mention of enhancing children's quality of life.

Palliative care should not be overly focused, as it appears in the proposed Action Plan, on end of life care, rather it should also encompass enhancing quality of life and this should be reflected in the final Action Plan. A critical element of child-specific pathways to post-diagnostic support is timely and immediate referral to paediatric palliative care, a different approach to adult palliative care. Referral to specialised paediatric palliative care is associated with improved quality of life for children and better caregiver outcomes (Marcus et al., 2020). As such, it should be uniformly provided to all families whose child is diagnosed with dementia.

The *Nightingale Program*, run by Dementia Australia in South Australia, is a good example of a palliative model of care, providing strategies and advice to support people living with dementia, their families and care providers with a focus on promoting choice and wellbeing (Dementia Australia, n.d.). No such program is currently available to support children with dementia and their families. Its introduction would deliver significant value and be greatly welcomed by those affected.

Objective 5: Supporting people caring for those living with dementia

Psychosocial impacts

Childhood dementia impacts the entire family unit – the child/ren experiencing dementia, their parents, siblings, and the broader family network.

Children with dementia suffer from severe sleep disturbance, deterioration of communication skills, loss of hearing and vision, movement disorders, mood disorders, incontinence and psychosis. The conditions they have are severely life-limiting and life-threatening with their cause of death including respiratory complications such as pneumonia, neurological complications and cardiac events (Nevin et al., 2022).

Behavioural challenges associated with dementia, including aggressive behaviours, hyperactivity, agitation, inability to communicate and toileting challenges are particularly draining and distressing. Parents frequently report a lack of available information and support to assist with management and coping (Hoffmann et al., 2020). Watching a child experience these challenges while having to manage them has a significant impact on parents' and other family members' mental, physical and financial wellbeing (Nous Group, 2023).

Parents with children who have dementia usually spend an extended amount of time and energy visiting clinicians to obtain a diagnosis and report heightened chronic stress during this period. This is regularly followed with decisional uncertainty after a diagnosis due to limited access to information about how to manage their child, facing obstacles to managing the daily care required and a lack of help and advice on how best to support their child.

In addition, over time, children become reliant on full-time supportive care, with the impact on family members significantly exacerbated where there is more than one child with dementia. Evidence points to excessive supports being borne by family carers with children due to the assumption of 'parental responsibility' and the 'natural parenting role' (Nous Group, 2023). In the absence of appropriate and responsive care pathways and support services, parents are left to fill the gaps.

This leads to manifold psychosocial challenges which encompass economic, social and psychological implications for parent carers (Nevin et al., 2022). Unaffected siblings also can be adversely impacted as parents spend increased time and energy on the child with dementia (Needham et al., 2014) (Grant et al., 2012) (Dermer et al., 2020) (Hoffmann et al., 2020).

Economic impacts

While the psychological and physical impacts of having a child with dementia should not be underestimated, financial and other related impacts also exist. Given the age of children with dementia, much of the impact of caring for them falls on working-age parents (primarily mothers) who find their careers interrupted, often leading to long-term effects on their career progression with flow-on consequences on superannuation and financial security.

A recent report found that, with current subsidy settings, Australian carers lose an average of $392,500 in lifetime earnings to age 67 and $175,000 in superannuation at age 67. Some people who are carers for extended periods lose substantially more, with the most affected 10% losing at least $940,000 in lifetime income and $444,500 in retirement savings (Furnival & Cullen, 2022). This is a substantial personal loss with significant societal and economic implications in terms of lost productivity and workforce participation.

Respite services and other carer supports

To address these challenges, health and care systems must be better designed to meet families' needs and provide appropriate support. This is even more essential at times when children transition between life stages and/or between key systems with parents identifying these moments as major pain points (Childhood Dementia Initiative, 2021) (Nous Group, 2023).

For example, parents report positive experiences once connected with palliative care, but timeliness of referral is vastly inconsistent. The transition from children's to adult health and disability systems results in a multitude of issues, often leaving families with reduced support at a time when care needs increase (Nous Group, 2023). Frameworks for care that address these matters are essential to guide improvements in systems and services to better meet needs.

The burden of caring for a child with dementia is immense, with one study indicating that mothers spent, on average, 88 hours per week caring for their child (Ammann-Schnell et al., 2021). Despite considerable need, there are very limited respite services available for children with dementia and their families. This results in significant psychosocial impacts, which are further compounded when a family has more than one child with dementia. Families report (Nous Group, 2023) that established paediatric respite services do not understand the needs of children with dementia, particularly BPSD, and are unable to manage the complex and high level of care and support required.

The diagram on page 39 of the proposed Action Plan includes respite services within the aged care system. This is not appropriate for children with dementia. Additional respite services for children delivered in an appropriate setting are critically needed.

Routines for children with dementia, as with many adults with dementia, can be vitally important to their wellbeing and, as a result, respite services delivered in out-of-home settings may not be appropriate for all children. Removing children from their family setting with parents and/or siblings may also prove distressing and disruptive and services provided in the home more effective in some instances.

Respite services should be provided, whether in or out-of-home, in hospice or other settings, in a place appropriate to the child receiving care. This flexibility is essential to providing effective and targeted care.

Objective 6: Building dementia capability in the workforce

As highlighted in the comments relating to Objective 4, building dementia capability needs to occur not simply in the health and care workforce but also and especially in the area of education. Children with dementia should be supported wherever possible to remain in the education system and awareness raising and capability building within the education workforce are central to achieving this.

Childhood Dementia Initiative has developed a suite of information resources[1], funded and endorsed by the Australian Federal Department of Health to build the capability of relevant healthcare professionals in relation to childhood dementia. Funding for this program will cease in June 2023. This program should be extended to deepen understanding and expanded to include the broader workforce, including the NDIS and education system. A sustainable, integrated approach to childhood dementia education is required and funding should be ringfenced – whether separate to, or within, current frameworks and programs – to ensure workforce capability development meets the needs of children and occurs in a timely manner.

Objective 7: Improving dementia data and maximising the impact of dementia research and innovation

Dementia data

Children are currently excluded from a number of research and data-related projects in Australia. These include:

- Australian Institute for Health and Welfare's (AIHW) National Centre for Monitoring Dementia Data;
- Australian Dementia Network's Clinical Quality Registry – based at Monash University and funded by the Federal Government; and
- MRFF Dementia Ageing and Aged Care Mission

While Childhood Dementia Initiative recognises there may be costs to including children in datasets, excluding them is unacceptable and discriminates against a vulnerable population. The fact that the AIHW – Australia's premier institution for health data – fails to collect this data is objectionable and should be addressed immediately. The Action Plan should also specifically state that any future systems for data collection on dementia should include children. This is particularly critical given the mechanism for reporting progress against the Action Plan and inclusion in future Implementation Blueprints will be based on an Action Plan Report Card (page 73) prepared by the AIHW.

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[1] https://www.childhooddementia.org/professionals

Dementia research and innovation

A 2022 study to better understand the landscape of childhood dementia research globally revealed just 353 childhood dementia clinical trials have been undertaken across 48 countries (Research Australia, 2022) (Childhood Dementia Initiative, 2022). The inadequacy of this clinical trial activity is especially striking in relation to other better-known disease groups. The number of childhood dementia clinical trials per patient was 18 times less than cystic fibrosis, 12 times less than childhood cancer and 4 times less than motor neurone disease, despite a comparable incidence, death rate and prevalence respectively (Childhood Dementia Initiative, 2022:16-17).

Research and subsequent clinical trial activity has transformed patient outcomes for comparable disorders in developed countries. For example, a combination of research and advances in disease management have seen the life expectancy of cystic fibrosis patients increased from the first few years of life in the mid-twentieth century, to at least 50 today (Scotet et al., 2020). Similarly, over the last 60 years, the survival rates for childhood cancer rose from 10% to over 80% (O'Leary et al., 2008).

In addition, the clinical trials that are occurring for childhood dementia are out of step with need. Some relatively common disorders have little or no clinical trial activity while more than half of the childhood dementia disorders currently have no clinical trial options available to patients anywhere in the world (Childhood Dementia Initiative, 2022:18-19).

This is particularly disappointing when it is clear that significant potential exists for research to be relevant across the life course of dementia, including in children.

Childhood Dementia Initiative supports the Action Plan in relation to advancing dementia research and innovation but notes that, in developing an Australian dementia research strategy, research funding and clinical trial activity needs to increase. Additionally, if such a strategy is developed, it needs to include children. Large-scale funding is urgently needed for research which concurrently studies multiple childhood dementia disorders and develops new therapeutics. This will enable more clinical trials and, ultimately, accelerate the development of treatments and cures.

Innovative clinical trial designs are also required to streamline testing of more potential treatments for a greater number of childhood dementia disorders.

In addition, collaboration and shared resources and infrastructure are needed to accelerate the development of new treatments and cures. This is especially important for advanced therapeutics, which have enormous potential but are costly. Advanced therapeutics, such as gene therapy, aim to target and correct the genetic change in a small group of patients. Economies of scale can be created by sharing platform technology and infrastructure across disorders, giving children access to treatments that otherwise would have been too expensive to develop.

Implementing the Action Plan

Implementation Blueprints

Given the critical importance of supporting children with dementia and their families, specific activities to address the needs of this subset of the dementia community must be included in the first Blueprint (2023-2026).

As a priority, an analysis of the appropriateness and accessibility of current services and programs available to adults should be undertaken to determine those that might be adapted and extended to meet the needs of children with dementia. This should be included as a specific activity in the first Blueprint.

This would help to recognise this subset of the dementia population and the impact that dementia has on children and their families. It would also build on the work already being undertaken by the Childhood Dementia Initiative (see the Appendix) and offer hope that the challenges currently faced will be addressed over time. Undertaking this assessment and acting on its outcomes would enable an appropriate, evidence-based approach to care and supports to be developed, alleviate some of the burdens experienced by families and generate greater understanding of childhood dementia by care and other professionals and the broader community.

In addition, the following key activities should be included in the first Blueprint:

- Workforce capability development - Extend current program undertaken by Childhood Dementia Initiative to deepen understanding and expand to include the broader system workforce, including the NDIS and education system.
- Dementia data - Include children in dementia data collection. This includes but is not limited to AIHW National Centre for Monitoring Dementia Data and Australian Dementia Network's Clinical Quality Registry.

The inclusion of these activities in the first Blueprint would enable the development of future Blueprint priorities that consider the needs of the entire lifespan of dementia and do not exclude a subset of the dementia population, as has been the case with historic policies globally.

Monitoring

Given the key role of the National Centre for Monitoring Dementia at the AIHW in collecting data and monitoring progress against the Action Plan, it is critical the current exclusion of children from their dataset is addressed in the first Blueprint as outlined above. If this does not occur, this will further perpetuate the discrimination of this vulnerable subset of the dementia population.

Performance measures for all implementation activities should also consider and include children.

Reporting

The outcomes reported in the annual Action Plan Report Card must include those impacting children with dementia, whether they are specific to children with dementia or general to all people with dementia regardless of lifestage.

Governance

The National Dementia Action Plan Governance Structure must include representation of all areas of the dementia life course in order to ensure inclusion of all people living with dementia. This includes children. This is particularly important in relation to the contribution to future Blueprint priorities, which will incorporate findings from emerging research during the first Blueprint period of 2023 - 2036.

Without this representation, the systemic discrimination against this vulnerable subset of the dementia population will be exacerbated.

APPENDIX: Work undertaken by Childhood Dementia Initiative

As indicated above, Childhood Dementia Initiative is undertaking substantial research and work on how the needs of children with dementia and their families might be better and more efficiently met.

The below is an overview of some of this work grouped by Objective for 2023 - 2026. Whilst Childhood Dementia Initiative has made some progress since inception in 2020, it is not adequately resourced, nor appropriate, to take responsibility for all outcomes needed for the childhood dementia community. While all effort is currently made to work as collaboratively as possible, we look forward to broadening our collaborations and partnerships in future.

Tackling stigma and discrimination

Lived Experience Consumer Network: Childhood Dementia Initiative established a consumer network of advocates across Australia, including bereaved families, to inform and advise based upon their lived experiences and insights. The Childhood Dementia Family Advocates Program[2] builds greater understanding and awareness of childhood dementia and addresses stigma and discrimination experienced by children, young people and their families and carers.

Driving community awareness: Awareness pushes undertaken by Childhood Dementia Initiative in traditional and social media have increased mainstream awareness and understanding of childhood dementia. This includes work in September 2022 that resulted in media stories across national television, print and radio, including, SBS, Channel 10, ABC, Channel 9, The Age, Sydney Morning Herald and 2GB. This had a combined potential reach of approximately 88.5 million people and featured families, health professionals and researchers.

Improving dementia diagnosis and post-diagnostic care and support

Nous Group research: Childhood Dementia Initiative has commissioned a significant report from the Nous Group that is examining the experience of families living with children with dementia as they navigate health and care systems (Nous Group, 2023). Timeliness of diagnosis is a significant theme emerging from this work, which will be published in early 2023, with parents reporting:

- Protracted diagnosis of their child/ren, often extending to years;
- A lack of coordinated diagnostic approach among healthcare professionals;
- Delays in genetic screening; and
- Perceptions by health professionals of parents being ‘neurotic’ or overly worried about their children’s health, progression and wellbeing.

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[2] https://www.childhooddementia.org/join-us/for-families/advocates-program

Improving treatment, coordination and support along the dementia journey

National rollout of Childhood Dementia Information Resources: Childhood Dementia Initiative has developed a suite of information resources[3] that have been presented across the country to health and care professionals to build awareness and understanding of childhood dementia. This has included provision of in-services to hospitals and service providers on demand, and in some instances to organisations best placed to expand services to children with dementia, for example Dementia Australia, Dementia Support Australia (HammondCare), Starlight Children's Foundation.

Nous Group research: The project that Childhood Dementia Initiative has commissioned from the Nous Group has clearly identified that children and families who are referred to paediatric palliative care are more likely to receive coordinated post-diagnostic care than those families who do not receive a referral. These research findings will be disseminated broadly throughout the paediatric health sector to affirm early and timely transitions for children with dementia to palliative care.

Childhood Dementia Community of Practice: Childhood Dementia Initiative is establishing a Community of Practice to embed ongoing understanding and education across the community of those who are affected by and care for children and young people with dementia. The Childhood Dementia Community of Practice will foster knowledge exchange between consumer networks and other stakeholder groups including support and treatment.

Supporting people caring for those living with dementia

Psychosocial study: Childhood Dementia Initiative have been joint authors on a systematic review of the psychosocial impact of childhood dementia on children and their parents (Nevin et al., 2022). This review, presented at the Australian Paediatric Palliative Care Conference in October 2022 and shortly to be published, found that parents experience extensive challenges navigating their child's care, accessing timely therapies and connecting with clinicians who are knowledgeable regarding their child's diagnosis. Parents reported difficulties balancing multiple roles including managing their child's complicated and progressive condition and caring for siblings, whilst simultaneously grieving losses associated with the child's deterioration. Limited treatment options, combined with lack of information about their child's prognosis, compromised parents' coping capacity and increased social isolation. Unmet information and support needs were associated with chronic levels of stress, poorer mental health outcomes, and lower satisfaction with healthcare services (Nevin et al., 2022).

Nous Group research: this research is clearly identifying significant impacts on long term carers of children with dementia including on their mental health as well as on their physical, social and emotional wellbeing. This burden is exacerbated for those families who have more than one child living with dementia. Further, bereaved parents who participated in this research reported the need

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[3] https://www.childhooddementia.org/professionals

for post bereavement care and support. This is essential given all children and young people diagnosed with dementia will die from their condition.

Building dementia capability in the workforce

Information resources for healthcare professionals: Funded by the Australian Federal Department of Health, Childhood Dementia Initiative has developed a suite of online information resources[4] to support health and care professionals. Resources cover issues such as understanding childhood dementia, supporting families, the clinical perspective (for clinicians) and palliative care and end of life. Unfortunately funding for this initiative ends in June 2023; continuation of funding is sought.

Information sessions: Childhood Dementia Initiative regularly runs information sessions on various elements of childhood dementia as well as supporting the roll-out of the above training materials to health and care professionals. In-services are provided to service delivery organisations on-demand.

Over 500 health professionals attended our information sessions on childhood dementia. 98% said the presentation increased their understanding of childhood dementia and 97% said they wanted to find out more.

Targeting relevant conferences: Childhood Dementia Initiative is actively engaged in the dissemination of in-house research of the lived experience through cross-sector conferences (paediatric health, palliative care, dementia care and support). A key goal is to extend conversations and professional capacity around dementia throughout the life course.

Childhood Dementia Project ECHO Hub: Project ECHO is a virtual knowledge sharing model that builds the capacity of professionals and extends education into regional, rural and remote communities. This model is already active in other paediatric settings including mental health, diabetes and palliative care. Childhood Dementia Initiative is exploring opportunities to establish a national Childhood Dementia Project ECHO Hub where a monthly education series will enable connections, conversations and learning between a growing community of practice in Australia.

Improving dementia data and maximising the impact of dementia research and innovation

Research symposium: Childhood Dementia Initiative held the inaugural Childhood Dementia Symposium in Sydney in March 2022. This symposium was an opportunity for researchers, clinicians and experts to learn about and discuss the needs, challenges, opportunities and priorities in the development of therapeutics for children with dementia. A report from the symposium[5] was published and the second annual symposium is scheduled for March 2023.

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[4] https://www.childhooddementia.org/professionals

[5] https://d1iap1m2kaw9nt.cloudfront.net/29b05d60fc81760efd247394494c3985.pdf

Childhood Dementia Knowledgebase: The Childhood Dementia Knowledgebase[6] is a database containing all the essential information about the more than 70 conditions that cause childhood dementia, gathered from the literature and with input from experts in the field. This is a free resource that includes information about incidence; prevalence; life expectancy; age of onset and diagnosis; genetic cause; and signs and symptoms. Information regarding disease mechanisms is currently under development.

The knowledgebase is a powerful resource that provides the capacity to identify disorders with a particular symptom or which are amenable to a certain treatment approach, encouraging the concurrent study of multiple childhood dementia disorders. It was designed as a public resource for all clinicians and researchers to interrogate their research and plan new and innovative research projects.

Collaborative research model: The collaborative research model adopted by the Childhood Dementia Initiative supports and encourages researchers and others operating in the area of childhood dementia to work together, to share information and knowledge and, as such, acts as a conduit to monitor emerging developments and data.

Enabling Innovative Practice: Childhood Dementia Initiative partners with key research bodies investigating innovative practice. Childhood Dementia Initiative facilitates consumer participation and co-design processes and enables dissemination of findings on a national basis.

Childhood Dementia Community of Practice: Childhood Dementia Initiative is building a Community of Practice to connect research to practice and foster knowledge translation between researchers, policy and consumers. This innovative approach will maximise collaboration and inform best practice between these key stakeholder groups.

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[6] https://www.childhooddementia.org/knowledgebase

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