



Current models of health service delivery for people with intellectual disability – Literature review

Never Stand Still

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May 2015

Prepared for:

New South Wales Agency for Clinical Innovation (ACI) Intellectual Disability Health Network

Acknowledgements

We would like to thank Tracey Szanto, Les White, Maria Heaton, Jacqueline Small and other ACI Intellectual Disability Health Network members for their advice in the project.

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© UNSW Australia 2015
ISSN: 1446-4179
ISBN: 978-1-925218-38-1
SPRC Report 12/2015

The Social Policy Research Centre is based in the Faculty of Arts & Social Sciences at UNSW Australia. This report is an output of research funded by the New South Wales Agency for Clinical Innovation (ACI) Intellectual Disability Health Network.

Suggested citation

Giuntoli, G, Newton, B., Fisher, K.R. (2015). *Current models of health service delivery for people with intellectual disability: Literature review* (SPRC Report 12/2015). Sydney: Social Policy Research Centre, UNSW Australia.

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Executive summary

The Social Policy Research Centre (SPRC), UNSW Australia, conducted a literature review on current models of health service delivery for people with intellectual disability. The review was commissioned by the New South Wales Agency for Clinical Innovation (ACI) Intellectual Disability Health Network as part of the *Blueprint* that ACI is developing to deliver improved health services for people with intellectual disability in NSW. This document reports the findings of the literature review.

The review focused on publications in English language from January 2011 to January 2015. Keyword searches were undertaken in four databases: PsycINFO, Social Science Citation Index, Medline and CINAHL; in these latter two databases relevant keywords were searched only as MeSH (Medical Subject Headings) terms.

The review identified nine models of health service delivery for people with intellectual disability, seven from the UK and two from Australia. All the models identified in the literature review stress the need for interagency collaboration. It seems to be increasingly accepted that generic models of health care are not resourced sufficiently to appropriately meet the needs of people with intellectual disability. Integration of the expertise from specialist services within mainstream services is often presented as potentially the most advantageous approach. This approach entails a way of delivering services based on co-operation and integration between generic and specialist teams.

The models were categorised along two main conceptual axes: the type of interagency framework they propose, whether multidisciplinary or interdisciplinary, and their approach to serving people in remote locations, whether based on central hubs or including outreach services. In particular, multidisciplinary frameworks are described as teams of professionals from different disciplines who approach the client from their own perspective and then meet to review the clients' needs in 'case conferences' which are usually undertaken in the absence of the client. Interdisciplinary frameworks consists of multi-professional teams whereby practitioners from different professions often meet the client at once, integrating their disciplinary approaches into a single consultation and more often involving clients in any discussions regarding their condition, prognosis and the plans about their care.

The majority of models addressed the wider health service needs of all people with intellectual disability. Four models focused on the interactions between health services in specific life passages: post-school transitions, hospitalisation, and end of life care. Five of the reviewed models were multidisciplinary and centralised: the Community Intellectual Disability Services (UK), the Tertiary specialist services (UK), and the Learning Disability Liaison Nurses (UK), person-centred planning, and the model for partnership practice between specialist palliative care and intellectual disability services. Two of the reviewed models were multidisciplinary and decentralised: the Hub-and-Spoke model (Australia) and the Birmingham

Community Assessment and Treatment Service (UK) and two were interdisciplinary, decentralised models: the 'Fair Horizons' model (UK) and the 'wobbly hub and double spokes' (Australia). The review did not find any interdisciplinary, centralised models. None of the literature met the systematic review standards of high research quality, because it did not include rigorous evaluations.

1 Introduction

The Social Policy Research Centre (SPRC), UNSW Australia, was commissioned by the New South Wales Agency for Clinical Innovation (ACI) Intellectual Disability Health Network to conduct a review of the literature on current models of health service delivery for people with intellectual disability. The literature review is a part of the *Blueprint* that ACI is developing to deliver improved health services for people with intellectual disability in NSW. This document reports the findings of the literature review.

Over the last three decades, provision of disability services in Australia has undergone significant reform in relation to structure, services and approaches (NSW Health, 2012). Evidence shows that many people with intellectual disability experience a high incidence of significant medical problems and their health conditions are often unrecognised, misdiagnosed and poorly managed in Australia (DoDDN, 2014; Emerson & Hatton, 2014b; Trollor, 2014c) and internationally (Anderson et al., 2013; Fear, Scheepers, Ansell, Richards, & Winterbottom, 2012; Krahn, Walker, & Correa-De-Araujo, 2015).

There is still a lack of consensus on how best to organise care for people with intellectual disability. The co-existence of multiple and complex health needs impacts on the capacity of generic services in primary and secondary care to effectively assess, identify and meet the range of needs in this client groups (Lennox & Kerr, 1997; NSW Health, 2012).

1.1 Objectives

This document reviews recent Australian and international literature on health service delivery models and their outcomes for people with intellectual disability. The objectives of the review were:

- 1) To identify current academic literature and reports commissioned by government and other agencies (i.e. 'grey' literature) on:
 - Models of health service delivery and their outcomes and longer term impact on people with intellectual disability, including their personal experiences of them
 - The efficacy and efficiency of different national and international models of health service delivery
- 2) To summarise the identified literature and, where possible, tabulate and map the identified health delivery models against their outcomes and longer term impact for people with intellectual disability, service providers and the service delivery systems
- 3) To inform future policy, service delivery and advocacy in NSW and Australia.

1.2 Methodology

The literature review was informed by a purposive review methodology. Searches were undertaken using a combination of keywords related to health (physical and mental) and wellbeing outcomes, service barriers, systemic barriers, and service delivery models (across the tiers of health, including primary, community, acute, mental, and specialist health services) for people with intellectual disability (Appendix A).

The review focused on publications in English language from January 2011 to January 2015. Although the literature on models of health service delivery dates back many years, a focus on the last four years of literature allowed the research team to identify and retrieve specific older works through scanning the reference lists and analysing existing review studies.

The searches were undertaken in four databases, which were chosen as the most likely to include relevant literature: PsycINFO and the Social Science Citation Index, in which keywords were searched in all the main fields, including title, abstract and subject headings, and Medline and CINAHL, in which relevant keywords were searched only as MeSH (Medical Subject Headings) terms.

In order for the literature review to include relevant grey literature, the research team asked the ACI network's members to share their knowledge of relevant official documents, such as governments' or organisations' reports, factsheets or documentation on principles, practices or models of health service delivery for people with intellectual disability.

Titles and abstracts of studies identified by the searches were downloaded in an Endnote library (reference manager software). These were then screened based on their relevance in relation to the review objectives. The full text of chosen papers was retrieved and included for analysis.

For the purpose of the literature search, the review adopted the definition of intellectual disability from the American Psychiatric Association's (2013) Diagnostic and Statistical Manual of Mental Disorders:

Diagnostic Criteria

Intellectual disability (intellectual developmental disorder) is a disorder with onset during the developmental period that includes both intellectual and adaptive functioning deficits in conceptual, social, and practical domains. The following three criteria must be met:

- (1) Deficits in intellectual functions, such as reasoning, problem solving, planning, abstract thinking, judgment, academic learning, and learning from experience, confirmed by both clinical assessment and individualized, standardized intelligence testing.

- (2) Deficits in adaptive functioning that result in failure to meet developmental and sociocultural standards for personal independence and social responsibility. Without ongoing support, the adaptive deficits limit functioning in one or more activities of daily life, such as communication, social participation, and independent living, across multiple environments, such as home, school, work, and community.
- (3) Onset of intellectual and adaptive deficits during the developmental period.

Note: The diagnostic term intellectual disability is the equivalent term for the ICD-11 diagnosis of intellectual developmental disorders. Although the term intellectual disability is used throughout this manual, both terms are used in the title to clarify relationships with other classification systems. Moreover, a federal statute in the United States (Public Law 111-256, Rosa's Law) replaces the term mental retardation with intellectual disability, and research journals use the term intellectual disability. Thus, intellectual disability is the term in common use by medical, educational, and other professions and by the lay public and advocacy groups.

The review focused on 'models of health service delivery', i.e. studies that proposed or investigated the outcomes of specific ways in which health care services are/can be linked to each other, accessed by and delivered to people with intellectual disability. Studies that investigated specific interventions or health care services were excluded unless these were proposed and analysed as part of a specific approach, i.e. model, to the delivery of health services to people with intellectual disability. Similarly, the review excluded studies that conceptualised the word model either as an approach to explain the origin and impact of disability within society, as for example in the expressions 'medical model of disability' and 'social model of disability', or as a framework aimed at guiding practice in a specific health profession, as for example in the expression 'nursing models'.

The review findings are reported as a narrative description by grouping the model types by relevant dimensions.

Limitations to the review are that it is not a systematic review and some areas of health services are overrepresented compared to others. Within the restrictions of the time and budget, the project focused on recent English language literature from four databases, of which two were searched in all the main fields, including title, abstract and subject headings (PsycINFO and Social Science Citation Index) and two only using MeSH terms (Medline and CINAHL). As is common in health services research, none of the literature met the systematic review standards of high research quality, because it did not include rigorous evaluations. Further, much of the literature was about access to mental health services. Generalised implications to other health care have been drawn from that specific application. Further research could extend the review, for example, by searching for studies that evaluated specific services within a given model of health service delivery to people with intellectual disability; extending the review to other countries; other databases;

related social services other than health care; and an inclusive focus on the lived experience of access to health services by people with intellectual disability.

1.3 Report structure

The next section of the report is a brief overview of the needs and experiences of access to services of three main subpopulations of people with intellectual disability: people with intellectual disability and a coexisting mental illness, people with intellectual disability living in rural and remote locations, and Aboriginal and Torres Strait Islander People. The following section reviews current knowledge about suitable health care for people with intellectual disability by mainstream or specialist services and discusses current models of health service delivery.

2 Accessing services: experiences of people with intellectual disability

This section briefly reviews the literature about the relationship between the right to the 'highest attainable standard of health' (UN General Assembly, 2007) and access to services; and additional health service needs likely for specific population groups of people with intellectual disability.

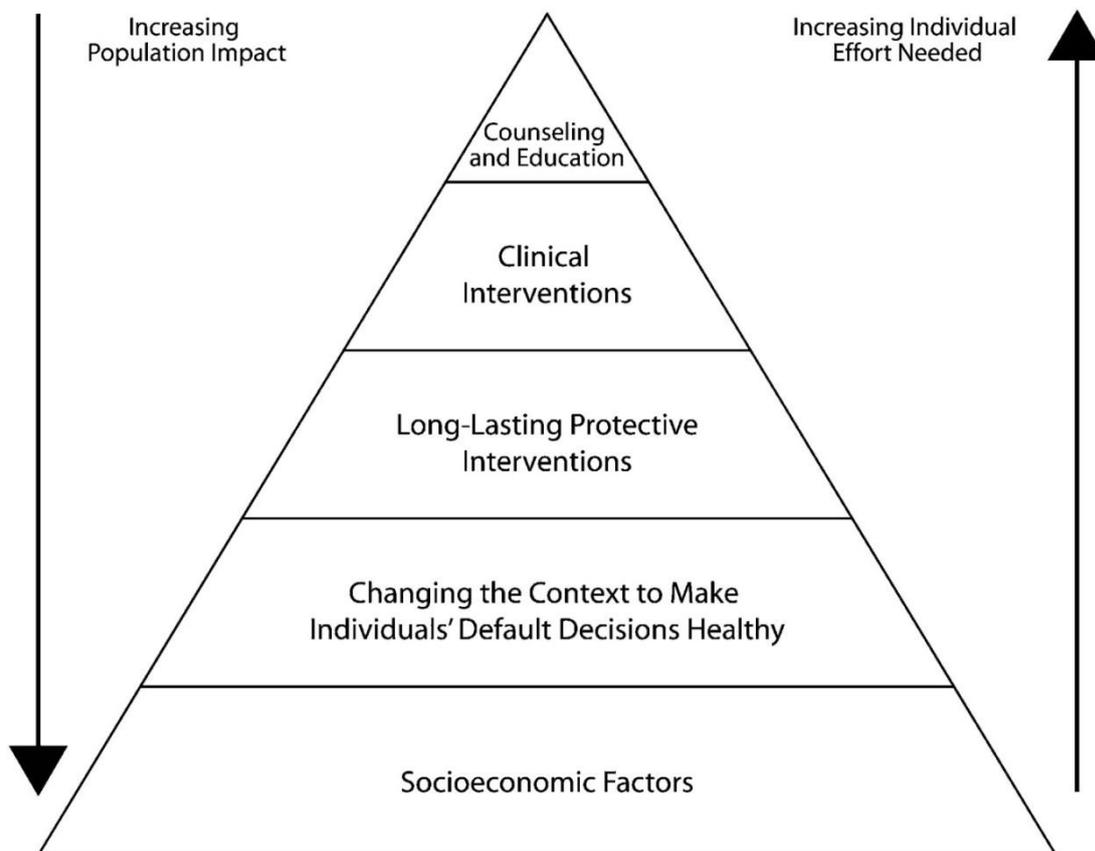
2.1 Health inequalities

The National Disability Strategy (Commonwealth of Australia, 2011) commits Australian governments to action to implement its obligations under the United Nations Convention on the Rights of Persons with Disabilities (UN General Assembly, 2007). The Convention recognises that people with disability have the right to the enjoyment of the highest attainable standard of health on an equal basis with others, ensuring access to the same range, quality and standard of health care, including population based public health programmes, and provision of disability specific health services as close as possible to people's own communities, including in rural areas (UN General Assembly, 2007, Art. 25). Improving health and wellbeing outcomes of people with intellectual disability is therefore identified as a priority in Australia and internationally (Australian Shadow Report to UNCRPD, 2012; WHO, 2011). Nevertheless, there is growing evidence suggesting that people with intellectual disability have poorer health outcomes and greater difficulty obtaining health services in comparison with the general population (Anderson et al., 2013; Emerson & Hatton, 2014a, 2014b; NSW Health, 2012).

Emerson & Hatton (2014a) stress that the health inequalities that characterise people with intellectual disability can be accounted for by the same wider social and economic determinants that apply to the rest of the population. Emerson & Hatton (2014a) distinguish between different levels of social and health policy intervention which they exemplify in the five-tiers of the health impact pyramid (Figure 1). The health impact pyramid (Frieden, 2010) aims to describe the health impact of different types of public health interventions. The base of the pyramid (Level 5) includes efforts to address the socioeconomic determinants of health, for example improvements in housing quality, 'poverty reduction strategies, strategies to improve employment opportunities, and, for disabled people, strategies to reduce stigma, discrimination and disablism throughout society' (Emerson & Hatton, 2014a, p. 103). In ascending orders, the pyramid refers to: interventions that change living environments to make individuals' default decisions healthy (Level 4), for example smoking bans or interventions to improve people's healthy nutrition choices; clinical interventions that require limited contact with services but confer long-term protection (Level 3), for example vaccination programs and health screening programs; ongoing direct clinical care (Level 2), including surgical and drug

treatments for existing acute and long-term health conditions; health education and counselling (Level 1), which aim to educate and/or counsel individuals to engage in more healthy behaviours, for example increasing physical activity, reducing alcohol intake, stopping smoking and engaging in less risky sexual behaviours (Emerson & Hatton, 2014a).

Figure 1. Health impact pyramid



Source: Emerson & Hatton (2014a, p. 106, Figure 5.1).

This document reviews recent Australian and international literature on models of health service delivery and, where available, evidence on their outcomes for people with intellectual disability. Therefore it has focused on services and interventions typical of the first three levels of the health impact pyramid (Figure 1). However, as Emerson and Hatton (2014a) point out, the maximum possible sustained public health benefit for people with intellectual disability are likely to be achieved by implementing interventions at each level of the health impact pyramid.

2.2 Health Care assess

A recent systematic review of the literature of the health care of people with intellectual disability identified 94 systematic reviews on specific health issues of

people with intellectual disability, which were categorised using the 10th revision of the International Statistical Classification of Diseases and Related Health Problems (ICD-10) (Robertson, Hatton, Baines, & Emerson, 2015). Of these systematic reviews, 52 related to mental or behavioural disorders (Chapter V of the ICD-10), 28 to factors influencing health status and contact with services (Chapter XXI of the ICD-10), and 14 encompassed multiple chapters of the ICD-10. Only two of the reviews on contact with services of people with intellectual disability included a substantial amount of studies. One was the systematic review by Robertson, Roberts, Emerson, Turner and Greig (2011), which reviewed 38 studies on the impact of health checks and concluded that these are effective in identifying unrecognised health needs, including life-threatening conditions, in people with intellectual disability. The other was the systematic review by Kozma, Mansell and Beadle-Brown (2009), which reviewed 68 studies on outcomes in different residential settings for people with intellectual disability and concluded that small-scale residential settings are superior to large, congregate options in most domains studied.

Bradbury-Jones, Rattray, Jones and MacGillivray (2013) undertook a structured literature review aimed at identifying the influences on the health, safety and welfare of adults with learning disabilities in acute care settings. Bradbury-Jones et al. (2013) found eight qualitative studies that met their inclusion criteria; no quantitative studies met their review's inclusion criteria. Based on the analysis of the eight reviewed studies, Bradbury-Jones et al. (2013) proposed a diagram that identifies six areas of influence on the health, safety and welfare of adults with learning disabilities in acute hospitals: care provision (meeting health and personal needs); communication; staff attitudes; staff knowledge; supporters; and carers (valuing their role); physical environment. These six areas are represented diagrammatically as a layer of rings closest to the person to indicate the fact that they have direct influence compared to other factors, such as education/training and support/ liaison services, which the review has shown have some less direct influences (Figure 2). The arrows in the Figure show that Bradbury-Jones et al. (2013) propose that adults with learning disabilities are not passive recipients of care, but should be active agents, capable of exerting outward influence in relation to healthcare.

This review builds from these health care access studies to examine models of health service delivery that might improve these health outcomes. The remainder of this section discusses issues raised in the literature regarding disability service access for four main population groups likely to have additional needs: children and young people, people with intellectual disability and a coexisting mental illness, people with intellectual disability living in rural and remote locations, and Aboriginal and Torres Strait Islander peoples. An extensive discussion of these issues is beyond the scope of this review, however suggestions for further reading are provided.

Figure 2. Influences on the health, safety and welfare of adults with learning disabilities in acute care settings



Note: Source: Bradbury-Jones et al. (2013, Figure 2, p. 1504)

2.3 Children and young people

Children with intellectual disability benefit from access to early intervention and assistance in health, disability support and other social services. Effective early support requires coordination between health and other service sectors to address their physical, development and social needs, as introduced in the health outcomes and health access literature above.

When they reach school age, children with intellectual disability face challenges in transition to school (AIHW, 2008). The 2009 Survey of Disability, Ageing and Carers (SDAC) reported that around 60 per cent of children with disability at school had an intellectual disability, 34 per cent had sensory disability, 30 per cent had physical disability and 17 per cent had psychological disability (ABS, 2013a). Of those with intellectual disability, more than half attended regular classes in mainstream schools (ABS, 2013b). In comparison, 70 per cent of children at school with physical disabilities attended regular classes (ABS, 2013b). In 2009, about 61 per cent of children with disability reported experiencing difficulty at school (ABS, 2013a). Overall, the 2009 SDAC (ABS, 2013b) found that, regardless of the school settings, just over half of all school children with disability (54 per cent) received additional

assistance, such as special tuition, and access to counsellors or disability support workers.

Based on analyses of the 1998 and 2003 SDAC, the Australian Institute of Health and Wellbeing (AIHW, 2008) found that people aged 15–64 with intellectual disability years were less likely to complete Year 12 studies, participate in tertiary education, participate in the labour force, to be employed working full-time, or work in the government sector compared with people without disability of the same age. Instead, people aged 15–64 years with intellectual disability were more likely to be unemployed, have never married, rely on a government pension or allowance as their main source of cash income (AIHW, 2008).

2.4 People with mental health problems

Some people with intellectual disability have a coexisting mental illness or mental health disorder. In 2003, 57 per cent of the Australian aged under 65 with intellectual disability also had psychiatric disability (AIHW, 2008). Services for this client group are scarce (Trollor, 2014c), despite the fact that in Australia the onset of mental health disorders in this client group is earlier than the general population and comorbid intellectual disability and mental health conditions are two to three times more prevalent than the wider population (DoDDN, 2014). As such timely access to appropriate services is crucial.

Where services are available, research shows that the uptake of mental health services for people with intellectual disability is low. If left untreated mental health problems can become chronic (DoDDN, 2014). Barriers to accessing adequate mental health services for people with intellectual disability (Trollor, 2014a, p. 395; 2014c) include a lack of:

- knowledge about the prevalence of mental illness in people with intellectual disability and the way they manifest
- clarity concerning roles and responsibilities and service coordination between disability services and mental health service providers
- training of mental health providers
- coherent service models and funding for intellectual disability mental health services
- specific inclusion of people with an intellectual disability in mental health policy.

2.5 People living in rural and remote locations

Access to disability therapies and health services in rural and remote areas of NSW can be difficult because clinicians are primarily based in metropolitan cities and regional centres (Dew et al., 2014). Dew et al. (2014) argue that despite recent

increases in government funding in the disability sector, the problem of recruitment and retention of clinicians to service rural and remote areas remains. For instance, this type of work requires long distance travel and can be isolating with little opportunity for professional development or team interaction (Dew et al., 2014).

Veitch et al. (2012) identify three main models of service delivery in rural communities:

- Service teams located in regional centres that meet local needs but require more distant clients to travel
- Service teams from regional centres that travel to smaller communities to provide outreach services
- Urban-based 'fly-in and fly-out' services provided to selected rural communities.

In addition, remote health support through technologies, such as telemedicine, supplements physical presence in rural communities. Sections 5.2.1 and 5.3.2 review two models which are an extension of the outreach services model: the 'hub and spoke' model and the 'wobbly hub and double spokes' models. These models are characterised by the fact that outreach staff in several remote locations ('spokes') are supported by a regional centre 'hub'.

2.6 Aboriginal and Torres Strait Islander People

The number of Aboriginal and Torres Strait Islander people with disability in Australia is unknown, although estimated from ABS Census to be over one third. With such a high incidence, it is likely that many Aboriginal people are underrepresented and underserved in access to health services, the consequence of which leads to further hardship for an already significantly disadvantaged group (Stephens, Cullen, Massey, & Bohanna, 2014). Stephens et al. (2014, p. 261) commented that 'Indigenous people experience a profound or severe core activity limitation, or disability at more than double the rate of non-Indigenous Australians'.

These figures reflect the high health issues prevalent in many Indigenous people, who experience significant disadvantage and high overrepresentation in negative social indicators (SCRGSP, 2001). It also indicates that some locations have a lack of available primary care resources and, and in some instances hospital admissions may be due to lack of alternative options for healthcare.

The barriers to adequate care for Indigenous people with disability are well documented and have been extensively discussed elsewhere (Biddle, 2012; Dew et al., 2012; Stephens et al., 2014). Some of these barriers to accessing disability and health services for Aboriginal people and communities include:

- Inaccurate data regarding the gaps in and needs for services

- Cultural understandings of the concepts health and disability differ for Aboriginal groups
- Issues engagement with the service system such as being unaware of entitlements and having a mistrust of mainstream service institutions
- Shortcomings within service systems such as a lack of culturally competent staff and the inability to address multiple complex issues simultaneously
- The isolated or hard to access location of some Indigenous communities.

3 Framework for analysis

There is ongoing discussion on the best way to organise health services for people with intellectual disability. The following sections review the current options on the appropriateness of care for people with intellectual disability by mainstream or specialist services. They explore both community service and inpatient care models.

All the models identified in the literature review stress the need for interagency collaboration. Some rely on multidisciplinary frameworks, whereas others use interdisciplinary frameworks. Although there is no agreed definition of these two concepts (Jessop, 2007), multidisciplinary frameworks are often described as teams of professionals from different disciplines who approach the client from their own perspective and then meet to review the clients' needs in 'case conferences' which are usually undertaken in the absence of the client. Interdisciplinary frameworks also consist of multi-professional teams, however, in this case, practitioners from different professions often meet the client at once, integrating their disciplinary approaches into a single consultation. Interdisciplinary frameworks tend to be more person-centred than multidisciplinary approaches because clients tend to be more involved in any discussions regarding their condition or prognosis and the plans about their care (Fear et al., 2012).

Further, some models account for geographical remoteness through provision of outreach services, whereas others entail more distant clients to travel to regional or urban centres. This review distinguishes the models of health service delivery for people with intellectual disability along two main axes:

- the type of interagency framework they propose, whether multidisciplinary or interdisciplinary and
- their approach to remoteness, whether based on central hubs or include outreach services for remote areas.

Consequently, the reviewed models are presented in two main subsections, multidisciplinary models and interdisciplinary models, within which we further distinguish between centralised and decentralised models. Although most of the reviewed models were developed with reference to specific subgroups of people with intellectual disability, in particular people with intellectual disability and a coexisting mental illness, their solutions and approaches represent important examples that can be adapted to meet the health needs of the wider population of people with intellectual disability.

The next section briefly reviews the literature around mainstream services and their capacity to address the complex needs of people with intellectual disability, with a particular focus on reasonable adjustments and pathways to care, which are two approaches aimed at including people with intellectual disability in mainstream services. It then reviews the models of health care delivery identified through the literature review based on the two axes identified above.

4 Mainstream services

A mainstream services approach entails facilitating access to generic services for people with intellectual disability wherever possible. Although this approach supports concepts of inclusion and human rights, it is increasingly argued that it is unusual for mainstream services to be adequately resourced or staffed to provide quality care to this client group, such as people with intellectual disability and mental illness (Chaplin, 2004, 2009, 2011; Sheehan & Paschos, 2013).

4.1 Access to mainstream services

A recent forum discussing the roll out of the National Disability Insurance Scheme (NDIS) and integration of health care for people with intellectual disability several recommendations were made for Australia (CID NSW, 2014). The main ones include: annual Medicare funded health assessments; strengthening health care and wellbeing in the NDIS overall planning process; strengthening health care providers' capacity to respond to peoples' needs (including reducing barriers around communication); and stronger integration between health care and disability services (CID NSW, 2014, p. 21f).

Like the general population, inpatient care remains a necessity for some people at certain times, although most people receive health services in the community (Sheehan & Paschos, 2013). Whether patients with intellectual disability and other conditions, such as mental illness, should be admitted to generic wards or specialist inpatient units remains open to debate, depending on the person's needs and the accessibility of the services (Sheehan & Paschos, 2013). Proponents of admission to generic wards argue that this helps to achieve policy goals of inclusion and acceptance of people with intellectual disability. Those who favour admission to specialist units highlight the benefits of staff highly trained and skilled for the specific needs of this client group.

The Australian Department of Health National Guide on Intellectual Disability Mental Health for Providers (The Guide) (DoDDN, 2014) articulates how mental health services should be provided to persons with intellectual disability across Australia. The Guide was designed 'as the first in a series of resources which includes an as yet unfunded implementation toolkit, as well as a self-audit tool and a resource to inform carers, families and consumers of the obligations of mental health service providers' (Trollor, 2014b, p. 397).

The Guide identifies the following guiding principles as central to the development of models of care and policy for mental health service to people with intellectual disability (DoDDN, 2014, pp. 11-13), which also have implications for other health services:

- Rights; a human rights framework in health care identifies people with a disability as having a right to health and health care
- Inclusion; people with intellectual disability should be able to access all components of mental health services, including mainstream and specialised mental health services
- Person-centred approach; the person with intellectual disability should be provided with choices about their mental health care, in keeping with their age and capacity. While the person is the focus, family and carers should be consulted where appropriate
- Promoting independence; mental health care for people with intellectual disability should recognise the autonomy of individuals with intellectual disability whilst acknowledging their age and capacity, and work in a manner that maximises independence
- Recovery oriented practice; this principle relates specifically to the mental health of the person rather than support for their intellectual disability (Howlett, 2013). Adopting a recovery-oriented approach for people with intellectual disability may require additional effort and resources because of the complexity of supports needed
- Evidence based; decisions made by mental health professionals should be informed by the best available evidence, which can assist in achieving the best possible mental health outcomes.

In particular, the Guide proposes some key components of accessible mental health services (DoDDN, 2014):

- Adaptation of clinical approach including:
 - Preparation for consultations
 - Making 'reasonable adjustments' (e.g. allowing for longer consultations)
 - Effective communication
 - Engaging the person with intellectual disability in decision making
 - Working effectively with family and carers
- Access to mainstream mental health services and typical care pathways
- Availability of specialised intellectual disability mental health services
- Identified care pathways
- Availability of training and education for professionals
- Multidisciplinary approach and inter-agency collaboration
- Data collection, evaluation and reporting
- Inclusion of the needs of people with intellectual disability in policy developments

Two approaches for adapting mainstream services for accessibility to people with intellectual disability are resourcing reasonable adjustments and pathways to care.

4.2 Reasonable adjustments

The first approach is reasonable adjustment to ensure the care received by people with intellectual disability is appropriate and of quality. This approach also aligns with the human rights framework (Section 2.1) that all service provision should be person centred and meet the individual's needs (MacArthur et al., 2015). The Convention on the Rights of Persons with Disabilities states (UN General Assembly, 2007, Art. 3) that 'reasonable accommodation' (i.e. adjustment) means necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms.

Reasonable adjustments are small or significant changes to the way a service or practitioner interacts with a client with intellectual disability in order to make the service suitable for the person. Reasonable adjustments in health services for people with intellectual disability come in many different forms and may include (DoDDN, 2014; Tuffrey-Wijne et al., 2014):

- Making changes to the environment as necessary for example to accommodate mobility or sensory issues
- Allowing for extended consultation and extra time with the client to suit the situation
- Making appointment times that are most appropriate and least distressing for the client
- Adjusting both written and verbal communication styles to suit the capacity of the client
- Being inclusive of, and seeking assistance from, the client's support person.

When making reasonable adjustments it is important that they are tailored to the person's level of functioning and specific needs (DoDDN, 2014). Implementing reasonable adjustments to improve care for people with intellectual disability is crucial for an effective service uptake and for the wellbeing of the client. Research has found that a failure to make appropriate reasonable adjustments in hospital for patients with intellectual disability can lead to poorer outcomes and even contribute to death (Tuffrey-Wijne et al., 2014).

Some barriers can make it difficult to effectively make reasonable adjustments to services, including a lack of knowledge by staff about working with people with disability, difficulty shifting workplace cultures and norms, a lack of support or motivation to make reasonable adjustments from service management due to a lack of awareness and accountability, and a lack of resources and funding to implement changes (Tuffrey-Wijne et al., 2014). One practice to implement reasonable adjustments is through Liaison Nurses who facilitate for access by determining and arranging the reasonable adjustments specific to the person's needs (Section 5.1).

4.3 Pathways to care

The second approach for access to mainstream services is to map out and resource pathways to care. Pathways to care approaches consist of stepped or tiered models of care for people with intellectual disability. Pathways provide an overview and detailed explanation on how the person and carer may access and participate in their care and treatment in health services. They also usually provide a statement of service expectation consumers and carers can expect when accessing health services.

The NSW Health Service Framework (NSW Health, 2012) suggests a tiered approach aimed to reduce health inequalities for children, adolescents and adults with intellectual disability in Australia. It sets out to:

- Establish specialised intellectual disability health services
- Create a centre for clinical leadership, education and training
- Enhance the capacity of the generic health system to meet the needs of people with intellectual disability
- Improve access to health services.

It consists of five tiers:

- Tier 1, 'Strategic health policy and population health', which promotes health and wellbeing in the community
- Tier 2, 'Primary health and community health care', which represents the first point of contact with health services and the pathway to further treatment
- Tier 3, 'Acute health services', including emergency and inpatient services/, which focuses on improving the secondary health care system to care for and manage the additional health care needs of people with intellectual disability who need to access both hospital-based inpatient and outpatient services.
- Tier 4, 'Specialised area/local health services', which refer to services that support primary care services and others by providing advice, assessment, interventions and treatments for complex specialised intellectual disability health needs. There are currently three clinical pilot multidisciplinary services funded for three years in NSW, each of which includes a mental health component. These three pilot services are undergoing formative and summative evaluation by an external body (KPMG).
- Tier 5, 'Specialised regional/state-wide support and clinical leadership', which led to the establishment of the Intellectual Disability Network of the Agency for Clinical Innovation.

Tier 4 and Tier 5 relate to each other and other tiers, forming an integrated framework.

Another example of tiered system, is proposed by Dossetor (2011) with the goal to alleviate some of the difficulties in the provision of mental health services to young people with intellectual disability. Dossetor's (2011) framework is based on the 'holistic model of bio-developmental-psycho-socio-cultural mental health and wellbeing, along with problem solving and collaborative approaches across clinicians and organisation' (Dossetor, 2011, pp. 529-530) (Figure 3).

Figure 3. Tiered pyramid of services for children and adolescents with intellectual disability and mental health problems

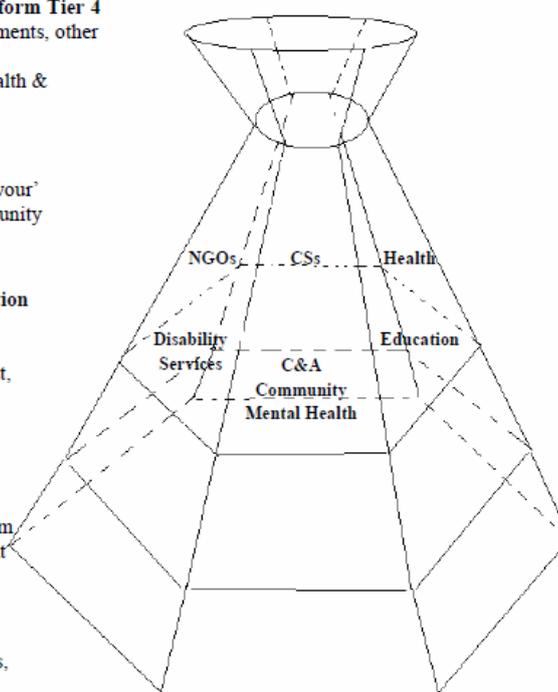
Tier 5: Acute short/medium term interventions that inform Tier 4
Includes: Emergency departments, MH in-patients assessments, other residential behaviour services; and Specialist/Tertiary MH in ID clinicians from mental health & disability services.

The Tier 4 Circle: The Final Common Pathway
Complex case management decision making: 'best endeavour' obligations including decisions about out of family community placements.

Tier 3: Multidisciplinary and Multi-agency Collaboration
Disability Service: ADHC behaviour clinician, speech pathologist, OT, other specialist psychology service;
Health: GP, paediatrician or neurologist; MH Psychologist, SW, family therapist, psychiatrist; and
Education: teacher, aide, school counsellor, principal, behaviour support specialist.

Tier 2: Community Disability Services providing case management and specialist parent training. Mainly from ADHC but can be MH or other agency or non-government organisations.

Tier 1: Generic Health Provision for families
Includes: GPs, community nurses, child community teams, Families NSW, Triple P



3D Model provides for all other human services to be part of the pyramid

Source: Dossetor (2011, p. 538, Figure 25.1)

The five tiers are (Dossetor, 2011, pp. 531-534):

- Tier 1, 'Generic Health Provision', which involves service integration of the mental health needs in general health, education and community services.
- Tier 2, 'Community Disability Service: Case Management And Targeted Prevention Interventions (e.g., specialist parent training)', which involves a first level of specialist disability or mental health clinician with responsibility for case management for the individual/family.
- Tier 3, 'Multidisciplinary And Multi-Agency Collaboration', which, in NSW, may include such agencies as Ageing, Disability and Home Care (ADHC, Department of Human Services NSW), Department of Education and Community (DEC), Department of Health, possibly Mental Health,

Community Services (CS; that provide social and welfare services) and other non-government services.

- Tier 4, 'Complex Case Management Decision Making Model', which entails a cross agency, multidisciplinary management decision making capacity that involves both intellectual disability and mental health specialist expertise.
- Tier 5, 'Acute Short Term Psychiatry Model', which refers to emergency mental health involvement, mental health inpatient assessment and treatment and the input of specialist mental health services of intellectual disability.

5 Specialist services

In addition to approaches within mainstream services, reviewed in section 4, the literature review also identified a variety of approaches to specialist service delivery in the community for people with intellectual disability. The models are reviewed below distinguishing between the type of interagency framework they adopt and their approach to remoteness. Two different models of inpatient care are discussed respectively as a multidisciplinary, centralised model and a multidisciplinary decentralised model. None of the models have been thoroughly evaluated.

5.1 Multidisciplinary, centralised models

The first type of specialised support is multi-disciplinary, centralised models. Five of the reviewed models – the Community Intellectual Disability Services (UK), the Tertiary specialist services (UK), and the Learning Disability Liaison Nurses (UK), person-centred planning, and the model for partnership practice between specialist palliative care and intellectual disability services – are multidisciplinary approaches based on the delivery of services through a centralised service hub. The first two models aim to address the wider health service needs of all people with intellectual disability. The last three models focus on the interactions between health services in three specific life passages: post-school transitions, hospitalisation, and end of life care. Consequently, they are more focused on specific age and service user groups.

5.1.1 Community Intellectual Disability Services (CIDS)

Community Intellectual Disability Services were the first type of services to develop in the UK following the deinstitutionalisation of people with intellectual disability¹, that is the process of replacing large-scale residential facilities for people with intellectual disability with community based living (Young & Ashman, 2004). CIDS consist of multidisciplinary teams that operated as a partnership between primary care health services, social care services and mental health trusts. The multidisciplinary teams include social workers, intellectual disability nurses, physiotherapists, occupational therapists, speech therapists, psychiatrists, psychologists, and community psychiatric nurses. Although CIDS aim to provide a comprehensive and integrated service to clients, they are criticised for continuing the social exclusion of people with intellectual disability and sometimes neglecting the psychiatric aspects of care, in favour of social needs (Sheehan & Paschos, 2013). The service has not been formally evaluated.

¹ In the UK 'intellectual disability' is referred to as 'learning disability' and these two terms will be used interchangeably.

5.1.2 Tertiary specialist services

Tertiary specialist services are multidisciplinary teams similar to CIDS, with the difference that they are targeted specifically at the care of mental health for clients with intellectual disability. In particular, tertiary specialist services have 'clear definitions of their target patient groups, a fixed capacity, and an explicit range of treatments offered' (Sheehan & Paschos, 2013, p. 163). The multidisciplinary teams operate across intellectual disability and general mental health services. Service providers meet regularly to review and respond to the client's needs. They support clients to access generic services while at the same time providing specialised knowledge and expertise.

An explicit aim of the team is to support and promote access to generic services, whilst retaining the depth of knowledge and experience that specialised services can provide (Sheehan & Paschos, 2013). The service has not been formally evaluated.

5.1.3 Learning Disability Liaison Nurses (LDLN)

The Learning Disability Liaison Nurses (LDLN) is a UK program to assist in supporting reasonable adjustments for both clients and staff. Liaison nurses help families to understand and navigate confusing hospital systems and also provide assistance to hospital staff to make reasonable adjustments to provide better care to clients and carers (MacArthur et al., 2015). Additionally, their expertise in the hospital setting regarding policies, laws and systems enables them to know how to best influence the implementation of reasonable and achievable adjustments for clients in a way that overcomes the specific barriers for each individual client (MacArthur et al., 2015). There is also scope for this role to educate the wider hospital organisation through training and mentor support about best practices for people with learning disability, as well as influencing policy and governance (MacArthur et al., 2015).

Brown et al. (2012) conducted a mixed methods study involving four health boards in Scotland with established Learning Disability Liaison Nurses services. The project analysed 323 referrals made over 18 months and qualitative data from interview and focus groups with 85 participants, including patients with intellectual disability, carers, primary care healthcare professionals, general hospital professionals and learning disability liaison nurses. Brown et al. (2012) found that although the four services had subtly different emphases, the LDLN services had three broad dimensions: clinical care (including facilitation of communication, assessment of care needs and promotion of co-ordination of care), education and practice development of hospital staff in relation to addressing the needs of people with intellectual disability, and strategic development (including the development of quality indicators). In particular, Brown et al. (2012) found that the liaison nurse role had seven key elements that were significant within each of the three above mentioned dimensions: advocating, collaborating, communicating, educating,

facilitating, influencing and mediating. Brown et al. (2012) concluded that allied health professionals, clinicians and carers all benefited from the role of liaison nurses and their assistance in supporting or influencing reasonable and achievable adjustments for service users with learning disability in their hospitals.

5.1.4 Person centred planning

Person centred planning is used in health and other social services as an approach that aims to:

put the person with disability at the centre of the planning, listens deeply to them and their family and friends, learns over time what it is they want for their life now and in the future, and then acts on this (DADHC, 2009, p. 7)

The literature suggests that the components of person-centred planning are complex and hard to define and that person-centred processes need to be fully described to permit the attribution of effects to specific components of interventions informed by this framework (Kaehne & Beyer, 2014).

Kaehne and Beyer (2014) undertook a documentary analysis of the nature and content of 44 person-centred reviews of post-school transition planning of young people with intellectual disability in a local authority in the UK. They found that conducting transition review meetings within a person-centred planning framework was associated with higher attendance rates than usual at transition meetings for young people, families and some professionals throughout the project. However, they also found that some agencies, in particular adult social services and employment agencies, were consistently absent at transition review meetings. Kaehne and Beyer (2014) stress that the involvement of post-transition agencies, their flexibility and contribution to planning outcomes is of central importance for how successful review meetings organised within a person-centred planning framework are in producing improved post-school options and hence better choices for service users. Kaehne's and Beyer's (2014) study findings are consistent with previous studies that also proposed that person-centred transition planning can influence outcomes for users only if all stakeholders take part in the review meetings, receive and accept their responsibility to contribute to the future of the young person, and commit to take account of the young person and the families' wishes.

Kaehne and Beyer (2014) also point out that person-centred transition reviews are likely to create new service demands, which services might struggle to meet. They therefore warn against the potential risk that young people are placed into available service structures against their original preferences, if services cannot address their preferences.

5.1.5 Partnership practice between specialist palliative care and intellectual disability services

McLaughlin, Barr, McIlpatrick and McConkey (2014) suggests that despite a strong emphasis in the literature on the need for collaboration between intellectual disability and specialist palliative care services to enable people with intellectual disability to receive quality end-of-life care, there is limited collaboration and partnership practice between them. Based on the findings from a mixed methods study consisting of self-completed questionnaires with a sample of 66 services (Phase 1) and semi-structured interviews with 30 health professionals (Phase 2), McLaughlin et al. (2014) developed a partnership framework for specialist palliative care and intellectual disability services (Figure 4).

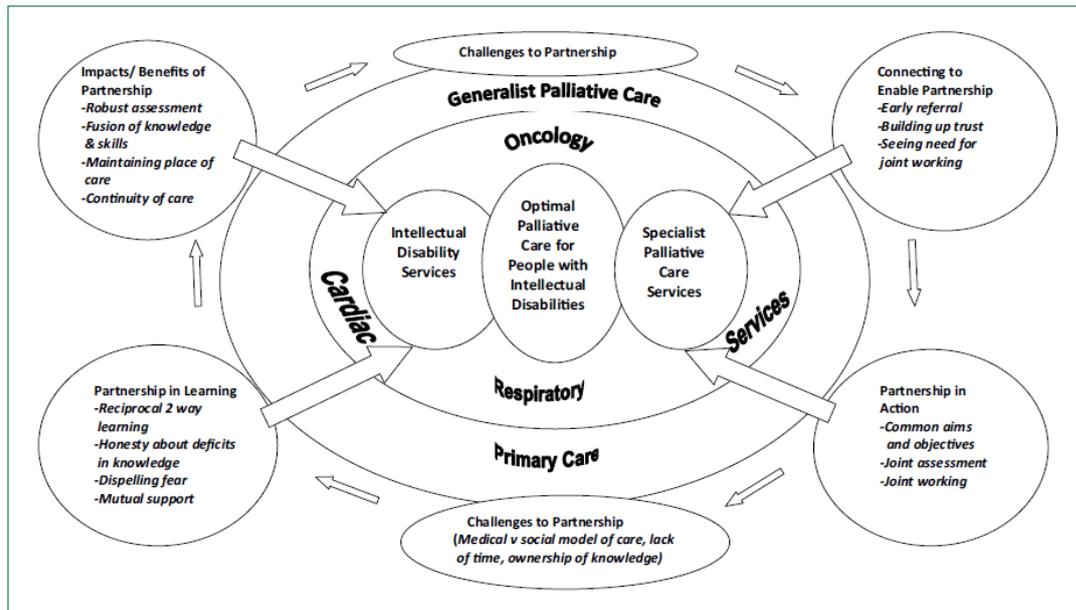
The model adapts the conceptual framework proposed by Boydell, Rugkåsa, Hoggett and Cummins (2007), which depicts a possible pathway of partnership practice between health sectors based on connecting, learning, actions, impacts and barriers (represented by the four circles and two ellipses along the perimeter of Figure 4) and relating to joint working that could impact on health inequalities and further inform collaborative working in palliative care.

The large arrows that point to the core of the model (Figure 4) indicate the provision of optimal palliative care to be delivered to people with intellectual disability and family carers through partnership. Nevertheless, McLaughlin et al. (2014) stress that optimal care requires not only collaborative practice between generalist palliative care services and services for people with intellectual disability, but also support by other specialist services and primary care, including oncology, cardiac and respiratory services.

McLaughlin et al. (2014) point out some key factors that can enable partnership between specialist palliative care and intellectual disability services. The factors include the willingness to learn from each other, trust and respect for the reciprocal roles and skills and more emphasis on interdisciplinary education as an antecedent to collaborative working.

A strength of this study is that intellectual disability and specialist palliative care services contributed to the data collected and informed the emerging framework for partnership practice. This includes over half of the learning disability services in the region in UK.

Figure 4. A framework for partnership practice between specialist palliative care and intellectual disability services.



Source: McLaughlin et al. (2014, Figure 1, p. 1219)

5.2 Multidisciplinary, decentralised models

The second type of specialised support is multidisciplinary, decentralised models. The review found two models that fall into this category: the Hub-and-Spoke model (Australia), which is a multidisciplinary approach based on outreach services and the Birmingham Community Assessment and Treatment Service (England), which integrates assertive outreach, day assessment and inpatient components and is integrated with existing community learning disability teams.

5.2.1 Hub-and-Spoke model

The current model for providing outreach therapy services in regional and rural NSW is the 'hub and spoke' model, whereby the service is located in the hub, a larger regional area, and provides outreach services to spoke towns with limited visits throughout the year. Clinicians are based or reside in or near one of these spoke towns so they are closer to clients and therefore able to engage with the communities, than if they were based in the hub regional town. In turn the services in the hub locations are equipped to provide support to multiple spoke clinicians both administratively, and in terms of professional relationships and development (Dew et al., 2012). However, the barriers impeding this model include staff recruitment and retention, and access to the services for those clients that reside a significant

distance from the spoke town (Dew et al., 2012). An evaluation of the model is not available.

5.2.2 Birmingham Community Assessment and Treatment Service (BCATS)

The Birmingham Community Assessment and Treatment Service (BCATS) is a service for people with intellectual disability and severe mental health needs which started in Birmingham, England, in February 2007 (Richings, Cook, & Roy, 2011). It consists of three components: assertive outreach, day assessment places and inpatient beds.

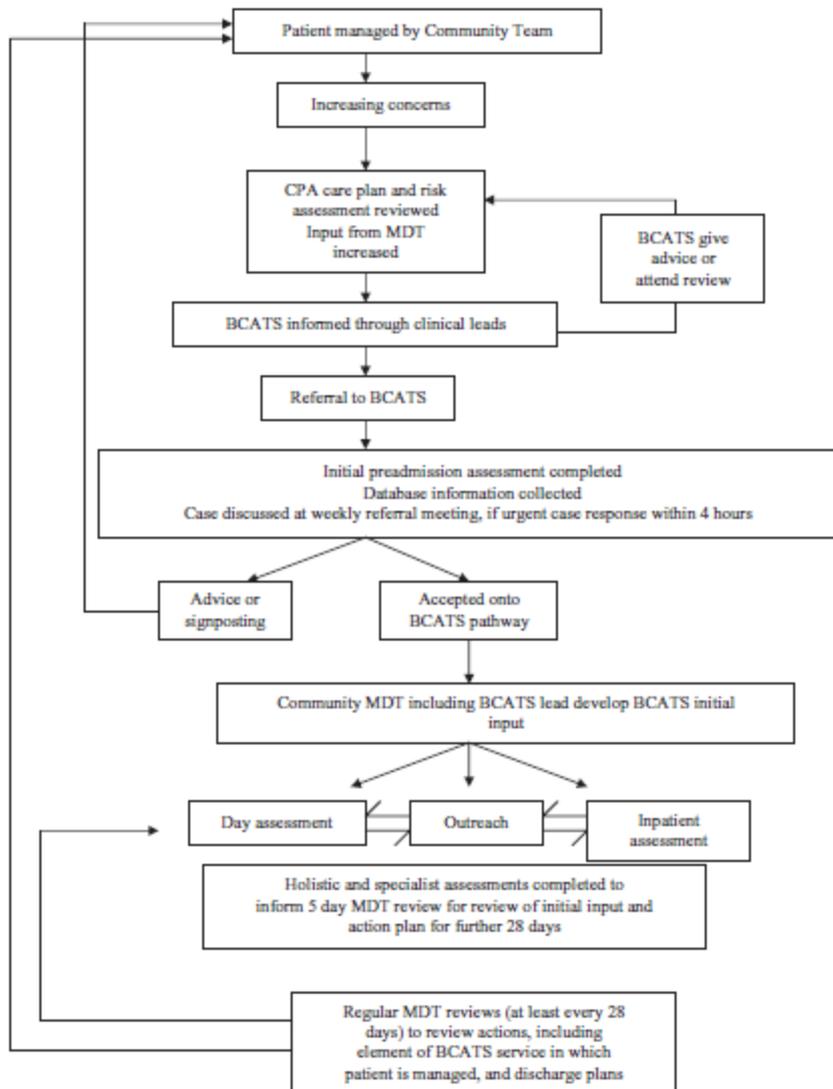
Referrals to the service are made by the clinical lead for the community intellectual disability team (Richings et al., 2011). In order ensure that care plans and risk assessments are up to date, every person referred to the service is on the care programme approach², in receipt of care coordination, and BCATS staff can attend a community intellectual disability team meeting before a referral is made (Richings et al., 2011). Once referrals are made, they are discussed in multidisciplinary referral meetings, including the BCATS team and the clinical leads from the community teams, in which the most appropriate BCATS service component for the client is decided (Richings et al., 2011).

BCATS has six inpatient beds, nevertheless, the BCATS team plays a central role in commissioning new beds and aims to remain involved in the service user's management and to return them to the BCATS service as soon as a bed becomes available (Richings et al., 2011). An occupational therapist, a speech and language therapist and a psychologist have also been appointed to the team; in line with the multidisciplinary nature of BCATS, these professionals oversee the input of their particular aspect of care, coordinate with their disciplines in the community, and provide specialist training to staff in BCATS (Richings et al., 2011).

The BCATS pathway (Figure 5) specifies the assessments which must be carried out and how frequently these should be done, the frequency of multidisciplinary reviews and how outcomes should be measured (Richings et al., 2011). The BCATS pathway was developed in consultation with all professional groups.

² The Care Programme Approach (CPA) is an English national system through which services are assessed, planned, co-ordinated and reviewed for someone with mental health problems or a range of related complex needs (NHS choice, 2015).

Figure 5 The Birmingham Community Assessment and Treatment Service (BCATS) pathway



Note: Source: Richings et al. (2011, Figure 1, p. 11)

Richings et al. (2011) evaluated BCATS based on its utilisation (numbers referred, diagnoses, reasons for referral), the way in which referrals have been managed (outcome of initial assessment, length of BCATS involvement, use of different components of the service and, where applicable, length of inpatient admission), and outcomes (preservation of the service user's original placement, adverse incidents amongst inpatients and HoNOS-LD scores). Over its first two years, the BCATS service managed a higher number of service users than the more traditional inpatient model which it replaced. Richings et al. (2011, p. 15) suggest that 'the use of outreach seems to have prevented admission in 37% and shortened length of stay in a further 28%'. In particular, although lengths of inpatient stay in the first year of operation of BCATS compared very favourably with lengths of stay under the previous model, with time there was a rise in the numbers of service users for whom discharge was delayed, including cases for whom lengths of stay compared to those

seen under the previous model (Richings et al., 2011). However, although the BCATS experienced similar problems to the previous, more traditional inpatient model in relation to agreeing funding and finding suitable alternative placements for service users, it still had the advantage that it could continue to offer assessment, treatment and support even when a bed was not immediately available (Richings et al., 2011)

Richings et al. (2011) concluded that the BCATS model was far more successful than the previous model at preserving community placements. They explained this as a consequence of the fact that:

outreach allows behavioural assessment to be carried out in the service user's own home environment and enables staff from the assessment and treatment unit to work alongside carers, observing their interactions with the service user, modelling new approaches, communicating confidence and improving morale. Lengths of inpatient stay of those admitted under BCATS in its first year compared very favourably with lengths of stay under the previous model (Richings et al., 2011, p. 17)

Finally, Richings et al. (2011: 11) found that the BCATS model was associated with a decrease in the incidence of aggressive incidents in general and of incidents involving physical violence.

Although the evaluation of the BCATS model by Richings et al. (2011) used performance and outcome indicators, it was not based on a theory of change and did not include the perspective of the service users, which the authors acknowledged.

5.3 Interdisciplinary, decentralised models

The final type of specialist support is interdisciplinary, decentralised models. Two of the reviewed models – the 'Fair Horizons' model (UK) and the 'wobbly hub and double spokes' (Australia) – are interdisciplinary models that cater for urban, regional and remote areas. In particular, the 'wobbly hub and double spokes' model is about allied health therapy services, e.g. physiotherapists, occupational therapists, speech pathologists and psychologists, which are delivered by the disability sector, not by the health services. In Australia, allied health professionals either work in the health sector – for example in hospitals, primary health care services, acute rehabilitation services, and private practice – or in the disability sector, for example within government services, non-government agencies, schools, community, and private practice (Veitch et al. 2012, p. 2 of 8). In New South Wales, where the 'wobbly hub and double spokes' model is operated, disability services provide allied health therapy, which is the focus of the model, case management, behaviour support, accommodation, employment, day services, respite care, information and advocacy across the life span to people with a disability. These services are planned, funded and supported by the NSW Government Family &

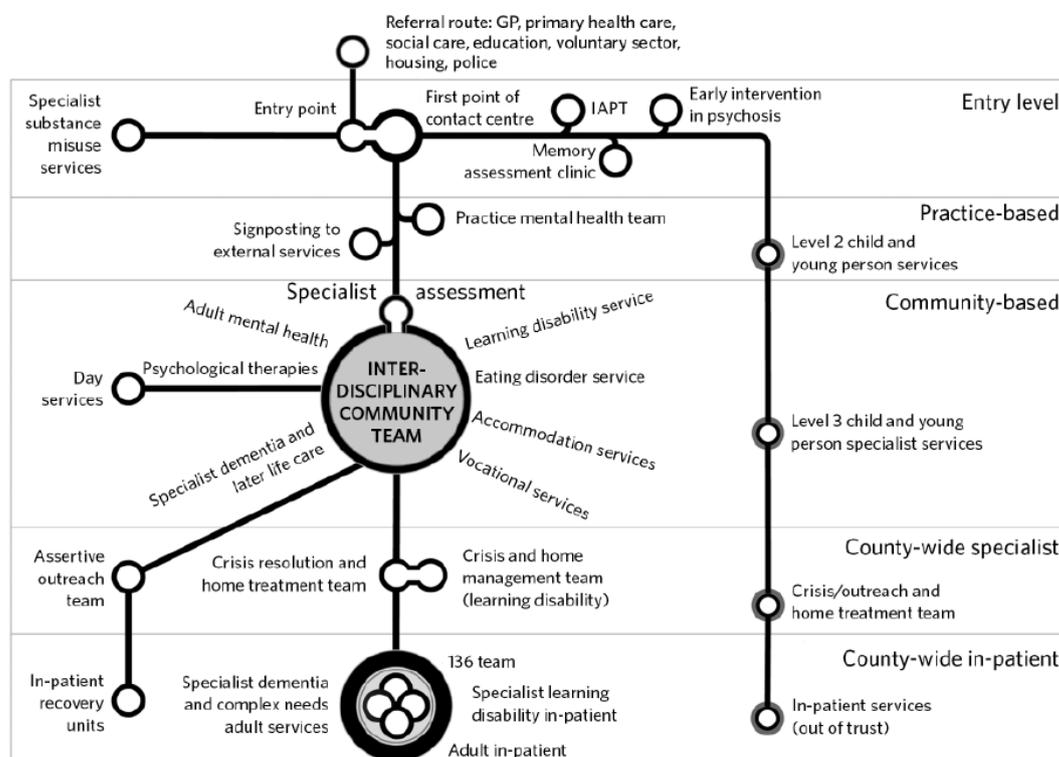
Community Services - Ageing, Disability and Home Care (ADHC), which is ministerially and administratively separate from the state health department (NSW Health) (Veitch et al. 2012, p. 2 of 8).

5.3.1 Fair Horizons model

The Fair Horizons model has been developed in the UK (Fear et al., 2012). It is a person-centred, interdisciplinary model of mental health care for people with intellectual disability. The Fair Horizons model (Figure 6) has one point of entry for the client and follows a number of care pathways depending on their need. Reasonable adjustments are made to tailor the care for each person. In the Fair Horizons model, care is implemented based on the clients' need rather than their circumstances or demographics. This addresses barriers to service access present in other models of care that exclude clients who did not meet their target group, such as older people.

However, Tyrer (2012) points out that the Fair Horizons model remains untested and that there is uncertainty about how far costs this new system will reduce costs. Tyrer (2012) suggests that success with this model is more likely if clinicians are committed to the new service and work harder. The model has not been evaluated.

Figure 6. Fair Horizons organisational model



Source: Fear et al. (2012: 26). IAPT, Improving Access to Psychological Therapies; GP, general practitioner

5.3.2 Wobbly hub and double spokes

To remedy the ongoing issue of access to services for clients who live in very remote areas, the ADHC-Western Region have developed a five-year project implementing a 'wobbly hub and double spokes' service model to people with disability (Veitch et al., 2012). Under this strategy, interdisciplinary clinicians (from any location) form a temporary service team to meet with the clients at a make-shift hub to provide the appropriate consultation and integrated service. 'This enables therapy services to be provided in areas where there are no resident therapists' (Veitch et al. 2012, p. 2 of 8).

This model helps to minimise service gaps and enhances best practice through a collaborative service where services can all see the client at the same time. It also decreases travel time and resources for clinician and clients compared to the alternative models. However, the challenge is that it does not allow for regular consultations as a team or with the client (Veitch et al., 2012). An evaluation has not been published yet.

6 Conclusions

The reviewed models suggest the need for comprehensive and integrated services to people with intellectual disability drawing together aspects of both mainstream and specialist services. Most of the models were developed to address gaps in mental health services, but their approach appears to suggest that their implications can be generalised to other health service needs. The implications are cautious because robust research evidence to support any particular model of service provision is not available.

It seems to be increasingly accepted that generic models of health care for people with intellectual disability are not resourced sufficiently to appropriately meet their needs (Chaplin, 2004, 2009, 2011). Integration of the expertise from specialist services within mainstream services is often presented as potentially the most advantageous approach (Chaplin, 2009; Fear et al., 2012; Howlett, 2013). This approach entails a way of delivering services based on co-operation and integration between generic and specialist teams. The review revealed that some models adopt a multidisciplinary approach to integrating services and teams, while others adopt an interdisciplinary approach. Although both approaches aim to capitalise on the breadth of experience, knowledge and insight of different professionals in addressing health care needs of people with intellectual disability, they show important differences in the way clients access services and are included in decision-making around their care plans.

Further, the research shows that some models require clients travel to the service locations, whereas others support outreach services. There is a growing body of research investigating how the use of telehealth technologies (Glueckauf, 2002; Koch, 2006) can enhance the health service delivery and therefore address some of the issues typical of centralised models. As stated in the NSW Service Framework (NSW Health, 2012), it is important that service provision is flexible and adaptable in order to meet the different and specific needs of people with intellectual disability, particularly those who live in regional and remote areas.

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Appendix A. Search strategies

The literature searches were undertaken in two steps:

- 1) First, we searched (using the Boolean operator OR) all the keywords related respectively to:
 - our study population, i.e. people with intellectual disability (for example intellectual disabilit* OR learning disabilit* OR cognitive disabilit*...);
 - the terms 'model' or 'system'
 - the remit of the literature review, i.e. health services (Table 1).

- 2) Second, we combined the keywords related to each thematic group in Table 1 with each other, using the Boolean operator AND, as in the following example:
Population keywords and Models keywords AND Specific focus keywords

No keywords for outcomes were included in order to keep the searches as inclusive as possible.

The keywords were searched as Subject Headings, where available, and in all fields of PsycINFO and MEDLINE in order to get an idea of the amount of literature available. If needed, searches were limited to Titles and Abstracts. The searches covered from January 2011 to January 2015.

Table 2 reports the MeSH terms that were searched in CINAHL and Medline.

Relevant literature was identified by tracking references and authors names from the retrieved papers and from the papers obtained through personal contacts.

The titles and abstracts of the studies and publications identified were screened based on their relevance in relation to the review objectives. In case of uncertainty on the relevance of specific references, these will were discussed with the client.

Table 1. Groups of keywords

Thematic groups	Keywords
Population	intellectual disabilit*/disorder*/retard*, learning disabilit*/disorder*/difficult*/retard*, mental retard*, cognitive disabilit*/disorder*, intellectual developmental disability*/disorder*, acquired brain injury (limited to people <18), developmental delay/ disabilit*/disorder*
Models/Systems	Model*, system, framework*, program*, platform*, protocol*, strategy/strategies, scheme*, blueprint, pattern*, pathway*, process*, route, step*, plan, road map, practice/practise, diagram, flow-chart, diagnos*, screening, assess*, networks, networking, escalation, connectedness, hub-and-spoke, integration, integrated
Specific focus	Health (including allied health), service* (including social service, specialist and generalist), care (including social care, primary care, acute care and tertiary care), hospital, inpatient, health promotion, health prevention, early intervention, person-centred, partners in care, tertiary, tiered, access*, challenging behaviours, recovery, communication, key worker

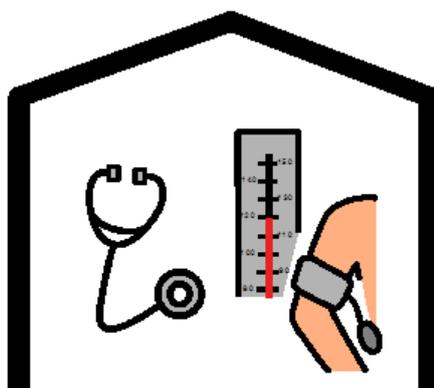
Note. The asterisk symbol (*) implies that different word ending variations will be searched.

Table 2. MeSH terms searched in CINAHL and Medline

Thematic groups	CINAHL	Medline
Population	(MM "Intellectual Disability+") OR (MM "Learning Disorders+")	Intellectual Disability/
Models/Systems	(MM "Nursing Models, Theoretical+") OR (MM "Models, Structural+") OR (MM "Models, Theoretical+")	Community Health Services/ or Community Mental Health Services/ or Models, Organizational/
Specific focus	(MH "Patient Centered Care") OR (MM "Continuity of Patient Care+") (MM "Multidisciplinary Care Team+") OR (MM "Health Services Needs and Demand+") OR (MH "Transcultural Care") OR (MM "Patient Care Plans+") (MH "Health Care Delivery, Integrated") OR (MM "Health Care Delivery+") OR (MM "Nursing Care Delivery Systems+")	"Delivery of Health Care, Integrated"/ or Primary Health Care/ Health Services Accessibility/ or "Delivery of Health Care"/ Patient-Centered Care/

Appendix B. Easy Read report

What do we already know about health services for people with intellectual disability?



What is this report about?



The Social Policy Research Centre was asked to find out about different types of health services for people with intellectual disability.



Health services include people who help you when you are sick or help you with your body or mind. For example:

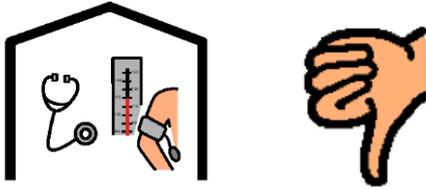


- Seeing a doctor
- Seeing a nurse
- Seeing a counsellor
- Seeing a therapist, for example, a speech therapist (for talking and eating)
- Going to hospital
- Seeing a team of different people who help with your health



The report is to make sure that health services for people with intellectual disability can keep on getting better.

Why is this report important?



This report is important because often people with intellectual disability do not get good health services. Sometimes it is hard to get in or doctors or nurses don't know how to help them.

But people with intellectual disability have a right to good health services, so it is important to find out how to make the services better.

Some people with intellectual disability find it even harder to get good health services than other people:



- Children and young people



- People who also have mental health problems



- People who live in rural or remote areas (areas outside the city)



- Aboriginal and Torres Strait Islander people

Mainstream services



Sometimes people with intellectual disability use the same health services as people without disability.

This is called using 'mainstream services'.

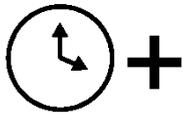
Reasonable adjustments



Sometimes mainstream services need to be changed a little bit or a lot to make them better for people with intellectual disability.

This is called making 'reasonable adjustments'.

A reasonable adjustment could be:



- Extra time for the appointment



- Giving easy information



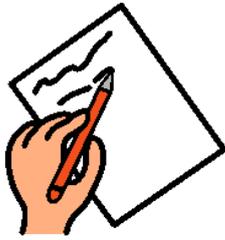
- Letting a person that the person with intellectual disability trusts to also come to the appointment

Pathways to care

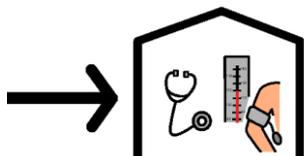


Sometimes it is not clear how people with intellectual disability should use mainstream services.

It might be hard for them to get in or hard to know how to take part.



When this happens, sometimes there is a plan for how they will use health services. The plan is called a 'pathway to care'.

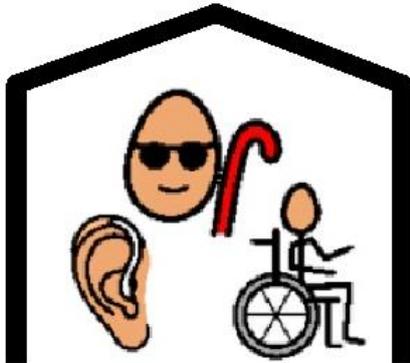


The 'pathway to care' plans for:

- How to get in to the health service
- How the person with intellectual disability can take part in managing his or her own health
- How a person the person with intellectual disability trusts can also take part



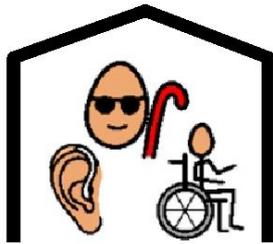
Specialist services



Sometimes people with intellectual disability use health services that are just for people with intellectual disability.

This is called using 'specialist services'.

Different types of specialist services



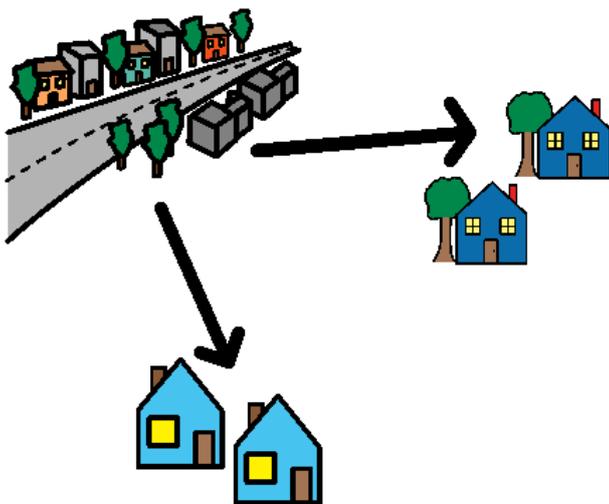
There are different types of specialist services.



- Sometimes a team of different people who know about intellectual disability work together to look after someone's health. This could be a team of doctors, nurses, therapists and other staff.



- Sometimes there is one nurse in a hospital who teaches all the other doctors and staff about people with intellectual disability. The nurse can also teach people with intellectual disability and families about health or about what to do in hospital.



- In rural or regional areas (outside the city), sometimes doctors, nurses, therapists or other staff work from one big town and help people in all the other little towns around the big town.

Sometimes it is a team of different people working in the big town.

Sometimes it is just one person working in the big town, but that person knows how to look after lots of different areas of health.

There are also specialist services that focus on particular issues:



- Person-centred services for young people with intellectual disability – these are about putting the young person first



- End of life services for when people with intellectual disability die



- Outreach services for helping people with intellectual disability stay in their own home

What now?

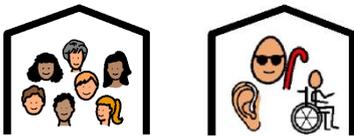


It is important that health services for people with intellectual disability keep on getting better.

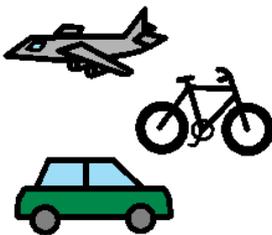


The next steps are to:

- Find out what types of health services work best for people with intellectual disability



- Think about how mainstream services and specialist services can work together



- Think about what will help health services to work better, for example, more resources or helping people with intellectual disability travel to the health services

This report is an Easy Read version of the following main report:

Giuntoli, G, Newton, B., Fisher, K.R. (2015). *Current models of health service delivery for people with intellectual disability – Literature review* (SPRC Report 12/2015). Sydney: Social Policy Research Centre, UNSW Australia. Available from:

https://www.sprc.unsw.edu.au/media/SPRCFile/SPRC_Report_Current_Models_of_Health_Service_Delivery_for_People_with_Intellectual_Disability.pdf

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