Executive Summary

Australian models of healthcare for people with intellectual disability

A scoping review

National Centre of Excellence in **Intellectual Disability Health**

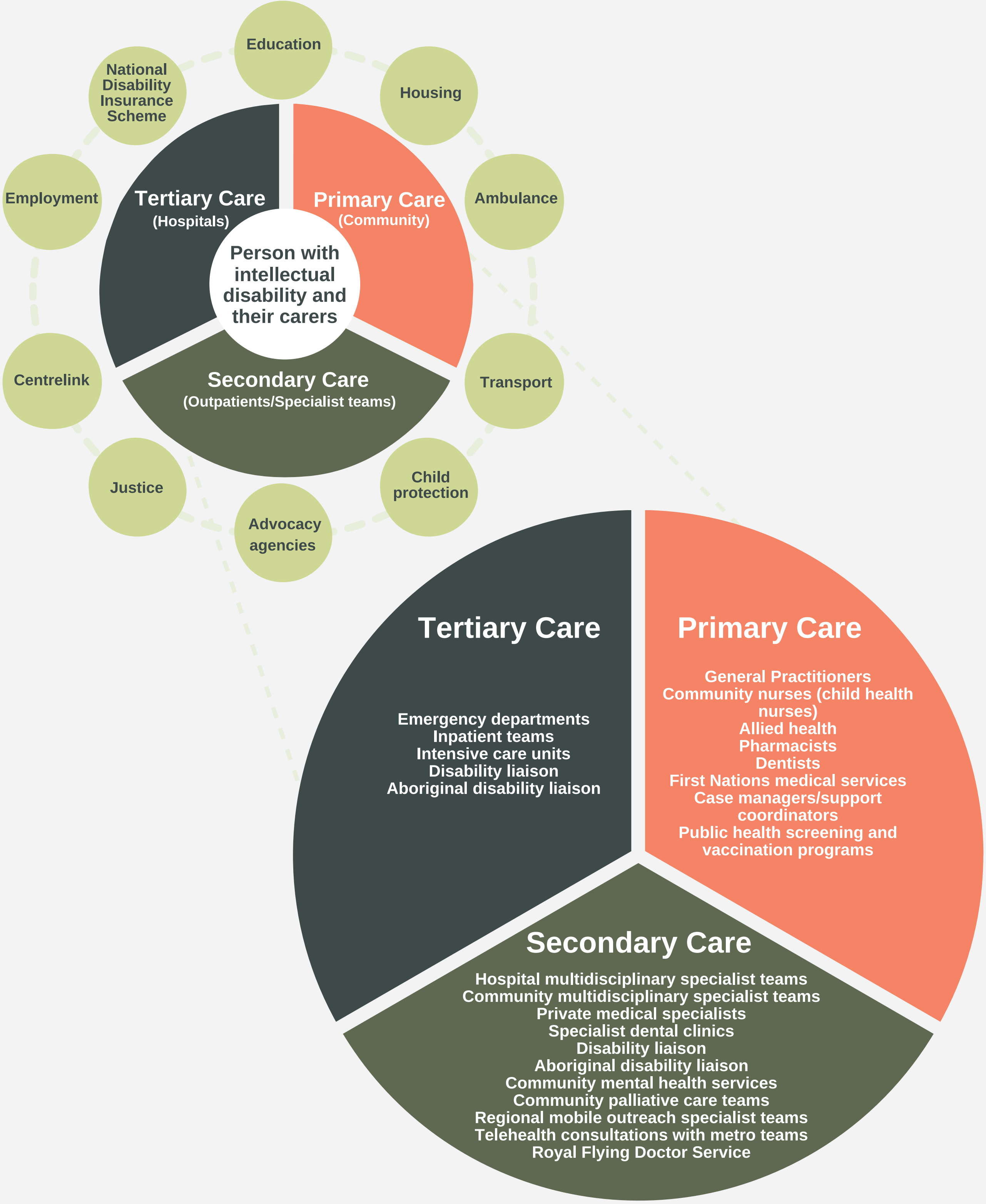
Executive Summary

Approximately 2% of the Australian population lives with intellectual disability. They experience inequities in accessing healthcare and poorer health outcomes compared to their peers without intellectual disability. To improve health services, we need to understand how current practices work.

The health system is a complex structure comprising service providers and organizations across primary, secondary and tertiary care sectors. Funding is shared between the commonwealth, state and territory governments and the private sector. It is important to look outside the health system and consider social factors which influence health, such as housing, employment, education and justice. Lack of integration and coordination within the health system and between health and non-health support organisations is a risk factor for inadequate provision of supports for health in intellectual disability. Figure 1 presents stakeholders across the health, community and social service sectors in Australia.

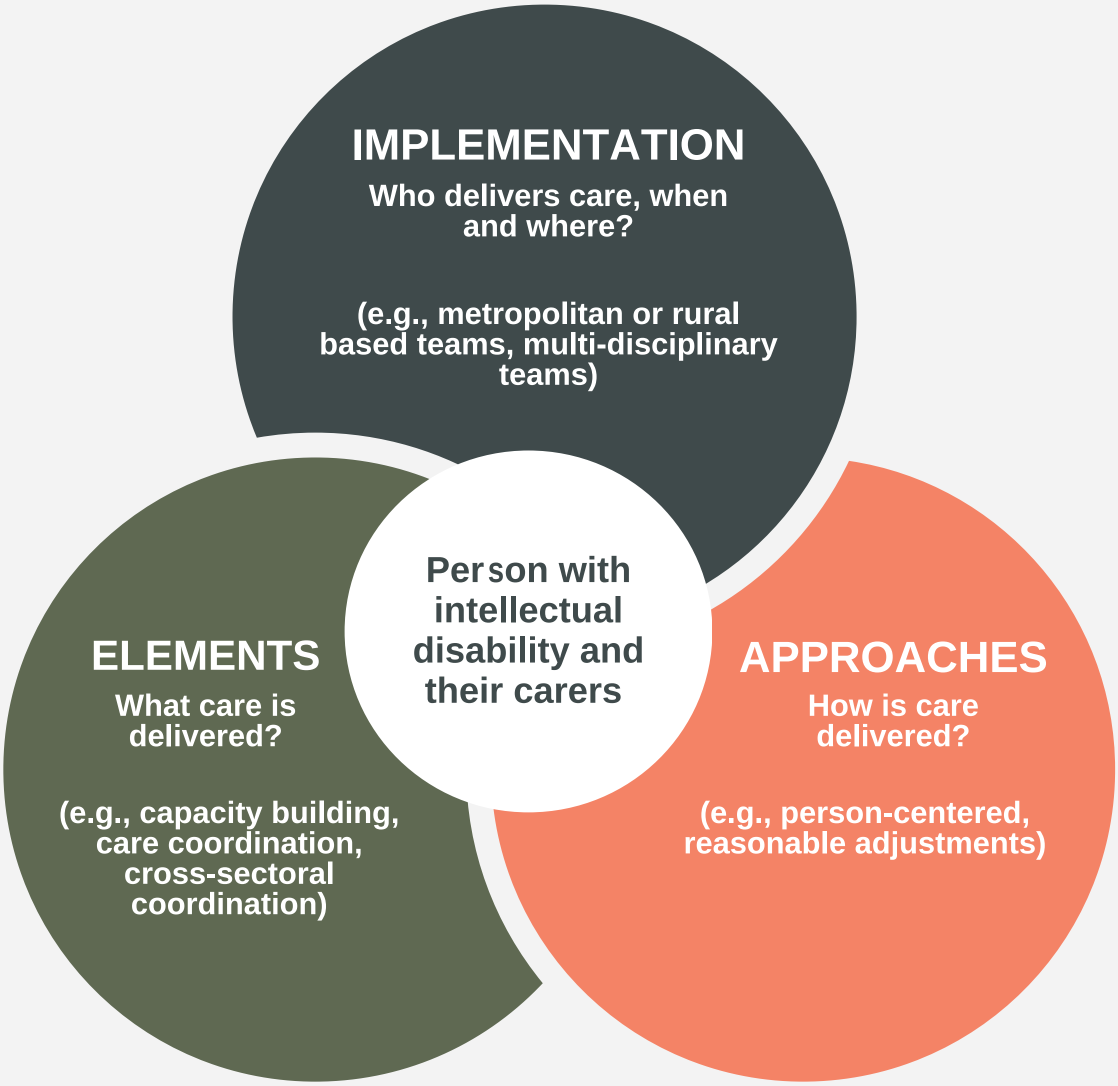
The National Centre of Excellence in Intellectual Disability Health (the Centre) conducted a scoping review of models of healthcare for people with intellectual disability in Australia. Peer-reviewed and grey literature were included. The full report describes detail of the scoping review and the evidence for effectiveness and cost-effectiveness of models of healthcare in Australia.

Figure 1: Interface between healthcare services and non-healthcare and social services in the community for people with intellectual disability in Australia. The range of stakeholders vary by the category of healthcare, geographic location and cultural groups.



First, a preliminary search of the literature was conducted to identify components of models of healthcare in intellectual disability settings. The components were collated and categorised to develop a working definition of a model of care (Figure 2). For this scoping review, a model of care outlined healthcare interactions that described (1) the implementation of care, (2) approaches to care and (3) elements of care.

Figure 2: Components of models of care in the working definition.



Second and searching to February 2025, the scoping review identified ten peer-reviewed studies and five grey literature reports for four services. Studies were distributed across primary, secondary and tertiary healthcare settings. There were three randomised controlled trials, one comparison study with a historical control group, five before and after studies and one post-test study. Data extracted from each study demonstrated positive outcomes. Reported improvements included increased use of preventive health actions, improved access to health evaluations and care for patients, less time in hospital settings, better continuity of care across healthcare settings, and increased knowledge and job satisfaction for treating clinicians. Additionally, care coordination models demonstrated significant cost savings.

The healthcare models were analysed to identify components that were associated with these positive outcomes. Common components across the models of care included person-centred care, reasonable adjustments, capacity building, health sector care-coordination, cross-sectoral care coordination and multi-disciplinary teamwork.

These findings enhance our understanding of current clinical practices and provide insights into ways that healthcare services can be improved.

The data informed eight advocacy recommendations to improve delivery of healthcare for people with intellectual disability. Lead and stakeholder organisations for each recommendation are suggested in the full report.

Table showing eight advocacy recommendations	
Primary care	**1.** Fair remuneration for GPs to administer comprehensive healthcare assessments and follow up.
	2. Investigate how nursing, allied health and Aboriginal and Torres Strait Islander health staff can help with primary health tasks.
Training and capacity building	**3.** Develop standardised intellectual disability health training.
	4. Implement standardised intellectual disability health training.
Measurement	**5.** Measure effectiveness and cost effectiveness of models of care including care coordination.
	6. Measure the effectiveness and cost effectiveness of models of care including cross sectoral coordination.
Immediate funding priorities	**7.** Prioritise funding of evidence-based care coordination.
	8. Prioritise funding of evidence-based cross-sectoral care coordination.

Because of the general scarcity of evidence, further research is essential to determine optimal models of care for different healthcare needs and settings, assess their effectiveness in clinical practice across healthcare settings and inform policy decisions and resource allocation. It is strongly recommended that people with lived experience participate in co-designing outcome measures and developing services, to ensure that future research and healthcare interventions are both relevant and meaningful to the target population. The evidence also informed three research recommendations to improve models of healthcare for people with intellectual disability.

Table showing three research recommendations	
Patient reported experience and outcome measures	**9.** Adapt existing patient reported experience measures (PREMs) and patient reported outcome measures (PROMs), and/or develop new ones where needed, for future evaluations across diverse settings. Specific PREMs and PROMs with culturally relevant clinical indicators are required for Aboriginal and Torres Strait Islander and Culturally and Linguistically Diverse communities.
Transition	**10.** Evaluate the experiences of people with intellectual disability and their families, clinicians, and service planners for transition services, and propose and test solutions.
Telehealth	**11.** Review the uptake and cost-effectiveness of Telehealth services in Australia, across healthcare settings, e.g. GP, allied health, Healthdirect, virtual ED.

The National Centre of Excellence in Intellectual Disability Health is committed to collating best available evidence for models of healthcare and advocating for their implementation across the life course and across the health, disability and other care and support systems. We call for renewed effort by our national, state and territory governments to improve the delivery of health services for children and adults with intellectual disability. This includes long-term funding for evidence-based models of healthcare, working with health providers to achieve better screening, treatment and shared care, enabling the collection of clinical evaluation data as standard practice, funding more research including clinical trials for comparative effectiveness, and building a world class training system for healthcare professionals.

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