

Position Description: Childhood Dementia Isla Guide

Position Details

- **Reports to:** National Services Manager
- **Location:** Perth WA (hybrid + travel)
- **Position Type:** Part Time (0.6 FTE)
- **Term:** Contract 18 months (with intention to extend/ongoing)
- **Classification:** SHCADS Level 5/6 (\$105,558 to \$120,437 FTE) + superannuation + NFP salary packaging

At Childhood Dementia Initiative (CDI) we are working to create sustainable global health solutions for childhood dementia. We drive world-first action for every child and young person living with dementia so that we may achieve the following outcomes:

1. Treatments and cures available for children with dementia;
2. Access to equitable and quality care for children with dementia and their families; and
3. Childhood dementia is a global health policy priority.

Our Values: Our work is guided by our values: Bold, Transparent, Flexible, Amplify & Unite

4. We are **bold** in all we do and seek to achieve.
5. We **amplify** the voices of our families and the case for change.
6. We are **transparent** and **flexible** in all aspects of our work.
7. We **unite** bringing together those who can make the changes needed

Role Purpose

The childhood dementia Isla Guide works with families and with the systems around them, building capacity across the professional and service networks surrounding each family through education, information-sharing and consultation with treating teams and sector professionals. This combined focus strengthens both family functioning and the responsiveness of the wider care system across the trajectory of childhood dementia, from diagnosis through the stages of illness and into bereavement.

This role is a world-first pilot, co-designed from the ground up with families affected by childhood dementia to close a gap the care system has long recognised but never filled. Working under the direction of the National

Services Manager, the Isla Guide is a specialist family navigation and coordination role that reduces the burden that fragmented systems place on children and families living with childhood dementia.

The Isla Guide supports a caseload of families and the professional and service networks around them, building capability through education, information-sharing and consultation with treating teams and sector partners. This combined focus strengthens both the family experience and the responsiveness of the broader care system, from diagnosis through the stages of illness and into bereavement.

The Isla Guide walks alongside families, supporting navigation, coordination, and family capacity-building in partnership with treating teams. This role does not provide clinical care, clinical assessment, or case management.

The Isla Guide's practice is underpinned by 5 core principles of service delivery:

- Interdisciplinary collaboration
- Trauma-informed practice
- Family-centred care
- Ecological, whole-of-system thinking
- Community capacity building

Key Operational Responsibilities

1. Family Service Navigation

- Combine specialist knowledge of childhood dementia with systems navigation skills – information, education, and emotional and wellbeing support – alongside cross-sector service coordination, building family confidence, systems literacy and self-determination.
- Apply relational, trauma-informed approaches to family-centred care as families navigate each stage of their child's condition, with a primary focus on continuity of care.
- Facilitate Participatory Holistic Assessments (PHA) to identify strengths, map resources, gaps and needs across family domains – physical, emotional, spiritual, social and cultural – and across professional and informal networks, using this understanding to guide support toward family priorities and goals.

2. Connecting People and Pathways

- Act as a point of connective resourcing for health and care professionals, linking them to specialist knowledge and education on childhood dementia to build shared practice and systemic capacity to care for families.

- Collaborate with families to establish story- and information-sharing protocols that relieve secondary trauma, bridge communication gaps between health, disability, education and community providers, and support informed-consent information sharing and advocacy at both individual and systems levels.

3. Anticipatory Care Planning

- Apply knowledge of childhood dementia conditions to engage families in anticipatory care planning, offering guidance on illness progression and the impacts of significant changes and transitions.
- Consult with health stakeholders and advocate on families' behalf to trigger timely equipment and funding reviews ahead of disease progression.

4. Brokerage

- Identify, map and maintain an active database of local, state and national supports – from material and financial assistance (for example, micro-grants for essential household items) to specialist psychosocial and allied health referrals.
- Provide direct support to families preparing and lodging complex applications, submissions and system-level referrals for grants, trials or statutory supports.

5. Bridging Gaps

- Actively participate in stakeholder collaboration across care sectors, including health, social care, NDIS, education and community support services.
- Apply adaptive communication and knowledge brokerage to support collaborative approaches to care, building capacity across formal and informal stakeholder networks.

6. Professional Development and Quality Improvement

- Participate in regular professional supervision to support sustainable practice and quality service delivery.
- Maintain professional learning and development relevant to childhood dementia, paediatric palliative care, communication, person-centred practice and trauma-informed care.
- Contribute to reporting, monitoring and evaluation processes, and to quality improvement activities including documentation and data collection, to demonstrate the impact and value of the Isla Guide pilot.

Required Capabilities

Technical

- Clinical and Health, Disability and Education Systems Literacy
- Systems Navigation and Service Mapping
- Digital and CRM Literacy: Proficiency with interoperable digital systems (for example, shared databases, CRM/case-management platforms) to reduce duplication in family information-sharing
- Structured Non-Clinical Assessment and Planning Tools

Professional

- **Collaboration:** Demonstrated ability to act as a trusted connector within a non-hierarchical triad, using strong communication to guide families through transitions.
- **Autonomous Practice:** Ability to function as a trusted anchor within a fragmented system, operating independently to provide rapid, responsive support that prevents minor issues escalating into crises.
- **Fieldwork:** Willingness to travel across the state to meet families in their own environments (home or school), building trust through a “do with” rather than “do to” style of support.
- **Service Promotion and Stakeholder Engagement:** Ability to build trust and awareness with families, professionals and sector partners, promoting the value and reach of CDI’s services to support referral pathways, uptake and effective adoption.

Behavioural

- Commitment to the philosophy of Childhood Dementia Initiative, advocating for childhood dementia to be recognised as a distinct cohort with one of the highest levels of unmet need in the health system.
- Deep empathy for children with childhood dementia and their families, grounded in trauma-informed and family-centred practice.
- Resilient and adaptable, able to sustain quality practice in an emotionally demanding and evolving pilot environment.
- Willingness to actively contribute to the ongoing development of the Isla Guide model, including codesign, review and reference group processes, as the pilot evolves.
- Collaborative mindset, working effectively across interdisciplinary and cross-sector networks.

Experience Required

- Degree or tertiary qualification in nursing, allied health, human services or an equivalent field.
- Experience mapping and navigating complex systems across health, disability, NDIS, education and community services.

- Knowledge of, or demonstrated ability to rapidly learn, the specific challenges faced by children and families living with childhood dementia.
- Demonstrated ability to build trust and act as a connector across interdisciplinary, cross-sector networks.
- A genuine commitment to Childhood Dementia Initiative's mission, including a willingness to contribute to the ongoing development of this role through codesign and review processes.
- Willingness to travel to meet families in their own homes or schools.
- The role will require travel and the use of your private vehicle, for which a kilometre allowance is payable. You must have a current unrestricted WA driver's licence and a suitable vehicle, insured for work purposes.
- Current Police & WWC Checks
- The right to reside and work in Australia