

## Summary of response submitted to National Dementia Action Plan - January 2023

Childhood Dementia Initiative welcomes the opportunity to respond to the proposed National Dementia Action Plan (Action Plan) as outlined in the [Public Consultation Paper](#).

### General feedback

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 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.

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

## Response to Action Plan Objectives

Provided children are definitively addressed, Childhood Dementia Initiative is aligned in principle with the objectives and immediate priorities proposed in the Action Plan. However, following is a summary of the feedback provided in our response for each objective.

### **Objective 1: Tackling stigma and discrimination**

The following actions should be included within the National Dementia Action Plan:

- Enable equitable access to dementia services regardless of life stage.
- Assess and adapt / extend where appropriate existing dementia services to meet the needs of children with dementia and their families.
- Allocate funds to services for children to reduce discrimination and inequitable access.
- Continue to build the capacity of relevant professionals through education.

### **Objective 2: Minimising risk, delaying onset and progression**

Expanding and improving newborn screening programs and rapid diagnosis pathways is key to delivering equitable, quality care and progressing the development of urgently needed therapeutics for children with dementia.

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

Broad awareness of childhood dementia is required across health, disability, care and education settings to support early diagnosis and ongoing responsive care for children with dementia.

Additionally, there is need for evidence informed, nationally consistent dementia care pathways appropriate to all life stages. Critical to child-specific pathways is the immediate referral to paediatric palliative care.

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

To achieve this objective for children with dementia, the various systems with which they and their primary carers (parents) interact need to be included and associated challenges addressed in the Action Plan. Outlined in our submission are some of the challenges that must be addressed within the NDIS, respite services and palliative care.

### **Objective 5: Supporting people caring for those living with dementia**

This objective is of particular importance to families impacted by the complex, severe and terminal conditions that cause childhood dementia. An inequitable burden of care is placed on families resulting in significant economic, social and psychological implications for parent carers. Health and care systems need to be better designed to meet families' needs with urgent focus on improving support when transitioning between life stages and/or key systems.

**Objective 6: Building dementia capability in the workforce**

Capability needs to be built in the health and care workforce as well as the education sector in order to deliver high quality care for children with dementia. Funding for the development of education materials for health professionals due to cease in 2023 should be extended and expanded to reach broader workforces.

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

The Action Plan should specifically require that current and future systems for data collection on dementia include children. This is critical given the mechanism for reporting and inclusion in future Implementation Blueprints will be based on an Action Plan Report Card prepared by the AIHW.

Future dementia research strategies must include children and promote innovative and efficient research activity. Of particular importance is large-scale funding for the concurrent study of multiple childhood dementia disorders to enable more clinical trials and accelerate the development of treatments and cures.