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The Current Provision of Mental Health Services for Individuals with Mild Intellectual Disability: A Scoping Review

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ABSTRACT

Background: People with mild intellectual disability (ID) experience a higher prevalence of mental health (MH) problems in comparison to the general population, yet there is little consensus on the most appropriate type and nature of services for support and treatment for this specific group of individuals.

Objective: The objective of this scoping review is to explore the current evidence for the organization, structure, and delivery of mental health services for people with mild ID.

Methods: The PRISMA-SCr (Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews) checklist was followed. Online databases were used to identify systematic reviews, meta-analyses, scoping reviews, or guidelines published between 2003 and 2020. Articles were reviewed using Roever & Zoccai criteria for critical appraisal of systematic reviews and meta-analyses.

Results: 130 records were identified, of which 91 were long-listed. Of these, 28 articles were shortlisted after review of abstracts prior to review of full-text papers. The review included 11 studies: one meta-analysis, eight systematic reviews, and two scoping reviews. These studies approached the provision of mental health services for individuals with mild ID from various angles – including service organization and access, therapies, and patient feedback.

Conclusions: According to the Roever & Zoccai criteria, there was a lack of high-quality evidence, which limited the findings and conclusions. The available evidence suggested that despite higher levels of psychopathology there is not a corresponding consideration in care for individuals with mild ID in general psychiatric services. There was no conclusive evidence on better level of services or outcomes being provided either by the general psychiatric services or specialist ID psychiatric services. Some evidence was found for intensive case management and assertive outreach for individuals with mild ID, but this was not replicated in further studies.

KEYWORDS

Mild intellectual disability; policy; mental health services; learning disability; access to services; equality

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In terms of treatment, there was no high-quality evidence found for pharmacological interventions, with some limited evidence around psychological therapy for the treatment of depression in this vulnerable population. Overall, it was found that an increase in staff training would be beneficial in terms of timely access to services and appropriate treatment.

There is a need for inclusive, evidence-based guidance as regards service development for people with mild ID and MH problems.

Abbreviations: ID: intellectual disability; MH: mental health; CBT: Cognitive Behavioral Therapy; RCT: randomized controlled trial; ACT: assertive community treatment; ECT: electroconvulsive therapy

BACKGROUND

Adults with intellectual disability (ID) have a higher rate of mental illness in comparison to the general population (Bhaumik et al., 2008; Sheehan et al., 2015). A systematic review has established a wide-ranging prevalence of 14–75% for clinically distinguishable mental illness in people with ID (Buckles, 2013). It is quite likely that the true prevalence is much greater than that of 20% of individuals in the general population (Singleton et al., 2001) and that figures will underestimate the scope of psychiatric illness in the ID population, due to under-diagnosis caused by, for example, diagnostic overshadowing (Sheehan & Paschos, 2013).

The International Classification of Diseases version 11 (ICD 11) informs that a mild disorder of intellectual development is to be considered when the condition has originated in the developmental period and characterized by significantly below average social adaptive behavioral and intellectual functioning (two to three times standard deviation below the mean 0.1–2.3%). Individuals with mild ID constitute the majority of the ID population (Harris, 2006). The relative burden of psychiatric morbidity in this group highlights the need that psychiatric services are accessible, appropriate, and equitable (Sheehan & Paschos, 2013). It is therefore important that both the management of specific psychiatric conditions and delivery of effective health-care systems are based upon sound evidence. The House of Commons (UK) learning disability overview of policy and services (Parkin, 2016) makes it clear that the UK Government's mandate is to narrow the gap in health inequalities for people with ID. Further to this, the Welsh Government's "Improving Lives Programme" for people with ID (Irranca-Davies et al., 2018) emphasizes the need for a whole government approach and integration of services to help improve life chances, services and allow for more effective use of funding. The report highlights the importance of reasonable adjustments in all mainstream services for people with ID to reduce health

inequalities, and access to specialist services when needed. This is also acknowledged in NICE guidelines relating to management of common mental health problems in people with mild ID (NICE, 2011).

The model of MH service provision for ID has developed and transformed over time, with the closure of large institutions of the 19th and 20th centuries. Between 1971 and 2000 the number of individuals with ID living in hospitals dropped by over 90% – with the majority being rehoused in small staffed residences within the community (Cumella, 2007). A significant proportion of these individuals would have required specialist support. The relatively rapid relocation to the community would have been challenging for community mental health services that had little previous experience of ID (Sheehan & Paschos, 2013). There continue to be people placed or living inappropriately in hospitals or institutions in the UK and the ongoing closure and reduction of these facilities is at the forefront of the UK government's ongoing work (Parkin, 2016) following the Winterbourne report (Bubb, 2014). This seismic shift from inpatient to community care emphasizes the need for a joined-up approach with general mental health services to provide appropriate support for these individuals.

The process of de-institutionalization has resulted in different service structures for individuals with ID internationally. For example, in the UK, the Community Learning Disability Teams (CLDT) were developed in order to meet both the physical and MH needs of an individual (Hamlin & Oakes, 2008). The concern with this model of care has been the by-passing of mainstream services and therefore potentially less equitable access to the required specialist service (Hassiotis et al., 2000) – in particular for those people with mild ID with less support needs. In the UK, there exist specific training competencies in the Psychiatry of Intellectual Disability specialty training scheme (RCPsych, 2017). However, the political and clinical thinking is that people with ID, where possible, should be supported and enabled to access mainstream services to ensure inclusion. While those with moderate to profound ID by the nature of their needs gravitate to specialist services, there is a lack of clarity in political and clinical establishments as to how best care needs should be organized for those with borderline and mild ID.

By comparison, in the United States, there has been a reliance on the more “mainstream” health-care systems – however, with resultant concerns regarding “*insufficient capacity to meet the specialist needs of the ID population*” (Balogh et al., 2016). The Australian model of care has been historically similar to that of the United States. It has been recognized that people with ID need specialist support if they are to access generic services (New South Wales Ministry of Health, 2012). The differing approaches to MH care for ID internationally will all have strengths and weaknesses, and the national context from which evidence has arisen should be taken into consideration when comparing outcomes.

Objectives

Individuals with mild ID make up the majority of the ID population (Harris, 2006) and there is increased psychiatric morbidity in this population (Borthwick-Duffy, 1994; Holden & Gitlesen, 2004). However, there is little consensus on how mental health services should be organized and delivered for this subgroup, with evidence of international variation. The objective of this scoping review is to explore the breadth of evidence for the structure and delivery of mental health services for people with mild ID, taking into consideration patient experience (Bombard et al., 2018). The specific research questions (RQs) are:

RQ1) What models of service for mental health care exist for people with mild ID?

RQ2) What is the scope of the evidence for specific models of care and treatment?

RQ3) What is the experience of patients with mild ID accessing mental health care?

METHODS

Agency

The scoping review was required by the Royal College of Psychiatrists (RCPsych) as a rapid-scan of the evidence in order to inform RCPsych College Report 226: Mental Health services for adults with mild intellectual disabilities (Shankar et al., 2020).

Protocol

The review protocol was drafted using the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-SCr) (Tricco et al., 2018). Study protocol available on request.

Inclusion Criteria

The inclusion criteria were developed using the PCC (Population, Concepts, and Context framework (Peters, 2020).

Population

People with mild ID (adults over 16 years)

Concept

The current provision of mental health services for individuals with a mild ID, including models of care and treatment. The experience of people with mild ID accessing mental health services.

Context

Mental Health Services. Focus on the current provision of general MH services therefore excluded studies from the forensic setting.

Types of Evidence Source

Systematic review, meta-analysis, service review, or guideline regarding MH service, provision, or access. Publication date within the past 15 years in English.

The rationale for excluding primary research was the requirement for a rapid-scan of existing evidence and literature for the purpose of informing about existing evidence for the RCPsych CR 226 (Shankar et al., 2020).

Information Sources

A computerized search using the following databases was undertaken: Cochrane Library, Medline, Medline Inprocess, Embase, PsychINFO, Trip and NICE Evidence. This was for English language, peer reviewed journals published between 10th January 2003 and 10th January 2018. An updated literature search was undertaken covering the period 15th January 2017–15th January 2020.

The initial search was undertaken in 2018 and an updated search undertaken in 2020 to ensure the article included all the relevant and most up to date articles. There was intentional overlap of the second search to ensure no articles were missed.

Hand search of the bibliography of editorial reviews, and relevant journals was also undertaken.

Search

An example of the search strategy is available (see [Appendix A](#))

Selection of Sources of Evidence

When the search terms (see [Appendix A](#)) were combined on the individual databases the resulting titles were screened by two of authors (CW, GM). To ensure consistency amongst reviewers, the titles and abstracts were independently reviewed, then discussed and consensus reached by both authors for

inclusion. Full-text articles were then reviewed and selected with a discussion with the third author (RS) for any articles where consensus could not be reached. For the updated search the same approach was undertaken involving three of the authors (CW, GM, and DM) with consensus support from RS.

Data Charting Process

Data charting was undertaken by two authors (DM and CW). An agreed process for data extraction was agreed prior to initiation by all authors and tabulated. Disagreements were resolved through discussion between the two reviewers, and, when necessary, adjudication from RS.

Data Items

Data were extracted on article characteristics (title and type of review, date of publication), the objectives of the review, and the main findings specific to mild ID (Appendix B).

Critical Appraisal of Individual Sources of Evidence

The quality of all sources of evidence was assessed utilizing the Roever & Zoccai criteria for *Critical Appraisal of Systematic Review and Meta-analyses* (Roever & Zoccai, 2015).

Synthesis of Results

The studies were grouped together according to the main objectives and research questions. For example, RQ1: Models of service for MH care: general service appraisal. The grouped studies were then tabulated and main findings presented with an appraisal of the quality of the evidence in the final column.

RESULTS

Selection of Sources of Evidence

Figure 1 outlines the search results.

One hundred records were initially identified by database searches, and a further two by hand searching. From the 102 studies screened a total of 71 abstracts were reviewed by the authors and selected as described. Twenty-five articles were selected at this stage. Upon reviewing the full text of these studies, a further 15 were excluded because the articles were opinion, commentary or editorial pieces, primary research or not directly relevant to the research questions.

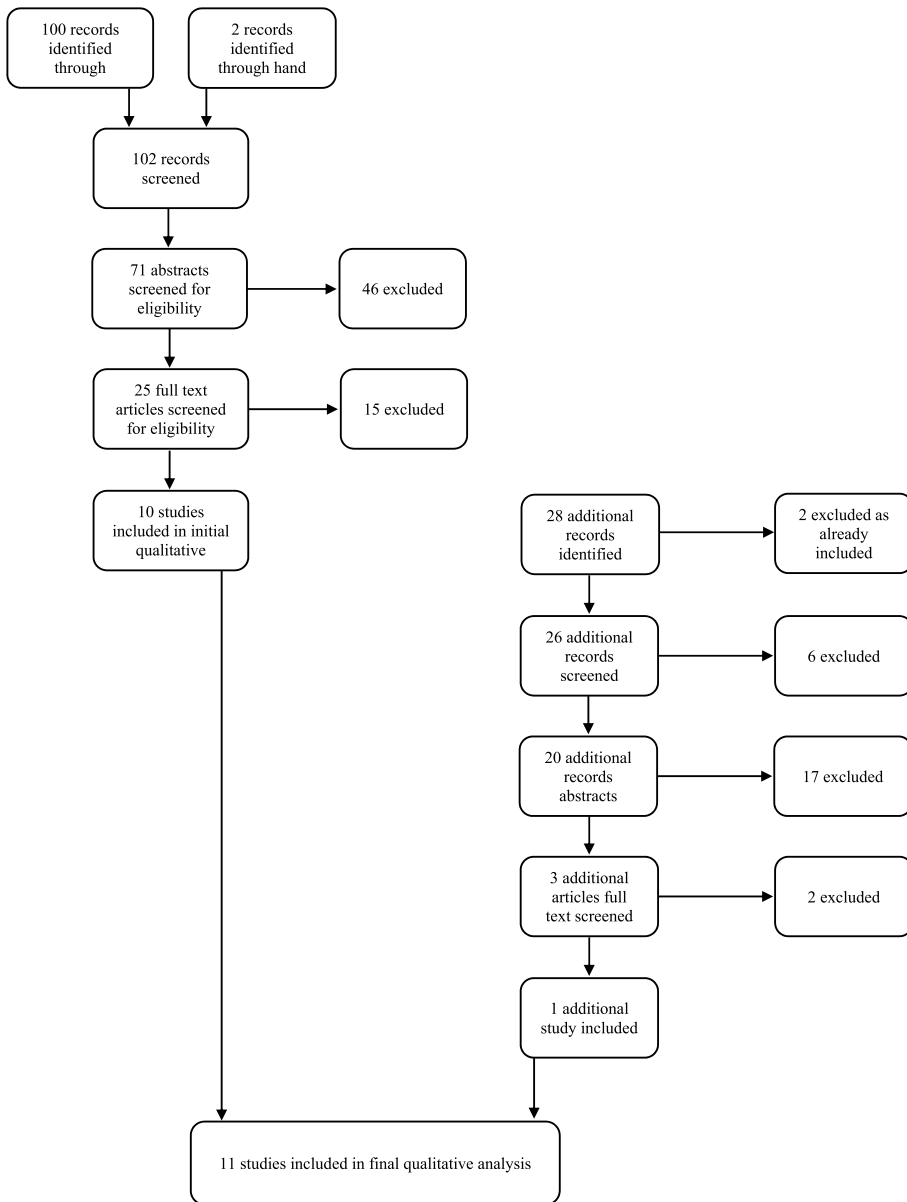


Figure 1. Results of search strategy as per PRISMA guidance for the current provision of mental health services for individuals with a mild ID as per (Moher et al., 2009).

An updated search was undertaken covering 2017–2020 using the same search criteria. The time frame was intentionally overlapped with the initial search to ensure no relevant articles were missed. To ensure consistency, all new articles found in the updated search were reviewed by all authors. One further study was identified for inclusion (Robertson et al., 2019).

Review Characteristics

Tables 1 – 5 show a summary assessment of each review. Each table focusses on a different aspect of the research questions. Individual studies' design, aim and the main findings for mild ID are tabulated.

Critical Appraisal within Sources of Evidence

All of the included studies were assessed for methodological quality (Roever & Zoccai, 2015) which is shown in the final column of the four tables. Although the majority of reviews were found to be of medium or high quality, it is important to note the common theme, that the evidence included within each review was generally of low quality. This follows the phenomenon of “garbage in, garbage out” (Egger et al., 2001; Yuan & Hunt, 2009) whereby no matter how good a review is, the strength of the information synthesized will be limited by what original studies are available and included.

High-quality reviews (Balogh et al., 2016; Chaplin, 2004; Chaplin, 2009); Osugo & Cooper, 2016; Robertson et al., 2019) included: consideration of risk of bias, limitations clear (for example, differing methodologies made valid comparisons difficult), comment on low quality of included studies (lack of randomized controlled trial), and inclusion of a wide range and design of studies. Medium quality reviews (Chaplin, 2011; Hemmings et al., 2009; Kosiowski et al., 2016) contained many of the features of the high-quality reviews but comparison of studies was not permitted due to varied study design and methods, or there was a low number of included studies. Low-quality reviews (Slevin et al., 2008; Whittle et al., 2017) used varied literature methods and objectives leading to a lack of consistent measures of quality of the retrieved studies, and in the case of Slevin et al. (2008) a systematic review was unable to be undertaken due to paucity of evidence found.

Results of individual sources of evidence:

RQ1: WHAT MODELS OF SERVICE FOR MENTAL HEALTH CARE EXIST FOR PEOPLE WITH MILD ID?

General Service Appraisal: Organization or Access to Services –Table 1

Five systematic reviews were identified regarding the organization or access to MH services for individuals with ID. Balogh et al. (2016) conducted a systematic review according to the Cochrane Database of Systematic Review criteria. Nothing specific was included in the overall analysis relating specifically to mild ID. Nonetheless, Balogh et al. (2016) describes one study (Hassiotis et al., 2001) that shows that individuals with mild or borderline ID in receipt of care from intensive case-management teams with small case-loads spent fewer days in hospital, and had fewer hospital readmissions for

Table 1. General service appraisal.

Title and type of review	Objectives	Main findings for MILD ID	Comment upon Quality of Evidence/Utilizing criteria of Roever and Zoccai (2015)
Organizing healthcare services for persons with an intellectual disability Cochrane Review Balogh et al. (2016)	To assess the effects of organizational interventions for mental and physical health problems of persons with an ID	Nil specific for mild ID in overall analysis – however, one study showed that individuals with mild/borderline ID receiving care from intensive case management teams spent fewer days in hospital (Hassiotis et al., 2001). Effects of organizational interventions on behavioral problems and comorbid psychological and psychiatric function:-Uncertain whether increasing frequency and intensity of service delivery decreases behavioral problems (2 studies) or improves quality of life (3 studies)- Increasing the frequency or intensity of service delivery makes little or no difference to care giver burden (2 studies)-Community based specialist behavioral therapy may slightly decrease behavioral problems (1 study)	High quality appraisal – risk of bias considered Unable to pool results of studies due to heterogeneity of studies Low numbers of studies Authors comment upon the quality of the included studies: in the main very low or low certainty of the evidence: small sample sizes, risk of bias, wide confidence intervals, lack of blinding, sub analysis of a broader study.
New research into general psychiatric services for adults with intellectual disability and mental illness Systematic Review Chaplin (2009)	Assess the difference in outcome for people with ID and mental disorder treated in general or specialized ID mental health services.	Borderline intellectual function: 2 studies found from the systematic review commented upon borderline ID. Those with borderline ID have a higher rate of psychopathology and disability than those without ID but do not receive a relative increase in care from general psychiatric services (one study). They may be helped by assertive outreach from general psychiatric services (one study). Across all ranges of ID; general psychiatric care can be improved by specially trained staff and in-reach from community ID teams.	High quality appraisal Acknowledgment by author of low level of good quality evidence, in particular randomized controlled trials. Studies under consideration for this review included small scale qualitative research, studies investigating length of stay, and cross-sectional studies. Comment upon the difficulty in undertaking this type of research, with difficulties in recruitment of both patient and services due to ethical considerations in comparing services for people with ID.

(Continued)

Table 1. (Continued).

Title and type of review	Objectives	Main findings for MILD ID	Comment upon Quality of Evidence/Utilizing criteria of Roever and Zoccai (2015)
General psychiatric services for adults with intellectual disability and mental illness Systematic Review Chaplin (2004)	Assess for evidence for a difference in outcome for individuals with ID utilizing either general or specialist ID services.	Unable to find conclusive evidence favoring the use of general or specialist ID psychiatric services due to paucity of good quality literature. Tentative conclusions: shorter length of stay for individuals with ID on general as opposed to specialist ID beds (no specific theme of outcome improvement). Marginally improved outcomes (some anecdotal) reported by 'before-after' approach for people with ID utilizing general psychiatric beds after specific service improvements targeting people with ID introduced such as liaison service, crisis beds, crisis intervention, intensive home treatment (American studies and model of care). Evidence that staff working in general services perceive that they lack training and that individuals with mild ID receive reduced access to their service.	High quality appraisal. Acknowledged lack of randomized controlled trials. Inclusion criteria included studies published over 20 years ago. Differing methodologies and definitions reduce valid comparisons. No replicated studies. Concerns from authors with regard to studies included and the level of bias: including for 'novel' services being set up.
Barriers and Enablers to Accessing Mental Health Services for People with Intellectual Disability: A Scoping Review Scoping Review using systematic search techniques Whittle et al. (2017)	To identify barriers and facilitators to access mental health services for individuals with ID Four dimensions of access explored: <ul style="list-style-type: none"> ● Availability ● Utilization ● Relevance ● Effectiveness 	Nil specific for mild ID Common themes across the literature for ID in general: <ul style="list-style-type: none"> ● Diagnostic overshadowing, lack of skilled workforce, and failure to integrate services. ● Inconsistent eligibility criteria, conflict, and competition between services ● Lack of services ● Lack of consensus about appropriate service models. ● Enablers ● Multidisciplinary approach and collaborative working. Clear referral pathways, single point of access 	Medium – low quality appraisal Lack of empirical knowledge as regards the effectiveness of interventions to improve access to mental health services: Bulk of the literature relied upon expert opinion (11/ 32 were empirical). Due to varied nature of the literature methods and objectives there was no consistent measure of quality of the retrieved reviews, therefore appraisal of the quality of the evidence not done.

(Continued)

Table 1. (Continued).

Title and type of review	Objectives	Main findings for MILD ID	Comment upon Quality of Evidence/Utilizing criteria of Roever and Zoccai (2015)
<p>What do we know about the health and health care of people with intellectual disabilities from minority ethnic groups in the United Kingdom? Systematic review Robertson et al. (2019)</p>	<p>To establish what is known about the health and health care of people with intellectual disabilities from ethnic minority communities in the UK.</p>	<p>Overall the paper concludes that very little is known about the health status of people with ID from minority ethnic communities in the UK. There was no specific information for mild ID – often grouped mild-moderate ID. Overall felt that there was less access to a variety of services for people from minority ethnic groups, highlighting inequalities. This is consistent with research in to health inequalities for people from ethnic minority groups more generally. There was a comment on one study not including a representative sample of adults with mild intellectual disabilities because they are less likely to access specialist support.</p>	<p>High quality appraisal/Acknowledgment by author of low level of good quality evidence (mix of service evaluations, cross sectional studies and qualitative research) Authors commented on limitations including most papers being limited to 2 geographical regions (Leicester and London), as well as age of some studies and changes to services for people with intellectual disabilities over that time scale.</p>

a psychiatric reason. The participants of this study were identified as a subset of individuals with unrecognized borderline or mild ID (subset UK700 trial) and a concurrent psychotic illness. However, two further studies (both also UK based) were unable to replicate this finding in populations under the care of community learning disability teams with broader psychiatric diagnoses and more significant cognitive impairments (Martin et al., 2005; Oliver et al., 2005). Upon consideration of intellectual disability as a whole, there was little evidence for organizational interventions; such as increased frequency or intensity of service delivery, that could impact upon psychiatric, behavioral or psychological morbidity (Balogh et al., 2016). Community-based specialist behavioral therapy may slightly decrease behavioral problems (Hassiotis et al., 2009). Overall, Balogh et al. (2016) surmised that there was a need for coordinated and targeted services with clear responsibilities to best meet the needs of this population.

Chaplin (2004, 2009) undertook two systematic reviews with similar methods to assess the difference in outcome for people with ID and mental disorder treated in general or specialized ID MH services. Chaplin (2004) was unable to find conclusive evidence favoring either option due to the paucity of good-quality literature. It was highlighted that staff working in general services perceived that they lacked training in ID, and that individuals with mild ID had reduced access to their service. The systematic review was replicated in 2009, and more recent studies included (Chaplin, 2009). Within this review, two studies commented upon borderline intellectual function. Those who fell in to the borderline intellectual functioning category had a higher rate of psychopathology and disability than those without ID but do not receive a relative increase in care from general psychiatric services (Bouras & Holt, 2004). Outcomes for people with borderline intellectual functioning may be aided by intensive case management (Hassiotis et al., 2001). Across the range of ID, Chaplin (2009) concluded that general psychiatric care could be improved by specially trained staff, and in-reach from community ID teams.

Whittle et al. (2017) undertook a scoping review in order to identify barriers and facilitators to access to MH services for individuals with ID. There was no discussion of evidence for individuals with mild ID, however there were common themes found across the literature for ID in general. Barriers to access MH services included diagnostic overshadowing, lack of skilled staff, and failure to integrate services. Enablers included a multidisciplinary approach, collaborative working, and clear referral pathways.

Robertson et al. (2019) conducted a systematic review in order to establish the current knowledge base for the health care of people with ID from ethnic minority groups in the UK. There was very limited good-quality evidence on this topic, due to low study numbers. However, the evidence was suggestive of there being further inequality in access to services for people with ID from ethnic minority groups. One study included within the review, (McGrother

et al., 2002), highlighted that the sample may not have been representative for people with mild ID due to less frequent access of specialist ID services by people with mild ID.

RQ2: WHAT IS THE SCOPE OF THE EVIDENCE FOR SPECIFIC MODELS OF CARE AND TREATMENT?

Inpatient Care – Table 2

Chaplin (2011) undertook a systematic review of psychiatric services for ID, in particular for inpatient care. The review included a trial (Lunsky et al., 2010) that examined the outcome of individuals by level of ID on a specialized inpatient unit in Canada. The individuals with mild ID improved substantially on the Global Assessment of Functioning; however, the length of stay, and improvement in psychiatric symptoms did not differ (Lunsky et al., 2010). For the full range of ID, Chaplin (2011) included two studies (Hall et al., 2006; Xenitidis et al., 2004) that showed positive outcomes in terms of symptoms and function on a general ward where staff had received extra training. Direct comparison of general as opposed to specialist ID services showed mixed results (Hemmings et al., 2009); those with more complex needs were less likely to have them met on a general adult ward. Those discharged from specialist units were prescribed less medication upon discharge (S. E. White et al., 2010).

Community Care – Table 3

Slevin et al. (2008) undertook a structured review of community learning disability teams in order to consider challenges to effective working. The review raised concerns with regard to those with mild ID and dual diagnosis, that is, autism or ADHD, and not fitting specific social care or health criteria, therefore being excluded or experiencing long delays in access. Concerns as to barriers to good community care in community ID teams were adequate specialist skills. Conversely, in general services, concerns were raised regarding staff having the adequate skills to meet the needs of an individual with ID, with inadequately trained staff being a barrier to equitable mental health care. This could infringe individuals' rights under human rights legislation.

Hemmings et al. (2009) reviewed the preceding 3-years evidence for community services, ID and MH problems. The evidence for Assertive Community Outreach (ACT) was discussed; including Hassiotis et al. (2001) UK700 trial data; as well as the subsequent controlled trials by Martin et al. (2005) and Oliver et al. (2005). As mentioned previously, the follow-up trials were unable to replicate the UK700 trial data results, finding no significant differences between assertive and standard community outreach.

Table 2. Inpatient care.

Title and type of review	Objectives	Main findings for MILD ID	Comment upon Quality of Evidence/Utilizing criteria of Roever and Zoccai (2015)
Mental health services for people with intellectual disabilities/Systematic review/Chaplin (2011)	Review of psychiatric services for people with ID, in particular inpatient care.	Mild ID – (one trial) those with mild ID treated at a specialist inpatient (in Canada) improved substantially on the Global Assessment of Function assessment (length of stay/improvement of symptoms did not differ). All levels of ID: Qualitative review of patient experience on general ward reported negative experience, due to feeling unsafe and concerns about drugs and alcohol, diagnostic overshadowing, lack of staff understanding of an individual's competency.Integrated services (2 studies) showed positive outcomes in terms of symptom and function on a general ward where staff had received extra training.Direct comparison of generalized with specialist ID services showed (3 studies) mixed results. In particular, those with more complex needs were less likely to have needs met on general wards. Those on specialist units were prescribed significantly less medication on discharge.	High – medium quality appraisal.Lack of evidence comparing outcome and experience of people with ID using general in comparison to specialized ID services, in particular randomized control trial level of evidence.No possible comparison of studies due to the varied study design and methods.

Therapeutic Interventions – Table 4

Two systematic reviews were published in 2016 examining the evidence base for therapeutic interventions for adults with mild ID and MH problems. Osugo and Cooper (2016) identified that group cognitive behavioral therapy (CBT) was found by four studies (McCabe et al., 2006; McGillivray et al., 2008; McGillivray, 2013; McGillivray & Kershaw, 2015) to be effective for the treatment of depressive symptoms, which was maintained at follow-up. Group exercise was found to have a positive effect upon anxiety and depressive symptoms (Carmelli et al., 2009; Carraro & Gobbi, 2014). Five papers explored the use of antipsychotics (Antonacci & de Groot, 2000; Boksanska et al., 2003; Shedlack et al., 2005; Thalayasingam et al., 2004; Williams et al., 2000) and two antidepressants (Bhaumik et al., 1995; Bhaumik & Wildgust, 1996). All showed efficacy; however, concerns regarding study design and methodology were highlighted. There were no randomized controlled trials; most were uncontrolled, not standardized and on the whole, retrospective studies. There was no investigation of sensitivity or differential dosing schedule – therefore the “*much quoted*” hypothesis of increased sensitivity to side effects of psychotropics for people with ID was not explored, and therefore could cause sub-optimal dosing and treatment (Osugo & Cooper, 2016).

Similarly, Kosiowski et al. (2016), found non-conclusive results for therapeutic interventions. A meta-analysis of the available evidence (11 randomized controlled trials and one non-randomized study) showed no statistically significant effect size for – behavioral problems, depressive symptoms, anxiety, quality of life or function. Treatment for depressive symptoms (all CBT) showed the effect size as just below significance, which might have been caused by low-power studies. The methodology of the included studies varied widely and Kosiowski et al. (2016) commented upon the issue of standardization and definition within these trials. For example, how “*behavioural problems*” was defined. This included a range from “*anger*” to a definite mental illness, such as “*depression*.”

RQ3: WHAT IS THE EXPERIENCE OF PATIENTS WITH MILD ID ACCESSING MENTAL HEALTH CARE?

Patient Feedback – Table 5

A scoping review was undertaken by Venville et al. (2015) to investigate and compare the experiences of individuals with ID and MH problems in mainstream adult and specialist ID facilities. This reported that negative experiences in mainstream psychiatric services appeared to be more pronounced (in comparison specialist ID facilities) with an increased likelihood of physical restraint. Patients felt poorly informed about treatment options. In comparison, specialist ID services were viewed as offering limited opportunities for

Table 3. Community care.

Title and type of review	Objectives	Main findings for MILD ID	Comment upon Quality of Evidence/Utilizing criteria of Roever and Zoccai (2015)
Community learning disability teams: developments, composition and good practiceStructured review following principles of systematic reviewSlevin et al. (2008)	Structured review of community learning disability teams: consideration of challenges and barriers to effective working.	Mild ID:Concerns raised for those with dual diagnosis and mild ID e.g. autism or ADHD as to not fitting specific social care or health criteria. Therefore, are excluded from services, or experience long delays in general – good practice examples considered. Barriers to good care from community ID teams discussed. Concerns raised with regard to staff training and having adequate specialist skills.Comment upon inadequate trained staff being a barrier to equitable mental health care as general population, which may infringe their rights under human rights legislation.	Low quality appraisalFull systematic review not possible due to paucity of evidence found, lack of systematic review level evidence.Quality of evidence presented not considered. No comment upon the type of studies reviewed (including if qualitative), the size of the data-sets, and the consideration of bias within the studies.
Community services for people with intellectual disabilities and mental health problemsLiterature review of the previous 3 years' studiesHemmings (2008)	Review most recent literature for community services for people with ID and mental health problems (3 years preceding publication)	Mild ID: Assertive Community Treatment (ACT) Following results drawn from the UK-700 study (Tyrer et al., 1999) for individuals with borderline ID that showed reduced inpatient stay with intensive rather than standard community care – 2 further RCT's have been conducted. Oliver et al. (2005), Martin et al. (2005) attempted to evaluate forms of ACT in comparison to standard community treatment, no significant differences were found in either study between assertive and standard community treatment.	Medium quality appraisalClear comment from authors upon drawing conclusions from the RCT evidence presented: in terms of difficulties in research methodology and ACT implementation in ID services. Differing definitions of ACT. Ethical and methodological issues include difficulties in recruiting sufficient participants and consent.

Table 4. Interventions for adults with mild intellectual disabilities and mental ill health.

Title and type of review	Objectives	Main findings	Comment upon Quality of Evidence/Utilizing criteria of Roever and Zoccai (2015)
Interventions for adults with mild intellectual disabilities and mental ill-health: a systematic review Osugo and Cooper (2016)	Review evidence for psychological, pharmacological and electroconvulsive therapy (ECT) treatment for adults with mild ID and mental ill health.	14 studies were included.No studies regarding ECT/dementia/autism or dementia were found. Psychosocial treatments:Studies on group CBT (4 studies) showed effectiveness in treating depressive symptoms and maintained at follow up. One study found no efficacy of individual RCT (small sample). Small feasibility study (non-randomized) suggested behavioral activation may be effective in treating depression. Group exercise also showed a positive effect for symptoms (anxiety and depression). Pharmacological:5 papers explored the use of antidepressants, 2 antidepressants. All showed efficacy – however study design and methodology was of concern by the authors. There was no investigation of sensitivity or differential dosing schedule – therefore the ‘much quoted’ assumption of increased sensitivity of psychotropics for people with ID was not explored.	Medium – high quality appraisal.Good quality systematic review – however limited findings. Significant lack of good quality evidence found. Commented upon lack of RCT level evidence, studies were limited in quantity and methodology.Pharmacological studies were uncontrolled, not standardized, and often retrospective. No RCT’s found for pharmacological treatment.
Effectiveness of interventions for adults with mild to moderate intellectual disabilities and mental health problems: systematic review and meta-analysis Kosowski et al. (2016)	Assess effectiveness of interventions for mental ill health in mild ID to moderate population.	Meta-analysis showed none of the interventions described had statistically significant effect size for the following domains:Behavioral problems: Six studies showed no overall effect (included psychotherapy, biological treatment). Depressive symptoms:Four studies (psychotherapy) showed moderate (non-significant) effect size.AnxietyTwo studies showed no significant effect (psychotherapy) Quality of lifeThree studies showed no significant effectFunctioningThree studies delivering system level intervention showed no effect	Medium – high quality appraisal: PRISMA checklist (Moher, et al., 2009) followed.Significant heterogeneity between studies. Risk of bias commented upon as moderate to high. Concerns regarding size of studies and power. Only a small number of studies fitted the inclusion criteria (included need for a controlled study).



Table 5. Patient feedback.

Title and type of review	Objectives	Main findings for MILD ID	Comment upon Quality of Evidence
<p>Supporting people with an intellectual disability and mental health problems: a scoping review of what they say about service provision (preliminary assessment of depth and breadth of published research) (Venville et al. (2015))</p>	<p>Scoping review (assessing depth and breadth of literature) investigating the formal support experiences of adults with ID and MH problems.</p>	<p>Nil specific for mild ID (Individuals with ID and MH problems describe experiences of distress in both mainstream and specialized services, more so in mainstream. Mainstream psychiatric services: Negative experiences were far more pronounced in mainstream settings – more likely to experience physical restraint and find the environment stressful. Felt poorly informed about their treatment options, upset by other service users and relationships with staff. Inpatient units were viewed as disempowering, unsafe and intimidating. Specialist services: Limited opportunities for meaningful participation in education and therapy, and developing relationships with staff and peers. Negative views of the experience with staff – described being verbally berated and threatened. Integrated services (specialist ID in-reach to general adult psychiatry wards): Positive experiences reported for integrated facility, settled more quickly onto ward, felt less scared or vulnerable, increased knowledge and understanding of medications. Positive comments about nursing care. Ward rounds still intimidating but more positive in integrated setting. Experience of stigma, respect for personhood. Focus on the importance of person-centered approach. More about the quality of the care received as opposed to who delivered it. Upon comparing individuals from self-described racial groups, self-described Black individuals reported fewer positive experiences of mental health services in comparison to self-described White participants. There is less consensus amongst Black participants in comparison to White participants which could suggest a more varied experience of service and support received by Black participants.</p>	<p>Qualitative review: Authors comment upon the lack of qualitative research in this area, call for more inclusive research with adults with ID and MH problems. Highlighted the need for meaningful research from the perspective of the increased risk of suggestibility and a bias toward positive responses in the ID population. Requirement for more conceptual clarity about 'fidelity, feasibility and rigor' of inclusive research</p>

education and therapy. One study (Chinn et al., 2011) reported patients being verbally abused in specialist psychiatric inpatient units away from their home area. Integrated services, for example, ID in-reach on a general ward had positive feedback (Parkes et al., 2007). Patients described feeling more settled with an increased understanding of medications and made positive comments about nursing staff. When the experience of individuals from ethnic minority groups was examined, individuals self-identifying as black reported fewer positive experiences (Bonell et al., 2012). There was less consensus of experience reported by black in comparison to white participants, which could suggest a more varied experience of services and support. The authors commented upon the lack of qualitative research in this area, and called for research that is more inclusive with consideration given to increased suggestibility leading to bias (Venville et al., 2015).

DISCUSSION

This scoping review included eleven studies: one meta-analysis, eight systematic reviews, and two scoping reviews. The objective of the review was to explore the breadth of evidence for the structure and delivery of mental health services for people with mild ID, taking into consideration patient experience. The evidence was explored focusing upon three specific research questions regarding evidence for current models of service, current care and treatment, and the experience of people with mild ID.

IMPLICATIONS FOR CLINICAL PRACTICE

There is evidence to suggest that people with mild intellectual disability accessing mental health services benefit from improved staff training (Hall et al., 2006; Xenitidis et al., 2004) and integrated services (Parkes et al., 2007). There is also some weaker evidence to suggest that intensive case management (Hassiotis et al., 2001) can result in better outcomes for people with borderline or mild intellectual disability and comorbid mental illness.

A lack of resources results in poorer outcomes (Bouras & Holt, 2004). Furthermore, individuals with intellectual disability from ethnic minority groups have even poorer experiences (Robertson et al., 2019). This is further exacerbated by a lack of good-quality research on pharmacological and psychological interventions for people with mild intellectual disabilities (Osugo & Cooper, 2016).

IMPLICATIONS FOR SERVICE DEVELOPMENT AND FUTURE RESEARCH

A significant amount of progress is needed to unify access to services that people with mild ID have. In the United Kingdom, there is no agreed National model of integration of general mental health services with learning disability services (Hawramy, 2020). Farnklin et al. (2019) makes note of the challenges in delivering specialized ID services and suggests a consultation-liaison model between general and specialist services to aid accessibility for service users. The Royal College of Psychiatrists (Shankar et al., 2020) provide a good-practice framework to inform and enable psychiatrists and service leads to provide high-quality care for this patient group. This framework supports the use of The Green Light Toolkit (Department of Health, 2017) which utilizes a self-assessment checklist to evaluate current provision, in line with National guidance.

The drive to improve equitable mental health care for all is further emphasized in a report by the National Collaborating Center for Mental Health (NCMH, 2019). This aims to ensure that all MH care is responsive to the strengths of each individual and to achieve equality for all. In particular, it discusses access to psychological services for people with ID. It notes that appropriate care and treatment should be accessible to all, which is in line with the Equality Act (Equality Act, 2010), with duty of care imposed on service providers to make reasonable adjustments for people with disabilities.

STRENGTHS AND LIMITATIONS

The strengths of this review include following the PRISMA-SCr (Tricco et al., 2018) assessment of the quality of systematic reviews using well-known criteria (Roever & Zoccai, 2015) and we have utilized a broad search strategy. Limitations may include that by only including systematic reviews and service appraisals there is potential that we may have missed evidence that hadn't been included in any of these systematic reviews, unpublished interventions and gray literature. The conclusions made by the individual papers included need to be considered in the context of the quality of evidence they are drawn from.

CONCLUSION

This scoping review aimed to review the evidence with regard to MH services and treatment for mental disorders in individuals with mild ID. A lack of high-quality evidence for individuals with MH problems and mild ID was a continued concern throughout the review. The lack of high-quality evidence is likely to reflect a lack of research evidence rather than therapeutic effect size.

There are additional ethical and methodological difficulties of recruitment of people with ID into studies in terms of consent, adequate subjects, and suggestibility in qualitative research.

There is the potential for improved outcomes with increased staff training and awareness as well as therapeutic interventions such as CBT. A common theme of needing targeted and well-coordinated services was identified, however delays with access to services for individuals with dual diagnosis was noted. There was a lack of data on the interaction between, and distinct roles and responsibilities of, ID and MH services. The review also found a lack of coherent service models, co-ordination between treating agencies, and of specific inclusion for ID within MH policy.

Utilizing the current evidence, no clear conclusions regarding MH services and treatment for mental disorders in individuals with mild ID can be drawn. There is a need for further good-quality research, including from the patient perspective and expert by experience. At this stage, there is no clear evidence for divergence from evidence-based guidelines and normal good practice for MH problems in the general population. A debate continues as to where, and from whom, individuals with mild ID should receive care and treatment. However, an increase in awareness and training would be beneficial in terms of timely access to services and appropriate treatment.

There is a need for inclusive, evidence-based guidelines for people with mild ID accessing MH services. However, without good-quality evidence, the services developed will always be based upon extrapolated and standardized evidence.

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Ethical Conduct Statement

This is a scoping review and as such does not require any ethical approval as no new information has been gathered.

Data Statement

All relevant data could be made available upon reasonable request to the corresponding author.

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Appendix A. Search strategy

At this stage, search terms were kept broad, in order for as many studies to be found as possible. Searches were conducted in the Cochrane Library, Medline, Medline Inprocess, Embase, PsychINFO, and NICE Evidence. An example of the full search strategy from Medline in 2018 is included below.

Search terms were as follows:

Developmental disorder
Intellectual disability
Intellectual impairment
Learning disability
Learning disorder
Mental retardation
Mentally disabled person
Mild intellectual disability
Combined with:
Community mental
Community services
Delivery of healthcare
Health service accessibility
MH
MH services

It was noted that initially only 2 articles directly relating to mild ID were found by this method – therefore the search was repeated excluding the link for the term “mild” *and* “intellectual disability.” Included papers were also limited to systematic reviews, guidelines, or RCTs to keep within the aims of the project.