Australian models of healthcare for people with intellectual disability

A scoping review

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

Australian models of healthcare for people with intellectual disability: A scoping review

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Cover image

Natalie and Sam Hevron

Conflicts of interest

None declared

Acknowledgment of Country

We acknowledge the Traditional Custodians of Country throughout Australia, and their continuing connection to land, sea and community. We pay our respects to them and their cultures, and to elders both past and present.

We pay our respects to all First Nations people with intellectual disability and acknowledge the higher prevalence of intellectual disability among First Nations peoples and the distinct challenges they face, along with the contributions they make to society.

The model of care report was developed on the lands of the Nyoongar Wadjuk Elders, who are the Traditional Custodians of the lands where the Kids Research Institute Australia in Perth is situated.

National Centre of Excellence in Intellectual Disability Health

The establishment of the National Centre of Excellence in Intellectual Disability Health was in response to the significant health disadvantage experienced by people with intellectual disability. The Centre supports the delivery of the Australian government's National Roadmap for Improving the Health of People with Intellectual Disability.

The Centre builds on the work of 3DN and the Centre's nine consortium organisations – First Peoples Disability Network, Council for Intellectual Disability, Down Syndrome Australia, The Kids Research Institute Australia, Queensland Centre of Excellence in Autism and Intellectual Disability Health, Queenslanders with Disability Network, Centre for Disability Studies and UNSW.

Our vision is that every person with intellectual disability in Australia gets high quality health care.

Our mission is to work together with people with intellectual disability to make their health as good as it can be.

Our values

- We support the leadership of people with intellectual disability in their own lives and in the Centre.
- We are leaders in accessible communication and other inclusive practices.
- We respect family members and other advocates.
- We include people from diverse backgrounds.
- We listen to each other and value all perspectives.
- We are honest and open.
- We are accountable to people with intellectual disability and each other for what we do.

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Contents

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 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. This report describes the scoping review and the evidence for effectiveness and cost-effectiveness of models of healthcare in Australia that was found.

Evaluation data were limited, with ten peer-reviewed studies and five grey literature reports for four services identified. 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 practical advocacy recommendations to improve delivery of healthcare for people with intellectual disability. Lead and stakeholder organisations for each recommendation are suggested in the 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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Introduction

Approximately 2% of the Australian population lives with intellectual disability.[1] This means that approximately 550,000 or 1 in 50 individuals in Australia live with intellectual disability. The prevalence of intellectual disability is different for different population groups. For example, prevalence is higher for males compared to females and for Aboriginal people compared to non-Aboriginal people,[1] and is higher in rural and remote areas compared to urban areas and in those living with greater socioeconomic disadvantage.[2]

The Diagnostic and Statistical Manual of Mental Disorders, 5th edition (DSM-5) and the International Classification of Diseases (ICD-11) are commonly used to define intellectual disability as beginning in childhood and characterised by significant deficits in intellectual functioning and adaptive behaviours for conceptual, social and practical skills.[3] Intellectual disability is further classified by the level of severity and supports required.[4, 5] Although cognitive testing is still included in assessments where a score of approximately two standard deviations or more below the population norm (equivalent to an IQ score of about 70 or below) indicates intellectual disability, it is now recommended that the severity of impairment is based on adaptive functioning rather than IQ scores, consistent with a shift from a medical model of disability to a social model. The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)[6] is based on the social model of disability which shifts the focus from what the person cannot do to how they can be enabled by supports and policies to be healthy and participate fully in society.[7]

Health status of people with intellectual disability

Despite various initiatives from the Australian government, significant gaps in healthcare delivery persist for people with intellectual disability. Some of these were summarised in the Health Status of People with Intellectual Disability Evidence report[8] and included:

- premature mortality with a median age of death of 54 years
- more than double the death rate from potentially preventable causes compared with the general population
- high rates of emergency department (ED) presentations and approximately 4.5 times higher rates of potentially preventable hospital admissions
- reduced access to primary care and unmet needs in preventive healthcare, and
- more than twice the rate of mental health disorders compared with the general population.

Multimorbidity and complexity of care

People with intellectual disability have a high prevalence of multimorbidity[9, 10] defined as the presence of two or more chronic conditions.[11] Service provision can be challenging for people with multimorbidity within a siloed healthcare system that generally caters for the management of single conditions.

Complex health profiles coupled with variable support needs confers challenges in accessing appropriate and timely care, across the life journey and from preventive to end-of-life care.[12] Rates of access to primary and preventive health services are lower leading to greater dependency on hospital services.[13, 14] A Canadian data linkage study found that people with intellectual disability had higher rates of hospitalisations for potentially preventable conditions compared to the general population. For example, hospitalisation rates were 54 and 15 times higher for epilepsy and schizophrenia in people with intellectual disability than the general population, respectively.[15] Further, people with intellectual disability may receive suboptimal care evidenced by repeat presentations for further acute care after a mental health inpatient stay.[8] Many adults with intellectual disability face additional barriers with end-of-life care including under-utilisation of palliative care services,[16, 17] pain and symptom management,[16] communication difficulties, and limited access to experienced healthcare providers.[17, 18]

Similarly, children with intellectual disability are susceptible to poorer healthcare experiences and outcomes. Depending on the severity of their disability, their risk of hospitalisation is between two and ten times greater than that of children without intellectual disability[19] and when hospitalised, they are more vulnerable to health care errors and safety risks related to miscommunication and medication errors.[20]

The transition from paediatric to adult services has been highlighted as a time of increased vulnerability for young people with intellectual disability. For example, those aged 19-24 years are more likely to experience a mental health disorder than those aged 13-18 years[21] yet at this touchpoint, they encounter fragmented care coordination and little continuity of care.[22-24]

Organisation of Australian health services

In Australia, the funding of the health system is shared between the commonwealth, state and territory governments and private sector service providers.[25] The Australian health system uses a hybrid model, whereby governments pay for basic coverage of health services, and individuals can purchase private health insurance and gain access to private health service providers, in addition to free medical coverage.[26] The public health system is upheld by Medicare, a universal health insurance scheme, funded by tax payers, which ensures free access to public hospitals and includes rebates for services provided by general practitioners (GPs) and other health professionals.[25]

The health system is a complex structure comprising a mix of service providers and organizations across primary, secondary and tertiary care sectors.

Primary care is typically the first point of contact with the health care system and is provided across a variety of settings through frequently accessed services such as GPs, community nurses, allied health professionals, pharmacists and dentists.[25]

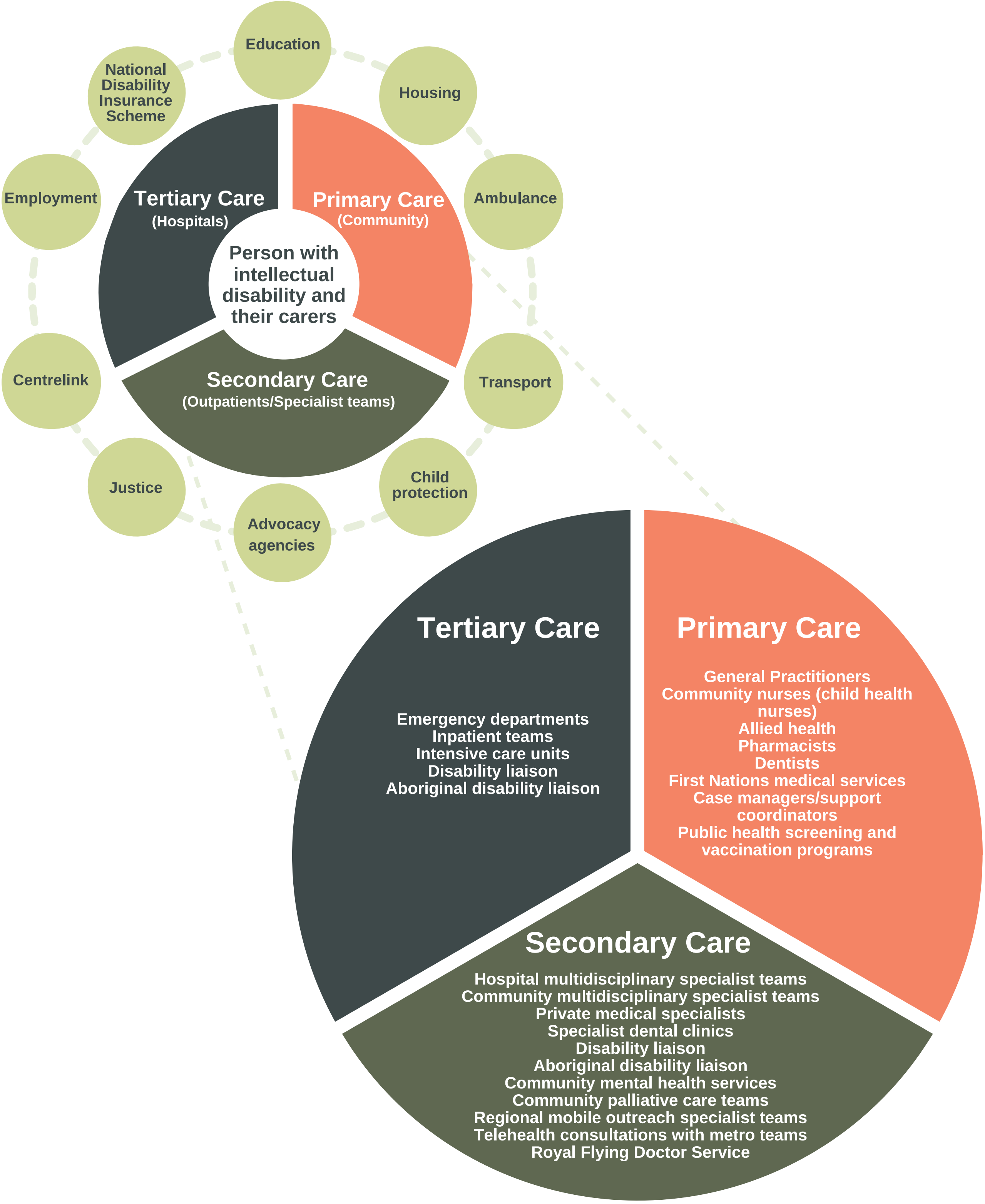
Secondary care provides services for specific or complex conditions or issues. GPs typically act as gatekeepers to secondary care by providing a patient with a referral for Medicare subsidized access to a range of services which can include cancer treatment, mental health services, alcohol and other drug services, palliative care and clinical assessment for surgery.[27] Secondary care also covers pathology, imaging and other diagnostic services.[25]

Tertiary healthcare largely comprises hospitals which provide urgent and elective services to admitted patients and outpatients. Public hospital services can be accessed at no cost to public patients whereas costs for private hospitals, and private patients within public hospitals, may be covered by a combination of Medicare rebates and private health insurance.[25]

People who hold private health insurance have choice about where elective surgery is undertaken, what specialist might provide care, and the added advantage of avoiding waiting lists in the public sector. However, this option is generally not accessible to people with lower incomes due to the cost of health insurance. Aboriginal and Torres Strait Islander people can access holistic and culturally appropriate services through health organizations controlled by the Aboriginal community, including primary care, maternity and allied health. These services are designed to respond to the specific needs of the community and offer more flexibility than the mainstream health system.[28]

It is important to look outside the health system and consider social factors which influence health, such as housing, employment, education and justice. Relationships between physical, mental, and social health are well documented and have significant implications on wellbeing and quality of life.[29] For example, communities with socioeconomic disadvantage suffer a higher burden of intellectual disability[30, 31] and have greater vulnerability to the social determinants of health, including poverty, unemployment, discrimination, violence, and barriers to healthcare access.[29, 32] Risk factors for adequate provision of supports for intellectual disability health include lack of integration within the health sector that is further complicated by lack of coordination between health and non-health sectors such as disability, housing, justice and employment. **Figure. 1.** presents stakeholders across the health, community and social service sectors 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 varies by the category of healthcare, geographic location and cultural groups.



New initiatives and capacity to respond

The National Roadmap for Improving the Health of People with Intellectual Disability (the Roadmap) was developed by the Commonwealth Government of Australia in 2021 and is part of the Primary Health Care 10 year plan.[33] The Roadmap sets out a vision and outlines actions across the health system to meet the needs of people with intellectual disability in an integrated way. The priority actions under the Roadmap are to:

- promote the uptake of annual health assessments for people with disability, using best practice assessment tools
- improve tertiary education curricula for health professionals so they are better equipped with knowledge and skills needed to provide high quality care to people with intellectual disability, and
- scope a model for a new National Centre of Excellence in Intellectual Disability Health that provides national leadership on the health care of people with intellectual disability and can be a central hub of expertise and resources for all health and disability service providers across the country.

The National Centre of Excellence in Intellectual Disability Health was subsequently established in 2023 with the goal of improving health care for people with intellectual disability. The core functions of the Centre are to provide leadership in intellectual disability health, drive innovation and collaboration, build capability of health services and develop best practice models of care.[34] In order to understand how healthcare can be improved, it is important to identify how services are currently being delivered.[35] Hence, this scoping review aims to equip the sector with information to develop and implement better models of care for people with intellectual disability by documenting what has worked and where more evidence is needed.

Objectives

Healthcare is regarded as effective when it achieves the desired outcomes for patients, clinicians and the community.[25] This review examined Australian models of care and available evaluations of effectiveness and cost-effectiveness for people with intellectual disability.

The objectives of the review were to:

1. Identify Australian models of care, their components, and available evaluations of effectiveness and cost effectiveness across peer-reviewed and grey literature.
2. Summarise available evidence of effectiveness and cost-effectiveness.
3. Identify recommendations and gaps in the application and evaluation of models of care for people with intellectual disability.

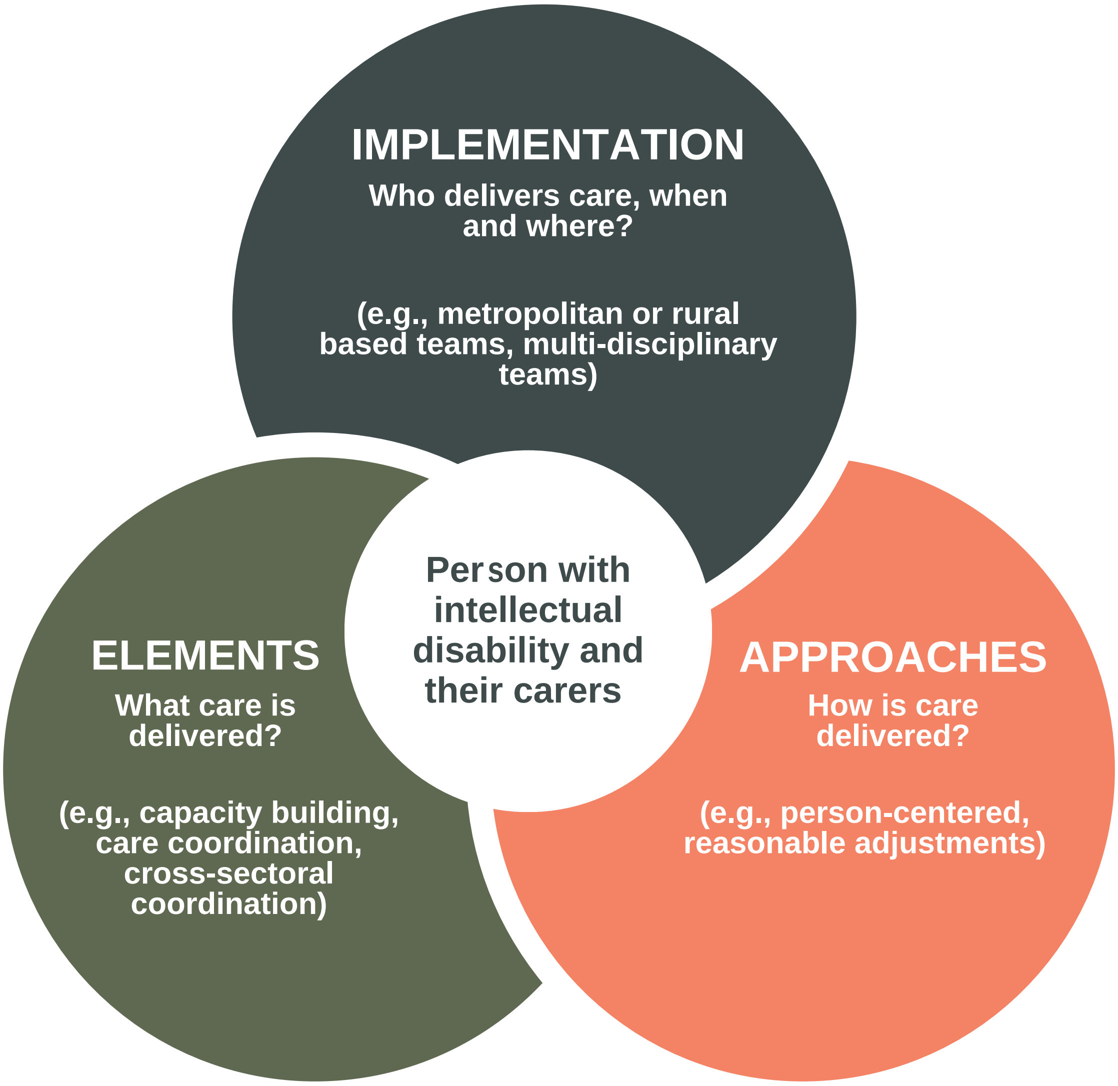
Methodology

Working definition of a model of care

The term model of care is used variably in the literature, however it generally refers to how health services are delivered and outlines best practice care and services for a person or population group.[35] Models of care differ widely and are influenced by local culture, professional and societal resources, community attitudes, stigma, and the level of support available for investment and development of services.[36] Applying an appropriate model of care is important to ensure a quality service for the target population.

A preliminary search of health services for people with intellectual disability in the Australian setting was conducted to generate an initial conceptualisation of a model of care for intellectual disability. The components of healthcare within these services were collated and categorised to develop a working definition of a model of care, presented in **Figure 2**. The terms are defined in a glossary in **Appendix A**. For this scoping review, a model of care outlines interactions that describe (1) the implementation of care, (2) approaches to care and (3) elements of care.

Figure 2: Diagram showing the components of models of care in the working definition.



Reviews of effectiveness and cost effectiveness

A search of peer-reviewed and grey literature was undertaken to identify models of care in Australia, and their components, with evaluations of effectiveness and cost-effectiveness. The protocol is registered with Open Science Framework Registries (https://doi.org/10.17605/OSF.IO/XJ5NC).

Peer reviewed literature

The protocol for this review was developed amongst the authors adhering to the PRISMA reporting guidelines for scoping reviews (PRISMA-ScR). The peer reviewed literature search was first conducted in August 2024, and updated in February 2025, across four databases (MEDLINE, CINAHL, PsycINFO, Cochrane). The review considered all types of studies, regardless of design, provided that evaluative data were presented. The search strategy is presented in **Appendix B**.

During study planning, colleagues identified reports on healthcare services for people with complex medical needs that included genetic and chromosomal disorders in their study cohorts. Rare genetic neurological disorders collectively affect 2 to 5% of the population. There are various complex syndromes suspected to have a genetic basis, however, the underlying genetic aetiology may not have been identified. Additionally, many rare genetic conditions (e.g., Rett syndrome, Fragile X syndrome) and chromosomal disorders (e.g., Trisomy 21) have overlapping intellectual disability[37-39] hence, we included terms for intellectual disability and complex medical needs in our search terms. Results that described complex medical needs were further screened using full text to ensure they met the inclusion criteria.

Extracted data on outcomes were classified as relevant to the person with intellectual disability, carers, clinicians/service providers, or health services.

Grey literature

An online search was conducted via Google search engine using the following keywords: “models of health care in Australia,” “health services in Australia,” “intellectual disability health Australia,” “Aboriginal health intellectual disability” and “complex medical care Australia” to map health services described for people with intellectual disability. The Commonwealth Department of Health and each Australian state and territory website were searched for relevant descriptions of healthcare. Services indicating provision of care for people with intellectual disability and/or conditions associated with intellectual disability, such as rare genetic and chromosomal conditions, were included. Data relating to the health sector, service location, components of a model of care, effectiveness and cost-effectiveness outcomes were extracted.

Further, websites of relevant government departments (e.g., Australian Commission on Safety and Quality in Health Care), health professional bodies registered with the Australian Health Practitioner Regulation Agency (AHPRA) and advocacy bodies (e.g., Down Syndrome Australia) were screened for documents that could have evaluated models of care.

Consultations with People with Lived Experience

We met with a person with intellectual disability and their supporter, as well as a parent of an adolescent with intellectual disability and complex care needs. We sought their thoughts about the results and recommendations of this review and asked them what they wanted others to learn from the report. Their feedback is presented in the results and discussion sections.

Results

Peer reviewed literature

The search identified 120 potentially relevant publications (108 from the database search and 12 from other sources including back searching). Twenty-three duplicates were removed, and 87 publications were excluded following screening by title, abstract and full text. Any differing views between the investigators were discussed until consensus was reached. See the PRISMA flowchart (**Figure 3 in Appendix C**) showing the selection of papers based upon the pre-defined criteria outlined in **Appendix B**. The included papers comprised cluster randomised controlled trials, pre-and-post intervention evaluations, descriptive studies and retrospective case review studies.

A quality assessment summary of the 10 publications is presented in **Appendix D - Table 1**. Apart from one study, included papers did not specify the definition of intellectual disability that was used in their cohort. In other aspects, one study had a small sample size, otherwise major flaws were not identified. The research questions were clear, sample sizes were generally adequate, drop out was low, and outcomes were relevant to the evaluations.

The components of each model of care and evaluations of effectiveness and cost-effectiveness are presented in **Appendix E - Table 2**. Each study was associated with at least some positive outcomes such as an increase in preventive health actions for patients, use of less invasive procedures, reduced hospital use, better continuity of care and cross-sectoral collaborations, increased skills and job satisfaction for clinicians, and cost savings.

Three randomized controlled trials in Queensland examined effectiveness of the Comprehensive Health Assessment Program (CHAP) and Ask Health Diary (Ask) during GP consultations, two of which recruited adults and one enrolled adolescents.[40-42] The use of the CHAP increased preventive health actions for people with intellectual disability such as vaccinations, hearing and vision testing, identification of previously undiagnosed conditions, and management review.

Three studies examined care coordination programs amongst children with complex needs in tertiary care settings in New South Wales and Western Australia. Care coordination was associated with positive patient outcomes, for example a decrease in ED presentations and admissions, saving families and health services time and money.[43, 44 45]

Use of a Disability Liaison Officer to coordinate care during an ED visit in a tertiary healthcare setting in Victoria was associated with reduced length of stay in ED for people with intellectual disability.[46] In Queensland, another study evaluated the effectiveness of a Dual Disability Coordinator role in supporting clinicians who treated people with intellectual disability and mental health needs in a tertiary healthcare setting. The work of the Dual Disability Coordinator increased the clinicians' knowledge and self-efficacy.[47]

A specialised procedural model of care for selecting and implementing appropriate sedation procedures in a Victorian metropolitan community secondary healthcare setting was evaluated. This model of care resulted in the majority of people with intellectual disability receiving the correct sedation techniques and less use of invasive procedures.[48]

In New South Wales, a multidisciplinary intellectual disability clinic based in a socially disadvantaged area used a retrospective case review to evaluate their clinical care assessments and development of care plans for children and adolescents with intellectual disability. Interventions included medication review, referral for assessment for comorbid neurodevelopmental diagnoses, individual advocacy and referrals to more comprehensive healthcare services. Although the service was designed for one off assessment, nearly half accessed the service on multiple occasions. In the qualitative assessment, positive improvements in presenting complaints and overall function were observed in approximately three quarters of patients.[49]

Grey literature

Fifty-five services were described for people with intellectual disability across Australia. These were categorised into paediatric and adult services, and further divided into support for physical, mental, and dental health. Each service was reviewed, and their contributing components were extracted and summarised in **Appendix G - Tables 4a - 4i**.

Of these, five had evaluative data, and two described the same model of care. These included two mental health services in New South Wales,[50, 51] one capacity building program for local primary healthcare services spanning New South Wales, Queensland, Victoria and Tasmania,[52] and a model of care for children with rare and undiagnosed diseases in Western Australia.[45, 53, 54] The evaluations are summarised in **Appendix F - Table 3**. Most evaluations were qualitative, and one report estimated the value of cost savings. Each evaluation identified positive findings for patients (e.g., better satisfaction with healthcare, increased wellbeing), clinicians (e.g., capacity building, continuity of care) and service use (e.g., increased access to services but less use of emergency services).

Commonly featured components of care included using a person-centred framework, reasonable adjustments, capacity building, cross-sectoral care coordination and delivering services from multidisciplinary teams. Trauma-informed care, advocacy, co-design and integrating research and evaluation were described in more recent reports.

The Aboriginal Disability Liaison Officer (ADLO) Program was specific to Aboriginal and Torres Strait populations and administered through Aboriginal Community Controlled Health Organisations in all states and territories except the Australian Capital Territory, with a specific focus on providing healthcare within a culturally safe environment. ADLO described utilizing a care coordination model including linkages with other services, advocacy, capacity building and empowerment for clients. Although the program was recently formally evaluated, it did not specify whether it included people with intellectual disability therefore it did not meet the inclusion criteria of this review.

Documents from websites of government agencies, health professional bodies and key advocacy agencies were identified, including (1) position statements (e.g. Royal Australian College of General Practitioners - Care and support for people with disability; Royal Australian & New Zealand College of Psychiatrists - Intellectual disabilities: Addressing the mental health needs of people with intellectual disability), (2) clinical care standards (e.g. Professional Association of Nurses in Developmental Disability Australia - Standards for Nursing Practice) and (3) practice guides (e.g. Australian Psychological Society - Ethical guidelines for psychological practice with clients with an intellectual disability). These documents did not contribute evidence of effectiveness or cost-effectiveness of models of healthcare for people with intellectual disability. However, advocacy agencies had developed capacity building and accessible information resources for people with intellectual disability and their carers (e.g. It’s Doctor Time), and health professionals (e.g. Reasonable adjustments checklists for health professionals and administrative staff). For general information, these found resources are listed in **Appendix H - Table 5**.

Feedback from people with lived experience

Findings of the report and an Easy Read summary were provided to a person with intellectual disability and his supporter, and a parent of a young person with intellectual disability. They discussed how:

1. Person-centred care and care coordination were highly valued because they reduced the need to repeat their story each time they encountered a new medical professional.
2. People with intellectual disability wanted to be directly involved in their healthcare discussions rather than encounter assumptions about their reduced capacity which resulted in interactions occurring only with their proxies.
3. Service evaluations had an important role in building trust with the intellectual disability community. Those with lived experience wanted to know why evidence was not available to indicate which services were meaningful and effective.
4. People with intellectual disability experienced feelings of anxiety before appointments. The logistics involved in attending appointments highlighted discrepancies between healthcare needs and socioeconomic capacity, because cost was a factor. Logistical supports such as transport, resources to assist them in preparing for health appointments and procedures, and use of telehealth, were thought to be helpful and advantageous.

Discussion and recommendations

In this scoping review, the focus was on effectiveness and cost-effectiveness of Australian models of care for people with intellectual disability. Ten peer-reviewed studies and five online reports with evaluation data were found indicating the general scarcity of research and health outcomes data.

The models of care, healthcare settings and their components were diverse, but all were associated with positive outcomes. However, there were limitations in the scope of evaluations, for example, there was limited replication across settings and geographical locations, few randomised controlled trials and no evaluation data for models of care for transition from paediatric to adult care and telehealth.

Recommendations are derived from the evidence presented in this review and other literature and focus on (1) increasing use of effective components of care and (2) addressing broader gaps in the body of evidence.

Evidence for the component of models of care

Implementation of care

Different healthcare settings and multidisciplinary teams

Like the general population, people with intellectual disability need to access health services from a variety of providers across primary, secondary and tertiary settings. Settings evaluated in the peer-reviewed literature included GP practice, ED and specialist clinics. Services identified in grey literature delivered healthcare from metropolitan, specialist, multidisciplinary teams. If mainstream services are not adequately skilled to provide an effective model of healthcare to this population, specialist teams continued to be essential in the management of people with complex needs. To ensure generalisability of effects, efforts to upskill mainstream service providers are important to achieve population-based effects.

There are concerns that rapidly changing demographics, such as Australia's ageing population, will overwhelm the existing healthcare system imposing serious financial strain and redesign has been recommended. Discussions are being held in various high income countries about shifting towards value-based healthcare in contrast to the fee-for-service model.[55] Value-based healthcare is a concept where healthcare providers are renumerated based on health outcomes rather than output or the quantity of services provided, emphasising patient outcomes, cost-effectiveness and holistic care.[56] Australia has moved somewhat towards these outcome-based payment models although current efforts remain very small scaled.[56]

Additionally, the Australian Government has recognised the significance of multidisciplinary care in delivering comprehensive and high-quality primary care.[57] The Government's vision for coordinated multidisciplinary primary care teams working to their full scope of practice was further described in the Strengthening Medicare Taskforce[58] and the Scope of Practice Review reports.[59] Financial incentives such as The Workplace Incentive Program (WIP) Practice Stream are in place to help general practices with the cost of engaging nurses, allied health practitioners and Aboriginal and Torres Strait Islander health workers and practitioners.[60] However, evaluation of the WIP Practice Stream found that it fell short of its intended aim of increasing multidisciplinary care. Suggested reasons for its limited impact and effectiveness included reduced awareness of the program, inadequate remuneration due to lower MBS rates for nurses and allied health services, administrative burden, and broader workforce shortages.[61] Fair remuneration and re-design of reporting and administrative procedures is required to improve outcomes of such programs.

These considerations informed Recommendations 1 and 2.

Approaches to care

Person-centred care

In this scoping review, a person-centred approach was used in models of care evaluated for complex care[45] and mental health[50, 51] and is consistent with international clinical guidelines.[62] A person-centred approach creates better engagement with patients by guiding health professionals to address concerns that are meaningful to the individual. For example, co-creation of a shared care plan, between health professionals and families, was implemented successfully in Ireland for children with complex needs who frequently required primary and acute care.[63, 64] Culturally appropriate information and services play a vital role in creating a safe and trauma-informed environment to engage Aboriginal and Torres Strait Islander communities[65] and formal evaluations are needed for Aboriginal and Torres Strait Islander intellectual disability health.

Through our consultation, consumers highlighted it was important to be asked whether they preferred to be spoken with directly by their doctor, or through their carer, however health professionals often default to communication through a support person based on assumptions about the patient's capacity. When people with intellectual disability are excluded from discussions about their health due to perceived fragility and limited capacity to understand or give informed consent, this leads to the person being shielded from their diagnosis, prognosis, and treatment options, leaving healthcare decisions to be made by a proxy.[18, 66] There is less evidence of effectiveness of interventions supporting children and adolescents with intellectual disability in healthcare decision making.[67] In a specialist clinic, person-centred care enabled the use of less invasive sedation procedures associated with lower clinical risk[48] and engaging patients with intellectual disability and cancer in discussions empowered them to participate in their treatment which then improved their psychological well-being.[18]

These considerations informed Recommendations 3, 4, 9 and 10.

Reasonable adjustments

Use of reasonable adjustments supports a person with intellectual disability to participate optimally in healthcare activities and can vary according to context and individual needs. Wallace (2024) audited services for adults with Down syndrome attending a mainstream outpatient clinic after making small adjustments to their usual clinical practice.[68] For example, longer and more frequent appointments were made, extra seats for support people were provided, descriptive letters were sent out to patients outlining information about the clinic, and a comprehensive treatment plan was delivered and reviewed.

While targeted structured assessments such as the CHAP in general practice require a longer consultation and more clinic resources, they conferred positive outcomes. Similar assessments tools have been utilised in the UK and Canada[62, 69] where their use has shown an increase in diagnosing previously undiagnosed conditions[70, 71] and reduction in avoidable deaths.[70] In Australia, comprehensive assessments are limited by GP appointment time and funding constraints.[72-75] In 2007, a specific Medicare Benefits Schedule (MBS) item (Medicare Health Assessment for People with an Intellectual Disability) was established to incentivise GPs to provide these assessments, however, the item was combined with other time-tiered appointments in 2010. The same time-tiered assessment items are used across multiple patient cohorts including those with Type 2 diabetes, elderly patients above 75 years, aged care residents, refugees, and people with intellectual disability. This makes specific uptake impossible to gauge using Medicare Benefits Schedule data alone, although use for people with intellectual disability could be determined with more complex data linkages.[76] Reinstatement of a specific MBS line item for comprehensive assessments for people with intellectual disability could enable better uptake monitoring.

Consumers who reviewed this report proposed that better preparation for healthcare procedures would be an important reasonable adjustment to them (e.g. receiving clear information regarding upcoming appointment and wait times involved) setting expectations and reducing health anxiety.

These considerations informed Recommendations 1, 3, 4 and 9.

Elements of Care

Capacity building

Capacity-building for health professionals featured in all evaluated models of care. For example, CHAP resources were provided to GPs,[40-42] the Dual Disability Coordinator enabled better knowledge, self-efficacy and job satisfaction amongst mental health clinicians working with dual diagnosis,[47] while the Primary Care Enhancement Program (PCEP) improved use of intellectual disability health resources and care coordination across local networks.[52] However, GP participation with the PCEP was low warranting further investigations into barriers and strategies to increase GP engagement.

GPs in Australia and New Zealand have reported receiving inadequate training despite their role as primary care providers for patients with intellectual disability.[73, 77] In the UK, GPs expressed challenges working with patients with communication difficulties[78] highlighting the need for better training for doctors. Patients and their families have described healthcare providers' insufficient understanding and negative attitudes towards disability caused difficulties in hospital settings, leaving patients more dependent on a familiar carer during a hospital stay.[79, 80] While carers should continue to play part in bridging the communication gap where appropriate, the primary responsibility should not be placed on them.[81]

Training requirements for intellectual disability health in medical and nursing curricula remain limited and vary greatly across Australia.[82, 83] An audit of eight medical schools found limited change to content of intellectual disability teaching across a 20-year period.[84] This is a missed opportunity as adequate training could promote better mainstream capacity, reduce diagnostic overshadowing, and challenge subconscious bias. Integrating training on intellectual disability health for health professionals working with this population needs to be prioritized, consistent with recommendations from the Disability Royal Commission.[85]

Standardized training would likely provide benefits beyond the intellectual disability population and could be applied to other vulnerable groups such as people from CALD backgrounds, people with low literacy, and those with acquired or other neurological conditions.

These considerations informed Recommendations 3 and 4.

Care coordination

Care coordination examples used in Australia included outpatient or community services programs that coordinated care, ED-based Disability Liaison Officers, and Aboriginal Disability Liaison Officers offering culturally sensitive community-controlled services.

Two publications examining the role of care coordination in children with complex needs demonstrated effectiveness in decreasing ED presentations and admissions and substantial cost savings. Both the Ambulatory Care Program in Western Australia and Kids GPS program in New South Wales reported cost savings in excess of A$1 million per annum, with the New South Wales Program further estimating a saving of A$4.9 million over two years.[43, 44] Continuity of care improved with more linkages to local services and families benefited from less travel to hospitals and fewer missed days at work and school.

A disability liaison officer service was associated with faster discharge from ED in a tertiary hospital in Victoria.[46] Similar disability liaison nurse roles in the UK, Norway and Scotland, were central in facilitating medical examinations in the least restrictive manner with patients reporting that they felt respected and their needs were accommodated.[86-88] A system navigation and coordination role was equally valued in a Canadian primary care setting.[89]

Our consultation highlighted that consumers value communication across disciplines as it reduces the need to repeat their story to each health professional they encountered.

These considerations informed Recommendations 5 and 7.

Cross-sectoral care coordination

People from a socioeconomically disadvantaged backgrounds experienced adverse impacts of social determinants of health and rates of mild to moderate intellectual disability are increased amongst children with higher levels of social disadvantage and family poverty.[31] Brenner and colleagues highlighted that cross-sectoral coordination was generally inadequate in meeting the needs of children with complex needs living across the European Union.[64] In a model of care established in Ireland specifically for children with complex needs, Brenner et al. emphasized that the very nature of complex care needs means that care cannot be administered by a sole provider but requires collaboration across sectors with multi-agency agreements in place.[63] Patients and stakeholders particularly valued individualised care, specialist knowledge and advocacy within this model of care.[63]

In our consultations, consumers described how the lack of logistics management between services was concerning, for example cost and transport involved in attending frequent appointments was left to patients to manage on their own. In contrast with care-coordination, attendances could be streamlined. Collaboration across sectors could further enable a smoother transition between time in hospital and life in the community and reduce dependence on tertiary healthcare, yet few studies addressed this.

Recent evaluations of mental health,[50, 51] rare diseases[42, 51,52] and a specialist service in a socially disadvantaged area[49] found cross-sectoral coordination to be effective across different complex needs cohorts. Positive outcomes included cost savings, with preliminary evaluations of the Rare Care Centre in Western Australia estimating a saving of $4+ for every $1 spent, improved health and satisfaction for patients, better access to disability supports in the community, as well as capacity building for health professionals and the wider community. Similar benefits were demonstrated amongst inpatient adults with intellectual disability[90] and end-of-life care for people with intellectual disability in the UK.[17]

These considerations informed Recommendations 6 and 8.

Broader gaps in available evidence

Evaluation data

Data evaluating models of care and their economic impacts were generally limited given the wide scope of population groups and healthcare settings, making it difficult to draw conclusions on effectiveness and cost-effectiveness. Embedding evaluations for purpose-built models of care in clinical practice is warranted as a next step to investigate quality of care and allocate resources appropriately across the healthcare system. People with intellectual disability should have access to service outcome data to inform their treatment choices. Transparency of healthcare practice evaluations is needed to build trust between health professionals and patients.

Evaluation frameworks were variable and often did not include patient perspectives. Broader outcome measures that examine quality of life need to be included in research and clinical practice. Quality of life outcomes can then be incorporated into cost modelling.

Clinical indicators alone are not enough to provide a full picture of health care experiences. A greater understanding of patients' experiences is needed and has to be incorporated into practice to pave the way for better care.[91] Patient-Reported Experience

Measures (PREMs) and Patient-Reported Outcome Measures (PROMs) are used in health services to collect information on patients' perspectives of the care they received and The Australian Commission on Safety and Quality in Healthcare has published a list of validated Generic and Conditions-specific PROMs.[92] No PROM was identified for people with intellectual disability.[93] Globally, new measurements are being designed and existing validated tools are being evaluated[93, 94] and adapted[95] to reduce cognitive demand and increase access for people with intellectual disability. In Australia, the Listen to Me project[96] is underway to co-create innovative PREMs with researchers with lived experience. Its products are anticipated to be adopted in partner hospitals nationally with direct impact on healthcare utilisation and experiences.

Evaluation data on models of care for Aboriginal and Torres Strait Islander and Culturally and Linguistically Diverse communities was sparse and is vitally necessary.

These considerations informed Recommendations 3, 4, 9 and 10.

Transition from paediatric to adult healthcare and other touchpoints of change

Our grey literature search identified four Australian services for intellectual disability that incorporated the transition process into their model of care, but limited data was reported on their processes and outcomes.

The transition period is complex, adolescents and their families are particularly vulnerable, and healthcare needs must be carefully managed as fragmentation in care throughout this process can lead to worsening of health outcomes for young people and their families.[97, 98] In international jurisdictions, families have reported dissatisfaction, poor preparation, lost medical information and lack of coordination.[99, 100] Parents described abandonment by health professionals, a sense of loss, and having to "let go" of trusted health staff and services in the paediatric setting. Parents raised concerns around their fears of inadequate resources in adult healthcare and that their adult child would be reviewed in "parts" rather than as a whole person.[98, 101]

Brown and colleagues described the needs to support youth to find balance between self-management and supported decision-making and preparing for the transition process earlier with a lead agency coordinating care.[22] Care coordinators were highly valued in the UK and regarded as key supports for a smooth transition[64] while The Fearless, Tearless Transition model of care in Victoria proposed shared care between paediatricians and GPs to tackle these issues.[102]

These considerations informed Recommendation 10.

Telehealth

Whilst the majority of specialist services for people with intellectual disability were located in metropolitan cities, many people living in rural and remote regions of Australia have reduced access to disability and health services.[103] A scoping review suggested that telehealth was feasible and effective for people with intellectual disability across high income countries, by reducing transportation time and stress for both patients and service providers, and allowing better healthcare access in rural and remote geographical regions.[104] Whilst it is reasonable to assume telehealth is commonly used by healthcare providers since the Covid-19 pandemic, few evaluations were found in Australian literature. A study in New South Wales indicated that whilst telehealth had potential to provide timely, quality, and low-cost services for people living in regional Australia, policies and guidelines on its use were limited.[105] Additionally, telehealth could help address the nation-wide shortage of health professionals and would have wider benefits for people living in metropolitan areas who have difficulty in physically attending appointments.

These considerations informed Recommendation 11.

Policy recommendations

The following table presents each of the eight policy and practice recommendations together with the potential lead organisation and stakeholders who could be involved in actioning each recommendation.

Recommendations	**Lead**	**Stakeholders**	**Related Components**
Primary care			
1. Ensure fair remuneration for GPs to implement validated primary healthcare assessments such as the CHAP and necessary follow up	• Australian Government Department of Health, Disability and Ageing	• Primary Health Networks • The Royal Australian College of General Practitioners (RACGP) • Australian College of Rural and Remote Medicine (ACRRM)	• Primary care • Reasonable adjustments

Recommendations	Lead	Stakeholders	Related Components
Primary care			
2. Investigate models where nursing, allied health staff, and Aboriginal and Torres Strait Islander health workers can implement primary health care tasks to ensure comprehensive care	• Australian Government Department of Health, Disability and Ageing	• Primary Health Networks • Australian Primary Health Care Nurses Association • Allied Health Professions Australia • The Professional Association of Nurses in Developmental Disability Australia (PANDDA) • National Association of Aboriginal and Torres Strait Islander Health Workers and Practitioners (NAATSIHWP) • RACGP • ACRRM	• Multidisciplinary • Primary care

Recommendations	Lead	Stakeholders	Related Components
Training and capacity building			
3. Develop standardised intellectual disability health training for: (3a) undergraduate and postgraduate health programs at universities and support workers, (3b) continuing professional development (CPD) curriculum for current workforce	• The Centre	3a: Undergraduate, postgraduate and support worker training: • Universities and colleges • Technical and Further Education (TAFE) and similar institutions • NDIS Quality and Safeguards Commission	• Capacity building • Person-centred care • Reasonable adjustments
		3b: CPD • Professional colleges • National Aboriginal Community Controlled Health Organisation (NACCHO) • Australian Indigenous Doctors' Association (AIDA) • NAATSIHWP • Indigenous Allied Health Australia	

Recommendations	Lead	Stakeholders	Related Components
Training and capacity building			
4. Implementation of intellectual disability health training for:		• The Centre Knowledge Exchange Hub	• Capacity building • Person-centred care • Reasonable adjustments
4a. Undergraduate and postgraduate health programs	• Department of Health, Disability and Ageing	4a: Undergraduate and postgraduate health programs • Accrediting authorities • Universities and colleges	
4b. Continuing Professional Development for current health workforce	• Australian Government Department of Health, Disability and Ageing for specialists in private practice • State and territory Department of Health for public hospitals and community health	4b: Undergraduate and postgraduate health programs • Professional colleges • Self-regulated Australian health professional bodies (e.g. Speech Pathology Australia)	

Recommendations	Lead	Stakeholders	Related Components
Training and capacity building			
4c. Support workers	• Department of Health, Disability and Ageing	4c: Support workers • Australian Government Department of Employment and Workplace Relations • Relevant state and territory Departments of Education or Workforce Development • TAFE and similar institutions • NDIS Quality and Safeguards Commission	

Recommendations	Lead	Stakeholders	Related Components
Measurement			
5. Measure effectiveness and cost effectiveness of models of care including care coordination	• Medical Research Future Fund	• State and territory health ministries • Department of Health, Disability and Ageing • Independent Hospital & Aged Care Pricing Authority	• Care coordination
6. Measure effectiveness and cost effectiveness of models of care including cross-sectoral coordination	• National Disability Insurance Agency	• Australian Government Department of Health, Disability and Ageing • Department of Social Services • Department of the Prime Minister and Cabinet • Department of Finance • Department of Treasury	• Cross-sectoral care coordination

Recommendations	Lead	Stakeholders	Related Components
Immediate funding priorities			
7. Prioritise funding of evidence-based care coordination	• State Health & Disability Ministries	• Public hospital sector • Independent Hospital and Aged Care Funding Authority	• Care coordination
8. Prioritise funding of evidence-based cross-sectoral care coordination	• National Disability Insurance Agency	• Australian Government Department of Health, Disability and Ageing • Department of Social Services • Department of the Prime Minister and Cabinet • Department of Finance • Department of Treasury	• Cross-sectoral care coordination

Research recommendations

The following Table presents each of the research recommendations together with the potential lead organisation and stakeholders who could be involved in actioning each of recommendations.

Recommendations	Lead	Stakeholders	Related Components
9. Adapt existing PREMs and PROMs, and/or develop new ones where needed, for future evaluations. Specific PREMs and PROMs with culturally relevant clinical indicators are required for Aboriginal and Torres Strait Islander and CALD communities	• The Centre	• Consortium members, partners and collaborators e.g. Macquarie University • Australian Commission on Quality and Safety in Health Care	• Person-centred care • Co-design • Reasonable adjustments

Recommendations	Lead	Stakeholders	Related Components
10. Evaluate the experiences of people with intellectual disability and their families, clinicians, and service planners for transition services, and propose and test solutions	• The Centre	• Consortium members, partners and collaborators	• Person-centred care • Transition
11. Review uptake and cost-effectiveness of Telehealth services in Australia across healthcare settings e.g. GP, allied health, Healthdirect, virtual ED	• The Centre • National Health and Medical Research Council • Medical Research Future Fund	• Consortium members, partners and collaborators • State and Territory Health Ministries • Local Hospital Networks	• Telehealth

Limitations of this review

International literature and papers in languages other than English were excluded as the focus of the review was Australian models of care, although we drew on international literature when discussing the value of the various components of care.

Despite extensive literature describing barriers and challenges for people with intellectual disability receiving high quality healthcare, there were few evaluations of effectiveness and cost-effectiveness for how healthcare is delivered, and representation of healthcare settings and populations was therefore limited.

In available studies, it was challenging to compare different models of care since there is no agreed definition of a model of care for intellectual disability. Building on our working definition, further development of a definition of a model of care for people with intellectual disability is needed, including consultation with people with intellectual disability and consideration of how healthcare is financed.

The grey literature search yielded numerous descriptions of services for intellectual disability across Australia but few evaluations. We acknowledge that service descriptions found on websites may not represent the full picture of what care is delivered. Ideally, we would have consulted with health providers to clarify details that may not be visible on their websites however this was out of scope for this review.

Finally, it is acknowledged that models of care for people with intellectual disability may exist in private practices and not-for-profit settings. However, due to the vast number of these services across Australia (e.g., there were 39,449 registered GPs in Australia in 2023),[106] they could not be systematically searched and evaluated within the constraints of this review.

Conclusion

A range of healthcare initiatives and models of care have been evaluated in Australia with the broad goal of improving the quality of healthcare and health outcomes for people with intellectual disability. Despite pockets of critical thinking and evaluation, the healthcare sector in general falls short in responding to the varied and urgent needs of this population.

Our review showed that positive health outcomes and cost savings were achieved when appropriate models of care were applied. Approaches like person-centred care, reasonable adjustments, care coordination and capacity building, were foundational strategies for achieving best practice service delivery and better health outcomes. Most models of care recognized the need to provide targeted supports for people with intellectual disability. There were limited evaluations of building linkages between health and non-health sectors. Addressing social determinants of health would reduce patient and family burden with potential for larger cost-savings than building linkages within the health system alone. All components of health and social care can then interact and influence successful application of one another.

While driving change is a long-term process, healthcare initiatives in Australia typically receive short-term funding that hinders sustainability. Limited research in this area may have contributed to the lack of progress, however, some evaluations have been embedded from the design phase in more recent models of care. Without long term commitment to funding evidence-based models of care, change cannot happen and Australians with intellectual disability will continue to experience poorer health outcomes.

The National Centre of Excellence in Intellectual Disability Health is committed to collating best available evidence for models of care and advocating for their implementation across the health, disability and other care and support systems, and across the life course. We call for renewed efforts by our national, state and territory governments to improve health outcomes for children and adults with intellectual disability by taking a proactive role in improving models of care for this population. This includes providing reliable long-term funding for evidence-based models of healthcare, working with health providers towards better screening, treatment and care coordination, evaluations of care as standard healthcare practice, more research funding including for clinical trials for comparative effectiveness, and building a world class training system for healthcare professionals.

Appendix A

Glossary of terms

Accessible information	Information that is able to be read or understood by a person or group for which it is intended for.[107]
Capacity building	Skill building for people with intellectual disability and their carers to advocate for their needs; or skill building for health workers so they can provide better services.
Carer	A carer is typically a family member, or a friend, who provides care in an unpaid, informal capacity. A supporter typically refers to a paid person providing care. The terms “carer” and “supporter” are used interchangeably in this report.
Care coordination	Communication and coordination between health care workers involved in a patient’s care to achieve better outcomes.
Co-design	Process of including people with intellectual disability, and other stakeholders, in the planning, design, production and delivery of a policy, procedure or resource.[108]
Cross-sectoral care coordination	Communication and coordination between health and non-health sectors (e.g. NDIS, education, housing, medical staff) to achieve best patient outcomes.
Inter-disciplinary	A team of professionals from different disciplines who meet the patient simultaneously, integrating their disciplinary approaches in a single consultation.[109]
Multi-disciplinary	A team of professionals from different disciplines who approach the patient from their own perspective and then meet to review the patient’s needs.[109]
Person-centred care	Care that respects and responds to the needs, values and preferences of a patient.[110]
Reasonable Adjustments	Small refinements to usual clinical processes intended to reduce barriers, and improve access and participation, of people with disabilities in healthcare.[111]

Appendix B

Search strategy

Search strategy for:

(a) peer reviewed literature

Inclusion criteria:

Participants

The focus of this review was adults and children with intellectual disability and health care providers in the field of intellectual disability in Australia.

Concept

Studies addressing models of care were examined and given that limited research appears to have been published on models of care specifically, we looked at publications examining components of care. For the purpose of this review, components of models of care were defined as: elements - what care is delivered; approaches - how is care delivered; and implementation – who is delivering the care, when and where.

Examples of components we looked for included:

- accessible information
- reasonable adjustments
- person-centred care
- primary care
- specialist care
- tertiary care
- telehealth.

Context

Any models of healthcare, or components of models of healthcare, were described.

Any context where a model of healthcare, or a component of the model of healthcare, is evaluated was included.

Literature that described models of healthcare in Australia was included.

All literature from 2006 to August 2024 was included. The search was updated in February 2025.

Exclusion criteria:

For peer reviewed sources:

- studies conducted outside of Australia
- studies where the model of care examined did not include people with intellectual disability or people with conditions associated with intellectual disability
- studies focused on acquired brain injury or comorbid cognitive impairment in adults
- studies where the main model examined lacked a health component, and
- studies evaluating specific interventions rather than a model of care (e.g. effectiveness of an exercise program).

Search terms

- **POPULATION**
  “intellectual* disab*” OR “intellectual impair*” OR “intellectual* disorder*” OR “intellectual* handicap*” OR “intellectual* retard*” OR “intellectual* delay*” OR “learn* disab*” OR “learn* impair*” OR “learn* disorder*” OR “learn* difficult*” OR “learn* handicap*” OR “learn* retard*” OR “learn* delay*” OR “mental* impair*” OR “mental disab*” OR “mental handicap*” OR “mental retard*” OR “mental delay*” OR “cognitive disab*” OR “cognitive impair*” OR “cognitive disorder*” OR “cognitive difficult*” OR “cognitive

handicap*” OR “cognitive retard*” OR “cognitive delay*” OR “develop* disab*” OR “develop* impair*” OR “develop* disorder*” OR “develop* handicap*” OR “develop* retard*” OR “develop* delay*” OR “brain injur*” OR “complex medi*”

- **MODEL OF CARE**
  Model* OR system OR framework* OR program* OR strategy OR strategies OR scheme* OR pathway* OR process* OR “road map” OR hub-and-spoke OR integrat* OR care model* OR “care delivery framework”

- **HEALTHCARE**
  Health OR healthcare OR health care OR admitted OR service* OR care OR hospital OR inpatient OR “health promotion” OR “health prevention” OR “early intervention” OR “person-centred care” OR “partners in care” OR “tertiary care” OR tiered OR “accessible information” OR “capacity building” OR “reasonable adjustment” OR “family centered care” OR “primary care” OR “specialist care” OR multidisciplinary OR interdisciplinary OR telehealth OR outreach OR “Aboriginal health services” OR “care coordination” OR “service development to healthcare” OR “service provision to healthcare” OR “challenging behaviours” OR recovery OR “key worker” or emergency

- **OUTCOMES**
  Effect OR efficacy OR evaluat* OR cost OR test OR impact OR measure

- **AUSTRALIA**

Extraction:

Two screeners completed all title and abstract screening to remove duplicates and to check articles for relevancy. Both screeners completed full text reviews. If the screeners did not agree on a publication, they would attempt to resolve this through discussion by referring to inclusion/exclusion criteria. If the decision remained unresolved, the screeners consulted a third screener, who would come to a resolution.

(b) Grey literature:

Similar inclusion criteria as peer reviewed literature described above was applied to the grey literature search.

Exclusion criteria:

- models of care described were not relevant to intellectual disability
- models of care described for specific community services such as allied health or pharmacy. We note the significant contributions of primary healthcare services such as GPs, community nursing and allied health teams for people with intellectual disability, however it would not be possible to capture them adequately in this review due to the vast number, and our time and resource constraints, so they were excluded.

Extraction:

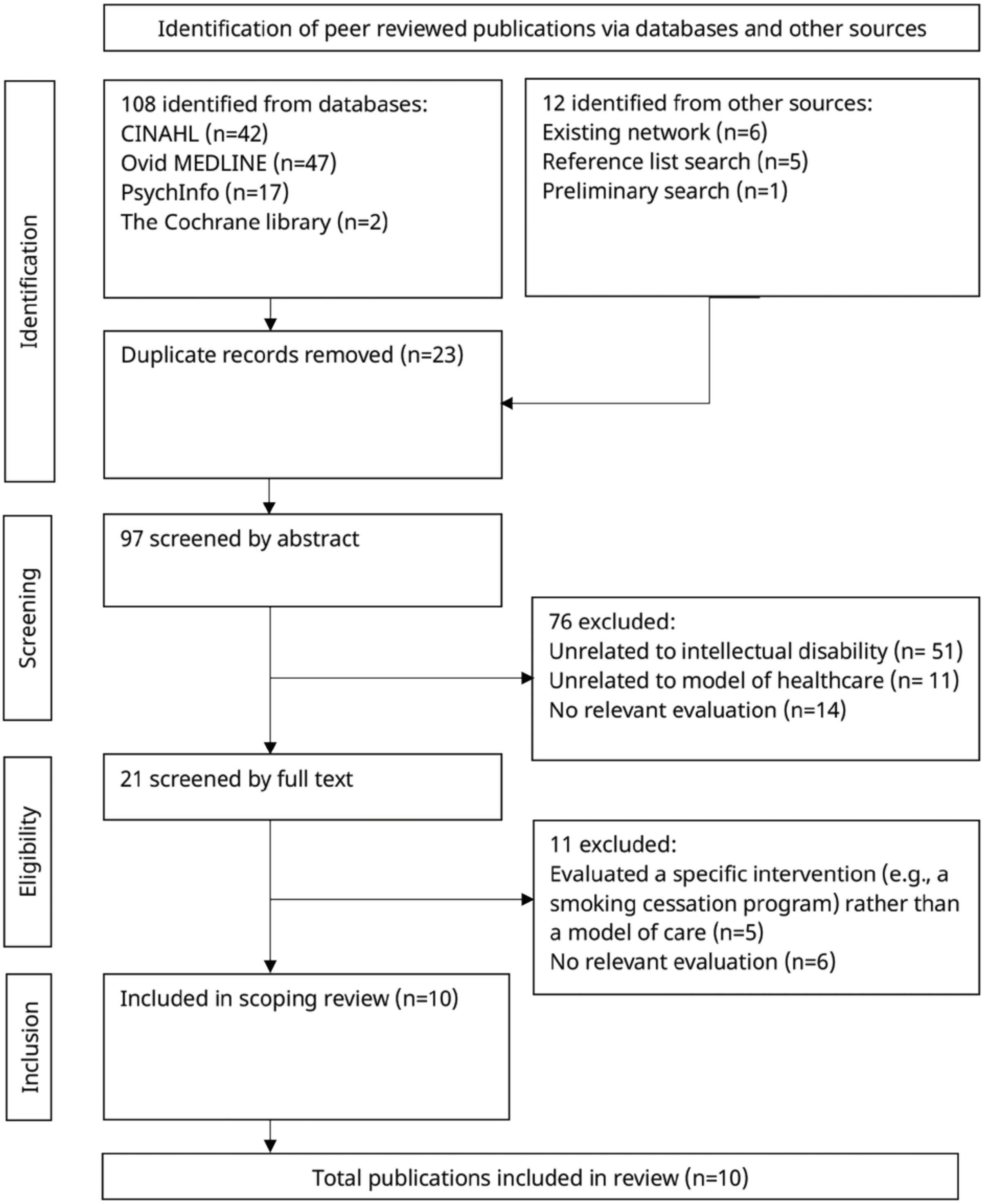
The first search strategy was utilising Google search engine for Australian health services for people with intellectual disability by one reviewer. The first ten pages of each search's hits on Google (representing the first 100 results) were reviewed and relevant Australian services were added to a spreadsheet. If there was uncertainty about the relevancy of the health service, a second reviewer was consulted.

The second search strategy was to screen all Australian state and territories' department of health websites and key disability organisations for services for people with intellectual disability. Any relevant services were added to the spreadsheet. If there was uncertainty about the relevancy of the health service, a second reviewer was consulted.

Appendix C

PRISMA flow chart

Figure 3: PRISMA flow chart



Appendix D

Quality assessment summary

Table 1: Mixed Methods Appraisal Tool (MMAT) 112

Category of study design	**Methodological quality criteria**	**Responses**									
		Lennox et al., 2007	Lennox et al., 2010	Lennox et al., 2016	Breen et al., 2018	Peter et al., 2011	Hendren & Kendall, 2015	Baynam et al., 2025	O'Shannessy et al., 2025	Golder et al., 2024	Bull et al., 2025
Quantitative randomized controlled trials	S1. Are there clear research questions?	✓	✓	✓	✓	✓	✓	✗	✓	✓	✓
	S2. Do the collected data allow to address the research question?	✓	✓	✓	✓	✓	? Uncertain		✓	✓	✓
	2.1. Is randomization appropriately performed?	✓	✓	✓							
	2.2. Are the groups comparable at baseline?	✓	✓	✓							
	2.3. Are there complete outcome data?	✓	✓	✓							
	2.4. Are outcome assessors blinded to the intervention provided?	✗	? Uncertain	✗							
	2.5. Did the participants adhere to the assigned intervention?	✓	✓	✓							
Quantitative descriptive	4.1. Is the sampling strategy relevant for the research question?				✓	✓	✓	? Uncertain			
	4.2. Is the sample representative of the target population?				✓	✓	✓	✓	✓	✓	✓
	4.3. Are the measurements appropriate?				✓	✓	✓	? Uncertain			? Uncertain
	4.4. Is the risk of nonresponse bias low?				✓	✓	✓	✓	✓	✓	✓
	4.5. Is the statistical analysis appropriate to answer the research question?				✓	✓	✓	? Uncertain	✓	✓	✓

Appendix E

Summary of peer reviewed publications

Table 2. Summary of components and effectiveness and cost-effectiveness outcomes from peer reviewed publications (statistical abbreviations in footnote)

Author / Year of publication / Title/ State	Study design/ description	Population	Component(s) of model of care	Outcome and effectiveness	Cost effectiveness
Lennox et al, 2007 Effects of a comprehensive health assessment programme for Australian adults with intellectual disability: a cluster randomized trial[40] Queensland	Cluster randomized controlled trial Intervention: CHAP Control: Usual care Follow up one year post intervention	N=453 Adults in 24-hour supported accommodation Intervention group (n=234) Control group (n=219)	**Elements** • Capacity building for person with intellectual disability and/ or carer • Capacity building for health professionals **Approach** • Reasonable adjustments **Implementation** • GP clinics • Metropolitan	**Patient** Compared with the control group, CHAP use increased health promotion, disease prevention and diagnostic activities, e.g. • Detection of vison impairment, risk ratio (RR) 6.6 (95% CI 1.1, 40.0) • Hearing tests RR 30.0 (95% CI 4.0, 230.0) • Tetanus/ diphtheria immunization updates RR 9.1 (95% CI 4.2, 19.0) • Papanicolau smear RR 7.9 (95%CI 1.8, 35.0) • New diagnoses RR 1.6 (95% CI 0.9, 2.8) **Service provider (clinician)** Not evaluated **Service use** Not evaluated	Not evaluated

Author / Year of publication / Title/ State	Study design/ description	Population	Component(s) of model of care	Outcome and effectiveness	Cost effectiveness
Lennox et al, 2010 Cluster Randomized-Controlled Trial of Interventions to Improve Health for Adults with intellectual disability who live in private dwellings[41] Queensland	Cluster randomized controlled trial, 2x2 factorial design to compare two interventions Comparison of interventions: 1.CHAP 2.Ask 3.CHAP and Ask 4.Usual care Follow up 12 months post interventions Healthcare activities in the preceding year included in the analyses	N=242 Adults living in supported accommodation Four groups: - Usual care (n=68) - Ask only (n= 51) - CHAP only (n=53) - CHAP + Ask (n=70)	**Elements** • Accessible information • Capacity building for person with intellectual disability and/ or carer • Capacity building for health professionals **Approach** • Reasonable adjustments • Person-centred care **Implementation** • GP clinics • Metropolitan	**Patient** Comparing CHAP and no CHAP groups, CHAP use increased health promotion, disease prevention and identification of new diseases e.g. • Pneumococcus vaccination Odds Ratio (OR) 7.4 (95% CI 1.5, 37.1) • Hearing tests OR 4.5 (95% CI 1.9, 10.7) • Hepatitis A vaccinations OR 5.4 (95% CI 1.8, 16.3) • Vision testing OR 3.4 (95% CI 1.4, 8.3) Comparing ASK and no ASK groups, there were no strong between-group differences: • Epilepsy review OR 2.3 (95% CI 0.7, 7.4) • Vision test OR 2.2 (95% CI 0.9, 5.6) • Constipation investigation OR 2.1 (95% CI 0.5, 9.5) **Service provider (clinician)** Not evaluated **Service use** Not evaluated	Not evaluated

Author / Year of publication / Title/ State	Study design/ description	Population	Component(s) of model of care	Outcome and effectiveness	Cost effectiveness
Lennox et al, 2016 A health advocacy intervention for adolescents with intellectual disability: a cluster randomized controlled trial[42] Queensland	Parallel group cluster randomized controlled trial Intervention: 1.Ask 2.Ask Project Curriculum 3.CHAP Control: Usual care Data extracted one year pre-intervention and compared with one year follow up data with a comparable time period for the control period	N=435 Adolescents aged 10-18 years recruited from Special Education Schools Intervention group (n=240) Control group (n=195)	**Elements** • Accessible information • Capacity building for person with intellectual disability and/ or carer • Capacity building for health professionals • Capacity building for community **Approach** • Reasonable adjustments • Person-centred care **Implementation** • GP clinics • Special Education teachers • Metropolitan • Regional • Schools	**Patient** Compared with the control group, adolescents who received the health intervention package experienced higher odds of health-promotion activities, e.g. • Vision check OR 3.3 (95% CI 1.8, 6.1) • Hearing check OR 2.7 (95% CI 1.0, 7.3) • Blood pressure check OR 2.4 (95% CI 1.6, 3.7) • Weight recorded OR 4.8 (95% CI 3.1, 7.6) There were no between-group differences in health service utilization e.g. GP visits, hospital visits and admissions, or identification of new diseases **Service provider (clinician)** Not evaluated **Service use** Not evaluated	Not evaluated

Author / Year of publication / Title/ State	Study design/ description	Population	Component(s) of model of care	Outcome and effectiveness	Cost effectiveness
Breen at al, 2018 Significant reductions in tertiary hospital encounters and less travel for families after implementation of Paediatric Care Coordination in Australia[44] New South Wales	Before and after evaluation Intervention: The Kids Guided Personalised Service (Kids GPS) Care Coordination Program – classified into three tiers depending on complexity of needs Six-month pre-and post-enrolment follow up for admission and ED presentation data Two years follow up from implementation of program The Rural Kids GPS Program was rolled out following Kids GPS, but no formal evaluations of this program were found	N=534 Children aged 0-19 years, with medical complexity – using criteria of frequent hospital use, medical fragility or complex psychosocial circumstances Included: • genetic or chromosomal disorders (19%) • cerebral palsy (3.4%) developmental delay (2.8%) [unable to distinguish children with intellectual disability in the sample and outcomes]	**Elements** • Care coordination • 24-hour telephone support • Referrals and linkages to other services • Capacity building for person with intellectual disability and/ or carer • Capacity building for health professionals • Capacity building for community • Telehealth **Approach** • Person-centred care **Implementation** • Specialist team • Metropolitan • Children's Hospitals (x2)	**Patient** Compared to previous 6-month period and after enrolment: • 52,416 km of travel and $98,317 of travel costs for families saved • 370 school absences avoided • Families linked with paediatricians in local hospitals or the community • Shared health information and personalised care plans developed for 83.5% • Of 84 children without a regular GP, 58 (69%) were linked with one • Fifty-five (10%) of families were linked to a 24-hour Hotline to enable remote access for support **Service provider (clinician)** • Shared health information and care plans **Service use** Compared to previous 6-month period and after enrolment: • Day admissions decreased 42% • ED presentations decreased 40% • Overnight admissions decreased 9% • 290 hospitalisations prevented • 204 day admissions prevented • 312 ED presentations prevented	Cost savings from reductions in ED presentation and admission estimated to be: • $1.2million in first 6 months • $4.9million over 2 years

Author / Year of publication / Title/ State	Study design/ description	Population	Component(s) of model of care	Outcome and effectiveness	Cost effectiveness
Peter et al, 2011 Care coordination for children with complex care needs significantly reduces hospital utilization[43] Western Australia	Before and after evaluation Intervention: Nurse led Ambulatory Care Coordination (ACC) program 10-month pre-and post-implementation of the program	=101 Children needing complex care using criteria of frequent hospital use or medical fragility Included: • cerebral palsy • seizure disorder • genetic disorder with chromosomal abnormalities [Unable to distinguish children with intellectual disability in the sample and outcomes]	**Elements** • Care coordination • Referrals and linkages to other services • Capacity building for person with intellectual disability and/ or carer • Capacity building for health professionals • 24-hour telephone support • Personal integrated health care plan • Reassessment and monitoring **Approach** • Person-centred care **Implementation** • Specialist team • Metropolitan • Children's hospital	**Patient** • The 24-hour telephone support was valued by families • Continuity of care across hospital and community **Service provider (clinician)** • Proactive discharge planning contributed to reduced demand for ward-based discharge coordinators, reduction in bed days and improved communication across patient services • System barriers identified and addressed (e.g. coordination of outpatient appointments, immunizations, medication orders) **Service use** • ED presentations decreased 15% • Hospital admissions decreased 9% • Hospital bed stays decreased 43% • Appropriate ED presentation increased 87% to 94%	Estimated $1.9 million cost savings per annum

Author / Year of publication / Title/ State	Study design/ description	Population	Component(s) of model of care	Outcome and effectiveness	Cost effectiveness
Hendren & Kendall, 2015 Impact of the role of senior dual disability coordinator on the perceived self-efficacy and job satisfaction of mental health clinicians[47] Queensland	Before and after study Intervention: Senior dual disability coordinator role Pre-and-post intervention questionnaires, time interval not specified	N=25 Mental health clinicians managing clients with dual disability	**Elements** • Capacity building for health professionals **Approach** **Implementation** • Specialist dual disability coordinator • Metropolitan • Regional	**Patient** Not evaluated **Service provider (clinician)*** Mean (95% CI) change score • Increased knowledge: -0.72 (95% CI -0.97, -0.46) • Increased clinical skills: -0.56 (95% CI -0.80, -0.31) • Increased service knowledge: -0.64 (95% CI -0.92, -0.35) • Improved self-efficacy: -5.00 (95% CI -6.6, -3.37) • Improved job satisfaction: -11.40 (95% CI -14.54, -8.25) * Negative change score represents improvement **Service use** Not evaluated	Not evaluated

Author / Year of publication / Title/ State	Study design/ description	Population	Component(s) of model of care	Outcome and effectiveness	Cost effectiveness
Baynam et al, 2025 Rare care - cross-sectoral care coordination[45] Western Australia	Post-intervention evaluation Intervention: Cross-sectoral care coordination	N=40 Children with rare and undiagnosed conditions	**Elements** • Cross-sectoral coordination (e.g. NDIS, education, Department of Communities) • Referrals and linkages to other services • Accessible information • Time limited direct intervention • Capacity building for person with intellectual disability and/or carer • Capacity building for health professionals • Advocacy **Approach** • Person - centred care • Reasonable adjustments • Cultural safety for Aboriginal and Torres Strait Islander and CALD communities • Co-design in development and implementation of the model of care **Implementation** • Specialist team • Multi-disciplinary • Health and non-health professionals • Metropolitan • Children's hospital	**Patient** • Reduced travel time and associated costs for families to hospital • Increased disability funding secured; 18% of families received an increase in disability support payments • Reduced anxiety and increased tolerance to medical investigations • Continuity of care with local GP • Better understanding of educational support needs • Increased access to supports for caregivers **Service Provider (clinician)** Not evaluated **Service Use** • ED presentations reduced 50% • Hospital bed stays reduced 82% • Outpatient appointments reduced 16%	$699,000 savings over a 12-month period from reduced hospital use (Projection based on data from first 3 months' post service discharge for the first 40 patients. Baseline data not presented)

Author / Year of publication / Title/ State	Study design/ description	Population	Component(s) of model of care	Outcome and effectiveness	Cost effectiveness
O'Shannessy et al, 2025 Effectiveness of a Disability Liaison Officer service in a metropolitan emergency department[46] Victoria	Retrospective cohort study Intervention: Disability Liaison Officer (DLO) service Control: Standard care Data compared between two cohorts: 1.1 Apr 2022 - 30 Sept 2022 (standard care) 2.1 Nov 2022 - 30 Apr 2023 DLO service	N=631 Adults presenting to ED between April 2022 - April 2023 and had a disability alert in their electronic medical record. Each person was classified as having communication, intellectual or other disability. Control group (n=305) and intervention group (n= 325)	**Elements** • Care coordination • Capacity building of health professionals • Telehealth **Approach** • Person-centred care • Reasonable adjustments **Implementation** • Specialist team • Multidisciplinary • Metropolitan • Hospital	**Patient** Not evaluated **Service provider (clinician)** Not evaluated **Service Use** • Earlier disposition from ED (HR 1.44 (95% CI: 1.23-1.69) • Earlier discharge home from ED (aHR 2.47, 95% CI 1.83, 3.33) • No significant effect for patients admitted to Emergency Short Stay Unit (aHR 1.67, 95% CI 0.99, 2.80) • No significant effect for patients admitted to inpatient ward (aHR 0.89, 95% CI: 0.65, 1.23) Hazard ratios adjusted for age, initial Glasgow Coma Scale (GCS) and disability type (adults with communication disability, intellectual disability or other)	Not evaluated
Golder et al, 2024 Evaluation of an Australian community-based model of care for adults with intellectual and developmental disabilities undergoing procedures under sedation[48] Victoria	Retrospective cohort study Intervention: Centre for Developmental Disability Health (CDDH) procedural model of care Data collected over 14 months (2021 - 2022)	N=127 Adults with intellectual disability and/or developmental disability who attended the CDDH for a procedure requiring sedation (most common type of procedure was immunization followed by oral examination and for pathology)	**Elements** • Care coordination • Assessment • Time-limited direct intervention • Referrals and linkages to other services • Accessible information • Telehealth **Approach** • Person-centred care • Reasonable adjustments **Implementation** • Specialist team • Multi-disciplinary • Metropolitan • Community-based disability service	**Patient** Not evaluated **Service provider (clinician)** Not evaluated **Service Use** • 98% of procedures used the simplest and safest effective technique under the sedation tier • 91.4% of sedation level assessed through model of care matched the sedation provided • 67% of procedures requiring less invasive sedation types • Efficiency of service use, 55% of participants consented for an additional procedure	Not evaluated

Author / Year of publication / Title/ State	Study design/ description	Population	Component(s) of model of care	Outcome and effectiveness	Cost effectiveness
Bull et al, 2025 Evaluation of the patient profile and health interventions offered by a multidisciplinary intellectual disability health team[49] New South Wales	Retrospective cohort study Intervention: Specialised Intellectual Disability Health Team Data collected over three years (2019 – 2022)	N=151 Paediatric and young people cohort – under 21 - priority population (e.g. refugee background, Indigenous Australians, living in Department of Housing, justice system involvement)	**Elements** • Care coordination • Cross-sectoral coordination • Assessment • Time-limited direct intervention • Referrals and linkages to other services • Accessible information **Approach** • Person-centred care Implementation • Specialist team • Multi-disciplinary • Metropolitan • Community – paediatric clinics in private and public sector	**Patient** At initial assessment: • 18.5% had changes to existing medication dosages • 47.7% had new medication recommended • 13.9% had on-going medication ceased • 34.4% received a new comorbid diagnosis • 26.4% received medical investigations such as blood tests and imaging • 56.3% received psycho-social support such as letters sent to school • Approx one third were supported with requests for increased NDIS funding • Approx one third were recommended commencement of allied health interventions such as psychologists and occupational therapists At 6 months follow up: • 82.9% of patients followed recommendations made by the health team **Service provider (clinician)** Not evaluated **Service Use** • Three-quarters of carers reported an ongoing improvement in function for the primary concern they presented with to the team at 6-month follow-up	Not evaluated

Statistical abbreviations: RR – risk ratio; CI – confidence interval; OR – odds ratio; HR – hazard ratio; aHR – adjusted hazard ratio.

Appendix F

Summary of grey literature

Table 3. Summary of components and effectiveness and cost-effectiveness outcomes from grey literature (statistical abbreviations in footnote)

Author / Year of publication / Title/ State	Description of service	Component(s) of model of care	Outcomes and effectiveness	Cost effectiveness
O'Shea et al, 2023 Intellectual Disability and Mental Health Hubs[50] New South Wales	Two statewide hubs established to support better access for children and adults with intellectual or developmental disability and mental health needs 1.Sydney Children's Hospitals Network Mental Health and Intellectual Disability Hub 2.Statewide Intellectual Disability Mental Health Outreach Service Program ran from March 2019 - March 2024	**Elements** • Assessment • Accessible information • Time limited direct intervention • Cross-sectoral care coordination • Referrals and linkages to other services • Capacity building for person with intellectual disability and/or carer • Capacity building for health professionals • Advocacy • Research and evaluation • Telehealth **Approach** • Person-centred care • Reasonable adjustments **Implementation** • Specialist teams • Multidisciplinary • Metropolitan	**Patient** Compared to previous year, in the first three months of the program, there was an overall increase in access to local mental health services with the greatest changes in: - clinical review (RR 8.0) - care planning (RR 4.8) - care management (RR 4.5) - assessment (RR 3.9) • Improved well-being e.g. clients felt involved, carers received helpful advice on self-care • Satisfaction with how they were linked with other services • Increased access to NDIS **Service provider (clinician)** Increased: • Capacity of local district/network regarding intellectual disability mental health • Access to specialist intellectual disability mental health support for local clinicians • Coordination and engagement across health and disability providers • Exposure to working with people with intellectual disability Improved: • Patient flow through mental health services • Access to targeted education for local clinicians • Confidence and skills of mainstream mental health professionals • Partnerships with other sectors such as Justice and NDIS **Service use** • ED presentation decreased by 28%	Not evaluated

Author / Year of publication / Title/ State	Description of service	Component(s) of model of care	Outcomes and effectiveness	Cost effectiveness
Purcal et al, 2021 The Intellectual Disability Mental Health National Disability Insurance Scheme Residual Functions Program (Residual Functions Program)[51] New South Wales	Program supporting people with intellectual disability and mental health needs Ten local health districts (LHD) and two Speciality Health Networks (SHN) aiming to improve clinical support, service capacity and coordination Three streams of activities: 1.Support for LHDs and SHNs 2.Support for six intellectual disability health teams 3.Centralised coordination Ran from 2018 - 2021	**Elements** • Accessible information • Cross-sectoral care coordination • Time limited direct intervention • Referrals and linkages to other services • Capacity building for person with intellectual disability and/or carer • Capacity building for health professionals • Telehealth **Approach** • Reasonable adjustments • Person-centred care • Trauma- informed • Co-design of research methods **Implementation** • Primary care • Specialist team • Multidisciplinary • Metropolitan • Regional	**Patient** • Improved wellbeing for person with intellectual disability and their carers • Increased involvement in the process e.g. felt respected and welcomed • Increased direct clinical contact • Decreased travel required • Increased comfort due to reasonable adjustments and accessible information • Reduced use of chemical restraints for behaviour management **Service provider (clinician)** • Increased coordination amongst services • Local contact point for care coordination **Service use** • Improved access to services in the community by 69% per person per month • Rate of ED presentations did not change. Slight reductions in admission from ED presentations: (4%), and reductions in two triage categories: resuscitation (4%) and urgent (7%) • 73% increase in rates of inpatient episodes per person per month due to mental and physical health. No change in the rates of admissions	Limited data precluded evaluation

Author / Year of publication / Title/ State	Description of service	Component(s) of model of care	Outcomes and effectiveness	Cost effectiveness
Department of Health and Aged Care, 2024 Primary Care Enhancement Program (PCEP) [52] New South Wales, Queensland, Victoria, Tasmania	Initiative aimed to: • Increase the skills of GPs and other health professionals to deliver effective health care for people with intellectual disability • Improve the health literacy of people with intellectual disability Pilot ran between July 2022 - June 2024 Delivered in four Primary Health Networks in four states	**Elements** • Accessible information • Referrals and linkages to other services • Capacity building for person with intellectual disability and/or carer • Capacity building for health professionals **Approach** • Reasonable adjustments • Person-centred care **Implementation** • Primary care • Multidisciplinary • Metropolitan • Regional	**Patient** • Health resources were described as helpful to facilitate discussions with service provider **Service provider (clinician)** • Knowledge of inclusive communication strategies increased from 40% to 92% • Confidence in supporting annual health assessments increased from 34% to 72% • 84% respondents reported they applied PCEP learning into reasonable adjustment practices always or most of the time • Improved awareness and use of intellectual disability health resources **Service use** Not evaluated Low engagement with the PCEP from GPs	Not evaluated

Author / Year of publication / Title/ State	Description of service	Component(s) of model of care	Outcomes and effectiveness	Cost effectiveness
Clinical Centre of Expertise for Rare and Undiagnosed Diseases, 2023, 2024 The CAHS Clinical Centre of Expertise for Rare and Undiagnosed Diseases (Rare Care Centre)[53, 54] Western Australia	Service for children with rare and undiagnosed diseases launched in 2022 and on-going Located at two metropolitan sites Two main clinical service streams: • Statewide cross-sector care coordination • Nurse Navigator Program A regional site to be launched in Pilbara (Northwest region of WA) in 2025	**Elements** • Cross-sectoral care coordination • Time limited direct intervention • Accessible information • Referrals to other services • Capacity building for person with intellectual disability and/or carer • Capacity building for health professionals • Telehealth • Digital Patient Portal (for real time exchange of information) • Advocacy • Research and evaluation • Collaboration with local universities to upskill students • Global partnerships/ networking to upskill the workforce **Approach** • Person-centred care • Co-design in development and implementation of the model of care **Implementation** • Specialist team • Multidisciplinary • Metropolitan	**Patient** • Families felt valued and received practical and emotional support • Parents reported decreased stress and increased overall wellbeing • Greater access to full-time special needs education supports • Facilitation of transition to adult services and employment opportunities • Increased access to NDIS, appropriate supports and assistive technology • Access to specialist care and therapy supports **Service provider (clinician)** • Shared information between health, community and education supports **Service use** • Connection to local GPs • Reduced hospital attendances with coordinated outpatient appointments • Reduced outpatient visits by 16% • Reduced number of bed days by 82% • Reduced ED presentations by 50%	In 2023-24: the savings is estimated at four times the cost Reduced travel costs for regional patients (approximately $5,250 per patient per year)

Statistical abbreviation: RR – risk ratio

Appendix G

Australian health services for intellectual disability

Table 4a: Physical health services described online for adults with intellectual disability

	NSW IDHS (7 teams, each run differently to suit local needs of local health district)	NSW STriDeS	NSW CDS Complex Care	NSW DARTYP	NSW Grow	NSW SIDHT	NSW, QLD, VIC, TAS PCEP#	NT Pilot Assessments
Who								
Specialist teams	X	X	X	X	X	X	X	X
Multidisciplinary	X	X	X	X	?	X	X	?
Interdisciplinary								
Single Discipline								
Where								
Metropolitan	X	X	X	X	X	X	X	X
Regional	X		X				X	X
What								
Diagnostic assessment								X
Health assessment	X	X	X	X		X		
Time limited direct intervention	X	X	X	X				
Outreach								
Telehealth	X		X		X		X	
Care coordination					X (Service navigators)			
Accessible Information	X	X			X		X	
Referrals and linkages to other services	X	X	X		X	X		X
Capacity building for person with intellectual disability and/ or carer	X	X	X	X			X	X
Capacity building for health professionals	X	X	X		X	X	X	
Capacity building for community							X	
How								
Reasonable adjustments	X							
Person-centred care	X	X	X					

The PCEP is not a direct health service, it is a capacity building model that supports primary healthcare services

Table 4b: Physical health services described online for adults with intellectual disability (continued)

	QLD QCEIDAH	QLD Nurse navigation	SA SAIDHS	TAS SHAID	VIC CDDH	VIC Austin Specialist Disability Service	VIC SPEAK Project	WA NDAS	NSW, NT, QLD, SA, TAS, VIC, WA ADLO
Who									
Specialist teams	X	X	X	X	X	X		X	X
Multidisciplinary	X		X		X	X	X	?	X
Interdisciplinary									
Single Discipline		X		X					
Where									
Metropolitan	X	X	X	X	X	X	X	X	X
Regional		?							X
What									
Diagnostic assessment			X					X	
Health assessment	X		X	X	X	X			X
Time limited direct intervention	X		X	X	X	X	X	X	X
Outreach			X						X
Telehealth			X		X	X			
Accessible Information		X	X		X	X	X		X
Referrals and linkages to other services		X	X	X			X		X
Care coordination		X			X (Disability liaison)	X (Disability liaison)	X (Disability liaison)		X
Capacity building for person with intellectual disability and/ or carer	X	X	X	X	X	X			X
Capacity building for health professionals	X	X	X	X	X	X	X		X
Capacity building for community									
How									
Reasonable adjustments			X			X	X		X
Person-centred care	X	X	X	X	X	X			X

The PCEP is not a direct health service, it is a capacity building model that supports primary healthcare services

Table 4c: Mental health services described online for adults with intellectual disability

	ACT Mental Health Service for People with Intellectual Disability	NSW SIDMHOS	NSW Residual Functions Program	QLD GCIDDMHS	QLD QCEIDAH	VIC CDDH	VIC VDDS	SA SAIDHS
Who								
Specialist teams	X	X	X	X	X	X	X	X
Multidisciplinary	X	X	X	X	X		X	X
Interdisciplinary								
Single Discipline						X		
Where								
Metropolitan	X	X	X	X	X	X	X	X
Regional			X					
What								
Diagnostic assessment			X					X
Assessment	X	X	X	X	X	X	X	X
Time limited direct intervention	X	X	X	X	X	X	X	X
Outreach								X
Telehealth		X	X			X	X	X
Accessible Information			X			X	X	X
Referrals and linkages to other services	X	X	X	X				X
Care coordination			X			X (Disability liaison)		
Capacity building for person with intellectual disability and/ or carer	X	X	X	X	X	X	X	X
Capacity building for health professionals	X	X	X	X	X	X	X	X
Capacity building for community	X		X					
How								
Reasonable adjustments			X					X
Person-centred care			X			X		X

Table 4d: Dental health services described online for adults with intellectual disability

	NSW SLHD Special Care Dentistry	NSW WSLHD Special Care Dentistry	SA Special Needs Unit Adelaide Dental Hospital	*TAS Special Care dental health	*VIC Special needs care unit	VIC Bellarine Inclusive dental	WA Special services Dental Health Services
Who							
Specialist teams	X	X	X	X	X	X	X
Multidisciplinary							
Interdisciplinary							
Single Discipline	X	X	X	X	X	X	X
Where							
Metropolitan	X	X	X	X	X		X
Regional				X		X	
What							
Diagnostic assessment							
Assessment	X	X	X	X	X	X	X
Time limited direct intervention	X	X	X	X	X	X	X
Outreach							
Telehealth							
Accessible Information							
Referrals and linkages to other services							
Care coordination							
Capacity building for person with intellectual disability and/ or carer		X					
Capacity building for health professionals		X					
Capacity building for community							
How							
Reasonable adjustments	X	X	X	X	X	X	X
Person-centred care							

* Special care was not defined but could include people with intellectual disability

Table 4e: Physical health services for children and adolescents with intellectual disability

	ACT CDS	NSW Tumbatin	NSW Paediatric Developmental Disability Clinic	NSW CDS	NSW DSU	NSW DDAT	NSW SIDHT	NSW DARTYP
Who								
Specialist teams			X	X	X	X	X	X
Multidisciplinary	X	X		X	X	X	X	X
Interdisciplinary								
Single Discipline			X					
Where								
Metropolitan	X	X	X	X	X	X	X	X
Regional								
What								
Screening/ developmental assessments	X	X						
Diagnostic assessment		X		X	X	X		
Health Assessment			X			X	X	X
Time limited direct intervention	X	X	X	X	X	X		X
Outreach						X		
Telehealth							X	
Accessible Information				X			X	
Referrals and linkages to other services	X			X	X	X		
Care coordination								
Capacity building for person with intellectual disability and/ or carer	X	X		X	X	X		X
Capacity building for health professionals			X			X	X	
Capacity building for community					X			
How								
Reasonable adjustments							X	
Person-centred care							X	

Table 4f: Physical health services described online for children and adolescents with intellectual disability

	NSW Grow	NSW Rare diseases NSW	NSW STrIDeS	NSW KidsGPS	NSW RuralKidsGPS	NT Children's development team	NT Pilot Assessments	SA CDU
Who								
Specialist teams	X	X	X	X	X			X
Multidisciplinary	?	X	X			X	?	X
Interdisciplinary								
Single Discipline				?	?			
Where								
Metropolitan	X	X	X	X		X	X	X
Regional					X	X	X	
What								
Screening/ developmental assessments						X	X	X
Diagnostic assessment		X					X	X
Health Assessment		X	X	X	X			
Time limited direct intervention		?	X			X		
Outreach						X		
Telehealth	X	X		X	X			
Accessible Information	X		X					
Referrals and linkages to other services	X		X	X	X	X	X	X
Care coordination	X (Service Navigators)	X (Care coordination nurses)		X (complex care coordinator)	X			
Capacity building for person with intellectual disability and/ or carer		X	X	X	X	X	X	
Capacity building for health professionals	X	X	X	X	X			
Capacity building for community				X	X			
How								
Reasonable adjustments								
Person-centred care		X	X	X	X			

Table 4g: Physical health services described online for children and adolescents with intellectual disability

	QLD CDS Queensland Children’s Hospital	QLD Nurse Navigator	TAS CHaPS	VIC Child health teams	#VIC YATS	#VIC Fearless, tearless transition	WA NDAS	WA CDS	WA Rare Care Centre
Who									
Specialist teams		X			X	X	X		X
Multidisciplinary	X		X	X			?	X	X
Interdisciplinary					X				
Single Discipline		X				?			
Where									
Metropolitan	X	X	X	X	X	X	X	X	X
Regional		?	X	X					
What									
Screening/ developmental assessments	X		X	X				X	
Diagnostic assessment	X						X		X
Health assessment					X				X
Care coordination	X					X			X
Time limited direct intervention	X	X		X	X			X	X
Outreach									
Telehealth									X
Accessible information	X	X				X			X
Referrals and linkages to other services		X		X	X	X		X	X
Capacity building for person with intellectual disability and/ or carer	X		X	X	X	X		X	X
Capacity building for health professionals	X					X			X
Capacity building for community									X
How									
Reasonable adjustments					X	X			
Person-centred care		X				X			X

service for transition from paediatric to adult services, states developmental disability but not intellectual disability specifically

Table 4h: Mental health services described online for children and adolescents with intellectual disability

	NSW Mental Health Intellectual Disability Hub (MHID)	VIC Alfred Health Infant, Child and Youth Area Mental Health and Wellbeing Service
Who		
Specialist teams	X	X
Multidisciplinary	X	X
Interdisciplinary		
Single Discipline		
Where		
Metropolitan	X	X
Regional		
What		
Screening/ developmental assessments		
Diagnostic assessment		
Assessment	X	X
Time limited direct intervention	X	X
Outreach		
Telehealth	X	
Accessible information	X	
Referrals and linkages to other services	X	
Care coordination		
Capacity building for person with intellectual disability and/ or carer	X	X
Capacity building for health professionals	X	
Capacity building for community		
How		
Reasonable adjustments	X	
Person-centred care	X	

Table 4i: Dental health services described online for children and adolescents with intellectual disability

	NSW WSLHD Special Care Dentistry	SA Special Needs Unit Adelaide Dental Hospital	*TAS Special Care dental health	*VIC Special needs care unit	VIC Bellarine Inclusive dental	WA Special services Dental Health Services
Who						
Specialist teams	X	X	X	X	X	X
Multidisciplinary						
Interdisciplinary						
Single Discipline	X	X	X	X	X	X
Where						
Metropolitan	X	X	X	X		X
Regional			X		X	
What						
Diagnostic assessment						
Assessment	X	X	X	X	X	X
Outreach						
Telehealth						
Time limited direct intervention	X	X	X	X	X	X
Accessible information						
Referrals and linkages to other services						
Care coordination						
Capacity building for person with intellectual disability and/ or carer	X					
Capacity building for health professionals	X					
Capacity building for community						
How						
Reasonable adjustments	X	X	X	X	X	X
Person-centred care						

* Special care was not defined but could include people with intellectual disability

Abbreviations of Australian states: NSW - New South Wales; SA - South Australia; VIC - Victoria; TAS - Tasmania; WA - Western Australia, QLD – Queensland; NT – Northern Territory; ACT – Australian Capital Territory

Appendix G

Resources from key government departments, advocacy and health professional bodies

Table 5: Resources from websites of key Australian health professional bodies, government departments, and advocacy agencies offering healthcare resources for people with intellectual disability, inclusive of health professional bodies registered with the Australian Health Practitioner Regulation Agency (AHPRA).

Professional body or government department	Resource/ information	Website
Audiology Australia	No specific information identified	-
Australian Association of Developmental Disability Medicine (AADDM)	Position Statement. The importance of Physical and Mental Health for People with Intellectual Disabilities in the Criminal Justice System.	https://aaddm.com.au/wp-content/uploads/AADDM-The-Importance-of-Physical-and-Mental-Health-for-People-with-Intellectual-Disability-in-the-Criminal-Justice-System-Endorsement-August-2017.pdf
Australian Acupuncture and Chinese Medicine Association (AACMA)	No specific information identified	-
Australian Chiropractors Association (ACA)	No specific information identified	-
Australian College of Midwives	Caring for mothers with intellectual disability	https://midwives.org.au/Web/Web/Shop/Item_Detail.aspx?iProductCode=20210304DISA&Category=WEBINAR
Australian Commission on Safety and Quality in Health Care (ACSQHC)	Psychotropic Medicines in Cognitive Disability or Impairment Clinical Care Standard	https://www.safetyandquality.gov.au/sites/default/files/2024-05/Psychotropic-Medicines-in-Cognitive-Disability-or-Impairment-Clinical-Care-Standard.pdf
	Intellectual disability and inclusive health care	https://www.safetyandquality.gov.au/our-work/intellectual-disability-and-inclusive-health-care
	Intellectual Disability Actions for Clinicians Fact Sheet	https://www.safetyandquality.gov.au/publications-and-resources/resource-library/intellectual-disability-actions-clinicians-fact-sheet
	Principles for safe and high-quality transitions of care	https://www.safetyandquality.gov.au/our-work/transitions-care/principles-safe-and-high-quality-transitions-care
Australian Dental Association	Policy Statement 2.3.6- Individuals with Disabilities	https://ada.org.au/policy-statement-2-3-6-individuals-with-disabilities
Australian Health Practitioner Regulation Agency (AHPRA)	No specific information identified	-
Australian Indigenous HealthInfoNet	No specific information identified	-

Professional body or government department	Resource/ information	Website
Australian Physiotherapy Association (APA)	No specific information identified	-
Australian Podiatry Association	No specific information identified	-
Australasian College of Paramedicine	Paramedics and disabilities: Understanding ASD and recognising resource needs.	https://paramedics.org/recordings/PAD
Australian Psychological Society (APS)	Practice Guide. Alternatives to restrictive practices in intellectual and developmental disability	https://psychology.org.au/for-members/resource-finder/resources/assessment-and-intervention/clinical-guide/guidelines-restrictive-practices-disability-sector
	Ethical guidelines for psychological practice with clients with an intellectual disability	https://psychology.org.au/for-members/resource-finder/resources/ethics/ethical-guideline-psychological-disability
Australian society of medical imaging and radiation therapy	No specific information identified	-
Council for Intellectual Disability	My Health Matters	https://cid.org.au/resource/my-health-matters-folder/
	My Health Cards	https://cid.org.au/resource/my-health-cards/
	My Health Worker Guide	https://cid.org.au/resource/health-worker-guide/
	Me and my doctor	https://cid.org.au/resource/me-and-my-doctor-guide/
	Reasonable adjustments checklists for health professionals and administrative staff	https://cid.org.au/resource/reasonable-adjustments-checklist/
Down Syndrome Australia	Health screening tool	https://www.downsyndrome.org.au/services-andsupports/professionals/health-screening-tool/
	Communicating with people with Down syndrome	https://www.downsyndrome.org.au/wp-content/uploads/2020/02/DSA-Health-communication-tips-health-professionals-C03.pdf
	Resource Category Health	https://www.downsyndrome.org.au/blog/resource-category/health/
First Peoples Disability Network Australia	The National Disability Footprint	https://fpdn.org.au/national_disability_footprint/
	Disability Sector Strengthening Plan	https://www.closingthegap.gov.au/sites/default/files/2022-08/disability-sector-strengthening-plan.pdf
Inclusion Australia	It's Doctor Time! Resources	https://www.inclusionaustralia.org.au/resources/
Medicare Benefits Schedule	Time-Tiered Health Assessment- Health assessment for a person with intellectual disability	https://www9.health.gov.au/mbs/fullDisplay.cfm?type=note&qt=NoteID&q=AN.0.41
National Aboriginal Community Controlled Health Organisation (NACCHO)	The Aboriginal Disability Liaison Officer (ADLO) program (disability, not specified as intellectual disability)	https://www.naccho.org.au/wp-content/uploads/2025/06/NACCHO_ADLOProgram_EvaluationReport_250616_Online.pdf
	ADLO Gathering 2024 (disability, not specified as intellectual disability)	https://www.naccho.org.au/app/uploads/2024/10/ADLO-Gathering-Rydges-Esplanade-Resort-Cairns-13-%E2%80%93-14-August.pdf
National Association of Aboriginal and Torres Strait Islander Health Workers and Practitioners (NAATSIHWP)	No specific information identified	-

Professional body or government department	Resource/ information	Website
National Disability Insurance Scheme (NDIS)	Information for GPs and health professionals. Support person with disability to access services	https://www.ndis.gov.au/applying-access-ndis/how-apply/information-gps-and-health-professionals
	Disability-related health supports	https://www.ndis.gov.au/understanding/supports-funded-ndis/disability-related-health-supports https://ourguidelines.ndis.gov.au/supports-you-can-access-menu/disability-related-health-supports
	Who is responsible for the supports you need? Health	https://ourguidelines.ndis.gov.au/how-ndis-supports-work-menu/mainstream-and-community-supports/who-responsible-supports-you-need/health
	NDIS and other government services. Hospital Discharge	https://www.ndis.gov.au/understanding/ndis-and-other-government-services/hospital-discharge
Occupational Therapy Australia (OTA)	No specific information identified	-
Optometry Australia	No specific information identified Care for Diverse Populations education program to launch in November 2024.	-
Osteopathy Australia	No specific information identified	-
Pharmaceutical Society of Australia (PSA)	Medicine safety: Disability Care report	https://www.psa.org.au/wp-content/uploads/2022/07/PSA_DISABILITY-Report_2022_DIGITAL-FINAL.pdf
Pharmacy Guild of Australia	National Immunisation Program Vaccinations in Pharmacy (NIPVIP) rules update: Off-site vaccinations	https://www.guild.org.au/news-events/news/guild-alerts/2024/nipvip-rules-update-off-site-vaccinations
Professional Association of Nurses in Developmental Disability Australia Inc. (PANDDA)	Standards for Nursing Practice	https://www.pandda.org.au/files/PANDDA-2020-Standards.pdf
	Position Statement	http://www.pandda.org.au/files/PANDDA-2010-Position-Statement.pdf
Royal Australasian College of Physicians (RACP)	Policy Statement on Disability	https://www.racp.edu.au//docs/default-source/advocacy-library/disability-policy.pdf?sfvrsn=96a32f1a_8
	National Disability Insurance Scheme Guide for Physicians	https://www.racp.edu.au/docs/default-source/policy-and-adv/ndis-guide-for-physicians-2023.pdf?sfvrsn=5f66d71a_4
Royal Australian College of General Practitioners (RACGP)	Curriculum and syllabus for disability care	https://www.racgp.org.au/education/education-providers/curriculum/curriculum-and-syllabus/units/disability-care
	Position statement for the Care and Support for people with disability	https://www.racgp.org.au/getmedia/99340bfc-2f29-4681-a5f2-f33f20016ba9/RACGP-position-statement-Care-and-support-for-people-with-disability.pdf.aspx
	Specific Interest group for disability	https://www.racgp.org.au/the-racgp/faculties/specific-interests/interest-groups
Royal Australian & New Zealand College of Psychiatrists (RANZCP)	Position Statement	https://www.ranzcp.org/clinical-guidelines-publications/clinical-guidelines-publications-library/intellectual-disabilities-id-addressing-the-mental-health-needs-of-people-with-id
Speech Pathology Australia (SPA)	No specific information identified	-

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