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Barriers and Enablers to Accessing Mental Health Services for People With Intellectual Disability: A Scoping Review

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ABSTRACT
Background: It is well established that people with an intellectual disability have high rates of mental health problems, yet rates of uptake of services do not match need. *Aim*: To identify the current literature pertaining to the barriers and facilitators to access to mental health services for people with an intellectual disability. *Method*: A systematic search identified English-language articles that addressed barriers or enablers to access, mental health services, and intellectual disability from 2005 to 2016. Results were synthesized according to Gulliford et al.'s four dimensions of access: availability, utilization, relevance and effectiveness, and equity. *Results*: Barriers and enablers were identified across all the dimensions. Organizational barriers, lack of services, and poor-quality services related to deficits in knowledge were among the barriers discussed in the literature. Facilitators included emphasis on interagency collaboration, and training and education. Substantial gaps were also identified, particularly in relation to the lived experience of these barriers. *Conclusions*: Further research and evaluation across all aspects of access to mental health care for people with an intellectual disability is needed.

Introduction

It has been established that mental ill-health is overrepresented among people with an intellectual disability compared with the rest of the population. While prevalence has been shown to vary according to context and source (Buckles, Luckasson, & Keefe, 2013), it is understood that the prevalence of mental disorders in people with an intellectual disability is substantially elevated (Cooper, Smiley, Morrison, Williamson, & Allan, 2007). People with intellectual disability are more vulnerable to mental ill-health for a number of complex reasons which range from biophysical to psychosocial.

Research suggests that uptake of mental health services by people with an intellectual disability (Dekker & Koot, 2003; Einfeld et al., 2006; McCarthy &

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Boyd, 2002) does not match the prevalence rates of mental ill-health in this population (Cooper et al., 2007; S. Einfeld, Ellis, & Emerson, 2011; S. Einfeld & Tonge, 1996; McCarthy & Boyd, 2002; Morgan, Leonard, Bourke, & Jablensky, 2008). Einfeld and Tonge (1996) found that despite 41% of children with an intellectual disability experiencing mental ill-health, 47% of this group had sought no help at all in relation to the issue, and only 9% of this group had sought assistance from professionals with experience across both mental health and intellectual disability.

“Barriers to access” are widely cited as the primary reasons that prevent this population from accessing services. However, what is less clear is what form these barriers actually take. Further, the concept of accessibility in relation to mental health services has not been as thoroughly investigated as it has in relation to general health services (Buckles et al., 2013; Cooper et al., 2007). Previous reviews around health accessibility in relation to people with an intellectual disability have identified several common deficits in mental health services, including a lack of training for practitioners, a lack of specialized services, and ineffective service collaboration, but these reviews have not been specific to mental health (Buckles et al., 2013; Michael, 2008). The lack of substantive discussion and examination of both the barriers and enablers to access makes it difficult to develop and evaluate measures to improve service uptake. Bouras and Holt (2004) identified this evidence deficit in 2004, and it does not appear to have been rectified in the interim.

This review scopes recent empirical evidence related to the barriers and enablers for accessing mental health services for people with an intellectual disability. Identification of which of these factors are most important could inform a rationale for further targeted research in the area, as well shaping the development of initiatives and potential interventions.

Given the apparent paucity of empirical research in the area, this article includes multiple countries; however, it focuses mainly on the similar policy contexts in Australia, the United Kingdom, and Canada.

This review will discuss each of the barriers, then enablers, that have emerged from the literature corpus as they relate to each dimension of access. We define barriers to access as any process or intervention by which access to healthcare is impeded or blocked. Conversely, we defined enablers as any process or intervention by which access to health services and healthcare is facilitated.

Method

The key aim of this review was to establish the breadth and diversity of the literature around the area of intellectual disability and access to mental health services, and identify gaps in the research. To achieve this aim, the authors adopted the scoping review methodology espoused by Arksey & O’Malley

(2005), where the key goal of a scoping review is to describe the overall state of research activity in the area and identify crucial gaps. Given that the scoping review generally represents the first attempt at mapping the state of research, the scoping review does not attempt to assess the quality of the research (Arksey & O'Malley, 2005).

Following this process, a systematic search was carried with the aim of answering the following research question: "What are the key barriers and enablers to accessing mental health services for people with an intellectual disability currently identified in the literature?" In order to provide contemporary data, only literature published less than 10 years prior to the inception of the project (from 2005) was included. International literature was included, and anything in a language other than English was excluded. Three dimensions to the research question were identified: mental health services; intellectual disability; and barriers and enablers to access. Searches were built around each of these dimensions and their related search terms (see Table 1 for search terms). Search terms were mapped to subject headings where available, and were combined using the Boolean operator OR. The three dimensions were then combined using the Boolean operator AND (for example, mental health services AND intellectual disability AND barriers AND availability accessibility). The search was undertaken in Medline, PsycInfo, EMBASE, CINAHL, PubMed, and Sociological Abstracts databases. Reference lists of identified literature were then hand searched to identify other articles of relevance that were not identified using the search strategy. Citation indices (Web of Knowledge and Scopus) were searched to identify the most frequently cited literature in the area, and to ensure that the key literature was captured. The grey literature (for the purposes of this review, any literature that is commercially published or is not peer reviewed) was also extensively searched via Google using search limiters that restricted results retrieved to PDF (the bulk of grey literature is accessible as PDFs). Relevant national websites and peak body websites were also searched (particularly Australia and the United Kingdom), as well as databases of grey literature (PsycExtra, OpenGrey, New York Academy of Medicine: The Grey Literature Report). An email request was sent to key stakeholders and contacts in the area (in Australia and the UK) requesting any relevant literature of which they were aware. Once all databases were searched, all results were imported into Endnote and duplicates removed. Titles and abstracts were scrutinized and articles were excluded if there was no specific mention of intellectual disability (where the disability mentioned was either physical or nonspecific) and/or no mention of mental health or mental health services, and/or no mention of barriers or facilitators (or related terms). Articles were included if the article focused on autism, and also had a substantial intellectual disability component (articles which only referred to autism without explicitly referring to intellectual disability were excluded). To establish

Table 1. Search strings.

Mental Health Services	Intellectual Disability	Barriers & Enablers to Access
Mental health AND health services OR Mental health services (mental health mental disorder mood disorders mental illness psychopathology behavioral disorders emotional disorders mental disorders dual diagnosis) AND (Health services health services adolescent health services child care community health services dietary services emergency medical services genetic services health services for persons with disabilities health services for the aged health services for transgendered persons health services indigenous health services mental health services nursing care nursing services patient care personal health services pharmaceutical services preventive health services rehabilitation reproductive health services rural health services social work student health services suburban health services transition to adult care urban health services women's health services) OR (mental health services psychiatric services psychiatry psychological services)	Intellectual disability Mental retardation Developmental disability Learning disability	Health services accessibility Service access Barriers Health services needs and demands Health services research Health service evaluation Quality of healthcare Healthcare delivery Healthcare utilization Treatment barriers

interrater reliability and ensure that consistent search criteria were being used, two members of the research team conducted a second review of the retrieved publications to ensure that there was agreement on whether the articles met the thematic criteria. Initial interrater reliability between both team members was high (90%), and disagreement was subsequently resolved by consensus following discussion.

As the retrieved literature was so varied in method and type, no consistent method was able to be applied to rate articles for quality. As a result, all articles that met the subject matter criteria were included. This included review articles, as the authors found that where a review met the inclusion criteria, the original research that may have been included in that review did not, either via not discussing the three search concepts explicitly, or falling outside the listed timeframe.

Analytical Framework

Analysis of the literature was conducted using a framework derived from the literature pertaining to access to health services in general. Gulliford's definition of access was chosen as the basis for the framework, as it provides a pragmatic and useful account of the complex and interrelated facets of access. The framework differentiates between having access and gaining access. Having access refers to the potential to use the service if it is required, whereas gaining access refers to actually utilizing a service (Gulliford et al., 2002). This is crucial, as people may have access to services (as in the service exists), but may still have difficulties using those services (for various reasons which are discussed at length below—whether financial, logistical, or systems related), and a framework should take this into account to be meaningful. The four dimensions of this framework build on this differentiation: availability, which refers to the adequate supply of health care services; utilization, which extends beyond the availability of services to the personal, organizational, and financial barriers; relevance and effectiveness, which amounts to the right service at the right time, and is related to conceptions of quality; and equity, which refers to fairness in access for groups with equivalent needs. These four dimensions were used to present the analysis of the retrieved literature.

Results

Twelve empirical research articles were identified (see Table 2), and eight review articles (see Table 3). Twelve grey-literature documents were identified (see Table 4), consisting of reports from NGOs, government reports, fact sheets, guidelines, and frameworks. The barriers and enablers identified across the literature are listed by dimension of access at Table 5.

Table 2. Empirical literature.

	Author	Title	Year	Type	Study Size	Empirical Data (Y/N)	Design	Location	Key Issues Identified
1	Bhaumik, S. Tyrer, F. C. McGrother, C. Ganghadaran, S. K.	Psychiatric service use and psychiatric disorders in adults with intellectual disability	2008	Cross-sectional study	*N* = 2711	Y	Cross-sectional study of adults with intellectual disability using specialist services in Rutland & Leicestershire UK between 2001–2006	UK	Barriers include communication deficits, diagnostic issues, and diagnostic overshadowing. Enablers include close collaborative working, clear care pathways and pooling of resources.
2	Bonell, S.; Underwood, L.; Radhakrishnan, V.; McCarthy, J	Experiences of mental health services by people with intellectual disabilities from different ethnic groups: A Delphi consultation	2011	Mixed method	*N* = 24	Y	Delphi consultation with White British and Black British service users	UK	Barriers included poor knowledge of services, cultural insensitivity, communication difficulties, racism. Enablers were not identified.
3	Chinn, D., & Abraham, E.	Using ‘candidacy’ as a framework for understanding access to mainstream psychological treatment for people with intellectual disabilities and common mental health problems within the English Improving Access to Psychological Therapies service.	2016	Mixed method	*N* = 21 (interviews) *N* = 452 (survey)		Qualitative interviews with people with intellectual disability, carers and family members, survey of mental health workers	UK	Barriers and enablers operated at multiple levels, including individual, professional, organizational and structural. Barriers included “managerialist discourse,” identification of mental health issues and service design
4	Donner, Ben; Mutter, Robin; Scior, Katrina	Mainstream in-patient mental health care for people with disabilities: Service user, carer and provider experiences	2010	Qualitative study	*N* = 18	Y	Semi-structured interviews and focus groups conducted with service users and providers	UK	Barriers included diagnostic overshadowing, conflict between service systems, lack of understanding of relationship between intellectual disability and mental health. Enablers included advocacy and empowerment.

(*Continued*)

Table 2. (Continued).

	Author	Title	Year	Type	Study Size	Empirical Data (Y/N)	Design	Location	Key Issues Identified
5	Douma, Jolanda C. H.; Dekker, Marielle C.; De Ruiter, Karen P.; Verhulst, Frank C.; Koot, Hans M.	Help seeking process of parents for psychopathology in youth with moderate to borderline intellectual disabilities	2006	Survey	$N = 522$	Y	Questionnaire surveying parents of children with intellectual disability	The Netherlands	Barriers included identification of psychopathology on the part of parents/carers, limited awareness of services, help-seeking, desire to handle problems in-family. Enablers included suggested training and education.
6	Edwards, N.; Lennox, N.; & White, P.	Queensland psychiatrists' attitudes and perceptions of adults with intellectual disability	2007	Survey	$N = 175$	Y	Questionnaire sent to psychiatrists in Queensland	Australia	Barriers included knowledge deficits and a lack of training among psychiatrists, diagnosis and recognition of mental disorder, general information and training and especially related to pharmacotherapy. Enablers included training and education.
7	George, A. P.; Pope, D.; Watkins, F.; O'Brien, S. J.	How does front-line staff feel about the quality and accessibility of mental health services for adults with learning disabilities?	2011	Qualitative study	$N = 10$	Y	In-depth interviews	UK	Barriers from the perspective of service providers included poor service collaboration, service system issues including management and policy and identification of mental health disorder in people with intellectual disability. Enablers included collaborative learning and training between services, as well as "work arounds" implemented by staff Extremely poorly reported study

(*Continued*)

Table 2. (Continued).

	Author	Title	Year	Type	Study Size	Empirical Data (Y/N)	Design	Location	Key Issues Identified
8	Jackson, Tom	Accessibility, efficiency and effectiveness in psychological services for adults with learning disabilities	2009	Case study	*N* = 1	N	Description of a local service	UK	Enablers to access included simplified referral pathways and a designated referral officer and close multidisciplinary working No evidence available as to efficacy of model
9	Jess, Gillian; Torr, Jennifer; Cooper, Sally-Ann; Lennox, Nicholas; Edwards, Nicole; Galea, Jennifer; O'Brien, Gregory	Specialist versus generic models of psychiatry training and service provision for people with intellectual disability	2008	Survey	*N* = 499	Y	Questionnaire sent to psychiatrists in UK and Australia	UK/ Australia	Barriers included flexibility/ inflexibility of intellectual disabilities model, lack of psychiatric facilities, lack of multidisciplinary support, lack of confidence around treating people with intellectual disability, financial disincentive. Enablers included up-skilling and collaborative working.
10	Lunsky, Y. Gracey, C. Gelfand, S.	Emergency psychiatric services for individuals with intellectual disabilities: Perspectives of hospital staff	2008		*N* = 6	Y	Focus groups	Canada	Barriers identified were inappropriate care settings, lack of information regarding clients, lack of specialist training, communication issues. Enablers included caregiver training, system cohesion, interagency communication, alternative service models.

(*Continued*)

Table 2. (Continued).

	Author	Title	Year	Type	Study Size	Empirical Data (Y/N)	Design	Location	Key Issues Identified
11	Lunsky, Y.; Garcin, N.; Morin, D.; Cobigo, V.; Bradley, E.	Mental health services for individuals with intellectual disabilities in Canada: Findings from a national survey	2007	Survey	$N = 116$	Y	Questionnaire sent to key informants across Canada	Canada	Barriers included lack of training, lack of specialized services, long waitlists, distance, stage of deinstitutionalization, and a lack of data (both epidemiological and service). Enablers included specialist services.
12	Szeftel, R.; Federico, C.; Hakak, R.; Szeftel, Z.; Jacobson, M.	Improved access to mental health evaluation for patients with developmental disabilities using tele-psychiatry	2012	Case series - low	$N = 45$	Y	Retrospective chart review	United States	Key barriers identified were distance and identification of mental disorder among people with intellectual disability. Enablers included access to specialized mental health services. The study found that patients improved over time, required fewer visits as treatment progressed and had fewer medication changes. Externalizing disorders were identified at higher than previous rates.

Table 3. Review literature.

	Author	Title	Year	Type	Study Size	Empirical Data (Y/N)	Design	Location	Key Issues Identified
1	Costello, Helen; Bouras, Nick	Assessment of mental health problems in people with intellectual disabilities	2006	Review	N/A	N	Non-systematic narrative review	UK	Barriers include diagnostic overshadowing, identification of mental disorder, lack of diagnostic instruments, linguistic difficulties, lack of knowledge around service availability on the part of carers. Enablers include training initiatives, and multidisciplinary approaches.
2	Evans, E.; Howlett, S.; Kremser, T.; Simpson, J.; Kayess, R.; & Trollor, J.	Service development for intellectual disability mental health: A human rights approach	2012	Review	$N =$	N	Narrative review using a systematic search strategy	Australia	Barriers included poor public mental health services, inadequate numbers of services available, lack of integrated care, a lack of expertise, restricted funding and competition for funding. Suggested enablers include up-skilling the existing workforce, improved public mental health services, improved capacity for collaboration across disability and health services and improving infrastructure to minimize distance as a barrier.
3	O'Keefe, N.& O'Hara, J.	Mental health needs of parents with intellectual disabilities	2008	Review	$N =$ not reported	N	Non-systematic narrative review	UK	Key barriers to access identified included lack of expertise, funding, differing eligibility criteria, crisis driven services, resistance to help-seeking, and lack of confidence among practitioners. Suggested enablers included independent advocacy, early intervention and specialist management.

(*Continued*)

Table 3. (Continued).

	Author	Title	Year	Type	Study Size	Empirical Data (Y/N)	Design	Location	Key Issues Identified
4	Sin, Cih-Hoo; Francis, Rob; Cook, Chloe	Access to and experience of child and adolescent mental health services: Barriers to children and young people with learning disabilities and their families.	2010	Review	Not reported	N	Non-systematic narrative review	UK	Barriers included geography, information and knowledge deficits (including lack of knowledge around accessing mental health services), cultural insensitivity, diagnostic issues, lack of service provider competency, systems barriers, lack of communication, lack of interagency collaboration, lack of joint planning, lack of clear care pathways, lack of points of referral, transition, delayed access, inappropriate services, general inadequate service provision, poor structural integration. Enablers included service integration, staff training, person-centered approach, clear care pathways, joint commissioning and planning, available and easy access information.
5	Taua, Chris; Hepworth, Julie; Neville, Christine	Nurse's role in caring for people with a comorbidity	2012	Review	*N* = 21	N	Literature review using a systematic search strategy focusing on the role of nurses in relation to mental health and intellectual disability	Australia/ New Zealand	Barriers include a lack of training for nurses around intellectual disability, a lack of evidence around appropriate intervention and misidentification of challenging behavior and mental health disorder. Enablers identified included self advocacy, advocacy on the part of nursing staff, and the nurse as a central point for collaborative care

(*Continued*)

Table 3. (Continued).

	Author	Title	Year	Type	Study Size	Empirical Data (Y/N)	Design	Location	Key Issues Identified
6	Trollor, Julian	Making mental health services accessible to people with an intellectual disability	2014	Review/ opinion	N/A	N	Viewpoint/letter to the editor	Australia	Barriers identified include lack of data (epidemiological, service interaction), inadequate training for health professionals, identification of intellectual disability (carers, service providers & people with intellectual disability), lack of coherent service models, lack of service coordination, exclusion of people with intellectual disability from policy. Enablers include training & up-skilling, identified care pathways, multidisciplinary and interagency collaboration, frameworks for mental health care providers, peak body support & leadership
7	Wei, Ker-Chia	Improving mental health care for people with an intellectual disability in Singapore: Bridging the health-social care divide	2012	Review of service provision	N/A	N	Review of service provision in Singapore	Singapore	Barriers included misidentification or lack of identification, perception of mental disorder and untreatable, lack of specialist training, diagnostic overshadowing, lack of continuous care and foreign labor force, lack of early identification. Suggested enablers include collaborative care and multidisciplinary working.
8	Werner, S. & Stawski, M.	Knowledge, attitudes and training of professionals on dual diagnosis of intellectual disability and psychiatric disorder	2012	Review	N = 27	N	Narrative review using a systematic search strategy	Israel	Knowledge deficits, lack of training, lack of competence of practitioners, a lack of confidence and a lack of practitioners as a result and a cycle of poor training leading to poor treatment. Enablers included up-skilling, training and education.

Table 4. Grey literature and opinion.

	Author	Title	Year	Type	Study Size	Empirical Data (Y/N)	Design	Location	Key Issues Identified
1	Burke, Christine-Koulla	Feeling down: Improving the mental health of people learning disabilities	2014	Grey literature	N/A	Y	Informal qualitative study with people with intellectual disability and mental disorder	UK	Barriers included diagnostic overshadowing, "seeing only the intellectual disability," inaccessible information, lack of support and a failure on the part of health professionals to believe or understand that someone was suffering from a mental disorder, long waiting times, lack of GP support. Enablers included use of diaries, accessible information, specialist services, joint working and support during treatment and aftercare.
2	Chaplin, Eddie O'Hara, Jean Holt, Geraldine Bouras, Nick	Mental health services for people with intellectual disability: Challenges to care delivery	2009	N/A	N/A	N	Expert opinion	UK	Barriers include a lack of specialist services, out of area placements, eligibility issues, funding arrangements and overall inadequate service provision. Enablers included multiagency working.
3	Department of Development Disability and Neuropsychiatry (3DN), UNSW	The Guide: Accessible Mental Health Services for People with an Intellectual Disability	2014	Grey literature	N/A	N	Practice guidelines	Australia	Barriers include diagnostic issues & problems with assessment, stigma, exclusion from services, support issues, systemic barriers, a lack of interagency collaboration.
4	Dossetor, David	The National Roundtable on the Mental Health of People with an Intellectual Disability: A Summary	2013	Grey literature	N/A	N	Report on National Roundtable	Australia	Barriers include diagnostic difficulties, lack of training, lack of data around service provision. Enablers include early intervention.
5	Friedlander, Robin	Mental health for persons with intellectual disability in the post-deinstitutionalization era: experiences from British Columbia	2006	N/A	N/A	N	Expert opinion	Canada	Barriers include funding, geographical location, lack of service provider expertise, silo-ing of services, de-institutionalization and a lack of corresponding support. Enablers included collaborative and multidisciplinary working and specialized services.

(*Continued*)

Table 4. (Continued).

	Author	Title	Year	Type	Study Size	Empirical Data (Y/N)	Design	Location	Key Issues Identified
6	Howlett, S. & Trollor, J.	Clinical Services Planning for Adults with Intellectual Disability and Co-occurring Mental Disorders	2014	Grey literature	N/A	N	Report	Australia	Barriers identified include lack of data (epidemiological, service interaction), falling between gaps, diagnostic overshadowing. Enablers include training & up-skilling, identified care pathways, multidisciplinary and interagency collaboration, frameworks for mental health care providers, policy & legislation
7	National & NSW CID	The place of people with intellectual disability in mental health reform	2011	Grey literature	N/A	N	Position paper	Australia	Barriers identified include inadequate training for mental health professionals, communication issues, misdiagnosis and diagnostic overshadowing. Enablers include capacity building, holistic services and joint planning of services.
8	National Health Service	Learning disabilities: Positive Practice Guide	2009	Grey literature	N/A	N	Practice guidelines	UK	Barriers identified included social restrictions, challenging behaviors, GPs, limited specialist mental health services. Enablers included engagement with people with disabilities, training & up-skilling.
9	NSW CID	The National Roundtable on the Mental Health of People with an Intellectual Disability: Background Paper	2014	Grey literature	N/A	N	Background/briefing paper	Australia	Barriers include diagnostic overshadowing, misidentification of mental disorder, limited specialist services, lack of data, lack of education and training. Enablers include multidisciplinary working and capacity building, training and up-skilling of workforce.

(*Continued*)

Table 4. (Continued).

	Author	Title	Year	Type	Study Size	Empirical Data (Y/N)	Design	Location	Key Issues Identified
10	RC Psych	Enabling people with mild intellectual disability and mental health problems to access healthcare services	2012	Grey literature	N/A	N	Report		Lack of support, unclear care pathways, lack of training or staff, service boundaries & funding, silo-ing, lack of collaborative working. Enablers include protocols to encourage collaborative working, facilitate care pathways, information sharing, training & up-skilling.
11	Rubin, I. Fahs, Jeffrey J. Beasley, Joan B.	Delivery of health care for people with “dual diagnosis”: From the person to the policy	2007	Expert opinion	N/A	N	Expert opinion		Barriers include identification, lack of appropriate services. Enablers include multidisciplinary working and collaborative care models.
12	Sullivan, Danny; Robertson, Terri; Daffern, Michael; Thomas, Stuart	Building capacity to assist adult dual disability clients access effective mental health services	2013	Grey literature	N/A	N	Report prepared for the Senior Practitioner – Disability		Barriers include reduced help-seeking & presentations, diagnostic issues, communication issues & challenging behaviors, a lack of clinical and financial responsibility, breakdowns in interagency communication, lack of specialist knowledge and training. Enablers include adequate training and practical experience.

Table 5. Barriers and enablers.

Domain of Access:	Barriers:	Enablers:
Service availability	Limited and scarce services Logistical and geographical issues	Innovative models of service delivery
Utilization of services and barriers to access	Organizational barriers Silo-ing of service sectors Competing service models Failure of interagency communication Inconsistent eligibility criteria Conflict and competition between services Transition Unclear referral pathways Identification of need Lack of help seeking	Clear referral pathways Established protocols Single point of access Interagency collaboration Education
Relevance, effectiveness and access	Diagnostic overshadowing Misidentification of mental disorder Clinical knowledge deficits	Capacity building Up-skilling and training service providers
Equity and access	Severity of intellectual disability Social determinants	None identified

Availability

'Availability, in Gulliford et al.'s definition, (2002) refers to service availability specifically, whether there is an adequate supply of health services available to a population and whether the opportunity to access health care where it is wanted or needed exists.

Barriers to Access Related to Availability

Service availability is established as a barrier in health care generally for people with an intellectual disability (Krahn, Hammond, & Turner, 2006), and this is even more true in the case of mental health services (Chaplin, O'Hara, Holt, & Bouras, 2009; Lennox & Kerr, 1997). The number of service providers is generally found to be lacking, particularly in rural and regional areas, which is reflected in the wider literature around access across contexts (Chaplin et al., 2009; Lunsky, Garcin, Morin, Cobigo, & Bradley, 2007).

Physical and logistical issues (such as travel, distance, and location) are identified general barriers to accessing healthcare (Arcury, Preisser, Gesler, & Powers, 2005; Buzza et al., 2011), and were not specific to either mental health services or intellectual disability.

Lunsky et al. (2007) noted distance and scarcity of services for rural Canadians as an issue. Participants from rural settings referred to a sense of isolation experienced as a result of tertiary services being so far away. It was also noted that specialist services had not been rolled out universally and may have accounted for lower rates of service usage among people with an intellectual disability (Lunsky et al., 2007).

Enablers to Access Related to Availability

A key aspect across the literature of enabling availability was the adoption of innovative methods of service delivery, especially those that take into account the logistical issues outlined above. Some alternative models were described, including stepped-care models and tele-psychiatry (Jackson, 2009; Szeftel, Federico, Hakak, Szeftel, & Jacobson, 2012). For example, the Cedars-Sinai Telepsychiatry Clinic treats clients with intellectual disability by using a collaborative care model using tele-psychiatry methods (including telephone, e-mail, and remote videoconferencing). Many of the participants in the study had very limited communication (50 words or less) and 84% had mild to profound intellectual disability. The study found that clients showed improvement over time, requiring fewer visits and fewer medication changes. Psychiatrists also identified internalizing disorders in clients where previously none had been identified, indicating that specialist psychiatrists were able to communicate more effectively with clients with communication difficulties (Szeftel et al., 2012). The apparent effectiveness of this type of model indicates that there are alternative service models that are useful among people with an intellectual disability and assist in overcoming limited clinician availability and physical barriers such as transport and location.

Similarly, Jackson (2009) maintains that a stepped-care model is highly effective care for people with an intellectual disability, and describes a service of this type. Stepped care involves the intentional delivery of effective treatments using minimal resources according to the intensity of need. Low-intensity "minimal interventions" (for example, basic cognitive behavioral therapy interventions delivered by assistant psychologists, or group psycho-education and behavior arousal interventions) which are less resource intensive are delivered to clients, with the availability of more resource-intensive treatments available if the client support needs to be "stepped up" (Jackson, 2009). The model aims to improve accessibility to those with the greatest need by maximizing the delivery of scarce resources. Jackson identifies triage as a key aspect in the efficacy of this service. All clients (and any support people they would like to bring) meet with a psychologist for clinical assessment upon referral, as well as assessing how well the client is aware of and understands the referral process, and ensuring they consent to proceed with the intervention. Logistical and practical issues are also addressed, including transport, communication, and session scheduling (Jackson, 2009). While this model does not yet have empirical evaluation data to support its claims to efficacy, Jackson asserts that, based on anecdotal evidence and clinical opinion, this particular form of stepped-care model is an effective method of improving access to appropriate and effective services (2009). A similar service with some empirical evidence for its efficacy is outlined below (Chinn & Abraham, 2016).

Utilization

It is insufficient to characterize access in terms of the availability of services, as people in need may have access to services but still be unable to utilize the services in question for many reasons. Multiple factors are associated with utilization, from both the perspective of service users and service providers. Service providers must also be able to shift and operate between the different parts of a service system, as well as utilize and refer to services external to their own organization. Utilization is a dimension that encompasses personal, financial, and organizational barriers (Gulliford et al., 2002).

Barriers to Access Related to Utilization

Organizational Barriers—Systematic Variations in Referral Process, Delivery of Services, and Failure to Design Systems Appropriately. Historically, the demarcation between mental health and intellectual disability services stems back to the closure of most disability and mental health institutions and the inclusion of people with mental ill-health and intellectual disability in the community (deinstitutionalization). As per a report to the Senior Practitioner–Disability in the Victorian government (Australia), this separation has led to a profound "silo-ing" of mental health and disability services, making it difficult for people with intellectual disability and co-occurring mental ill-health to move between the two (Sullivan, Robertson, Daffern, & Thomas, 2013). Chaplin et al., in Sullivan et al.'s (2013) report, notes that the two systems have "competing paradigms which manifest in philosophical, operational and systems differences." These differences have substantive impacts on the accessibility of services for people with intellectual disability and co-occurring mental ill-health and can take a number of forms, from lack of interagency communication, to competing service models and competition for the allocation of limited resources. For example, Sullivan et al.'s (2013) report refers to studies (outside the time frame for individual inclusion in this review) that explicitly address breakdowns in communication between services that resulted in inadequate access for people with an intellectual disability.

Entry to the various service systems is frequently dependent on eligibility criteria that vary across mental health and disability systems, which can present an obstacle to access between systems. George, Pope, Watkins, and O'Brien (2011) refer to inconsistent eligibility criteria and service frameworks as a barrier to access, which results in a lack of agreement around which services are the most appropriate for people with an intellectual disability and mental disorders.

In one study, frontline staff at three organizations were interviewed to discuss their views on accessibility and quality in relation to mental health services for people with an intellectual disability. These staff identified a number of systemic barriers such as service collaboration issues, which included a lack of clarity around the scope and remit of various services, as well as negative experiences with staff of other services. Service providers also spoke of the necessity of being assertive and demanding in order to access other services (i.e., mental health service providers accessing intellectual disability services and vice versa) (George et al., 2011). This was an oft-repeated theme throughout the literature. Lack of service cohesion, inter-agency communication, and joint working, and conflict between services, was frequently cited as a considerable barrier to access (Donner, Mutter, & Scior, 2010). Lunsky, Gracey, and Gelfand (2008) also identified difficulties around communication and collaboration as a barrier to effective mental health service access. Service integration and collaborative care are increasingly widely acknowledged across health care for all groups as a facilitator to access, especially for people with complex support needs. It facilitates access into and through the system by encouraging collaborative working and communication between the elements, and is considered best practice in service design and management, particularly in relation to achieving person-centered models of care (Brophy, Hodges, Halloran, Grigg, & Swift, 2014). Failure to effectively communicate and integrate services impedes consumers from accessing appropriate services.

Designing systems that inadequately took into account the needs of people with intellectual disability was also a crucial barrier. Chinn and Abraham (2016) conducted a study to explore the barriers and enablers to accessing the Improving Access to Psychological Therapies service (IAPT) specific to people with intellectual disability. IAPT is a mainstream stepped-care model in the United Kingdom that is delivered by regional mental health teams. As with the service described by Jackson, clients are offered low-intensity self-management programs before being stepped up as necessary, usually to a cognitive behavioral therapeutic treatment (Chinn & Abraham, 2016). While Jackson described a stepped-care model as an effective model of providing access to people who would have difficulty otherwise contacting services, the service design and delivery of IAPT presented a number of barriers.

One of the primary barriers people with intellectual disability experienced when they presented to IAPT was what Chinn and Abraham described as a “managerialist discourse” present in the design and implementation of IAPT, which emphasizes “tightly defined eligibility criteria, measurable and uniformly operationalised process and outcome variables, efficiency and value for money” (Chinn & Abraham, 2016). This meant that people with intellectual disability often did not meet these criteria, excluding them from the service. The practical processes of referral were also designed in a way that barred people with intellectual disability, as they were made over the phone or in writing, excluding people with limited verbal or literacy skills. People with intellectual disability required longer times than were prescribed for efficiency within the service model, and a number of service providers felt that they were unable to adapt their practice to meet the needs of people with intellectual disability due to a lack of prioritization of the needs of people with intellectual disability (Chinn & Abraham, 2016).

Transition Points as Barriers. Organizational barriers to transition between services aimed at different age groups are a problematic area in many health service sectors, particularly mental health (Mandarino, 2014). This appears to be especially true in relation to mental health and intellectual disability services. Transition from adolescence to adult has been identified as a time when young people with intellectual disabilities are particularly susceptible to mental ill health, which can be exacerbated by simultaneously moving from one service structure to another. Only one of the articles identified specifically addressed the issue of transition as a barrier. The review by Sin, Francis, and Cook (2010) identified barriers at the individual, organizational, and structural levels. However, the bulk of their review (which tends to reflect the wider literature including adults) investigates systems-related (organizational and structural) issues (Sin et al., 2010).

Organizational and system barriers were the key issues in relation to child and adolescent mental health services and transition from child to adult services. Young people aged between 16 and 18 may fall between pediatric and adult services, as in the UK system, or between 16 and 25 in the Australian system. System barriers include a lack of a single point of referral, unclear service organization, a lack of clear referral pathways, and a lack of clarity around responsibility for clients (Sin et al., 2010). It is important to note this is not unique to child and adolescent mental health, but was flagged as a particular difficulty for this group. Transitions in later stages of life, especially around the transition into aged care services from adult services, have also been reported anecdotally and in the grey literature as problematic in both the UK and Australian systems; however, there is a lack of systematic empirical study available in for this area.

Referral Pathways. Referral pathways represented an organizational barrier to access in adult services as well. In a study by Lunsky et al., (2008) staff at six Canadian hospitals were surveyed and reported that people with an intellectual disability who accessed the emergency department for mental disorders were often not referred to appropriate services. This was attributed to several factors, including the limitations of the emergency department, the role of crisis nurses, and limited information about available services for referral (Lunsky et al., 2008).

In particular, Lunsky found that this was related to limited awareness on the part of emergency department nurses of the most appropriate services and referral pathways. Participants felt that they had inadequate information about services available to access for clients, and also felt that they did not have the skills, knowledge, or experience to serve people with an intellectual disability well (Lunsky et al., 2008). Lunsky et al. point out that training is inadequate across all sectors of health, including general practice, psychiatry, internal medicine, and nursing.

Personal Barriers. A number of barriers relating to the personal (individual) experience of access were identified across the literature. Gulliford et al. (2002) et al. point out that the first step in the road to access is for people to be aware of their need for health services. A report by the Senior Practitioner of Disability for the Victorian Government noted that people with an intellectual disability tend not to refer themselves to mental health services, but rather be referred, either by carers, family members, or other caregivers. However, a lack of knowledge of how mental health issues may present in people with an intellectual disability meant that carers were not able to recognize or identify symptoms of a mental health issue and therefore were less likely to recognize the need to access services (Sullivan et al., 2013). Costello and Bouras (2006) also emphasize the importance of family and carer staff correctly identifying mental disorders in people with an intellectual disability, and that a lack of knowledge around manifestations of mental disorder can restrict access to appropriate services, as carers were often unsure as to where to go or how to navigate systems (Costello & Bouras, 2006; Department of Developmental Disability Neuropsychiatry, 2014; Douma, Dekker, De Ruiter, Verhulst, & Koot, 2006; Sin et al., 2010). They point out that carers have a unique position in that they are well positioned to see changes in behavior or affect over time, rather than simply at the point of presentation. Douma et al. (2006) similarly found that parents were often the gatekeepers to accessing help for children that had comorbid mental disorders and intellectual disability, and that the identification of psychopathology was the first step in the process toward accessing services. This was reinforced by Chinn and Abraham's investigation of barriers to accessing IAPT mental health services in the UK. They found that the process of identifying candidacy (as an integral part of accessing mental health services) involved a process of negotiation that included multiple parties, including the person themselves, family, staff, and carers (Chinn & Abraham, 2016). Chinn and Abraham (2016) identified a process where reaching an understanding of people's symptoms was obtained through informal discussions and "having a chat," rather than a formal process of assessment.

A report produced by the senior disability practitioner in Victoria, Australia, identified a lack of help-seeking among adults with an intellectual disability as a barrier to accessing services. The report identifies the reasons for this as multifactorial and complex, including: fear of medical personnel and services, as well as low expectations of services and a reduced tendency to complain (Sullivan et al., 2013). Douma et al. (2006) also found that identification of the need for mental health support did not automatically imply that parents would access services. Even after parents indicated that they were aware of a need for mental health support, many barriers prevented them from taking the final step into service access (Douma et al., 2006). The barriers included not perceiving the problem as serious, a desire to handle it by themselves, a lack of awareness around where to go for help, and previous negative experiences with health care.

A clearer understanding of the mechanisms behind help-seeking and identification of mental disorder is needed to unpack how these mechanisms act as barriers in the process of access, particularly on the part of carers.

Enablers to Access Related to Utilization

Clarity of Referral Pathways. Clear referral pathways and system guidelines that emphasized the pathways were identified across the literature as an enabler to access. A report by the Royal College of Psychiatrists (2012) also emphasizes that the established protocols should facilitate referral and care pathways through adult mental health services for people with an intellectual disability. The report emphasizes that its guiding principle is that "service users with mild disability are supported at all times to manage the admission process" (Royal College of Psychiatrists, 2012). However, the report does not clearly indicate the specifics of the referral process.

Jackson's (2009) report on a successful psychology service for adults with intellectual disability emphasizes the importance of a single point of access for entry to the service, which streamlines the referral pathways into that service. A dedicated information-officer role was established to oversee the referral pathways into the service, with that officer being responsible for receiving, logging, managing, and tracking referrals for all parts of the service (Jackson, 2009). All referrals are discussed at a multidisciplinary meeting weekly. It was felt that this process streamlined admission and supported people with an intellectual disability through the process.

Similarly, the Guidelines for Collaboration developed by the Queensland Department of Health suggest that identifying designated liaison officers within each service may offer an effective way of smoothing referral processes. They also suggest that a central point of contact facilitates entry to the service and communication between services.

Interagency Collaboration. Co-location of services was also noted as a facilitator to improving access to services between mental health and intellectual disability systems. The *Guidance for Commissioners of Mental Health Services for People with Learning Disabilities* report posits that co-location of services can stimulate "effective and efficient multidisciplinary working" (Joint Mental Health Commissioning Panel for Mental Health, 2013).

The Royal College of Psychiatrists emphasizes interagency collaboration as the cornerstone of facilitating access to mental health services. It's *Enabling People With Mild Intellectual Disability and Mental Health Problems* report recommends that each organization providing mental health and intellectual disability services should have established protocols to address the specific needs of the population, and that these protocols should be jointly instituted with all services and local authorities (Royal College of Psychiatrists, 2012). Regular interface meetings should also be held between services. Bhaumik, Tyrer, McGrother, and Ganghadaran (2008) also emphasized the importance of close collaborative working between general and specialist services.

The guide *Accessible Mental Health Services for People With an Intellectual Disability* (Department of Developmental Disability Neuropsychiatry, 2014) also underscores the importance of interagency collaboration, and offers practical strategies as to how to achieve effective collaboration and communication between services, including information-sharing agreements and protocols, formal strategies, and memorandums of understanding between agencies to enhance cross-sector collaboration and the development of joint assessment protocols (Department of Developmental Disability Neuropsychiatry, 2014).

Relevance and Effectiveness

The dimension of relevance and effectiveness is related to the provision of the right service at the right time for the best outcome and the quality of available services. The "relevance" dimension measures access in terms of health outcomes, rather than simply the availability or utilization of a service. Gulliford et al. (2002) point out that poor-quality services may actually be associated with higher levels of utilization, whereas higher-quality services which achieve favorable outcomes for users may result in lower levels of utilization, as the need for health care is reduced.

Barriers to Access Related to Relevance and Effectiveness

Misidentification of Mental Disorders. Almost all the literature reviewed (both grey and peer-reviewed) noted that the misidentification of mental disorders in people was overall one of the most substantial barriers to accessing mental health services (Costello & Bouras, 2006; Department of Developmental Disability Neuropsychiatry, 2014; Donner et al., 2010; National & NSW Councils for Intellectual Disability, 2011).

As discussed earlier in the review, this is in part a personal barrier, held by some people with an intellectual disability and carers. However, this barrier also speaks to the quality of services available (rather than simply the individual service providers or clinicians) and the skill and knowledge levels of service providers. This is particularly evident in the issue of "diagnostic overshadowing," a phenomenon well documented in the wider literature (Costello & Bouras, 2006; Donner et al., 2010; Szeftel et al., 2012). Diagnostic overshadowing refers to the misattribution of mental health symptoms (or other symptoms) to a person's intellectual disability rather than being identified as related to mental health, whether that is a symptom of mental disorder, physical discomfort, or emotional unrest (Reiss, Levitan, & Szyszko, 1982).

Donner et al. found that service users, cares, and service providers all experienced the incidence of diagnostic overshadowing as a barrier: "everything is attributed to the intellectual disability" (Donner et al., 2010). The *Feeling Down* report produced by the Foundation for People with Learning Disabilities in the UK found that people with an intellectual disability often felt as though only their intellectual disability was seen, not their personal experience (Burke, 2014).

The phenomenon of diagnostic overshadowing is a clear illustration of the inaccuracy of diagnostics of mental disorder for people with an intellectual disability. This is attributable to several factors, including differential presentations of mental disorder, difficulties in communication, and especially the presence of challenging behavior (National & NSW Councils for Intellectual Disability, 2011; Sullivan et al., 2013). Challenging behavior refers to behavior which is culturally unusual and of such an intensity, frequency, or duration that the physical safety of self or others is endangered, or behavior which is likely to limit the person from accessing ordinary community facilities (Emerson, 1995). Challenging behavior can present a particular set of difficulties, as it can have a number of contributing factors including unmet need, frustration, or environmental factors. However, it can also be a manifestation of mental disorder (National & NSW Councils for Intellectual Disability, 2011).

The *Guidance for Commissioners of Mental Health Services for People with Learning Disabilities* report produced by the Joint Commissioning Panel for Mental Health in the UK also emphasizes that challenging behavior should not be confused with mental disorder (Joint Mental Health Commissioning Panel for Mental Health, 2013). It is of key importance for health workers to accurately identify the cause of challenging behaviors and not automatically attribute it to either mental disorder or as a part of intellectual disability (National & NSW Councils for Intellectual Disability, 2011)

Chinn and Abraham (2016) found that the process of identifying mental health disorder in people with intellectual disability was a key stage of accessing mental health services, and that this process involved not only the person with intellectual disability, but family, service providers, and carers. People with intellectual disabilities were (in some cases) disinclined to report mental ill-health, which was potentially attributed to stigma and concern over worrying friends and family. Diagnostic overshadowing was specifically identified as a barrier, as were assessment procedures that were not suitable for people with intellectual disability and their carers. The role of carers has been noted elsewhere as important in terms of facilitating mental health interventions in other arenas relating to the delivery of interventions (Willner, 2006).

Clinical Knowledge Deficits. Clinical knowledge deficits are one of the most significant barriers to accessing mental health services for people with an intellectual disability. Not only does a lack of clinical knowledge and expertise in the area result in a lack of services, it also clearly impacts the quality of services that are available. A frequently repeated theme throughout the literature was the inability of mental health professionals and primary care practitioners to adequately address the needs of people with an intellectual disability through a lack of training or familiarity with the presentation of mental disorder among people with an intellectual disability (Royal College of Psychiatrists, 2012). Mental health clinicians often view themselves as inadequately resourced and trained to meet the often complex needs of this population (National & NSW Councils for Intellectual Disability, 2011). The shortage of specialty psychiatrists and mental health clinicians is also a well identified. A review of knowledge and training among clinicians in relation to dual diagnosis found that 80% of psychiatrists who responded to three separate surveys in Australia agreed that they had inadequate training to manage people with mental disorder and intellectual disability (Werner & Stawski, 2012).

Edwards, Lennox, and White (2007) surveyed the attitudes of psychiatrists to people with an intellectual disability and identified several areas of deficit in relation to clinical knowledge. Psychiatrists felt that they had inadequate knowledge around best practices in diagnostics, prescribing, behavior management, and information with which to make evidence-based decisions. Psychiatrists also advised that they felt inadequately equipped to understand the complexities involved in collaborating with existing service delivery systems. They acknowledged that in general the knowledge and expertise necessary to treat and manage mental disorder among people with an intellectual disability was lacking (Edwards et al., 2007). However, the majority of respondents were eager to rectify this, suggesting that the deficit was not as a result of lack of interest in the area but rather the lack of opportunity, in terms of interacting with people with intellectual disability and in terms of training. This lack of opportunity may also be reflective of wider negative social attitudes (Edwards et al., 2007). Similarly, Jess et al. (2008) found that Australian psychiatrists felt that they had inadequate knowledge and were unskilled and unconfident, and lacked exposure to working with people with an intellectual disability.

Enablers to Access Related to Relevance and Effectiveness

Capacity Building and Training. Training and up-skilling was identified as relevant across the literature, particularly training that emphasized collaborative approaches, as a way to minimize diagnostic overshadowing and mitigate stigmatizing attitudes (Burke, 2014; Costello & Bouras, 2006; Department of Developmental Disability Neuropsychiatry, 2014; National & NSW Councils for Intellectual Disability, 2011; Royal College of Psychiatrists, 2012).

Several organizations and service systems have attempted to develop and implement guidelines and frameworks to improve access to services in recent years across both the UK and Australian contexts. These frameworks have in common an emphasis on improved training for clinicians in the area of intellectual disability mental health, facilitating interagency and inter-system collaboration and communication as a core component of improving access. For example, the *Feeling Down* report emphasizes that mandatory training modules should be in place for all health professionals, which includes psychiatrists, mental health clinicians, and general practitioners. Experience with people with an intellectual disability should be a fundamental requirement of training regardless of specialty, and training should in part be delivered by people who have intellectual disability (Burke, 2014).

Equity

The equity dimension of access is concerned primarily with the notion of fairness and social justice in relation to health care and particularly in relation to fairness of access for groups with equivalent (although not identical) needs (Gulliford et al., 2002). This dimension of access is perhaps the area that represents the biggest gap in the literature reviewed.

Barriers to Access Related to Equity

Severity of Intellectual Disability. The relative level of a person's intellectual disability may impact equity of access to services. Both mainstream and specialist services may be unprepared to accept people with more than very mild intellectual disability and comorbid mental disorders, who may then "fall through the cracks." The level of intellectual disability also affects presentation and assessment of mental health symptoms in some cases. People with borderline or mild intellectual disability, and who have good communication skills, tend to be able to describe how they are feeling, whereas people with more severe intellectual disability without assisted communication may not be able to do so. People with milder intellectual disability often tend to have mental health presentations that are more similar to those that mental health clinicians are used to (Department of Developmental Disability Neuropsychiatry, 2014).

Alternatively, even if there is there is a stated responsibility to treat people with an intellectual disability in a mainstream service, in practice the service may only be prepared to address people with borderline or mild levels of intellectual disability (Joint Mental Health Commissioning Panel for Mental Health, 2013). Chaplin et al. (2009) also noted that in the UK context there was variability in the threshold for eligibility for services according to local definitions. This resulted in people missing out on support, as they may not have fulfilled local care eligibility criteria even if they may have benefited from social care input.

In some cases, the level of the intellectual disability limited access specifically to appropriate and effective mental health services. Sin et al.'s (2010) review found that some areas in the UK provided limited or no services for children and adolescents with moderate to severe intellectual disability.

The lived experience of access as it relates to the level of intellectual disability is also underrepresented in the literature. The literature tends to focus on people with borderline to moderate intellectual disability, which disregards the experiences of people with greater intellectual disability, or who are less verbal. Facilitating communication and accessing people with greater intellectual disability is an acknowledged difficulty in intellectual disability research. However, methods are available (for example, augmentative and alternative communication [AAC]; Department of Developmental Disability Neuropsychiatry, 2014) that can facilitate the inclusion of people who use nonverbal communication, so this should not act as a deterrent to conducting research with this population.

Social Determinants of Health. The intersection of other social determinants of health with intellectual disability and mental health, and the combined impact of these three factors on access, was not widely discussed in the available literature. Sin et al. (2010) briefly discussed how children and young people who display offending behavior, are from minority ethnic backgrounds, or have complex needs tend to be more disadvantaged and may have increased difficulty when it comes to accessing appropriate services. Sin et al. also point out that services (in the UK context) rarely meet the "language, cultural and religious needs of South Asian service users," which can be particularly problematic if the families with a child with intellectual disability do not receive support from family and friends outside the immediate household. This, coupled with other social determinants experienced by cultural minorities ("pervasive discrimination," as well as housing, education, employment, and physical and mental health inequities), means that they are particularly disadvantaged relative to other parts of the population (Sin et al., 2010).

The *Guidance for Commissioners of Mental Health Services for People With Intellectual Disabilities* report also identified the intersection of social determinants such as cultural diversity as a potential barrier to access. This report acknowledges that the data do not exist on the specific experiences of people with an intellectual disability and mental disorder from diverse backgrounds. However, the report posits that given the particular disadvantages that people with mental disorders from diverse backgrounds (especially young black men) experience, it is highly likely that the intersection of these factors acts as a substantial barrier (Joint Mental Health Commissioning Panel for Mental Health, 2013).

Bonell, Underwood, Radhakrishnan, and McCarthy (2012) conducted a Delphi consultation with people with intellectual disabilities from different ethnic backgrounds who used mental health services. They identified a difference in knowledge of mental health services and where to seek help between Black and White users—the Black group did not reach a consensus about knowing which services were available to them. This may indicate a disadvantage associated with cultural diversity, but the mechanism behind the disparity is not explored in the study.

Discussion

There are clear commonalties across the literature corpus as to the key barriers and enablers. Lack of a skilled workforce, diagnostic overshadowing, and a failure to integrate services all represented the most commonly cited barriers across both the grey and peer-reviewed literature. Conversely, collaborative working and multidisciplinary approaches were identified as fundamental to improving access, treatment, and outcomes for people with intellectual disability and mental disorder.

The primary issue identified by the scoping review is the substantial gap in empirical knowledge about the effectiveness of interventions to improve access at the intersection of mental health and intellectual disability. This lack of empirical data means that it is not possible to establish with certainty what the most appropriate care models are to address unmet need. While some articles describe service models that appear to be effective (for example, Jackson, 2009) the majority of services and service models have not been formally evaluated. The bulk of the literature focuses on expert opinion, which is not a substantive grounding for service development. The notable exception to this is Chinn & Abraham's (2016) investigation into people with intellectual disabilities accessing mental health services via the mainstream Improving Access to Psychological Therapies service. This article provides one of the very few examples of empirical evidence into access for people with intellectual disability, and in particular the experience of accessing mainstream mental health services. Notably, it provides evidence into the lived experience of barriers and enablers to accessing these services, and provides insight into the ways in which mainstream services are not set up to accommodate the needs of people with intellectual disability.

The effects of other social determinants of health on access in the context of mental health and intellectual disability are rarely addressed. In the Australian context, while there is an extensive body of literature on the Indigenous Australian experience of accessing general health services and associated barriers and facilitators (Australian Institute of Health and Welfare, 2011), little to no data are available on the lived experience of Indigenous Australians with intellectual disability accessing mental health services. There is also no mention of barriers to access for the forensic population, despite the disproportionate prevalence of people with intellectual disability and mental health issues within the forensic setting (Baldry, Dowse, & Clarence, 2012). While Ouellette-Kuntz (2005) has addressed some of these social determinants in her work around the experiences of indigenous Canadians with intellectual disability, the implication of these determinants would change across contexts (for example, from the Canadian context to the UK or Australian contexts) and further work (particularly qualitative) is necessary. It is notable that no enablers were identified in the equity dimension.

The literature and data around the effects of gender on access for people with an intellectual disability (as well as their carers) are also weak, although there is some examination of the gendered experience of service users which does not address explicitly access to services, which thus has not been included in this review (Kroese, Rose, Heer, & O'Brien, 2013; Venville, Sawyer, Long, Edwards, & Hair, 2015). Further social determinants of health that have gone relatively uninvestigated (particularly in the Australian context) include rurality and urbanity, as well as socioeconomic status and complex support needs. It can be theorized that these determinants have similar effects on access to mental health care as they do to generalist health services; however, a lack of empirical data makes this difficult to verify.

The identification of these areas of deficit in the literature is crucial to determining where further research and evaluation is needed, and to developing solutions and facilitators. Conversely, the limited information about enablers indicates gaps about evaluated interventions which could be beneficial to improving access and therefore warrant deeper evaluation.

Substantive gaps in the knowledge and evidence base around the intersection between intellectual disability, mental health, and its impact on access to services were found. Chief among these is a comprehensive examination of the lived experience of these barriers and enablers from the perspective of a person with intellectual disability and mental health, as well as carers. While some of the literature examines the experience of service providers, this is insufficient to fully unpack the barriers as they are experienced. The lack of empirical data and the valuable "grassroots" perspectives around the lived experience of access to mental health services is also problematic in terms of a failure to meet the tenets of the participatory and inclusive paradigm that represents the increasing focus of service improvement and disability research.

As well as this, the available literature tends to focus on the experiences of people who have successfully accessed services (albeit often with substantial difficulty). In view of the disparity between the rates of mental ill health in this population and the uptake in services, a gap in the literature is clear. Inadequate information about people who have not received a diagnosis, but may be experiencing a mental disorder that goes undiagnosed as a result of diagnostic overshadowing, is also hampering service change. This may be a problem that is insurmountable, given that the population can be difficult to access due to many factors, but more extensive qualitative studies may assist with filling the knowledge gap.

Similarly, while the available epidemiological data is increasing, it does not capture information about people who have attempted to access services and been unsuccessful, and at what points the failure to access has occurred.

Limitations

As mentioned, the inclusion of multiple types of studies made it impossible to assess their quality in any rigorous or coherent way. The quality of the literature was varied, but it was beyond the remit of a scoping review to provide a quality assessment (Arksey & O'Malley, 2005). As well as this, the diffuse contributors to access potentially mean that some articles were missed, despite every effort to ensure that search terms captured all relevant discussions of access in relation to mental health services and intellectual disability. Every attempt was made to minimize this possibility by including extensive hand searching in the search strategy.

Conclusion

The conclusion remains consistent throughout the literature—people with an intellectual disability can face substantial barriers to access mental health services. However, data are insufficient to address the specifics of those barriers and further work in the area is imperative. Given that the quality of the literature available was varied, further high-quality research must be conducted to fill this gap.

The details and lived experience of these barriers remain unclear in many cases. The review found that barriers existed across the four dimensions of access. Organizational barriers were perhaps the most significant, while lack of services and a lack of consensus around the most appropriate service models to rectify this were also identified as important factors. The quality of the services that are available were also identified as being problematic, as gaps in clinical knowledge and diagnostic overshadowing contributed to poor recognition of need and subsequent inadequate treatment.

Enablers were also identified across the literature. Of primary focus was the emphasis on intersystem and interagency collaboration, which is highly vulnerable to the organizational barriers outlined above. As well as this, capacity building and improving the knowledge of service providers was identified as a way of improving access, particularly in relation to improving the quality of services. Improving the availability of training modules and supervision for health services staff was noted as a productive way of improving access.

In order to achieve health equity and full access to appropriate mental health care for people with an intellectual disability, it is imperative to fill these gaps with high-quality evidence around barriers and effective facilitators to mental health care for people with an intellectual disability.

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