

Evidence Check

Capacity building and intellectual disability health services

An **Evidence Check** rapid review brokered by the Sax Institute for
the NSW Ministry of Health. October 2017

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This report was prepared by:

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Executive summary

This report presents the findings of an Evidence Check on capacity building and intellectual disability health services. The NSW Ministry of Health commissioned the University of Technology Sydney (UTS) Faculty of Health's Centre for Health Services Management to conduct a rapid review that sought to identify and analyse the available evidence on methods to improve the capacity of healthcare services and systems to respond to the needs of people with intellectual disabilities (PWID).

The Evidence Check was conducted in three phases. Phase 1 was essentially a proof of concept search to identify whether there was enough evidence available to proceed. Phase 2 was a systematic scoping review including a primary analysis of any existing reviews addressing the provision of healthcare to PWID. The third phase is a review and analysis of single studies not covered by the preceding reviews and of the grey literature from selected countries. This report provides an analysis of a meta review of 35 systematic or comprehensive literature reviews identified in the first phase of the project. The research team cross-checked the remaining studies with the reviews, identifying 35 studies that were included and an additional 69 that were not. These additional studies were reviewed separately for this report along with an overview of the grey literature.

There is abundant evidence of the higher health risks and lower quality of care provided to PWID. There is also universal acknowledgement of the limited amount of research available that address strategies for the improvement of healthcare for PWID. The evidence that is available, however, points to several potential areas of capacity building, including structural responses, role definitions and development, communicative strategies, clinical, ethical/research and environmental responses.

The provision of adequate care to PWID is complex because of both the complexity of many intellectual disability conditions and a longstanding failure to respond adequately to the needs and concerns of individuals that have them. As a result, any form of capacity building requires a holistic systems approach that acknowledges the shortfalls — and potential improvements — at every point of interaction with health systems and services.

There is continued tension between the development and provision of specialists and generalist services. This tension does not arise out of an either one-or-the-other paradigm, rather it emerges from an understanding that due to the current shortfall in service provision and the preferences of PWID, both will be needed. Areas of particular focus in the literature are: palliative care; sexual and reproductive health; preventative and cancer screening; and mental and forensic health services. There is a continued need for the evaluation and capacity building in children's services, both generalist and specialist.

A clear starting point, therefore, is the mapping of exemplar journeys to identify individual, group and systems vulnerabilities both for PWID in general and for specific individuals with intellectual disabilities (ID), for example, those with dual diagnoses, pregnant women and older people. This mapping process also provides a way of understanding the current and changing roles of support staff (ie paid assistants) and carers for PWID, and their own interactions with healthcare systems.

System capacity building is necessarily based on organisational and individual capacity building. Structural responses, such as the creation of liaison officers for PWID were amongst the most commonly cited responses, although the implementation and efficacy of such roles is still open to debate. A consistent recommendation was for the development of specific assessment tools, guidelines and care plans for clinicians working with PWID, as well as appropriate information and communication tools for PWID, support staff, carers and family members. At the core of the use of such tools is improved understanding

and relationships between PWID and clinicians. This relationship building also requires a commitment to the engagement of PWID, and their carers and families in research, service planning and policy development.

The introduction of the National Insurance Disability Scheme (NDIS) will have impact on how PWID's access and utilise healthcare services. The specific role, responsibilities and rights of support staff within the hospital context remains largely unexplored but will need to be considered in the near future.

Physical and organisational environments have a particular significance for PWID. The need for safe spaces cannot be underestimated as a way of both reducing fear of health interventions for PWID and managing potentially challenging behaviours.

Background

In June 2017, the NSW Ministry of Health (MoH) commissioned the University of Technology Sydney (UTS) Faculty of Health's Centre for Health Services Management (CHSM), to complete an Evidence Check review that sought to identify and analyse the available evidence on methods to improve the capacity of healthcare services and systems to respond to the needs of people with intellectual disabilities (PWID).

Review questions

The review aimed to address the following questions:

Question 1: What strategies/approaches/interventions have been shown to be effective in building capacity in a health system for people with intellectual disability and special needs?

Question 2: What strategies/approaches/interventions have been shown to be effective in building capacity in health workforce for people with intellectual disability and special needs?

This Evidence Check report commences with a background section that contextualises health systems responses to PWID. It then summarises the search method, synthesises the key empirical and thematic findings, and highlights the policy-relevant implications in the discussion based on a meta review of 36 systematic or comprehensive literature reviews identified in the first phase of the project. The review team cross-checked the remaining studies with the reviews, identifying 35 studies that were included in the reviews, and an additional 69 that were not.

Context

This Evidence Check was and is not intended as a review of the healthcare needs of PWID per se. It is important, however, to briefly establish the context¹ within which this review and the MoH's goal of contributing to the improvement of state-wide healthcare service provision is to be understood. In this background section three issues are addressed: locating the study within the larger program of work undertaken by NSW MoH with PWID; a very brief overview of the health needs of and provision of services to PWID; and, the establishment of and impact from the National Insurance Disability Scheme (NDIS).

Definition

For the purposes of this review the definition of "carer" is in accordance with the Carer (Recognition) 2010 Act NSW (pg 3), which states:

"(1) ... a person is a carer if the person is an individual who provides ongoing personal care, support and assistance to any other individual who needs it because that other individual: (a) is in the target group (as referred to in section 5 (1) of the Disability Services Act 1993), or (b) has a medical condition (including a terminal or chronic illness), or (c) has a mental illness, or (d) is frail and aged.

(2) Despite subsection (1), a person is not a carer for the purposes of this Act in respect of care, support and assistance that the person provides: (a) under a contract of service or a contract for the provision of services, or (b) in the course of doing voluntary work for a charitable, welfare or community organisation, or (c) as part of the requirements of a course of education or training.

(3) To avoid doubt, a person is not a carer of another person for the purposes of this Act merely because the person: (a) is the spouse or de facto partner of the person, or (b) is the parent, guardian, child or other relative of the other person, or (c) lives with the other person."

It should be noted, however, that the nomenclature is not consistent nor clear across either the Australian or international literature. A variety of terms are utilised to denote the fiduciary relationship, for example *paid* versus *unpaid* carer (which is in contradiction to the definition provided by the NSW Act).

The terms become more confusing when legal rights and responsibilities are considered within a healthcare setting. For example, clearly not all (unpaid) carers are family members, and not all family members (or carers) have legal guardianship of the individuals for whom they are caring, whereas some court appointed non-family members may.

Throughout the review the Carer (Recognition) 2010 Act NSW definition of carer was used wherever possible and appropriate. In a small number of instances, however, it was more accurate to retain the specific term used in an article (such as *paid carer*), even though this is not the agreed usage in NSW.

NSW strategies to improve access to health services for people with intellectual disabilities

Over the last six years MoH has implemented a number of strategies intended to improve people with intellectual disabilities' access to health services. As well as the development of the Intellectual Disability Network (IDN), auspiced by the Agency for Clinical Innovation (ACI), the MoH established three specialist Intellectual Disability Health Team pilots. The pilots are being conducted at St George Hospital in South Eastern Sydney Local Health District (LHD) and the Disability Services Unit at Cremorne in Northern Sydney LHD, and in a new unit at Fairfield. The MoH describes the aims of the pilots as:

- Building the capacity of health services to provide specialist care for these patients
- Improving the integration of specialist services for patients with an intellectual disability with mainstream services
- Testing and enhancing the capacity of public health services to provide a coordinated, multidisciplinary approach to providing health services to patients with intellectual disability
- Building the overall capacity of the NSW public health system to provide appropriate and quality care to patients with intellectual disability.

Key issues in the provision of healthcare for people with intellectual disabilities

A recent paper by Weise et al.² on the provision of primary health care to PWID found that in line with previous research, *"People with an intellectual disability (ID) have more complex and different patterns of health care needs than the general population. They experience a greater burden of multi-morbidity, high levels of undetected and unmanaged health issues, and premature mortality than the general population."*

The risk of premature death for PWID increases with the severity of the intellectual disability³, and differs according to age and gender⁴. Common causes of death for PWID include, a lack of control of cardiovascular risk factors, epilepsy and dysphagia, lack of screening and/or management of thrombotic and colorectal risks⁵, respiratory and nervous system illnesses⁶, among numerous other preventable or ameliorable conditions.⁷ As Trollor et al.⁶ found, PWID have "... much higher proportions of potentially avoidable deaths than people without ID" with "[p]otentially avoidable deaths in people with ID ... dominated by deaths due to infections, diseases of the circulatory system, cancer and other external causes."

Significant differences have been found between the types, lengths and problems managed, medications and treatments provided, and referrals for PWID and people without them. While (primary care) consultations were found to be longer and with more problems managed in the Weise et al.² study, consultations were more likely to be addressing administrative issues rather than clinical treatments. PWID typically experience under-management of common health conditions, fewer procedural treatments, medications and "delays, difficulties or differences"⁶ in referrals and access to specialist services or specific interventions.^{2, 6} Additional contributing factors to higher mortality in PWID are a lack of adjustment to care as individuals' needs changed and providers not listening to their family.⁸ People with mild, non-syndromic ID are at particular risk of lower levels of care.⁵

Similar issues have been identified in tertiary care. Tuffrey-Wijne et al.⁹ found that along with a lack of involvement of family members, safety risks for PWID in hospitals most often related to errors involving omission of care and treatment compounded by both a lack of hospitals' recognition of the needs of PWID and shared and appropriate care protocols, and an inability or unwillingness to make reasonable adjustments to interventions.

While PWID continue to have a higher premature mortality rate than the general population, their average life expectancy is rising.^{4, 10, 11} As a result, there is an increasing number of carers (largely family members) who are themselves ageing with complex health issues.^{12, 13}

National Disability Insurance Scheme

It is impossible to understand the delivery of any type of service to people with disabilities (PWD) in Australia without acknowledging the current and potential impact of the National Disability Insurance Scheme (NDIS). The NDIS was established with the specific purpose of changing the delivery of specialist disability care and support to people with profound or severe permanent disabilities in Australia. At the core of the scheme is the belief that individuals should have choice and control over the support and services they receive. The scheme applies insurance principles to the cost of services and funding is said to be determined by individual needs (rather than through a fixed budget).¹⁴

As a result of this personalised (or individualised) approach, the NDIS may have an impact on when, which, and how services are provided. As noted by the Productivity Commission's latest report *"The National Disability Insurance Scheme (NDIS) is a complex and highly valued national reform. The scale, pace and nature of the changes it is driving are unprecedented in Australia. If implemented well, it will substantially improve the wellbeing of people with disability and Australians more generally."*¹³

As of March 2017, close to 100,000 people were enrolled in the NDIS. People with autism (28%) and intellectual disability (37%) are the largest disability groups and comprise almost two thirds of current scheme participants. Approximately 44% of all participants are under 14 years old (of these, 45% are on the autism spectrum and 34% have an intellectual disability, including developmental delay).¹³ The Productivity Commission noted that there was a higher prevalence of autism than had been expected across all NDIS trial sites but that intellectual disability was much higher in some sites than others. Although no single reason for this discrepancy has been identified, the Commission suggests that the rates may in part be due to the non-representative populations within the trial sites.¹³

As Trollor et al.⁶ note, the roll-out of the NDIS will bring with it both *"increased choice and control for people with ID and their families"* and the need for an increased level of awareness and attentiveness from health providers and support staff. Given the higher levels of morbidity and mortality of PWID, and the greater risks of inadequate, inappropriate or unsafe care, they argue that it is *"critical that the need for feeding and swallowing assessments, and awareness of vulnerability to infections and respiratory conditions [as well as all other higher risk conditions and procedures] are recognised, and that services are readily accessed and appropriately prioritised by people with ID and their carers under the NDIS."* As a result, there needs to be strong focus on integrated service delivery, and cross sector collaboration and coordination, to ensure that PWID have access to and are able to use safe, high quality services.

Methods

This Evidence Check proceeded through three phases. Phase 1 was essentially a 'proof of concept' search to identify whether there was enough evidence available to proceed. Phase 2 was a systematic scoping review including a primary analysis of any existing reviews addressing the provision of healthcare to PWID. The third phase was a review and analysis of single studies not covered by the preceding reviews and of the grey literature from selected countries.

Phase 1: proof of concept

The original search terms provided by the Sax Institute and used to scope for relevant papers are listed in Table 1, below.

Table 1: Scoping review search terms provided by Sax Institute

Scoping review search terms
Cognitive disability
Cognitive impairment disability
Communication disorder
Communication impairment
Complex communication needs
Developmental disability
Intellectual disability
Intellectual handicap
Intellectual impairment
Learning difficulty
Learning disability
Mental handicap
Mental retardation

A scan of outputs indicated that a number of these terms produced a reasonable number of appropriate studies and a large number of extraneous studies. For example, 'communication disability' was predominantly focused on children with speech and or language deficiencies, while 'cognitive impairment' held a focus on dementia, stroke and Alzheimer's disease, and 'mental retardation' primarily produced papers written before 2006 (as 'disability' has replaced 'retardation' as preferred language).

Phase 2: systematic scoping review

After discussion and agreement between the researchers, the Sax Institute and the MoH, a broad initial search was performed using Cochrane, Medline, PsycINFO and CINAHL, combining 'intellectual disability' with '2006-2017' and 'English language' delimiters. The search was designed to identify any systematic reviews relating to PWID, which could then be further reviewed for elements that addressed capacity

building in health. There was no need to cross-check for 'health' or 'healthcare' because of the scope of the databases searched. The search rationale was as follows:

- 'Intellectual disability' produced the most relevant results and covered the widest range of appropriate papers so, for phase one, the focus was shifted to identifying all relevant papers associated with this term with the objective of reviewing them for any references to service delivery or improvement
- By downloading all the references associated with 'intellectual disability' the researchers could scan each record for both direct and indirect references for capacity building in healthcare services, without needing prior identification of the most relevant cross-referenced terms for 'capacity building' (e.g. 'organisational development', 'policy', 'quality improvement' etc.).

On 17 June 2017, the review team conducted a search of the MEDLINE, Cochrane, CINAHL and PsycINFO databases restricted to English language papers published between 2006 and 2017. The team downloaded references into an EndNote library. Once duplicates were removed (3,552) 23,980 articles remained.

The team downloaded these references into the EndNote library and independently examined the results. Owing to the large number of papers identified, papers were restricted to studies conducted in, papers written in, or reviews involving evidence from Australia, New Zealand, Canada and the UK. This allowed for comparison between healthcare systems as they are largely similar in these countries. This restriction produced 7,253 papers, including papers published in Australia and New Zealand (1,162), Canada (525) and the UK (5,436). Of the references identified as published in the UK, 3,844 focused on countries outside the UK; namely Taiwan, South Africa, the United States and China. The final review list included 3,410 results.

Inclusion/exclusion criteria

The review team developed inclusion criteria, restricting papers to those focused on capacity-building and health service delivery. The majority of the papers the review team collected focused on diagnosis, treatment and prevalence. These were excluded as they provide little insight into capacity-building strategies and, therefore, do not meet the inclusion criteria. As the focus of the review is to identify research on interventions for capacity building, book chapters, book reviews, commentaries, pictorials and opinion pieces were also excluded. The remaining papers included reviews, studies and research papers.

Papers with no author or those that were irrelevant to the review (e.g. friendship studies, research on employment opportunities, criminal justice system articles and results of exercise programs) were excluded. The three reviewers discussed any uncertainty regarding inclusion or exclusion of articles until consensus was reached.

This resulted in the exclusion of 2,933 references, screened according to title and abstract. After reviewing titles and abstracts against the exclusion criteria once again, 161 papers remained. These were read in full to determine their eligibility, and categorised into 'systematic reviews', 'empirical studies' and 'other' (i.e. book reviews, opinion pieces and commentaries). A manual secondary search of the references of the reviews produced nine additional papers that were not identified in the initial search.

A total of 170 relevant references remained. Once the 'other' category and references that were not directly relevant to the primary review question (i.e. studies that addressed only training or the health status of PWID) were excluded, a total of 140 remained. Most of these could be sub-categorised into four types: attitudes of health services staff to people with intellectual disabilities; delivery of health services by service type (i.e. primary or tertiary care, with the bulk relating to mental health services); studies of client, carer or family preferences or expectations of services, which may provide insights into healthcare delivery; and, studies of sub populations (e.g. people with ID who are young, elderly, homeless).

A total of 36 reviews were included in this report. The remaining studies (n=104) were cross-checked with the reviews, identifying 35 studies that were included in the reviews, and an additional 69 that were not.

The search also produced many papers that, though not integral to the final review, provided insight into the unmet needs, health status and experiences of people with intellectual disabilities accessing and utilising the hospital system. This gave an excellent background to the topic and elevated understanding of the nuances of the area, with the most relevant included in the background section of this report. A flow diagram of the search process, criteria and outcomes is provided in Figure 1 on the next page.

Data extraction and analysis

The systematic reviews underwent data analysis. Once the systematic review articles met the inclusion and exclusion criteria, data were extracted and entered into an Excel spreadsheet under the following columns: author(s) and year of publication; topic and scope (aim); date range included in searches; language limits for searches; location; databases and or other sources of data; number of studies; finding; conclusion and recommendations (if any); and, type of review (i.e. narrative, systematic, scoping or Cochrane).

The authors of a majority of the review articles described them as 'systematic reviews' (n=22). However, in some cases they did not report certain elements of the search strategy, such as range of years reviewed or the total number of studies identified within scope, as indicated in Table 1. Several studies did not specify whether they limited the search to studies in certain countries, as they presumably searched the international literature.

The 69 additional studies were reviewed separately, comparing categories and themes identified in the systematic reviews and those identified in the grey literature. Additional themes were extracted and, after discussion, added to the review if the findings added to the depth and the breadth of those identified in the systematic review.

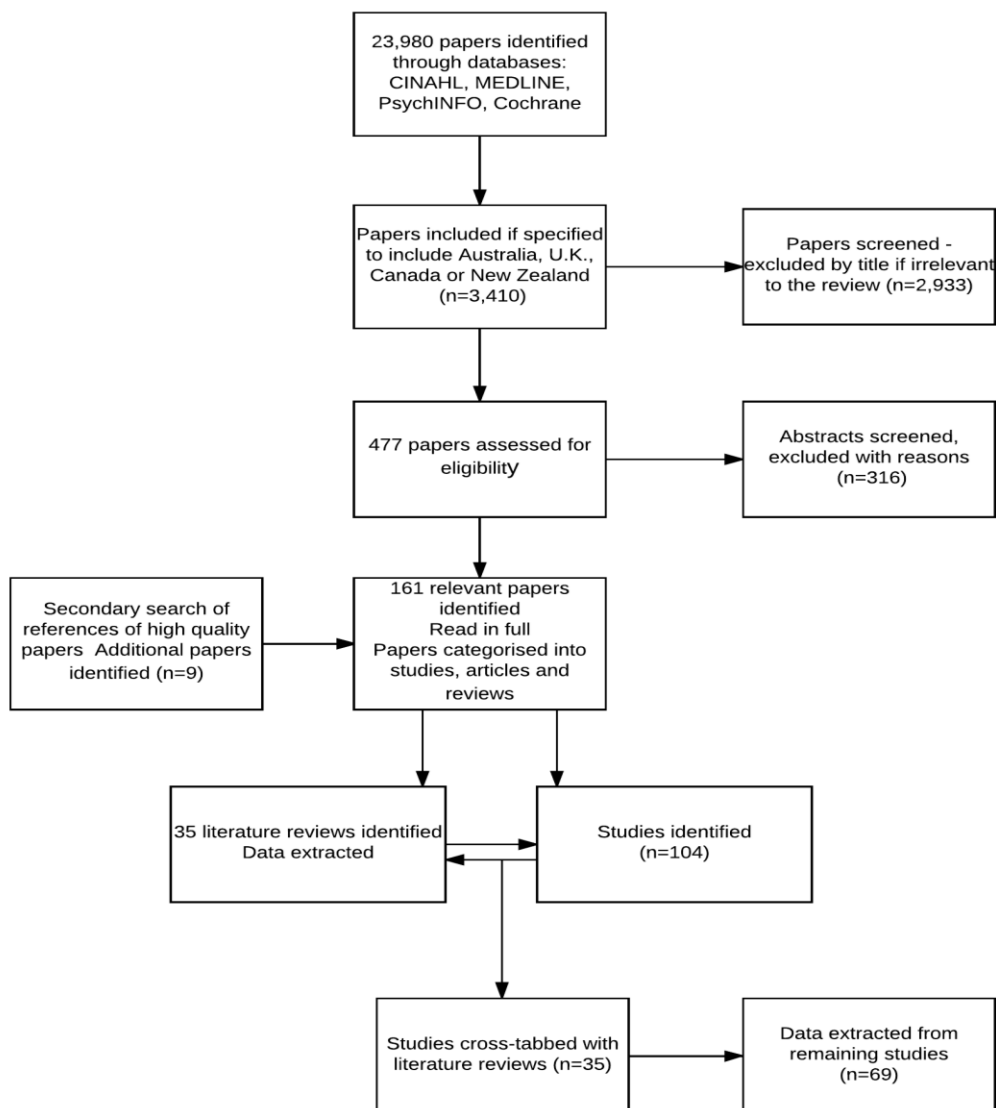


Figure 1: Results of Evidence Check

Results

Overview of systematic reviews

Table 2 summarises the components of each of the systematic reviews identified in this report. Text is italicised when quoted directly from the original source. Where authors have not specified the timeframe for the search, we have indicated the earliest and latest years of included studies in square brackets. Of the 35 systematic review papers, only one was a Cochrane Review.¹⁵ As that review noted, “... *there are currently no well-designed studies focusing on organising the health services of persons with an intellectual disability and concurrent physical problems. There is an urgent need for high-quality health services research to identify optimal health services for persons with an intellectual disability and concurrent physical problem.*”¹⁵ There are, however, indications in existing reviews of potential areas for capacity building supported by very recent individual studies that provide insight both into the barriers and potential solutions in this field (e.g. Trollor et al.)⁶

Table 2: Literature reviews (n=35 phase one search results)

Author Year	Scope	Date Range	Location	Databases	Studies	Findings	Recommendations/ Conclusions	Type of Review
Adshead, Collier and Kennedy. 2015	To explore whether mental health nurses are being appropriately prepared to care for learning disabled patients who also suffer from mental ill health	2001 – 2013	UK	CINAHL, Medline, ERIC, PubMed, Scopus	N=13	Staff attitudes affect quality of care delivered, and positive attitudes can be cultivated through increasing student contact with PWID. There is mixed evidence as to the favourability of generic or specialist services. While patients accessing specialist care often stay longer in hospital, their care is more comprehensive. There is a need for education for pre-registration nursing students, about mental health and other learning disability fields	Further research is required on education needs at pre-registration and post-qualifying levels. This could improve the delivery of mental health services to this group	Systematic review
Backer, Chapman and Mitchel. 2009	To identify studies on experiences of secondary healthcare for PWID	Jan 1990 – Mar 2008	UK	CINAHL, MEDLINE, PsycINFO, AMED, BNI, EMBASE, HMIC	N=13	Experience of care was affected by individual factors including the carer's role; the attitudes, knowledge and communicative style of health staff; and the physical environment. More research is needed, given that so few studies are published in this area.	Creation of specific teams that aim to improve access to secondary healthcare for PWID ID liaison nurses in general hospitals to provide direct care, support to carers and education for other providers, and also to extend roles Improved communication – 'positive discrimination' – e.g. special GP referral forms, accessible info to prepare PWID for hospital admission	Narrative review

Author Year	Scope	Date Range	Location	Databases	Studies	Findings	Recommendations/ Conclusions	Type of Review
						Initiatives to improve access to secondary healthcare need to be evaluated to inform the development of services	Improved physical facilities, e.g. side waiting rooms, adaptations to physical hospital environment Education, guidance and training for staff Support for carers, to acknowledge their role, to develop trust in the system, and to foster positive relationships	
Bakken and Sageng. 2016 ¹⁷	To summarize empirical mental health nursing studies including adults with intellectual disabilities and additional mental illness	1970 – 2013	Europe. US, Australia, New Zealand	Cochrane Central Register of Controlled Trials, Medline, PsycINFO, CINAHL	N=16	Although there are different needs for each group, the function of nursing for PWID and mental health issues are the same as for the general population with mental health issues	Interventions should target symptoms, not just behaviour. It is important to examine the impacts of the cognitive level on symptoms. More knowledge about effective nursing interventions is imperative to develop strategies for better mental health nursing for PWID. Nurse-patient communication research is vital	Systematic review
Balogh, McMorris, Lunskey, Ouellette-Kuntz, Bourne, Colantonio and Gonçalves-Bradley. 2016	To assess the effects of organisational interventions of healthcare services for the mental and physical health problems of PWID. This paper is an updated version of a 2008 review by the same authors	April 2006 – Sept 2015	UK/US	MEDLINE, CINAHL, EMBASE, PsycINFO, Cochrane Library (Cochrane Database of Systematic Reviews, Database of Abstracts of Reviews of Effects, Central Register of	N=7	There is uncertainty as to whether increasing intensity and frequency of service delivery decreases behavioural problems and there is little or no influence on carer burden. Community-based behavioural therapy may decrease behavioural problems	There is very limited evidence on the organisation of healthcare services for PWID. There are currently no well-designed studies focusing on organising the health services of PWID with concurrent physical problems. There are very few studies of organisational interventions targeting mental health needs; existing results need corroboration. There is an urgent need for high-quality health services research to identify optimal health services for PWID with concurrent physical problems.	Cochrane review

Author Year	Scope	Date Range	Location	Databases	Studies	Findings	Recommendations/ Conclusions	Type of Review
				Controlled Trials, Health Technology Assessment Database, National Health Services- Economic Evaluation Database, Methods)			Organisational interventions may improve health outcomes of persons with a dual diagnosis; however, this review found insufficient evidence to guide policy decisions to optimise services in different jurisdictions	
Bradbury-Jones, Rattray, Jones and MacGillvray. 2013	To identify the influences on the health, safety and welfare of adults with learning disabilities in acute hospitals	2000 – 2011	UK and Australia	Medline, PsycINFO, BNI, CINAHL	N=8	6 areas for improvement identified: care provision, communication, staff attitudes, staff knowledge, supporters and carers, and physical environment. Implications for research, policy and practice in terms of fiscal investment, and education and training	Improvement strategies should reflect the multi-faceted nature of influences on improved health service provision. Adults with ID should be supported to make decisions about their own care. They should also be involved with policy development, nurse education and research. Practical strategies include involving PWID in nursing education through informed input and in research as 'co-investigators'	Narrative review
Byrne, Lennox and Ware. 2016	To systematically review the effectiveness of primary healthcare interventions intended to increase health actions for PWID	1997 – 2010	Australia, England and Wales	PubMed, CINAHL, Web of Science, The Cochrane Database of Systematic Reviews Library, The Cochrane Central Register	N=5	Interventions reviewed: <ul style="list-style-type: none"> Health Checks: which prompted significant increases in health actions Health Diaries (held by PWID): alone did not significantly increase in health actions 	There is little information on how health outcomes can be improved in this population group, although health checks can improve outcomes. Recommends further research into long-term health outcomes as a result of these health checks, as well as strategies for their effective implementation	Systematic review and meta-analysis

Author Year	Scope	Date Range	Location	Databases	Studies	Findings	Recommendations/ Conclusions	Type of Review
				of Controlled Trials, EMBASE		<p>although they were effective when used in combination with health checks</p> <ul style="list-style-type: none"> Health Prompts: showed no significant differences 		
Chaplin. 2011	To summarize recent research into psychiatric services for adults with intellectual disabilities, with a particular focus on inpatient care	2004 – 2008	Not stated	MEDLINE, PsycINFO, EMBASE Psychiatry, CINAHL.	Not stated	<p>There is ongoing debate on whether specialised or generic services are preferable, as outcomes vary.</p> <p>PWID present with more severe problems than others, and receive more interventions in psychiatric units.</p> <p>Some general psychiatric inpatient units have a poor standard of care.</p> <p>Supported generic inpatient units have reported successful outcomes.</p> <p>Length of stay in specialised psychiatric units is not significantly longer than in general units.</p> <p>Delayed discharge and</p>	<p>Often PWID have negative experiences when accessing healthcare environments, so delivery of services needs to be adjusted to address this.</p> <p>The studies conducted offer a limited scope of results, and a more widespread base would more accurately demonstrate whether the results can be generalised</p>	Literature review

Author Year	Scope	Date Range	Location	Databases	Studies	Findings	Recommendations/ Conclusions	Type of Review
						restrictive practices need to be addressed. Some centres still struggle with emergency psychiatric care provision		
Cox, Dube and Temple. 2015	To review studies evaluating whether staff training influences client challenging behaviour, to identify emerging patterns, knowledge gaps and make recommendations for future research on this topic	Jan 1997 – July 2013	Not stated	Academic Search Complete, CINAHL, Child Development and Adolescent Studies, PsycINFO, Family and Society Studies Worldwide, Master FILE Premier, Mental Measurements Yearbook, PubMed, Social Work Abstracts, Teacher Ref. Centre	N=19	This study examined training interventions to address challenging behaviour. Positive behaviour support interventions resulted in decreased challenging behaviour. Active support appeared to achieve its purpose of 'increasing engagement in meaningful activity'. However, it also somewhat increased challenging behaviour post-training. Crisis-prevention and response training did not measurably increase staff confidence or challenging client behaviour. Communication program training, though initially decreasing challenging client behaviour, did not maintain this result longer term	Existing research should be extended to further develop these packages and maximise their utility value. Further research into effective staff training packages should also be conducted	Systematic review
Emerson and	To summarise the	Not	UK	Not stated	Not	Barriers to healthcare	The health inequalities faced by PWID are	Systematic

Author Year	Scope	Date Range	Location	Databases	Studies	Findings	Recommendations/ Conclusions	Type of Review
Baines. 2011	most recent evidence from the UK on the health status of people with learning disabilities and the determinants of the health inequalities they face. Update of search originally undertaken in 2002	stated			stated	services access include: scarcity of services, physical and environmental barriers, eligibility criteria, lack of reasonable adjustments to services, communication difficulties, lack of availability of interpreters forPWID from ethnic communities, lack of expertise/education for staff, 'diagnostic overshadowing' and mistaken attribution of other symptoms (ie. mental health) to ID	not only clear and measurable, but avoidable. By examining the determinants of these inequalities, solutions and strategies can be formed to address them	review
Goddard, Davidson, Daly and Mackey. 2008	To document the needs of this vulnerable population, and to consult with mothers of children with disabilities and with professionals working within disability services for people with an intellectual disability and their families.	1985 – 2006	Australia	Medline, CINAHL, PsychLit	Not stated	There has been a positive shift in health service delivery, particularly with the departure from institutionalisation. PWID are more likely to have more complex health issues and mental health issues. Healthcare for PWID is one of the most neglected areas, and PWID remain vulnerable in the hospital	Strategies to improve services include: a positive policy platform; improving the knowledge of health care workers including nurses (which will, in turn, improve outcomes); governance and monitoring systems to ensure the wellbeing of PWID; additional support to carers of children with ID and a greater focus on ID issues in the research arena. Investing in further research will serve to alleviate personal, carer and societal burden in this area	Narrative review

Author Year	Scope	Date Range	Location	Databases	Studies	Findings	Recommendations/ Conclusions	Type of Review
						<p>system.</p> <p>Barriers to adequate provision include:</p> <p>uncertainty of condition;</p> <p>providers dealing with the presenting problem instead of the overall issue;</p> <p>lack of 'health literacy';</p> <p>complexity of the system;</p> <p>paucity of funding; and</p> <p>stigma in planning services.</p> <p>The health of caregivers is also negatively impacted when caring for PWID, although not usually regarded as a 'burden' by the carer</p>		
Griffiths, Bennett and Smith. 2009	To provide an up-to-date empirical assessment that confirms that the evidence base for learning disability nursing practice remains limited in quality, extent and quantity	1996 – 2006	Not stated	Cochrane, Medline, PsycINFO, EMBASE, CINAHL, BNI	N=180	<p>There is strong research to suggest that learning disability nurses are essential in mediating between PWID and general health care services.</p> <p>There is a paucity of studies specifically on interventions delivered by these nurses themselves</p>	<p>Predominantly, studies in this area have been conducted as to the health status of PWID. Studies on relatives and centred on the experience of these groups, particularly parenting experiences and the interaction between care service responses and family member experiences. Research focused on nurses centred on education, knowledge and nursing experiences.</p> <p>There is insufficient research into the area of specific disability nurse practice to appropriately evaluate interventions for and in practice</p>	Systematic review
Hemm,	To locate, extract	[1996 –	UK and	MEDLINE,	N=13	Major themes:	Despite increased focus on improving	Systematic

Author Year	Scope	Date Range	Location	Databases	Studies	Findings	Recommendations/ Conclusions	Type of Review
Dagnan and Meyer. 2015	themes from and evaluate the current literature that had assessed the training needs of mainstream health professionals within this area	2010]	Australia	PsycINFO, CAB Abstracts, Scopus, Web of Knowledge		Prioritising communication; Training, to improve knowledge about the specific needs of PWID in the healthcare system, including profession-specific e.g. training for GPs in diagnosis, or psychiatrists in mental health service delivery; Increasing knowledge to equip staff to support clients by improving understanding of client consent; Adapting management strategies to cater to the needs of PWID	health service delivery for PWID in recent decades, they still face barriers to adequately accessing and utilising the healthcare system. These barriers can be addressed by providing appropriate, needs-based training to health care providers	review
Hithersay, Strydom, Moulster and Buszewicz. 2014	To review carer-led health interventions in various populations and healthcare settings, to investigate potential roles for carers in ID health care	[1996 – 2013]	US, UK, Australia, Belgium, Netherlands, Italy, Iran	Scopus + citation-tracking	N=24	Interventions were often poorly adhered to. Use of a health diary or profile (completed by carers) were well-received by PWID, carers and healthcare professionals. However, they were not used by a significant number of the people they were designed for. Developing parenting and	There is a paucity of research in this area and generalisation of findings is difficult as the interventions studied were diverse. However, carer-led interventions have had a somewhat positive effect for PWID. Screening, monitoring and health promotion were implemented in a range of healthcare settings. Including PWID and carers in further research may better inform strategies for improving healthcare services through a stronger adherence to carer-led	Systematic review

Author Year	Scope	Date Range	Location	Databases	Studies	Findings	Recommendations/ Conclusions	Type of Review
						life skills improved nutritional health for PWID, though there was no significant increase in parent knowledge after the intervention. Some studies indicated that improving parent knowledge has no effect on behavioural outcomes. Carer-led interventions were no more helpful than the current interventions for symptom management. Screening proved a 'promising example' with carer input reducing clinician time without impacting on reliability. Carer interventions for people with dementia were beneficial to the client while not increasing anxiety or burden for the carer	interventions	
Homeyard, Mont- gomery, Chinn and Patelarou. 2016	To identify and review the existing evidence on the provision of antenatal care among women with intellectual	1980 – May 2014	UK, Australia, Ireland, Sweden	EMBASE, Medline	N=16	Women with intellectual disabilities were viewed as 'unsuitable mothers'. Many experienced negative responses to their pregnancy and professional advice	There are gaps in the evidence relating to the experiences of pregnancy and antenatal health service provision by women with ID, as well as nurse and midwife perspectives. Information should be more accessible. Although most research focuses on parenting or	Systematic review, narrative synthesis

Author Year	Scope	Date Range	Location	Databases	Studies	Findings	Recommendations/ Conclusions	Type of Review
	disabilities					<p>included suggestions of termination. There were limited advocacy and ineffective or inadequate communication of helpful resources.</p> <p>Negative encounters indicate a lack of understanding about the nuances of ID.</p> <p>Care and communication was often 'about them, without them'.</p> <p>Women with ID experienced 'usual' emotions when pregnant, mainly excitement and happiness.</p> <p>Midwives have a responsibility to provide antenatal care for women with ID, but there is mixed evidence of midwife attitudes.</p> <p>Midwives struggle delivering information 'at the right level' and may need additional specialist education/resources to enhance knowledge about</p>	<p>mothering for people with ID, this review presents important information about experiences before birth</p>	

Author Year	Scope	Date Range	Location	Databases	Studies	Findings	Recommendations/ Conclusions	Type of Review
						women with ID and pregnancy. The research base focuses on parenting, as opposed to pregnancy. Women with ID often feel 'disempowered' by the carer and provider reactions to their pregnancy		
Iacono, Bigby, Unsworth, Douglas and Fitzpatrick. 2014	To conduct a content and quality review of research into the acute hospital experiences of both people with intellectual disabilities and their carers, and to identify research gaps	1990 – 2013	Australia	Medline, CINAHL, EMBASE, Sociological Abstracts, PsycINFO	N=16	Themes identified: Negative attitudes from hospital staff Limited knowledge and education about caring for PWID despite continued recommendations for training Fear when entering hospital settings Continued reliance on parents/family/carers People from culturally diverse backgrounds are at risk of additional discrimination	PWID continue to face barriers and inequalities in the healthcare system. The recommendations made by Mencap (ie. learning disability liaison nurses) have not been implemented in hospitals, indicating limited capacity to provide these services accounted for in policy. Further research is needed to identify and address gaps in health service provision, as well as the barriers to the implementation of the recommendations made in multiple studies	Systematic review
Innes, McCabe and Watchman. 2012	To critically evaluate the available research literature on aging among people with an intellectual disability	1990 – 2011	UK, Australia, US, Ireland, Israel, Canada,	PsycINFO, Web of Knowledge, CINAHL, Medline, EMBASE,	N=42	Accommodation issues: concerns about current/future accommodation for both PWID and their carers; issues with transitioning	The needs of older PWID are not being met by the current system for several reasons: the lack of accommodation, limited specialist knowledge amongst staff, and the view of retirement that is not conducive with the models of care –	Systematic review

Author Year	Scope	Date Range	Location	Databases	Studies	Findings	Recommendations/ Conclusions	Type of Review
			Taiwan, Belgium	Sociological Abstracts		between services Aging issues: different understandings of aging; population aging means aging of the population of PWID; changing and developing needs. Unmet needs include: accessibility issues i.e. funding, transport; anxiety when entering hospital settings; need for ongoing support; specialist services vs. generalised services	particularly day services – offered	
Jacobs, Downie, Kidd, Fitzsimmons Gibbs and Melville. 2016	To review the literature on mental health services for children with learning disabilities, to identify known models of service provision and what has been experienced as effective or challenging in providing good services	–> 2013	UK, US, Australia, Canada, South Africa, Greece, the Netherlan ds, Serbia, Bulgaria, Mexico, Italy and Germany	PsycINFO, Medline, EMBASE, Social Care Online	N=34	Children with ID often face barriers to accessing mental health services; there is some evidence that this is also related to ethnicity. Different models of care were evaluated. However, there is little to no evidence on the best and most appropriate model. Some parents feel that services provided to their children are inadequate. However, parents do report positive experiences	Services need to be developed to address the high rate of mental health issues among children with ID. The current services are inadequate, and cannot appropriately meet the needs of this population group	Systematic review

Author Year	Scope	Date Range	Location	Databases	Studies	Findings	Recommendations/ Conclusions	Type of Review
						<p>with the mental healthcare system, citing the 'small personal things' as having a great impact on their service utilisation.</p> <p>There is limited information on where to get help, making service access overwhelming for children and parents.</p> <p>The lack of resources poses barriers in effective service delivery (for staff)</p>		
Jenkins. 2012 ¹⁸	To review the research that investigates the role of nurses in meeting the needs of older PWID	1990 – 2011	UK and Ireland	CINAHL, EMBASE, PsycINFO, ASSIA, MEDLINE	N=11	<p>It is unclear what role nurses will be adopting in response to the aging of the population of PWID and their changing needs. Nurses working in this area require extended skills and knowledge, in order to adapt to these changing needs</p>	The population of PWID is ageing, and they are therefore likely to increasingly require nurse services. The limited research into the role of nurses in this area is problematic as evidence is essential to inform appropriate interventions. More research needs to be conducted, as much of the literature in this area is based on opinion, rather than research	Literature review
Lewis, Gaffney and Wilson. 2017	To describe how nurses experience caring for people with intellectual disability in an acute care setting	2006 – 2015	UK, Australia, Canada, the Netherlands	Medline, CINAHL, Web of Science, PsycINFO, Cochrane	N=14	<p>Nurses feel unprepared when caring for PWID. A lack of training contributes to negative attitudes and interactions with PWID.</p> <p>Disability Awareness Training seems to improve care provision.</p> <p>Pre-registration training</p>	<p>It is evident that nurses need better education, training and resources when delivering services to people with intellectual disabilities.</p> <p><i>"The enablers of and barriers to the delivery of nursing care in acute care settings need to be made explicit and researchers and nurses need to collaborate in the</i></p>	Narrative review

Author Year	Scope	Date Range	Location	Databases	Studies	Findings	Recommendations/ Conclusions	Type of Review
						<p>appears efficacious; it is difficult in practice to train nurses while they are working.</p> <p>Nurses experience communication barriers and believe that communicating with PWID is time-consuming. They are also unsure of their 'capacity to understand' the communication, resorting to stereotypes of PWID.</p> <p>Nurses have 'ambiguous expectations' of paid/unpaid care-givers, expecting them to provide additional support for their patients while in hospital. However, these expectations are often not met, leading to inadequate care</p>	<i>development, implementation and evaluation of care delivery strategies."</i>	
McKenzie. 2011	To address the question: what do evaluations of models of service provision for individuals with an	1990 – 2010	UK	Ovid, PsycINFO, EMBASE, AMED, Medline, Global Health, ISI	N=7	In-patient units can form a beneficial solution to community placement breakdown by providing acute support for people with specific healthcare	Services must be improved to better accommodate challenging behaviour. However, there is not one clear model for best care. Specialist care appears to use a more restrictive approach, with limited impact on reducing challenging behaviour.	Systematic review

Author Year	Scope	Date Range	Location	Databases	Studies	Findings	Recommendations/ Conclusions	Type of Review
	intellectual disability who display challenging behaviour indicate about best practice for this client group?			Web of Knowledge, Web of Science, CINAHL, Social Policy and Practice		<p>needs. However, the multitude of mixed needs in these units can aggravate challenging behaviour. One study found limited evidence of benefits.</p> <p>Peripatetic support levels take a behavioural approach to addressing challenging behaviour, with strategies e.g. on-site staff training and evidence-based practice.</p> <p>The limited evidence suggests this approach is effective, as perceived by both staff feedback and tangible outcomes.</p> <p>Community and volunteer partnerships proved effective at promoting staff and care-giver skills, although there were barriers to their efficacy.</p> <p>Despite a focus on training, staff felt unprepared when working with PWID and challenging behaviour.</p> <p>Guidance was provided, but rarely employed practically</p>	To address the gap in literature, further research into the impacts of different care models on behaviour should be conducted	

Author Year	Scope	Date Range	Location	Databases	Studies	Findings	Recommendations/Conclusions	Type of Review
Nguyen, Lennox and Ware. 2014 ¹⁹	To summarise evidence concerning the use of HHHRs (Hand-Held Health Records) with individuals with ID	1980 – August 2013	UK, Australia	Medline, CINAHL, Scopus, Web of Science	N=7	HHHRs promoted more discussion about health needs between PWID and those involved in caring for them. There was no short-term measureable benefit for service provision, though PWID and their families did see HHHRs as beneficial	The development of HHHRs may alleviate some of these barriers in accessing health care, such as recall, comprehension and consent difficulties	Systematic review
Osugo and Cooper. 2016	To synthesise the evidence on psychological, pharmacological and electroconvulsive therapy (ECT) interventions for adults with mild intellectual disabilities and mental ill health	1945 –>	Not stated	Medline, Embase, PsycINFO, CINAHL	N=16	There is a paucity of evidence in this area. Many conditions that need pharmacological interventions have few or no studies involving PWID requiring evidence from RCTs and follow-up to assess long-term efficacy. Although there is stronger evidence for the effectiveness of group cognitive-behavioural therapies on symptoms of depression, evidence is limited and needs follow-up. This also applies to exercise and behavioural interventions. This raises an ethical	RCTs of mental health management interventions for PWID should be a priority. The studies that indicated positive outcomes should be followed up	Systematic review

Author Year	Scope	Date Range	Location	Databases	Studies	Findings	Recommendations/ Conclusions	Type of Review
						<p>concern: should interventions be implemented if there is little or no evidence of effectiveness?</p> <p>Most evidence-based interventions are adopted from studies involving people <u>without</u> ID.</p> <p>Hopefully in future there will be more studies involving PWID to evaluate measures</p>		
Pelleboer-Gunnink, Van Oorsouw, Van Weeghel and Embregts. 2017	To stimulate inclusion in mainstream healthcare services, this systematic review focussed on barriers in attitudes of mainstream health professionals towards people with ID	1994 – 2016	UK, US, Australia, Canada, New Zealand, Sweden, India, Netherlands, Italy	PubMed, PsycINFO, CINAHL, ProQuest	N=30	<p>Limited knowledge by healthcare service providers leads to fear, anxiety and a lack of confidence in treating PWID. In addition to health knowledge they lack general unfamiliarity about PWID – what they do, what they like, how they live. There are conflicting attitudes in the healthcare system towards PWID and different expectations of their capabilities. Stigma surrounding PWID and their capabilities creates stereotypes which poses barriers to adequate</p>	Stigmatising attitudes towards PWID appeared to be present among mainstream health professionals, causing challenges to inclusion in mainstream healthcare services. Recommendations include contact and collaboration with experts- by-experience in education programs of health professionals. Future research should progress beyond descriptive accounts of stigma towards exploring relationships between cognitive, affective and behavioural dimensions as pointers for intervention. Finally, inclusion would benefit from an understanding of 'equal' treatment that means reasonable adjustments instead of undifferentiated treatment	Systematic review

Author Year	Scope	Date Range	Location	Databases	Studies	Findings	Recommendations/ Conclusions	Type of Review
						<p>health service provision.</p> <p>There is 'insufficient support of autonomy'.</p> <p>PWID are treated differently within the health system.</p> <p>There is consensus that PWID should be able to access adequate services in the mainstream system.</p> <p>However, providers can perceive PWID as a burden owing to their time-consuming and often complex cases</p>		
Phillips. 2012	To explore the unmet needs of people with learning disabilities in hospitals and to identify best practice	1990 – 2010	UK, US, Australia	Cochrane, PsycINFO, BNI, CINAHL, Medline, TRIP+	N=14	<p>Being in hospital often creates anxiety in PWID. Staff have negative attitudes toward PWID, and feel less confident about treating them.</p> <p>There is a lack of adequate resources and adaptations in the physical hospital environment.</p> <p>Carers play an immensely positive role in alleviating stress for PWID in hospitals and ensuring that they receive the best care</p>	<p>Pre-admission visits to hospital to familiarise the person with the setting and alleviate anxiety.</p> <p>Education and training for hospital staff.</p> <p>Acknowledgement of the importance of carers.</p> <p>Adjustment of the physical environment of the hospital to better cater for PWID.</p> <p>Learning Disability Liaison Nurses</p> <p>These recommendations are reasonable adjustments, and are consistent with the legal requirements of the Equality Act 2010. The issues and inequalities have been clear for years, and should be</p>	Literature review

Author Year	Scope	Date Range	Location	Databases	Studies	Findings	Recommendations/ Conclusions	Type of Review
						possible. However, carers often feel that they are placing a burden on staff if they leave the hospital. The relationships between carers and hospital staff need to be strengthened.	urgently addressed	
Ratti, Hassiotis, Crabtree, Deb, Gallagher and Unwin. 2016	To evaluate the effectiveness of Person-Centred Planning (PCP) on outcomes for individuals with intellectual disabilities across the age range	1990 – 2014	US, UK, Canada, New Zealand	PsycINFO, Embase, CINAHL, PubMed, Web of Science, Scopus, Medline	N=16	<p>PCP resulted in:</p> <ul style="list-style-type: none"> • Significant positive impact on community participation; • Moderate positive impact on quality of life, participation in activities and everyday choice-making; • No apparent improvement in problem behaviour or adaptive functioning; • No apparent improvement in participants' self-determination. <p>This indicates that although more involved in making everyday choices, PWID still do not have significant control over the wider decisions that affect their lifestyles or care. One study found a</p>	There is some evidence as to the positive effect of PCP on outcomes, and it can be shown to have an 'enriching' impact on the quality of life of PWID. However, there is also evidence to the contrary, though the reasons for this have been much discussed. More research into this area should be conducted	Systematic review

Author Year	Scope	Date Range	Location	Databases	Studies	Findings	Recommendations/ Conclusions	Type of Review
						negative impact of PCP, although this may be due to carers becoming more aware of health problems, as opposed to new issues emerging. This might also explain the decrease in life satisfaction scores identified by another study. This may indicate that PCP uncovers unseen problems, rather than creating them		
Robertson, Baines, Emerson and Hatton. 2015	To summarise research on service responses to people with intellectual disabilities and epilepsy	1990 –>	UK, US, Australia, Canada, Ireland	Medline, CINAHL, PsycINFO, Web of Science	N=35	There were no large-scale studies or randomised control trials, with most research focused on small, qualitative papers. There is a lack of access to specialist services and specialist nurses despite this being the predominant recommendation of many papers. Overall, there is little evidence of the efficacy of any approaches, although many have been proposed, their impact is yet to be evaluated.	The current studies focus on expanding the research base for these issues. This area is under-researched, and must be addressed to provide effective improvement strategies through evidence-based implementations. Further research into this area will equip services with the necessary skills in delivering adequate care to people with ID and epilepsy	Systematic review

Author Year	Scope	Date Range	Location	Databases	Studies	Findings	Recommendations/ Conclusions	Type of Review
						There is a need for staff training and education programs, particularly in delivery of medication to people with a dual-diagnosis of ID and epilepsy		
Robertson, Hatton, Emerson and Baines. 2014	To update a previously published review summarising evidence on the efficacy and impact of health checks on the health and well-being of people with intellectual disabilities	1989 – 2013	UK, US, New Zealand, Australia	Medline, CINAHL, Web of Science, PsycINFO	N=48 8 articles + 2 reports added to previous review (2010)	Health checks were beneficial in identifying previously undiagnosed health needs. Health checks led to specialist referrals, increased screening and further tests. Health checks are generally acceptable to PWID. There are also positive impacts for support staff, e.g. reported increases in knowledge, confidence and experience. Health checks provide GPs with an increased awareness of health needs for PWID, as the studies show that often GPs have a warped idea of the health disparities between people with and without ID. The long-term benefits of health checks are unclear.	New studies support the initial finding that health checks are received well by PWID and their carers. Communication with PWID should be improved to create positive associations with hospitals, instead of anxiety-inducing ones	Updated systematic review

Author Year	Scope	Date Range	Location	Databases	Studies	Findings	Recommendations/ Conclusions	Type of Review
						<p>The updated review identifies previously undetected barriers, e.g. communication, staff levels and skills, access to equipment and nursing management</p> <p>The updated review also highlighted the implications that health checks have on the wider audience, more than on an individual level, in identifying gaps in experience/ knowledge</p>		
Robertson, Hatton, Baines and Emerson. 2015	To provide an overview of recent systematic reviews on the health or health care of people with intellectual disabilities and to identify gaps and strengths in the coverage of these reviews	2008 – 2013	UK, Europe, North America, Australia	Cochrane Library, Database of Abstracts of Reviews of Effects, Medline, CINAHL, EMBASE, PsycINFO, Web of Science	N=94	<p>PWID are largely excluded from research conducted on mainstream/generalised health services. There is no tangible reason for this exclusion, as most studies would easily accommodate with some adaptations.</p> <p>There are challenges when conducting research into the experiences of PWID, particularly RCTs, including obtaining consent and conducting intervention</p>	Thus far, mental and behavioural disorders have formed the focus of the literature in this area. This has been very little research in relation to physical conditions. The evidence base in this area needs to be expanded, as the research done is either of insufficient methodological quality or quantity to draw accurate conclusions	Systematic review

Author Year	Scope	Date Range	Location	Databases	Studies	Findings	Recommendations/ Conclusions	Type of Review
						research across multiple sites with limited professional expertise in engaging PWID. Often intellectual disabilities are not properly identified in large-scale research, or not included enough to make accurate comparisons in the data		
Ryan and Scior. 2014	To review research on medical students' attitudes to people with intellectual disabilities. The attitudes of medical students warrant empirical attention because their future work may determine people with intellectual disabilities' access to healthcare and exposure to health inequalities	→ 2013	UK, US, Australia, Ethiopia, Canada, China	EMBASE, Ovid MEDLINE, PsycINFO, Scopus, Web of Science	N=24	There were mixed results in the studies reviewed. In some studies, medical students showed positive attitudes toward PWID, and were eager to see more inclusion in the healthcare system Some studies indicated that medical students were reluctant to work with PWID, although one of these is over 20 years old. Level of experience impacts student attitudes Proposed strategies: <ul style="list-style-type: none"> • More research to identify effective interventions to improve attitudes • Intergroup contact theory interventions 	Teaching and training are likely to improve the attitudes of medical students when addressing people with ID. More research into attitudes, and the effect thereon of education and training, should be conducted	Literature review

Author Year	Scope	Date Range	Location	Databases	Studies	Findings	Recommendations/ Conclusions	Type of Review
						<ul style="list-style-type: none"> Research into the association between student attitudes and the attitudes of their supervisors Opportunities for medical students to gain experience and work directly with PWID, which may reduce stigma in the training stages 		
Salvador-Carulla and Symonds 2016 ²⁰	To summarize research on healthcare utilization and costs for persons with intellectual disabilities/intellectual developmental disorders with a particular focus on context studies for evidence-informed policy	2011 – 2015	Canada, Spain, Taiwan, the Netherlands, US and the UK	Not stated	Not stated	<p>PWID have many unmet needs but are less likely to use generic services or to access health promotions. PWID and comorbid mental disorders have the highest rates of specialized service use, costs, and unmet needs. Intellectual disability has a high impact on the total direct health costs of mental disorders in Europe. Burden-of-illness studies show conflicting results when assessing PWID</p>	There are large gaps in the research of burden-of-illness and cost-of-illness in this area, which makes it harder to draw conclusive results. This may be compounded by the lack of international agreement on the naming, classification, and severity grouping of ID, particularly in comparison to other 'mental disorders'. This could be streamlined to produce more comprehensive results. The creation of 'evidence-informed policy' is hindered by the current lack of evidence	Narrative review
Taua,	To examine literature	2000 –	New	Proquest,	N=21	The complexities of a DD	PWID are, evidently, more prone to mental	Literature

Author Year	Scope	Date Range	Location	Databases	Studies	Findings	Recommendations/ Conclusions	Type of Review
Hepworth and Neville. 2012	on the role of the nurse caring for people with a dual disability (DD) of mental illness and intellectual disability	2010	Zealand	CINAHL, OVID, EBSCO Health Source, Medline, PsycINFO		<p>obstruct the delivery of health services, particularly owing to communication barriers between staff and patients, and the sometimes challenging behaviour of those with DD.</p> <p>There is evidence to support both generalised and specialised care models.</p> <p>Most current literature on mental health service provision for PWID is low quality.</p> <p>Hospitals are often unequipped to deal with patients with a DD, and lack adaptations to cater to specific needs.</p> <p>There are few specific DD-focused nurses, and nurses often feel inadequately prepared to deal with these patients</p>	illness. However, there is insufficient and 'erratic' evidence on effective service provision to this population group. Nurses need adequate training and education in this area, as they are the most frequent points of contact for PWID accessing the health system	review
Venville, Sawyer, Long, Edwards and Hair.	To investigate the following question: what do people with an intellectual disability say about	2004 – 2014	UK, Netherlands, Canada	CINAHL, Scopus, Proquest, Pubmed (Medline), PsycINFO, Trove,	N=17	Specialised services are somewhat beneficial, as they are better equipped to cater to specific needs and provide high-quality	Adjustments to care, including greater continuity and better support, would be greatly beneficial in improving quality of care in both specialist and mainstream services.	Scoping review

Author Year	Scope	Date Range	Location	Databases	Studies	Findings	Recommendations/ Conclusions	Type of Review
2015	their experiences of formal support for mental health problems? The term “formal support” is used throughout the article to designate support provided by formal services, as opposed to support from unpaid carers and family members			Google Scholar, Grey Literature Report, Grey Matters, Open Grey, Australian Indigenous HealthInfoNet OAlster, Google		care. However, there are also marked disadvantages, particularly socially. Specialised services can negatively impact social inclusion, normalisation of ID, and human rights, while exacerbating stigma and discrimination by removing PWID from the rest of the healthcare population and hindering general services’ capacity to cater to PWID. The notion of ‘self-advocacy’ is a beneficial tool. It is vital that PWID accessing the healthcare system have a ‘voice’ in studies and evaluations	Although improvements to both design and delivery are needed, there have been positive indicators of integrated inpatient units. More inclusive research would be beneficial in investigating user perspectives, by involving people who have a dual-diagnosis of mental illness and ID. It is imperative to listen to service users, who are calling even more for self-advocacy and personal involvement	
Werner and Stawski. 2012	To summarise the available literature examining the knowledge, attitudes and training of psychiatrists and other professional caregivers in regard to serving people with dual-diagnosis	1995 –>	UK, Australia, Canada, US and Greece	Medline, ERIC, PsychNet, Social Sciences Research Network, Web of Knowledge, EMBASE Psychiatry,	N=28	Use of mental health services by PWID is low, despite the prevalence of mental health issues in that population group. Service providers lack knowledge and training about the specific needs of PWID. Attitudes toward PWID are	Research should be conducted to further evaluate health care professionals’ knowledge about patients with a dual diagnosis. Training, knowledge-mapping, and attitude-changing programs may be beneficial in improving the knowledge base and thereby improving outcomes	Systematic review

Author Year	Scope	Date Range	Location	Databases	Studies	Findings	Recommendations/ Conclusions	Type of Review
				CINAHL, Google Scholar		<p>predominantly negative. However, there is a marked difference between the attitudes of psychiatry residents toward PWID and other health/hospital staff. It is evident that they value self-advocacy, empowerment and inclusion over exclusion and sheltering - the common attitudes. Proper training may improve both attitudes and knowledge. It needs to be specifically in dual-diagnosis (as well as in ID in general). There is evidence that people who work in ID services have not been trained to respond to people with ID and mental health issues</p>		
Wilson and Scior. 2014	To review studies measuring implicit attitudes towards individuals with physical disabilities (visual, motor or hearing) or intellectual	2000 – 2012	Predominantly USA	PsycINFO, CINAHL, EMBASE, ERIC, MEDLINE, PUBMED, Scopus, Web of Science	N=17	<p>Implicit attitudes were markedly different to explicit attitudes. Implicit attitudes were often negative, e.g. infantilising PWID – associating them with ‘child-like’ qualities</p>	<p>Negative implicit attitudes are predominant among service providers, and have been consistent for some time. Interestingly, explicit attitudes have improved over time and become less negative. Factors that influence implicit attitudes should be investigated to address and</p>	Systematic review

Author Year	Scope	Date Range	Location	Databases	Studies	Findings	Recommendations/ Conclusions	Type of Review
	disabilities via the Implicit Association Test (IAT; Greenwald, McGhee, & Schwartz, 1998)					<p>Sometimes, more contact with PWID was associated with less negative implicit attitudes. However, paid caregivers often also held negative implicit attitudes. One study concluded that there was no correlation between contact and attitude.</p> <p>There is little to no correlation between explicit and implicit attitudes (in these studies).</p> <p>Overall, there was a preference for people who were able-bodied over those with physical disabilities</p> <p>Often, disability is associated with disease</p>	better understand them. This would further inform strategies to improve quality of care	

Analysis of systematic reviews

As the latest Cochrane review in this area notes *“There is very limited evidence on the organisation of healthcare services for persons with an intellectual disability.”*¹⁵ However, a range of capacity building strategies were identified, either directly or indirectly, by reviewers. In addition to staff training¹⁶, suggested improvements included: structural responses (e.g. development of policies and procedures); roles (e.g. creation of ID liaison positions and meeting the needs of family carers); communication and information strategies (e.g. creation of specific information, creation of guidelines); clinical interactions (e.g. addressing issues of diagnostic overshadowing); environment (e.g. changes to environment); and, ethics and research (i.e. inclusion of PWID and their carers in research and policy development).

Structural responses

Structural responses to capacity building address issues such as organisational structures, policies and procedures, recognition and reward, quality improvement processes, and internal information systems. Iacono et al.²¹ provide a comprehensive rationale for the need for such structural as well as all subsequent categories of responses identified in this review. Staff and systems have: failed to adjust to the needs of PWID; failed to recognise PWID specific concerns and the impact of long treatment delays in medical service waiting rooms; demonstrated an inability to adjust to meet the communication needs of PWID; failed to provide required assistance to enable PWID to eat a meal or go to the toilet; and, failed to take into account differences in medication regimes across home and hospital settings, with potentially serious outcomes. A number of these themes will be taken up later in this section.

The literature on structural responses to the provision of healthcare services to PWID reverberates with debate on the merits of specialist ID services, other specialist services (notably, mental health^{22, 23}, psychiatry²⁴, gynaecology/obstetrics²⁵, paediatrics²⁶ or geriatrics²⁷⁻²⁹), and generalist services (including primary, tertiary and community care) for PWID. There is no clear answer provided in the evidence for a single resolution to this debate.

Different reviews found different benefits at different times for different types of services, depending on a range of factors including patient and community characteristics (including, comorbidity and whether the individual client displays challenging behaviours), specific service type or specialty, staff skills and attitudes.

Adshead et al.³⁰, for example, found that specialist services provided the best comprehensive care for PWID but, at the same time, resulted in a longer length of stay. Chaplin³¹ raises the risk of restrictive practices in specialist mental health services but notes that the emergency provision of psychiatric assessment and care remains a problem in generalist services. At the same time, this complexity and fragmentation across the system(s) of care has been found to contribute to PWID's ability to use existing services (Thyen et al.³², Nageswaran et al.³³, Wilkins et al.³⁴). The finding was supported by Adshead et al.³⁰ who argued that role confusion between ID and mental health care providers can affect access and use of services.

Pelleboer-Gunnink et al.³⁵ found that there is general consensus that PWID should be able to access adequate services in the 'mainstream system'. They make one key reflection: while this might be the case, clinicians can perceive that PWID are a 'burden' because of their time-consuming and often complex cases. Byrne et al.³⁶ suggest the use of financial incentives as a potential solution, at least with regard to general practitioners (GPs) in primary care. The issue of the time taken to provide appropriate care for PWID also raises issues around staffing levels and skills³⁷, as well as the availability of appropriate equipment and aids, and organisational investment in such resources.³⁸

Suggestions of mid-level structural changes (i.e. modification to mainstream services) include: the creation of specific teams that aim to improve access to healthcare by PWID¹⁶; intensive case management for PWID in mental health services³⁹; and, integrated models of care have been used for medical inpatients with psychiatric disorders and could provide a useful approach where appropriate.⁴⁰ Mechanisms to reduce

delays in service provision, particularly for parents of PWID who fear that they must battle in order to obtain services or that a crisis needs to occur before appropriate services are provided, need to be identified.²⁶

The core of this question is how PWID can be provided with the best care possible, particularly in the light of evidence that there are currently shortfalls in all types of care they require and that they are at higher risk of premature mortality from errors of omission during treatment. Iacono et al.²¹ conclude that more research is needed to identify and investigate care for PWID at specific points in the hospital journey, including admission, diagnostic testing, placement on a ward and discharge.

The links between improved quality of care and the provision of services to PWID is largely untested. A UK review notes a study that audited a specialist epilepsy clinic for PWID for its adherence to standards set out in NICE (National Institute for Health and Care Excellence) guidelines but, of all of the review studies, it was the only one to specifically mention the use of quality improvement mechanisms.⁴¹ Robertson et al.³⁷ note that nursing management support, leadership and direction was essential to the provision of adequate services.

Roles

Three areas dominated discussion around roles in relation to PWID. These were: the provision of specialist ID liaison staff; issues around the roles of other specialist staff; and, the role of carers and families.

The most commonly identified strategy to improve the capacity of health services to address the needs of PWID was the engagement of specialist ID liaison person (most often described as a nurse) who can provide direct care, support to carers and education for other providers.^{16, 21, 28, 42} This type of role was said to be able to provide support to PWID, particularly if they displayed what were considered 'challenging behaviours'.^{22, 23, 29, 31, 43} While these health professional can act as mediators or advocates for PWID engaging with general healthcare providers, Griffiths, Bennett and Smith⁴⁴ note that there was a relative lack of studies on interventions specifically delivered by ID liaison nurses. Other specialist workers include skilled interpreters with knowledge of ID²⁶, along with the use of multidisciplinary team approaches.⁴³

Recognition of and support for the role of both support staff and carers was frequently cited as an issue in this field. Findings ranged from the need for hospital staff to demonstrate positive regard for carers' roles and knowledge, develop trust within the system and strategies to better foster positive relationships with them¹⁶ to a greater recognition of the role of families⁴³ and the specific provision of information for and support to carers.¹⁶

Carers were found to play a positive role in alleviating stress for PWID in hospitals and ensuring that they receive the best care. As a result, however, carers felt that they were placing a burden on staff if they left the hospital⁴² and there was a specific call to address caregiver burden through, for example, the use of outreach treatments³⁹ and addressing over-reliance on carers to provide care assistance in hospitals.^{21, 38}

Several reviews noted an over-reliance on carers within hospitals to provide attendant care from toileting and meals all the way to assistance with medical care (including, for example, changing bandages and/or advocating for or assisting on appropriate investigations or treatments).^{21, 45}

Communication and information

The issue of communication between healthcare providers, PWID, and their families and carers was noted across all reviews (e.g. Robertson et al.³⁷), and in particular for parents who couldn't identify sources of assistance or information (Douma et al.⁴⁶, Faust and Scior⁴⁷, Samuel et al.⁴⁸, Wodehouse and McGill⁴⁹). The need to address communication is at the core of many strategies designed to meet the needs of PWID, both in terms of how relevant information is gathered from and how information is provided to PWID, and their carers and families — which in turn relate to the additional time that might be required to ensure adequate communication.³⁷

The need for appropriate and accessible information throughout the patient/client journey was identified as a core issue in both access to and use of services for PWID. Several reviews^{16, 28, 43} identified preparation for admission to hospital, specialist GP referral forms, accessible pre-admission assessments and processes, and user friendly information as key to reducing the fears of PWID and the families.^{21, 38} Suggested improvements included: developing liaison models of working; improving referral systems; creating local integrated pathways and protocols; and adapting appointment systems.^{21, 42} Appropriate tools for both the gathering and distribution of information (e.g. specialist assessment tools for pain and distress) need to be reviewed.¹⁶

Robertson et al.⁴³ reported on a study by Esan and Markar⁴¹ which examined an audit of a specialist epilepsy clinic for PWID for its adherence to standards based on the UK's NICE guidelines. The study found a number of administrative issues in addition to those listed above including: keeping all patient records in one file to ensure continuation of communication, without replication; accessible information on medication changes; clear care plans; clear information on contacts and appointments; a standardised risk assessment form developed to complete and share with carers or support agencies; and, leaflets on other relevant forms of specialised supports or services.⁴³

The health system's ability to address the fears of PWID is a recurrent theme. Both Iacono et al.²¹ and Phillips⁴² note that PWID experience high levels of fear in relation to healthcare, and in particular hospital encounters. PWID's fears are exacerbated because they are sometimes unsure what to expect as part of the encounter, do not know what to expect in the specific healthcare procedure, and are anxious about being in an unfamiliar situation and environment.

Reviews identified various potential mechanisms for improving communication for PWID who use healthcare services. These included ensuring that at least some staff have repeat experiences with the same client or patient; this was found to improve staff understanding and willingness to adjust to the needs of PWID.²¹ Another potential mechanism focused on developing hospital staff communication skills in general and their ability to use communication tools (e.g., hospital communication books, photographs, pictures, and symbols), in particular.¹⁶ Other suitable tools include videos, accessible booklets, augmentative and alternative communication modes.³⁸ Use of these tools is particularly important, where required, for communicating and providing information about treatment, procedures, medication and discharge for PWID.¹⁶

This may go some way to overcoming what has been noted as a reluctance to communicate with PWID by staff who are unsure of the patient/client's 'capacity to understand' the communication.⁴⁵ This may lead to the clinician talking to carers, rather than clients with intellectual disabilities themselves.¹⁶

As with all patients, several reviews identified that care needs to be taken to ensure that the specific needs of different groups of PWID are also addressed. This includes addressing the specific needs of PWID who are children (and their parents), PWID who have mental health issues, as well as those from a Culturally and Linguistically Diverse (CALD) background.²⁶ Several reviews note that people from CALD backgrounds and/or their children might be at risk of additional discrimination.^{21, 23, 26} Special attention also needs to be paid to the complexities faced by people with dual disabilities and those providing their care and in particular with for those patients who appear to have challenging behaviours.²² There also needs to be specific acknowledgement of the methods of communication used with both support staff and carers.⁴²

Women with ID are particularly vulnerable, especially if they are pregnant. Research indicated that they can experience negative responses to pregnancies, including 'automatic' suggestions of termination, and a lack of advocacy. As noted in Homeyard, this group in particular is often faced with care and communication being 'about them, without them'.²⁵

Clinical interactions

Capacity building responses to clinical interactions need to address some of the most commonly identified issues with current service delivery. These include: delayed or inappropriate diagnostic procedures; diagnostic overshadowing, where the patients' symptoms are incorrectly attributed to the intellectual disability; inability to identify or treat pain appropriately; inability or unwillingness to listen to or respond to carer information; inadequate discharge planning and strategies, including a lack of continuity of care²¹; inappropriate person-centred care planning which does not take into account the role of carers⁵⁰; and, an inability to address issues like polypharmacy.⁴³

Concern about the lack of expertise in working with PWID was a common concern, including primary care leading to brief and ineffective consultations.⁴³ One of the most prominent issues addressed in the literature was that of diagnostic overshadowing, where clinicians focus is on the patient's intellectual disability rather than on the health issue to be addressed. This can result in clinicians missing both general health problems and high-risk conditions (such as epilepsy) for PWID which can be exacerbated by challenging behaviours and comorbidities.^{22, 51} It has also been associated with direct discrimination in denying PWID diagnostic procedures or treatment.²¹ Suggestions for addressing and responding to this issue include the development of suitable assessment tools to prevent diagnostic overshadowing — often due to communication failures.^{30, 52}

Exposure to PWID rather than training may assist in development of relevant skills and capabilities.^{27, 30, 52, 53} Pelleboer-Gunnink, Van Oorsouw, Van Weeghel and Embregts³⁵ found that the healthcare providers' lack of knowledge about PWID (including what they do, what they like and how they live) led to fear and anxiety, and reduced their confidence in treating them.

As well as direct clinical interactions, healthcare services need to be able to respond quickly and effectively to the specific needs of PWID. In addition to the general fears identified previously, PWID may also experience frustration caused by long waiting times, and fear associated with lack of choice over, for example, whether their carer remains during the process or procedure and where they are treated. PWID may also have specific needs in terms of food and or continence.¹⁶ The role of non-clinical staff in providing more appropriate care for PWID has also been considered. For example, a systematic review of service responses to PWID and epilepsy reported a study in Belgium which looked at use of a decision tree for non-medically trained staff which treats seizures as medical emergencies.⁴³

Environment

Environmental capacity building refers to the ways in which health care systems can improve PWID' access to and use of services through systems redesign. This includes the need to both provide adequate resources for and make physical alterations to hospital environments.⁴² For example, consideration needs to be given to the use of inpatient specialist services by youth, particularly when these are located a significant distance from family and home.^{53, 54}

Fear continues to be a key factor in service provision for PWID. This includes the need to address what is experienced as the 'alien' environment of hospitals and healthcare settings, including addressing the fear of getting lost.²¹ Suggested improvements to the healthcare environment include: appropriate signage³⁸; addressing physical barriers of access^{42, 52}; creation of side waiting rooms or adaptations to physical hospital environment^{16, 22}; improvements to poor layout⁵²; easy access to equipment and resources³⁷; and, the creation of a relaxed environment.³⁸

Ethics and research

As with all vulnerable groups in society, clinical interactions are embedded in a wider social context. Venville et al.²³ argued that in order to improve the quality of care for PWID, clinicians and service providers who have an awareness of the discrimination and systemic social barriers and not just the interpersonal and

social factors, and who understand the notion of 'self-advocacy' and 'voice' are particularly important. Werner and Stawski²⁴ note that psychiatric models of care might prove useful to find an approach as psychiatrists are said to value self-advocacy, empowerment and inclusion over exclusion and sheltering, which are commonly found amongst other healthcare provider models.

The issue of adjustments to both treatments and physical environments (addressed in the next section) was a recurrent theme. The practice of inclusion, for example, was said to be understood as equal treatment meaning reasonable adjustments instead of undifferentiated treatment.³⁵

One issue to be addressed is how healthcare systems could ensure that assumptions are not made about a person with an intellectual disability to consent.⁵⁵ This is necessary because, as Pellebour-Gunnink et al.³⁵ identified, there are still conflicting attitudes in the healthcare system towards PWID, including stigma, different expectations of their capabilities and an 'insufficient support of autonomy'. In short, they argue, PWID are treated differently within the health system.

Given the recurrent call for additional evidence and research, several reviews including Robertson et al.⁷ note that PWID are generally excluded from research conducted on mainstream generalised health services. They conclude that there is "no tangible reason for this exclusion" as most studies could accommodate the involvement of PWID with some adaptations. PWID³⁸ and their carers⁵⁶ should also be involved in policy development and have a 'voice' in both studies and evaluations.²³

A related issue pertinent to this review was raised by Osugo and Cooper.⁵⁷ They question whether interventions should be implemented if there is little or no evidence of their effectiveness, particularly when most evidence based interventions are adopted from studies that don't include PWID.

Analysis of single studies

Once the systematic reviews were analysed, the single studies were reviewed and compared to the synthesised review findings. Along with providing more nuanced details and examples of the major categories identified in the overall review, the individual studies generated a small number of additional themes, each of which will be discussed in turn. Table 3 below provides a summary of the title and primary focus of the reviewed studies.

Table 3: Peer-reviewed studies (n=69 phase three search results)

Author and Year	Title	Primary Focus
Ajaz A and Eyeoyibo M. (2011)	Referral patterns to mental health of intellectual disability team. <i>Advances in Mental Health and Intellectual Disabilities</i> 5: 24-29.	Dual diagnosis, service delivery
Aston M, Breau L and MacLeod E. (2014)	Understanding the importance of relationships: Perspective of children with intellectual disabilities, their parents, and nurses in Canada. <i>Journal of Intellectual Disabilities</i> 18: 221-237.	Children WID, families, carers, paediatric services
Burgen B. (2010)	Women with cognitive impairment and unplanned or unwanted pregnancy: A 2-year audit of women contacting the Pregnancy Advisory Service. <i>Australian Social Work</i> 63: 18-34.	Gender issues, reproductive health service delivery
Burton H and Walters L. (2013)	Access to Medicare-funded annual comprehensive health assessments for rural people with intellectual disability. <i>Rural & Remote Health</i> 13: 2278.	Preventative healthcare, screening, rural health services
Buszewicz M, Welch C, Horsfall L, et al. (2014)	Assessment of an incentivised scheme to provide annual health checks in primary care for adults with intellectual disability: A longitudinal cohort study. <i>The Lancet Psychiatry</i> 1: 522-530.	Primary care, annual screening
Byrne JH, Ware RS and Lennox NG. (2014)	Health actions prompted by health assessments for people with intellectual disability exceed actions recorded in general practitioners' records. <i>Australian Journal of Primary Health</i> 21: 317-320.	Annual screening, primary health care
Carroll C. (2010)	'It's not everyday that parents get a chance to talk like this': Exploring parents' perceptions and expectations of speech-language pathology services for children with intellectual disability. <i>International Journal of Speech-Language Pathology</i> 12: 352-361.	Carers, paediatric services
Chaplin R, Barley M, Cooper SJ, et al. (2006)	The impact of intellectual functioning on symptoms and service use in schizophrenia. <i>Journal of Intellectual Disability Research</i> 50: 288-294.	Mental health services, dual diagnosis
Chaplin R, Roach S, Johnson H, et al. (2015)	Inpatient Children and Adolescent Mental Health Services (CAMHS): outcomes of young people with and without intellectual disability. <i>Journal of Intellectual Disability Research</i> 59, 995-998.	Paediatric services
Clayton O, Chester A, Mildon R, et al. (2008)	Practitioners who work with parents with intellectual disability: Stress, coping and training needs. <i>Journal of Applied Research in Intellectual Disabilities</i> 21: 367-376.	Paediatric services
Cobigo V, Ouellette-Kuntz H, Balogh R, et al. (2013)	Are cervical and breast cancer screening programmes equitable? The case of women with intellectual and developmental disabilities. <i>Journal of Intellectual Disability Research</i> 57: 478-488.	Screening, preventative care

Author and Year	Title	Primary Focus
Crates N and Spicer M. (2012)	Developing behavioural training services to meet defined standards within an Australian statewide disability service system and the associated client outcomes. <i>Journal of Intellectual & Developmental Disability</i> 37: 196-208.	Quality improvement
Cross H, Cameron M, Marsh S, et al. (2012)	Practical approaches toward Improving End-of-Life Care for People with Intellectual Disabilities: Effectiveness and Sustainability. <i>Journal of Palliative Medicine</i> 15: 322-326	Palliative care
Dagnan D, Masson J, Cavagin A, et al. (2015)	The development of a measure of confidence in delivering therapy to people with intellectual disabilities. <i>Clinical Psychology & Psychotherapy</i> 22: 392-398.	Capacity building
Disley P, Hatton C and Dagnan D. (2012)	Inputs and outcomes: what do staff in services for people with intellectual disabilities perceive they bring to and receive from their work-based relationships? <i>Journal of Intellectual Disabilities</i> 16: 297-306.	Relationship building, service provision
Durbin A, Brown HK, Bansal S, et al. (2017)	How HIV affects health and service use for adults with intellectual and developmental disabilities. <i>Journal of Intellectual Disability Research</i> 61: 682-696.	Service delivery response to comorbidities
Graves J. (2007)	Factors influencing indirect speech and language therapy interventions for adults with learning disabilities: the perceptions of carers and therapists. <i>International Journal of Language & Communication Disorders</i> 42: 103-121.	Role of paid support staff in the provision of interventions
Griffith GM, Hastings RP, Nash S, et al. (2011)	'You have to sit and explain it all, and explain yourself.' Mothers' experiences of support services for their offspring with a rare genetic intellectual disability syndrome. <i>Journal of Genetic Counseling</i>	Role of carers
Grindrod A and Rumbold B. (2017)	Providing end-of-life care in disability community living services: An organizational capacity-building model using a public health approach. <i>Journal of Applied Research in Intellectual Disabilities</i> 20: 165-177.	Palliative care
Hall I, Yacoub E, Boast N, et al. (2014)	Secure inpatient services: a needs assessment. <i>Journal of Intellectual Disabilities & Offending Behaviour</i> 5: 38-53.	Forensic mental health
Hall I, Yacoub E and Yusufi B. (2010)	Secure inpatient services for people with intellectual disability: Lessons from developing a new service. <i>Advances in Mental Health and Intellectual Disabilities</i> 4: 15-24.	Forensic mental health
Heer K, Rose J and Larkin M. (2016)	The Challenges of Providing Culturally Competent Care Within a Disability Focused Team. <i>Journal of Transcultural Nursing</i> 27: 109-116.	Cultural competence
Hempe E-M, Morrison C and Holland A. (2015)	Exploring the boundary of a specialist service for adults with intellectual disabilities using a Delphi study: a quantification of stakeholder participation. <i>Health Expectations</i> 18: 676-688.	Service delivery, specialist service development
Hubert J. (2006)	Family carers' views of services for people with learning disabilities from black and minority ethnic groups: a qualitative study of 30 families in a south London borough. <i>Disability & Society</i> 21: 259-272.	Culture, ethnicity

Author and Year	Title	Primary Focus
Hussain R and Tait K. (2015)	Parental perceptions of information needs and service provision for children with developmental disabilities in rural Australia. <i>Disability & Rehabilitation</i> 37: 1609-1616.	Communication and information
Jenaro C, Vega V, Flores N, et al. (2012)	Quality of services and quality of life from service providers' perspectives: analysis with focus groups. <i>Journal of Intellectual Disability Research</i> 57: 489-499.	Quality of care
Jensen KM and Davis MM. (2013)	Health care in adults with Down syndrome: A longitudinal cohort study. <i>Journal of Intellectual Disability Research</i> 57: 947-958.	Service provision
Johnson K, Bowden M, Coyne D, et al. (2013)	Competency based advanced training in Intellectual Disability Psychiatry: a NSW prototype. <i>Australasian Psychiatry</i> 21: 393-396.	Capacity development in staff
Jones J, McQueen M, Lowe S, et al. (2015)	Interprofessional education in Canada: Addressing knowledge, skills, and attitudes concerning intellectual disability for future healthcare professionals. <i>Journal of Policy and Practice in Intellectual Disabilities</i> 12: 172-180.	Interprofessional practice
Kelly CL, Thomson K, Wagner AP, et al. (2015)	Investigating the widely held belief that men and women with learning disabilities receive poor quality healthcare when admitted to hospital: A single-site study of 30-day readmission rates. <i>Journal of Intellectual Disability Research</i> 59: 835-844.	Quality of care
Kreitzer L, McLaughlin AM, Elliott G, et al. (2016)	Qualitative examination of rural service provision to persons with concurrent developmental and mental health challenges. <i>European Journal of Social Work</i> 19: 46-61.	Rural service provision
Kroese BS, Rose J, Heer K, et al. (2013)	Gender issues for people with intellectual disabilities and mental health problems: Asking what service users and staff think. <i>Advances in Mental Health and Intellectual Disabilities</i> 7: 181-190.	Gender and the provision of care
Kroese BS, Rose J, Heer K, et al. (2013)	Mental health services for adults with intellectual disabilities: What do service users and staff think of them? <i>Journal of Applied Research in Intellectual Disabilities</i> 26: 3-13.	Mental health services
Lin E, Balogh R, Cobigo V, et al. (2013)	Using administrative health data to identify individuals with intellectual and developmental disabilities: A comparison of algorithms. <i>Journal of Intellectual Disability Research</i> 57: 462-477.	Service usage
Lunsky Y, Gracey C, Koegl C, et al. (2011)	The clinical profile and service needs of psychiatric inpatients with intellectual disabilities and forensic involvement. <i>Psychology, Crime & Law</i> 17: 9-23.	Forensic mental health
Mac Giolla Phdraig C, Guerin S and Nunn J. (2015)	Should we educate care staff to improve the oral health and oral hygiene of people with intellectual disability in residential care? Real world lessons from a randomized controlled trial. <i>Special Care in Dentistry</i> 35: 92-98.	Service provision

Author and Year	Title	Primary Focus
Mac Giolla Phadraig C, Nunn J, Dougall A, et al. (2014)	What should dental services for people with disabilities be like? Results of an Irish Delphi panel survey. <i>PLoS ONE [Electronic Resource]</i> 9: e113393.	Service provision
Marriott A, Turner S and Giraud-Saunders A. (2014)	Improving access to screening for people with learning disabilities. <i>Nursing Standard</i> 29: 37-42.	Preventative care, screening
Marsham M. (2009).	Raising awareness of learning disability needs in acute sector care: a reflective account of a workshop from the guest facilitator perspective. <i>Nurse Education Today</i> 29: 770-774	Capacity building in staff
Martin L. (2014)	Re-examining the relationship between intellectual disability and receipt of inpatient psychiatry and complex continuing care services in Ontario, Canada. <i>International Journal of Developmental Disabilities</i> 60: 65-79.	Mental health services
Martin L, Hirdes JP and Fries BE. (2007)	Examining the characteristics of persons with intellectual disability receiving hospital services: Part 2—Complex continuing care hospitals/units. <i>Journal on Developmental Disabilities</i> 13: 105-117.	Mental health services
McClimens A, Bosworth D, Brewster J, et al. (2012)	Contemporary issues in the training of UK health and social care professionals — Looking after people with a learning disability. <i>Nurse Education Today</i> 32: 817-821.	Staff capacity building
Melville CA, Cooper SA, Morrison J, et al. (2006)	The outcomes of an intervention study to reduce the barriers experienced by people with intellectual disabilities accessing primary health care services. <i>Journal of Intellectual Disability Research</i> 50: 11-17.	Primary care
Morton-Nance S and Schafer T. (2012)	End of life care for people with a learning disability. <i>Nursing Standard</i> 27: 40-47.	Palliative care
Nicholson L and Cooper SA. (2011)	Access to healthcare services by people with intellectual disabilities: A rural-urban comparison. <i>Journal of Intellectual Disabilities</i> 15: 115-130.	Rural health care
O'Hara J. (2006)	Standards and quality measures for services for people with intellectual disabilities. <i>Current Opinion in Psychiatry</i> 19: 497-501.	Quality of care
Ong N, McCleod E, Nicholls LE, et al. (2017)	Attitudes of healthcare staff in the treatment of children and adolescents with intellectual disability: A brief report. <i>Journal of Intellectual & Developmental Disability</i> 42: 295-300.	Paediatric care
Read S and Cartlidge D. (2012)	Critical reflections on end-of-life care for people with intellectual disabilities: a single case study approach. <i>International Journal of Palliative Nursing</i> 18: 23-27.	Palliative care
Roberts A, Townsend S, Morris J, et al. (2013)	Treat me right, treat me equal: Using national policy and legislation to create positive changes in local health services for people with intellectual disabilities. <i>Journal of Applied Research in Intellectual Disabilities</i> 26: 14-25.	Structural responses, human rights

Author and Year	Title	Primary Focus
Ryan K, Guerin S, Dodd P, et al. (2011)	End-of-life care for people with intellectual disabilities: Paid carer perspectives. <i>Journal of Applied Research in Intellectual Disabilities</i> 24: 199-207.	Palliative care; perspectives of support staff
Ryan K, Guerin S and McEvoy J. (2014)	The nature and importance of quality of therapeutic relationships in the delivery of palliative care to people with intellectual disabilities. <i>BMJ supportive & palliative care</i> 6: 430-436.	Service delivery
Ryan K, McEvoy J, Guerin S, et al. (2010)	An exploration of the experience, confidence and attitudes of staff to the provision of palliative care to people with intellectual disabilities. <i>Palliative Medicine</i> 24: 566-572.	Palliative care
Sines D, Hogard E and Ellis R. (2012)	Evaluating quality of life in adults with profound learning difficulties resettled from hospital to supported living in the community. <i>Journal of Intellectual Disabilities</i> 16: 247-263.	Service transition
Smallman S, Engel B and Nelson J. (2011)	Obesity services for adults with learning disabilities. <i>Journal of Human Nutrition & Dietetics</i> 24: 304-305.	Specialist service delivery
Taua C and Neville C. (2016)	Appreciating the work of nurses caring for adults with intellectual disability and mental health issues. <i>International Journal of Mental Health Nursing</i> .	Service delivery
Taua C, Neville C and Scott T. (2015)	Mental health inpatient experiences of adults with intellectual disability. <i>International Journal of Mental Health Nursing</i> 24: 507-518.	Mental health services
Thompson VR, Stancliffe RJ, Broom A, et al. (2014)	Barriers to sexual health provision for people with intellectual disability: A disability service provider and clinician perspective. <i>Journal of Intellectual & Developmental Disability</i> 39: 137-146.	Sexual health services
Thompson VR, Stancliffe RJ, Wilson NJ, et al. (2016)	The content, usefulness and usability of sexual knowledge assessment tools for people with intellectual disability. <i>Sexuality and Disability</i> 34: 495-512.	Sexual health services
Tint A, Weiss JA and Lunskey Y. (2017)	Identifying the clinical needs and patterns of health service use of adolescent girls and women with autism spectrum disorder. <i>Autism Research</i> .	Gender and service delivery
Tremblay A and Morin D. (2015)	Assessment of an expert committee as a referral process within health and social services. <i>Journal of Policy and Practice in Intellectual Disabilities</i> 12: 162-171.	Referral processes
Trollor JN, Ruffell B, Tracy J, et al. (2016)	Intellectual disability health content within medical curriculum: an audit of what our future doctors are taught. <i>BMC Medical Education</i> 16: 105.	Capacity building in staff
Vermeltfoort K, Staruszkiewicz A, Anselm K, et al. (2014)	Attitudes toward Adults with Intellectual Disability: A Survey of Ontario Occupational and Physical Therapy Students. <i>Physiotherapy Canada</i> 66: 133-140.	Capacity building in students

Author and Year	Title	Primary Focus
Walsh N, Handley T and Hall I. (2014)	Training and developing staff in general hospitals: Intellectual disability liaison nurses and the RAID model. <i>Advances in Mental Health and Intellectual Disabilities</i> 8: 390-398.	ID liaison nurses
Wark S, Hussain R and Edwards H. (2013)	Rural and remote area service provision for people aging with intellectual disability. <i>Journal of Policy and Practice in Intellectual Disabilities</i> 10: 62-70.	Rural service delivery
Weise J, Pollack A, Britt H, et al. (2017)	Primary health care for people with an intellectual disability: an exploration of consultations, problems identified, and their management in Australia. <i>Journal of Intellectual Disability Research</i> 61: 399-410.	Primary care; diagnostic barriers; capacity building in GPs
Weiss JA, Slusarczyk M and Lunskey Y. (2011)	Individuals with intellectual disabilities who live with family and experience psychiatric crisis: Who uses the emergency department and who stays home? <i>Journal of Mental Health Research in Intellectual Disabilities</i> 4: 158-171.	Service usage, ED
Williams B, Boyle M and Fielder C. (2015)	Empathetic attitudes of undergraduate paramedic and nursing students towards four medical conditions: A three-year longitudinal study. <i>Nurse Education Today</i> 35: e14-18.	Capacity building in students
Williams F, Scott G and McKechnie A. (2014)	Sexual health services and support: The views of younger adults with intellectual disability. <i>Journal of Intellectual & Developmental Disability</i> 39: 147-156.	Sexual health services
Wood S, Gangadharan S, Tyrer F, et al. (2014)	Successes and challenges in the implementation of care pathways in an intellectual disability service: Health professionals' experiences. <i>Journal of Policy and Practice in Intellectual Disabilities</i> 11: 1-7.	Care pathways

Differentiating the needs of PWID

Underpinning many of the studies included in the systematic review were caveats that the needs of PWID should be understood as being as diverse as those of the general population. An understanding of these differences, whether related to age⁵⁸, gender^{59, 60}, ethnicity⁶¹ and/or illness/condition (e.g. HIV/AIDS⁶² or dual diagnosis⁶³), provides insights into the specific response capacities required by the healthcare system as a whole.

Responding to the specific needs of children, youth, their families and carers also emerged as an important theme in the review studies. Ong et al.⁵⁸ point out that children with ID have *“complex health needs that extend beyond the expected cognitive deficits, affecting a myriad of developmental domains.”* As with all PWID, they argue that the care provided to children with intellectual disabilities is often poorly managed or inadequate. Their survey, conducted through the Sydney Children’s Hospital Network, found that staff considered themselves largely, although not totally, competent in caring for children with ID, especially in areas such as managing challenging behaviours.

Other issues identified in the provision of care for children with ID include: the specific concerns of rural families with children with intellectual disabilities, including limited choice in service provision and feelings of isolation⁶⁴; potential benefits of admission to general adolescent units, which were associated with clinical improvement for young people with ID⁶⁵; the importance (as with palliative care) of building relationships between families and service providers⁶⁶; and, differences in parental expectations based on the location of the service provided (i.e. school versus clinic-based speech pathology).⁶⁷

The provision of appropriate healthcare to PWID who are ageing has become an issue of increased focus over recent years. Most barriers to accessibility and use of health care services remain the same as for all PWID, including attitudes and capabilities of staff, and availability of both specialist and generalist services.⁶⁸ One study found that that over half of the patients with Down Syndrome reviewed had failed to make the transition from child to adult-focused care, noting that further studies are required to assess the rationale behind this distinct care pattern, including its relationship with clinical outcomes and evaluations to identify which provider types deliver the highest quality care for adults with Down Syndrome (and associated comorbidities).⁶⁹

Tint et al.⁵⁹, for example, identified that a significantly greater proportion of girls and women with Autism Spectrum Disorder (ASD) accessed psychiatry and emergency department (ED) services, compared to boys and men with ASD. They concluded that *“Future research is required to examine factors associated with the increased proportion of females with ASD using emergency department services, with specific attention as to whether these visits are related to gaps in other community-based services.”*⁵⁹ Over-representation in the use of EDs and hospital admissions was also found in the case of PWID with HIV.⁶²

For people with dual diagnosis, the effectiveness of inpatient care in a mental health service was associated with specific elements of service provision. These included whether there were therapeutic and meaningful activities (i.e. whether the therapies utilised by the service providers, for example music, were meaningful to the clients), emotion-focussed care (i.e. the acknowledgement and addressing of PWID’s emotions, including anger, anxiety and stress) and whether the PWID were ‘feeling safe’ (notably in relation to medication and seclusion).⁶³

Women with intellectual disabilities experience specific issues in seeking and utilising healthcare services, including a greater vulnerability to stereotyping (being perceived as more ‘compliant’ than men) and abuse.⁷⁰ For example, the proportion of women without intellectual disabilities who are screened for cervical cancer is nearly twice that of those with ID and 1.5 times for mammography screening.

As with barriers to general health service access, Burgen⁶⁰ found that the records of women with intellectual disabilities who had accessed a pregnancy advisory service showed that: the majority needed someone to

facilitate their first contact with that service; most contacted the service late in their pregnancy with a quarter of the women leaving it too late to have the option for an abortion they were seeking; a quarter were in significant conflict with their support people over the pregnancy; and, more than half of those who already had children were currently involved with child protection services. Burgen's conclusion was that women with intellectual disabilities require more accessible information and assistance in accessing services and service providers, who, in turn need to demonstrate both a proactive and supportive approach.

Hubert⁶¹ conducted a study of family carers' views of services for PWID from black and minority ethnic groups. Its results demonstrated a significant mismatch between the carers' opinions of the services (in that they were largely satisfied with the services once they received them) and actual provision of services which, even for elderly and ill carers, was found to be 'highly' inadequate and ineffective. Support was, at that point, negligible and future planning 'rare', largely based on stereotypes about extended and supportive family networks.

Two identified studies addressed the service needs of PWID with forensic involvement. In both cases, there was a strong overlap for PWID between forensic involvement and dual diagnoses of mental health issues. The first study found that this group were most often younger males with longer lengths of inpatient stay. They were more likely to have personality disorders and less likely to have mood disorders (compared to other PWID), but less likely than other forensic patients to have been diagnosed with substance abuse or psychotic disorders. Overall, PWID had more severe symptoms, fewer resources and a higher recommended level of care than other forensic patients.⁷¹

The second study found that in the UK secure inpatient services for PWID are often provided in a piecemeal way, despite the clients having 'very high needs'. The authors argued that consultation with all stakeholders, good relationships with community teams and strong integration with mainstream forensic services were all essential to the provision of effective services.⁷²

Types of care

Primary care

Although the focus of this review is capacity building in the community and tertiary care sectors, as several Australian⁷³ and international studies⁷⁴ note, PWID and their families mainly rely on their GPs for primary care. As such, concerns about access to, use and integration of primary care services which emerged as a major theme in the individual studies, need to be considered. Studies found evidence of PWID arriving at tertiary care with more complex and chronic health problems, providing an impetus for the integration of care across PWID's lives and health cycles.

Despite PWID having been eligible to access annual comprehensive health assessments (ACHAs) under Medicare since 2007⁷³, Weise² found statistically significant differences in the types, length and problems managed in primary care consultations, the medications and treatments provided and referrals made for PWID (compared to the general population). They concluded that administration, rather than clinical care, dominated consultations with PWID and recommended that GPs require assistance to identify and manage common medical conditions experienced by them, to allocate the increased time required for such consultations and to develop the skills required to consult effectively.

The UK's NHS has addressed the issue of improving primary care to PWID by providing an opt-in incentive scheme to encourage GPs to undertake annual health checks for them. In comparing participants in this scheme to those who had not received incentives, Busewicz et al.⁷⁵ found that those practices that received incentives conducted significantly more general health and specific (e.g. hearing) assessments, blood tests and medication reviews. Incentivised practices also generated more health action plans and made more secondary care referrals. As a result, there were higher rates of identification of disorders including thyroid, gastrointestinal issues and obesity.

The location of the primary care services also matters. Burton and Walters⁷³ found that PWID faced additional barriers in accessing primary care in rural areas. While issues of limited knowledge, understanding and confidence were similar among rural and metropolitan GPs (including a lack of knowledge of specialist assessments), PWID in rural areas did have an increased reliance on practice nurses as the *“as knowledge holder, facilitator and implementer of care.”*

Preventative care

Several studies noted actual and potential preventative care strategies for PWID.^{73, 75, 76} Annual reviews were found, as previously discussed, to result in better identification and treatment of conditions common in PWID, including obesity.⁷⁵ In Australia, Byrne⁷⁶ found that the Comprehensive Health Assessment Program (CHAP) significantly increased health actions for PWID compared with usual care. These included increased hearing tests, breast checks and skin examinations.

Similar issues and outcomes have been identified with a range of cancer screening programs.⁷⁷ Marriot et al.⁷⁸ reported common barriers to screening, including practical issues such as:

- Mobility
- Comprehension of general cancer screening information
- Accessibility of PWID appropriate literature
- Understanding of appointment systems
- Communication barriers
- The attitudes and knowledge of PWID, families, support service providers and family carers, and healthcare professionals
- Concerns about PWID’s ability to consent to screening programs.

They then reported on strategies used in the UK to address these barriers including partnership between specialist services and primary care providers, pre-screening education (including through visual information), longer appointment times, primary care and screening liaison nurses, and guidance and education for staff.

Sexual health

Several papers addressed the needs for appropriate and accessible sexual health and reproductive services and/or education for both PWID and health providers.^{60, 79-82} In addition to the issues mentioned elsewhere about service delivery, studies have found that staff and family attitudes (including myths about the sexual health of PWID) as well as funding shortages and a lack of policy guidelines have acted as significant administrative barriers to the provision of sexual health services to PWID.⁸²

Mental health

A number of studies address the need for capacity building of generalist (e.g. Emergency Departments⁸³) and specialist (e.g. forensic mental health⁷¹) services providing support for PWID with mental health diagnoses. This is a particular concern, because, as identified by Martin, Hirdes and Fries⁸⁴, while most PWID in their study had more clinically complex conditions with higher rates of functional impairment and aggressive behaviour, the healthcare interventions they were provided focused largely on behaviour management; an argument supported by other studies.⁸⁵

As dual diagnosis is a significant area of study, many articles relating to mental health have been cited elsewhere in this section and will not be repeated here. However, some studies raise important and unique issues in the provision of care to PWID with dual diagnoses. These include the delivery of care to PWID within and upon release from secure inpatient services (such as the creation of local services and “step down” discharge places).⁸⁶

Kroese et al.⁸⁷ conducted a study in which they surveyed PWID, support staff and community team members, to find out what they considered to be desirable qualities for staff in mental health services providing care for patients with intellectual disabilities. The analysis identified a number of themes including:

- Being interested
- Having strong communication skills
- Competence-promoting support
- Past/present/future links
- Prevention
- Reviews and liaison
- Working with carers
- Looking after staff
- Staff training/supervision
- Interface between services.

This study aligns with another examination of the 'outputs' for staff of working in ID services: employers cited the terms and conditions of employment, opportunities for professional development, support, positive feelings, encouragement, challenge, and negative outcomes; co-workers cited overt behaviour, friendship/companionship, loyalty, negative feelings (anger and frustration); and, service users cited overt behaviour (appreciation, respect), feedback/information, rewards from making the lives of service users better, emotional attachment and positive feelings.⁸⁸

Palliative care

The provision of palliative care services to PWID is an emerging area of study as their lifespans increase.^{68, 89} As with all types of care, reticence amongst palliative service providers is often located in the perceived 'differences' and 'difficulties'⁹⁰ in offering care to PWID.

In a recent Australian study, Grindrod and Rumbold⁹¹ described the use of a public health palliative care framework in the development of an organisational change model which addressed organisational structure and culture within community living services in Victoria, in turn influencing their end-of-life practice. As with other forms of service delivery, effective palliative care was associated with the attitudes of support staff and collaboration between and the coordination of services across the fields of disability and palliative care. Their conclusion was that this collaboration should be led by disability services, although other studies indicate a need for leadership across all sectors and providers⁸⁹ as well as improved understanding of each sector's roles and capabilities.⁹²

The roles and capabilities of care providers is a common sub-theme in this area. Ryan et al.⁹³ looked at the quality of palliative care from the perspective of both disability service and palliative care staff. They found that both groups agreed that good quality care was dependent on trust, continuity of relationships and knowledge of the individual to whom the care was provided. Palliative care staff indicated that they experienced difficulties in providing care to PWID. A key element in the quality of care related to the formation of 'authentic relationships' between staff and PWID.

In a previous study, the same authors⁹⁴ examined the role of support staff in palliative care and found that they were keen to provide it as they believed the experience of doing so enriched their practice. This desire was mediated, however, by lack of preparation and skills, exacerbated in particularly challenging situations (including those involving decision making), by the relationships between PWID, staff and relatives, and where there was a lack of time or support to provide care and mourn the loss of the client.

Part of this relationship building includes an awareness of the cumulative impact of poor care. As Read and Cartlidge⁸⁹ argue, as *"health irreversibly deteriorates, disempowerment becomes inevitable, and the need for professionals to promote autonomy at this time is crucial, particularly among those individuals who have long-*

term health and social care needs ... Making such 'reasonable adjustments' to the care setting (Michael, 2008) will minimize additional distress for people with an ID, minimize the potential for 'death by indifference' of this marginalized population (Mencap, 2007), and maximize choice and participation for the individual at the end of life."

Although Read and Cartlidge did not expand on the concept of reasonable adjustments, Morton-Nance and Schafer⁹⁵ propose the following: *"communication, [that is] empowering patients by providing accessible information regarding diagnosis, treatment options and symptom management; support, including financial, spiritual and psychological support for the person with a learning disability and family members or carers; collaborative working, [including] joint agency working and partnership with carers; environment [including] introducing the preferred priority of care document early so that people with learning disabilities can make their wishes known with regard to receiving treatment and where they would prefer to die; and time, [that is] being proactive and allowing enough time and space to talk about death and dying."* They also make the case for specialist learning disability and palliative care nurses, who can help in the development of proactive palliative care strategies and the adaptation of existing palliative care pathways.

Other strategies to improve the delivery of palliative care to PWID include the proactive engagement of senior management of services⁹² and the use of tele-health services, including the establishment of parent-professional and peer support groups using digital technologies.⁶⁴

Location of care

Although rural settings are noted for their lack of services, particularly specialist services, several studies have found that community connectedness and social cohesion experienced within such settings might provide a protective factor, increasing the wellbeing of PWID.⁷³ One international (Scottish) study showed better than average use of services such as opticians and dentists.⁷⁴

While rural settings might provide some protective factors, specific challenges remain. As Hussain and Tait⁶⁴ identified, the parents of children with intellectual disabilities in rural settings experience a lack information about available support systems which, along with the limited experience, 'poor' attitudes and frequent turnover of healthcare service providers, added to their stress and sense of isolation.⁶⁴ A Canadian study of service providers' perspectives on the barriers that people with dual diagnoses (i.e. ID and mental illness) living in rural settings face accessing and using health care services, identified difficulties with: transport; resource inequities (i.e. lack of specialised resources and service providers); affordable housing in areas where support services and providers were available; a lack of (self-determined) skills in staff; difficulties in diagnosis; stigma; systems-level challenges, including issues with coordination and navigation of services; involvement of families; and, communication barriers. Similar barriers have been found in the delivery of care to ageing PWID in rural areas.⁶⁸

Structural responses

Debate about the best possible structural responses to meeting the healthcare needs of PWID continues^{96, 97} with distinctly different (although not necessarily incompatible) views expressed by PWID, carers, policy makers and service providers^{98, 99} as to what constitutes an effective service. The debate is further complicated by lack of accurate information about current service usage by PWID.¹⁰⁰

Differences in perspectives also apply within as well as across groups. For example, in a study of younger adults with intellectual disabilities, Williams, Scott and McKechnie⁸¹ found that although preferences differed between individuals, most wanted to attend mainstream sexual health services, arguing that staff from these services should be able to meet their needs. One exception (within the parameters of the study) concerned the quality of life for adults with profound learning difficulties resettled from hospital to supported living in the community. The results in this case were unequivocal, with statistically significant improvements in quality of life across the board.¹⁰¹

Whatever their specific conclusions, underpinning many of these studies is the argument that there is a “... need to match service delivery according to the individual's needs, wants and expectations rather than the disability type/diagnosis based service which predominates today”.¹⁰² This argument is supported within the context of a human rights approach for service delivery for PWID.¹⁰³

Pathways

There has been an increased call for and use of healthcare pathways in recent years. Wood et al.¹⁰⁴ identified a series of factors in developing and executing an ID healthcare pathway, including the need for changes in organisational culture and attitudes towards PWID, and more specific issues in need of address such as: communication between health professionals; dissemination of clear and relevant pathway documentation; the need for clear leadership as a part of multidisciplinary team working; the expanded role of health professionals as care coordinators; the role of administrative staff; differences in implementation across localities; the use and security of information technology systems; the visualisation (through patient journey storyboarding) of care pathway procedures; attitudes of professionals and staff toward care pathways; and, the perceived impact of pathways on clients.

Assessment of healthcare quality

Although studies of healthcare for PWID predominantly focus on access and use of services, at least two UK studies addressed the quality of care provided. In a largely descriptive piece, O'Hara¹⁰⁵ discussed quality measures from primary care through mainstream secondary care to those of specialist mental health services for PWID. She concludes that while no-one can “... argue with policies that address early health promotion and interventions, the provision of health checks at key life stages and the promise of more support and higher prioritization of mental and emotional wellbeing, long-term support needs and convenient local access to primary care for all ... the devil ... is in details, and often these details have no clinical evidence or sound quality base.”

In a study of overall 30-day hospital readmission rates, Kelly et al.¹⁰⁶ found that they were much higher for PWID at 69% compared to 29% for the the general population (an unexpected finding based on previous research). They conclude that this might indicate that PWID, particularly those with more profound disabilities, are “... at greater risk of experiencing poor quality care, if poor quality care is what causes readmissions. Patients with profound [IDs] more commonly experienced an emergency readmission within 30 days.”¹⁰⁶

Referral

Lack of appropriate referral remains a core problem in the delivery of care for PWID. In Canada, the complexity of the healthcare system (which mirrors Australia's) is considered a contributing factor to barriers that PWID face accessing and being referred to services. Tremblay and Morin¹⁰⁷ used an expert committee to review participants' files in order to determine the client-related variables that were associated with the level of services provided. They found that of the 30 participants, ten were not receiving the appropriate level of care. Lower levels of care were most strongly associated with the perceived challenging behaviours of clients. Their conclusion was that the primacy of clinical judgment, rather than the specific participant characteristics, affect whether a PWID is referred to services which best meet their needs.

Roles and responsibilities

As with the systematic reviews, individual studies identified the need for specific support roles both in Australia and internationally. Burton and Walters⁷³, for example, noted the need for support workers/carers in annual health assessment, and in the transfer of information about PWID between and within the health and disability sectors.

Although the role of specialist ID nurses was identified and discussed in the systematic reviews, the analysis of individual studies identified a call for upskilling different roles, including primary care practice nurses and paid support staff. Burton and Walters⁷³ advanced the argument that practice nurses can “... *develop expertise in the needs of people with ID and techniques for doing assessments thus facilitating the annual health assessment and care planning*” while Ryan et al.⁹⁴ found a willingness by support workers to take on some aspects of palliative care provision.

Another study looked at the emerging role of support workers as the provider of indirect (speech and language) interventions for PWID. It identified four key factors which might influence indirect interventions: diversity in the working context; the potential for conflict between the guiding values of speech and language therapists and support workers, in particular residential support workers; collaboration and support for the implementation of the intervention; and any doubts speech and language therapists might have about the effectiveness of formal support worker communication training. The key issues for support workers were: roles and values, awareness of communication needs, and motivation and opportunity to implement interventions.¹⁰⁸

Other issues affecting clinical practice with PWID identified include the support provided to staff in building confidence and understanding the complex behaviours of PWID¹⁰⁹ and their ability to deal with stressors such as workload, client-related difficulties, and organisational structure and processes.¹¹⁰

Communication and information

Clarity of communication is a recurring theme across the literature. Several strategies have already been discussed in relation to particular issues, for example the flow of information about PWID across sector boundaries (notably between disability and health⁷³) and the need for additional information for clinicians, who may be unaware of the availability of specialist and support services¹¹¹, or who may refer inappropriately.¹¹² Lack of timely communication and information was also identified as a significant barrier in providing healthcare services to children with intellectual disabilities in rural settings.⁶⁴

Burton and Walters⁷³ describe communication between PWID, carers and clinicians as the ‘communication triangle’ with the role of the carer as one of combined interpreter and advocate. In their study of PWID, carers and clinicians, they found that carers: provide support to PWID in communicating their needs and feelings; utilise their knowledge of PWID to convey relevant information in the clinical setting; and, act as an advocate for client-centred care. This, they argue, assists clinicians in the diagnosis, prescription and referrals for the PWID, in line with both their diagnoses and preferences.

Given the issues identified with later referrals and less comprehensive care for PWID, and the anxieties identified by clinicians in treating them, the need for better information about PWID and specialist services emerged as a significant theme in the studies. This included specialist obesity services.¹¹¹

Education and training

Although this review is specifically directed towards organisational, rather than individual capacity building, most of the studies (along with the systematic reviews) included calls for competency-based¹¹³ healthcare staff training and/or development¹¹⁴⁻¹¹⁶, including from students and clinicians themselves.¹¹⁷ The actual training and education of healthcare professionals and students have had mixed results. The diversity of the studies (context, number of participants, type of intervention, characteristics of participants) makes their findings impossible to generalise.

At an undergraduate level, there have been calls for increased education for doctors, who receive a median of less than three hours compulsory intellectual disability content across their five-year undergraduate program.⁷⁹ In comparison while paramedic students were found to have a higher regard (empathy) for PWID compared with their graduate paramedic and nursing counterparts, their level of empathy actually dropped

between their second and third years of training.¹¹⁸ In comparison, a study of inter-professional education on ID found improvements in participants' knowledge and skills for the majority of disciplines, including improvements in student learning and positive attitudinal change after participation in the program¹¹⁹, while another study found an improvement in confidence in delivering therapies to PWID post-training.¹²⁰

There is discrepancy between the apparent success of an intervention (i.e. whether the participants found it valuable) and its actual patient/client outcomes. For example, Melville et al.¹²¹ found that an intervention study with providers to reduce the barriers experienced by PWID accessing primary health care services was successful in meeting the 'previously unmet training needs' of the participants but also that, as a result of the intervention, 81.4% of the participants agreed that they were more able to meet the needs of PWID and 66.6% reported changing their clinical practice. Another study of education in behavioural training for healthcare providers found that their clients' outcome data showed significant improvement following the program, including decreases in severity ratings.¹²²

In contrast, a program directed at training healthcare providers to help educate PWID about oral hygiene did not lead to improvements in oral hygiene or periodontal health among their clients. The researchers concluded that their "... study contributes to the available evidence suggesting that *Train the Trainers training for care-staff is not effective at improving oral health among those for whom they care when using a randomized controlled trial design to assess this.*".¹²³

One study directly addressed the issue of culture or cultural competence in service delivery to PWID. Heer et al.¹²⁴ looked at the experience of service providers from different professions who work with South Asian families in the UK. They found challenges arising from issues in language and communication (primarily language barriers to therapeutic engagement) as well as the use of interpreters (due to their lack of familiarity with health-related concepts and perceived judgements and biases). They described a five-stage process in trying to engage with culturally and linguistically diverse families namely: addressing frustrations at barriers (tensions between provider and family perspectives of ID and care); struggling with engagement and process; accepting differences (by the provider of the family's cultural differences); making it work (dealing with the complexity of needs); and, looking for a way forward (to develop the skills require to engage with cultural complexity).

Grey literature

The grey literature indicates an international acknowledgement and agreement that PWID should have access to adequate and equitable health services.¹²⁵⁻¹²⁷ However, at the same time, it is generally recognised that this is not a current reality¹²⁸⁻¹³⁰ and that the capacity of the healthcare systems to address unmet needs can and should be improved especially in the provision of services adapted or adjusted for PWID.¹³¹

Common themes emerging across the grey literature include the need for: improved communication and trust between service providers and service users; empowerment and engagement of PWID and their families; capacity building in clinicians; and, service provision. Across all four countries reviewed for grey literature (Australia, Canada, New Zealand and the UK) the primary focus is on improving the system such that it has the capacity to include PWID in mainstream services, with reasonable adjustments and the support of specialist additions made to cater for their needs.

Improving communication

A primary theme that emerged from the grey literature was the need for improved communication within the healthcare system. Resources from all countries included in this review acknowledged that effective communication between clinicians, PWID, their carers and families is currently less than optimal.^{126, 127, 132, 133} This poses a barrier to equitable access and quality of care. Clearer and more accessible information for PWID entering the hospital system, is likely to significantly improve quality of care.¹²⁸

A number of interventions have been trialled in attempts to build the healthcare system's capacity to effect clear communication, most notably in the UK and New Zealand. The Health and Disability Commissioner of New Zealand published a 'Guide to Communication'¹³² that serves as a tool for health service providers to practice clear communication with PWID and their carers to make the system easier to understand, and therefore easier to access. This guide is intended to improve the communication skills of frontline practitioners who have called for additional training in caring for PWID.¹³⁴

The UK NHS website also promotes clear communication strategies through their information webpages.¹³⁵⁻¹³⁷ These pages include plain language explanations of what to expect when entering the hospital system and how and where to access dental services.

The NSW *Say Less, Show More* initiative¹³⁸ replaced complex, written instructions and explanations of care with visual aids in order to assist PWID to understand care being provided, particularly to children with an ID. This strategy has been implemented at Westmead Children's Hospital¹³⁹ and is intended to ease fear of services that may be particularly daunting to a child with an ID, such as dental services and blood tests. Using visuals, a more accessible medium, to 'show' rather than 'tell' about the system being accessed has been demonstrated to be an effective strategy in improving the accessibility and quality of care of the healthcare system.¹³⁸

Empowerment of and engagement with PWID and their families

Recommendations about improving service delivery regularly identify the need to involve PWID in their own care. Discussing care 'about them, without them' risks not addressing patients' actual (rather than assumed) needs, as well as disempowering them by diminishing their capacity to be involved in their own care.¹⁴⁰ Proposed remedial strategies to address this barrier include involving PWID in policy-making and in education and training of practitioners.¹⁴¹⁻¹⁴³

Increased contact with PWID is said to improve healthcare providers' attitudes and understanding of ID, and to inform the construction and application of adequate policies by ensuring that they will actually address the needs of PWID.^{143, 144} Essentially, using the experiences of PWID to inform policy can create a more person-centred model of care, which increases the capacity of the health system to provide adequate care and positive experiences to PWID accessing the system.¹⁴⁴

The NSW *Allied to Kids* newsletter¹⁴⁵ encourages PWID, their families and carers to get involved in the healthcare system by keeping service users up-to-date on the latest policies, research and changes made in the system. This has a twofold effect of enhancing communication by keeping PWID 'in the loop' about the healthcare system, and inciting involvement through presenting the current state of information and encouraging further participation.^{145, 146}

Empowering clinicians

Health care providers, including clinicians, can feel ill-equipped to provide adequate services to PWID.¹³⁴ This anxiety can pose barriers to the high standards of care. Studies have shown that clinicians who feel uncertain about treating PWID can develop negative attitudes towards them.¹⁴⁷ Building strong relationships and trust between providers and users assists in enhancing staff understanding of the nuances of ID.¹³⁴

The NSW Agency for Clinical Innovation has published videos¹⁴⁸ involving PWID discussing their experience of the healthcare system and how they feel about their hospital stays. These videos are intended to serve a dual purpose. Firstly, they enrich staff knowledge through firsthand accounts of the system through the eyes of PWID, which may encourage staff to adapt their models of care by responding to the different perspectives that PWID may have when accessing the system. The videos also facilitate the direct role of PWID in educating clinicians and can enable them to participate in the co-design of care.^{141, 140, 143}

Although this review specifically excluded staff training as a focus, it must be noted it is one of the most common strategies proposed to increase their knowledge of the needs of PWID.¹⁴⁹ Further, although this is argued in both the peer-reviewed and grey literature, such training is rarely provided or is inaccessible due to cost or location.¹⁴⁷

As with the reviews and studies, the role of staff also emerges as an issue in the grey literature. Staff roles in interacting with PWID are often unclear, and documents advise further clarification of these roles, particularly how they relate and differ to that of a carer.¹⁴⁴

Service provision

There is an ongoing debate about the best model of care for PWID but it is generally acknowledged that they should be able to access mainstream services with reasonable adjustments made to address their needs.¹³¹ 'Reasonable adjustments' are small but effective adaptations regarding time, environment, care and support that drastically improve the quality of care provided, as well as the experience of those accessing the system.¹⁵⁰ This proposed model adopts a 'generalised care, with specialist expertise' structure¹³¹, and is characterised by integration of care and collaboration across service sectors.

The introduction of Learning Disability Liaison Nurses (LDLN) in the UK has been shown to increase the inclusion of PWID in mainstream services, by ensuring that these services cater to their needs.¹³¹ LDLN are specifically trained in ID nursing, and can improve communication with patients and families while making the reasonable adjustments necessary. The introduction of specialist teams and clinics within general care has also been recommended in Australia as a strategy to promote inclusion.¹⁴¹ It is proposed that these specialised services can work within the general model to combine positive aspects of both generalised and specialised models; the inclusion into the mainstream with specialist knowledge and care.¹⁴¹

The University of New South Wales has conducted studies into the inclusion or exclusion of PWID in mental health services and concluded that policies currently do not cater for PWID, and that this should be addressed.¹⁴³ A suggested strategy for addressing this is the adoption of experience-based policy making. This operates by including PWID in policy-making by listening to their specific experiences and creating policies that can cater to their needs. The Canadian Institute of Health Information also calls for policies to be more inclusive of PWID, as a way of improving access to the health system.¹²⁶ This form of inclusion enhances communication and empowers PWID in their own care.

Other methods of practically and holistically involving PWID in their own care, for example, include the creation of a checklist by the IDN.¹⁵¹ Although not evaluated, this tool was designed to ensure that clinicians are aware of how to involve PWID in their care.

Service provision to groups with more complex needs, such as Aboriginal and Torres Strait Islander PWID, PWID living in rural areas, PWID with co-morbidities, older PWID and children with intellectual disabilities raises additional concerns. A number of strategies to combat these barriers have been proposed, including integrating community and health services, for example, as a way of building capacity for the healthcare system to meet both the unmet and evolving needs of these groups.¹²⁸ Communication with children with intellectual disabilities, as noted previously, requires additional attention, and can be achieved through visuals rather than words, as in the *Say Less Show More* initiative.¹³⁸

Physical environment adjustments may also need to be implemented for PWID living in rural areas. Such adjustments have included the creation of localised services that are equipped to deal with the additional needs of a PWID.^{128, 150}

Discussion

Evidence of the causes of poor health and premature death for PWID is substantial and well established.^{5, 10, 152-155} One subset of causes, the inadequate provision of health care to PWID, has led to catastrophic results for patients and their families. The Heslop Inquiry in the UK reviewed the deaths of 247 individuals with learning disabilities (the UK nomenclature) over the age of four-years-old and found that 42% were premature and that the most common causes were “... *delays or problems with diagnosis or treatment; and problems with identifying needs and providing appropriate care in response to changing needs.*”¹⁵⁶ Capacity building in healthcare services is essential if these issues are to be addressed quickly and appropriately.

The provision of adequate care for PWID is complex. Some conditions, such as epilepsy can occur more commonly in PWID than the general population.⁵ Others, including chronic conditions such as diabetes and obesity can occur as a combination of PWID’ difficulties in managing such conditions without support and the inability of healthcare providers to provide timely and accurate diagnosis.^{157, 158} Limited screening^{77, 78} and later referrals to specialist services exacerbates this situation¹⁰⁷, as does a lack of experienced staff and or specialist services in areas of increased concern such as palliative care^{91, 95} and forensic mental health.^{71, 86} Finally, and most relevant to this review, is the failure of health systems and services to adequately address the unique needs of PWID.

All the reviews cited in this Evidence Check noted the absence of adequate research into the provision of services to PWID and, more specifically, the absence of research conducted with the active involvement of PWID, their carers and families. This is of particular concern now as changes brought about by the NDIS will configure the role of support staff in particular. That said, there is enough evidence that points towards some key areas of potential capacity building, as noted in the findings section.

PWID and their carers, like the general community, have a range of experience and preferences when it comes to service delivery. Some of these have emerged from an acceptance or knowledge of what is available rather than what is appropriate or effective. A more detailed understanding of the **differences within as well as across the PWID communities** will help refine the strategies discussed below. These include the differences identified in the literature so far such as age, gender, mental health and location. However, a number of important communities were not identified in this review, but clearly require careful consideration, including PWID from CALD backgrounds, lower socio-economic backgrounds, are homeless or in transition, and those without carers or advocates.

The idea of **mapping patient journeys** for PWID should be considered. Given the absence of evidence driven responses, or more accurately, the absence of agreement on evidence driven responses, then the mapping of a number of ‘typical’ and ‘a-typical’ journeys could provide the start of a process for identifying vulnerabilities across the entire system of care from primary to tertiary, and across a range of PWID’ unique experiences. Such maps may also demonstrate if and where services are, or need to be, integrated, and where the location and types of efforts associated with capacity building need to be directed in the short, medium and long term.

Part of this mapping should be a process of understanding the role of **carers and family** members. It is clear from the evidence that not only do carers and family members play a unique role in the provision of care to PWID, but they too may be experiencing health impacts as a result of the expectations placed upon them. With the introduction of personalised care through the NDIS, health systems also need to address the organisational and ethical issues associated with the role of disability support staff.

Because of the lifelong difficulties for PWID and their carers in accessing and utilising appropriate healthcare (and related services) and, more specifically, in negotiating such services, **liaison officers** (nursing or general) and upskilling of practice nurses who can provide a combination of both advocacy and navigation of referrals, may be an important strategy to consider.

The **integration of health and social care** across the life cycle of PWID remains a core issue. What the research shows is that capacity building in the health sector cannot succeed if it does not address issues of access, use, quality and safety, and outcomes across all types of services (from prevention, through primary to tertiary, generalist to specialist) and at every stage of life.

The evidence also showed that there is significant potential to improve response capacity by clinicians through the development of specific **assessment tools, guidelines and care plans** for PWID. The Intellectual Disability Network established by the NSW MoH and the Agency for Clinical Innovation has already commenced some of this work but more resources and efforts are required to meet the demand, including in more specialised areas such as primary healthcare, health promotion and for specific groups such as pregnant women and PWID who are ageing.

Part of improving the quality of service delivery to PWID requires a better understanding of **clinician attitudes and capabilities**. This is not simply an issue of training. Two issues were identified repeatedly: that of clinician 'fear' of PWID resulting in a lack of certainty of responses — which appears to be best addressed for both clinicians and patients through exposure to PWID — and issues associated with diagnostic overshadowing. Organisational recognition of the complexity of conditions experienced by PWID — and the additional time and resources that may be required to respond adequately — also need to be formally recognised by leaders, managers and service providers.

Quality improvement is an issue across and throughout service types. There was limited direct discussion of quality improvement in the review documents considered as most focused on addressing existing shortfalls. This is an issue, along with safety of care.

Specialist communication resources are also required, along with staff skilled enough to use them. Communication and information tools are only as effective as they are accessible and appropriate. This applies for PWID and their carers, and support staff.

Environment is a significant issue. Reviews pointed to the anxiety provoking nature of health care settings, in particular hospitals and emergency departments. Capacity building needs to include infrastructure responses¹⁵⁹ and service adaptations, including the creation of safe places for PWID and their families. Such spaces have the potential to both reduce fear amongst PWID and to help manage otherwise challenging behaviours.

Any capacity building needs to take into account the unique knowledge of PWID and their carers.

Mechanisms for active inclusion of PWID and their carers in research, policy making and service delivery need to be clarified and extended. The issue of gaining and providing informed consent in particular requires additional and urgent attention.

Figure 2 below provides a brief summary of the key elements required for a holistic capacity building approach to the needs of PWID.



Figure 1: Preliminary model of holistic capacity building response to service delivery to PWID

Conclusion

All available evidence points to a need to improve the accessibility (timeliness), use (efficiency, equity), quality (effectiveness, safety, coordination and patient centeredness) and outcomes from health services for PWID. This Evidence Check provided to the NSW Ministry of Health provides key evidence informed pointers as to key areas for capacity building across the NSW health system.

A key element of this process is a holistic approach to capacity building. Addressing the healthcare needs for PWID from a systems perspective is essential, as failure to prevent, diagnose and treat ill health occurs at every point of the healthcare system and across the entire lifespan of PWID, with disproportionate effects on PWID, their carers, families and communities.

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