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Evidence to Inform the Revision of Guidance for Staff Providing Mental Health Services to Persons with Intellectual Disabilities

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Abbreviations

ASD:	Autism Spectrum Disorder
CAMHS-ID:	Child and Adolescent Mental Health Service-Intellectual Disability
CRPD:	United Nations Convention on the Rights of Persons with Disabilities
IDS-TILDA:	Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing
HIQA:	Health Information and Quality Authority
HSE:	Health Service Executive
MHC:	Mental Health Commission
MHID:	Mental Health Intellectual Disability
NADD:	National Association for Dually Diagnosed
NHS:	National Health Service
UN:	United Nations
WHO:	World Health Organization

Glossary of Terms

Intellectual disability 'is a condition characterized by significant limitations in both intellectual functioning and adaptive behaviour that originates before the age of 22' (American Association on Intellectual and Developmental Disabilities, 2021).

Dual Diagnosis 'refers to individuals with an intellectual/developmental disability…who concurrently experience a mental health condition' (NADD, 2022).

Executive Summary

Introduction

People with intellectual disabilities experience the same range of mental ill health as the general population but, when compared to the general population they have a higher reported prevalence rate of mental illness (Mazza et al., 2019). There are several factors that can impact on a timely and accurate assessment and diagnosis of mental ill health for the person with intellectual disabilities including; mental ill health may present differently in the person with intellectual disabilities, particularly in the person with moderate to profound intellectual disabilities, it may be attributed to the person's intellectual disability or the person may have difficulty interpreting and reporting their symptoms, thus making a timely assessment and accurate diagnosis can be challenging and complex particularly for healthcare professionals who don't have experience in this area.

In keeping with the health strategy, A Vision for Change: The Report of the Expert Group on Mental Health Policy (Department of Health and Children, 2006), the Health Service Executive's policy on decongregation, Time to Move on From Congregated Settings: A Strategy for Community Inclusion (HSE, 2011), recommended that people with intellectual disabilities would have the same access to mainstream health and social services in the community as those provided for members of the general population. The strategy endorsed specialist community based, multidisciplinary intellectual disability teams comprising psychiatry, psychology, nursing, social work and occupational therapy and offering a range of therapeutic interventions (Ramsey and Dodd, 2018). However, these community services were not developed in tandem with people moving to the community, who subsequently experienced difficulties trying to access services and supports, including timely mental health support (McCarron et al., 2018). New mental health intellectual disability (MHID) and child and adolescent mental health (CAMHS-ID) service models (HSE, 2012, 2022) are slowly being set up, with community, in-patient and respite envisaged, and as approved mental health services. The responsibility for regulating mental health services and for overseeing the implications of legislative changes falls under the remit of the Mental Health Commission (MHC), which was set up under the Mental Health Act 2001. The scope of this regulation is limited to services that are designated as 'approved centres' under the Act and registered with the MHC. These are in-patient services which may be situated in hospital of community settings. The MHC also has a remit to provide guidance in respect of quality mental health care and service provision. This is underpinned by the requirement for registered services to report in respect of specified safety and quality criteria (MHC, 2020). The MHC's remit was extended, through the Assisted Decision Making (Capacity) Act 2015, to the establishment of the establishment of the Decision Support Service, which is a part of the Commission.

The aim of this rapid review was to provide evidence to inform the revision of guidance for providers of mental health services to persons with intellectual disabilities. The review comprised:

- A comprehensive overview of current practice and policy regarding the treatment and care of persons with a dual diagnosis of mental illness and intellectual disability.
- A comprehensive overview of the key challenges faced by persons with a dual diagnosis of mental illness and intellectual disability in receiving quality care and treatment, highlighting strategies and best practice underscored in the literature as key enablers for service providers in mitigating those challenges.
- A review of any legislative considerations and rights-based considerations that may impact the treatment and care of persons with a dual diagnosis of mental illness and intellectual disability.
- A review of any standards or codes of practice relating to the regulation of mental health services for persons with intellectual disabilities.

Methods

Utilising a systematic approach, a rapid review was designed and undertaken based on the Cochrane guidance (Garritty et al., 2021). Rapid reviews serve to produce timely evidence to inform decision-making (Garritty et al., 2021), hence the decision to employ this approach for the task in hand. Each of the review objectives were scoped using the PEOS (Participants, Exposure, Outcomes, Study types) and the PICOS (Population, Intervention, Comparison, Outcomes, Study types) format as appropriate. Literature search strategies were developed by the research team in collaboration with a Subject Librarian. Initial scoping searches were run in five databases, with further searches in Google, OpenGrey and GreyNet to identify standards, codes of practice, legislative and policy documents which may have been published outside of peer review publications. These searches focused on Ireland, United Kingdom, United States of America, Canada, New Zealand and Australia. Data from each of the four objective-led searches were analysed for emerging themes using the multiple case study approach advocated by Cresswell (2013). Extracted data were synthesised in research-objective specific evidence tables and narrative accounts were developed in relation to the aspects of mental health services for people with a dual diagnosis of mental illness and intellectual disability: current practice and policy; barriers and challenges to accessing service; legislative and rights-based considerations; standards, codes and guidance for practice.

Key Findings

Three main areas emerged from the synthesis of the findings, service model, service delivery and interventions. These areas are contextualised by key value-based underpinnings, such that services

should be human rights based, person-centred, focused on the individual's capacity and consultatory. Recommendations arising from the rapid review include:

Service Model Recommendations

Recommendation 1: The national service model for supporting the needs of people with dual diagnosis of intellectual disability and mental illness should demonstrate inclusive governance with clear external and internal lines of accountability.

Recommendation 2: The service model should provide a tiered approach to service delivery, with a preference for addressing the mental health need of people with intellectual disabilities in primary care settings.

Recommendation 3: The Irish Government and HSE should ensure that funding is provided to realise all aspects of the MHID service models.

Recommendation 4: All mental health services for people with intellectual disabilities, whether community, hospital or forensic based, should fall solely under the regulation of the Mental Health Commission.

Service Delivery Recommendations

Recommendation 5: The HSE should develop a workforce strategy to identify the staffing needs, in terms of knowledge, skills and competencies, that are required to realise the MHID service models.

Recommendation 6: A competency framework should be developed to mainstream health and social care workers to meet front-line mental health support needs.

Recommendation 7: Higher education institutes and bodies responsible for the regulation of healthcare professionals in Ireland should require that education and training programmes provide content on intellectual disability (including mental health), as well as clinical placements supporting the needs of people with intellectual disabilities.

Interventions Recommendations

Recommendation 8: Services should ensure that a full range of interventions are available to meet the mental health needs of people with intellectual disabilities. Their usage should be based on assessed need.

Recommendation 9: Services should employ an integrated and consultatory approach in assessing the needs of people with dual diagnosis of intellectual disabilities and mental illness; this should extend to decisions regarding interventions.

Recommendation 10: Medication reviews, particularly in respect of psychotropic medications, should be enacted as a normal part of prescribing practice.

Recommendations for Research

Recommendation 11: Ongoing research is required in respect of the diagnosis of mental illness in people with severe and profound intellectual disabilities.

Recommendation 12: Research should be conducted regarding the prescription of medications for persons with severe and profound intellectual disabilities, particularly where symptoms and side effects can be self-reported.

Recommendation 13: Research is needed to explore the useability and usefulness of psychological and psychosocial Interventions for people with severe and profound intellectual disabilities.

Recommendation 14: Research into the effectiveness of non-pharmaceutical therapeutic interventions for people with intellectual disabilities and mental illness should be conducted, to include cohort and longitudinal studies.

Introduction

This rapid evidence review was undertaken to inform the revision of guidance for providers of mental health services to persons with intellectual disabilities. The review comprised:

- A comprehensive overview of current practice and policy regarding the treatment and care of persons with a dual diagnosis of mental illness and intellectual disability.
- A comprehensive overview of the key challenges faced by persons with a dual diagnosis of mental illness and intellectual disability in receiving quality care and treatment, highlighting strategies and best practice underscored in the literature as key enablers for service providers in mitigating those challenges.
- A review of any legislative considerations and rights-based considerations that may impact the treatment and care of persons with a dual diagnosis of mental illness and intellectual disability. (*international context but focused on those related to the Irish situation*).
- A review of any standards or codes of practice relating to the regulation of mental health services for persons with intellectual disabilities.

Current State of Evidence

People with intellectual disabilities can experience the same mental ill health as the general population yet, although the reported prevalence rates of psychiatric illness among people with intellectual disabilities varies widely, it is reported to be higher than that of the general population (Mazza et al., 2019). The reasons for this are unclear. Mental illness may relate to the specific causation of intellectual disability, for example, the severe anxiety seen in Fragile X Syndrome (Wadell et al., 2013), but it may also be a result of increased vulnerability to mental health concerns in the face of significant life events and experiences (Bond et al., 2019; Sheerin et al., 2019; Courtenay and Perera, 2020).

Published prevalence figures vary widely, with Cooper et al. (2007) reporting this at 40.9% in a Scottish study, Scott and Havercamp (2014) reporting 36.6% in a United States cohort and Schützwohl et al. (2016), 10.8% in a German population. The most recent Irish figures are those from Wave 5 of the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA), which reported an overall prevalence of 44.4%, noting this to be nearly a 5% reduction on levels seen in Wave 1 (Sheerin et al., 2023). These figures relate, however, to prevalence among adults and mental illness can occur at any point along the lifespan trajectory, and studies have pointed similar prevalence

rates among children and adolescents (Rutter et al., 1976; Dykens, 2000; Tonge and Einfeld, 2000; Emerson, 2003; The College of Psychiatry of Ireland, 2011). Further variance may be seen across genders with mental illness reported to be greater among women with an intellectual disability than men (McCarron et al., 2011, Mulryan et al., 2014). Moreover, level of intellectual disability may also be a factor for, whereas higher prevalence has been reported among those with mild to moderate levels of intellectual disability (McCarron et al., 2011, Mulryan et al., 2014), there are suggestions that it may also be particularly prevalent in individuals with more severe levels of intellectual disability (Gomez, 2021; Sheerin et al., 2023).

Although the word 'mental illness' is being used here, the reality is that many people with intellectual disability may be living with an undiagnosed mental illness, perhaps due to overlying challenging behaviour (Peña-Salazar et al., 2020). Despite Fletcher et al.'s (2018) modified diagnostic criteria for mental disorders (DM-ID-2), and the Royal College of Psychiatrist's (2001) earlier DC-LD manual (DM-ID), the assessment and diagnosis of mental illness in individuals with intellectual disabilities remains complex and challenging. Mental ill health may present differently in people with intellectual disabilities. The diagnosis may be overshadowed by the intellectual disability itself or people with intellectual disabilities may struggle to recognise, interpret and/or communicate their symptoms. Clinical manifestations of mental illness may be subtle, atypical and non-specific, and can include an individual people becoming withdrawn, agitated or losing interest in their usual activities (Sheerin et al., 2019; Kildahl, 2024). Thus, it may be difficult to detangle mental illness from other issues of concern. In recognition of the challenges in achieving a diagnosis, National Institute for Health and Care Excellence (NICE, 2016) guidelines recognise the need for broader perspectives based on knowledge of the person and propose that family members' or carers' perspectives may be useful in the diagnostic process based on their awareness and alertness to changes in behaviour or functioning or signs of distress. However, such input may be impacted by confirmation bias – for example a belief that symptoms are an indication of dementia – or by insufficient knowledge of an individual on the part of care staff (Kupara and Woodward, 2023).

Changing Demographics…Changing Services

Historically, people with intellectual disabilities in Ireland received wrap-around care from voluntary organisations with all services, including mental health services, provided in specialist settings. This usually included access to a multidisciplinary team comprising psychiatrists, psychologists, nurses, general practitioner, social workers and various professionals allied to medicine (for example, physiotherapist, occupational therapist and speech and language therapist). The advantage of this approach was that health services were typically available in a timely manner and the professionals had an understanding of intellectual disabilities. The principal mental health professionals were the

intellectual disability psychiatrists, psychologists and, in some cases nurse specialists/advanced practitioners. These services were a legacy from the original institutional model but meant that people with intellectual disabilities had limited engagement with mainstream community services (McCarron et al., 2018). It is possible that this, in turn, limited their access to specialist health care. This was highlighted by McCallion et al. (2013) and McCarron et al. (2013) who noted a lack of access to and use of preventive interventions, as well as non-preparedness of general health services in respect of meeting the needs of people with intellectual disabilities.

In 2011, the Health Service Executive (HSE) published its policy on decongregation, entitled Time to Move on From Congregated Settings: A Strategy for Community Inclusion. The policy proposed that people with intellectual disabilities would 'have the same entitlement to mainstream community health and social services as any other citizen, such as GP services, home help and public health nursing services, and access to primary care teams…access to specialised services and hospital services based on an individual assessment' (HSE, 2011:4). This was wholly in keeping with the then health strategy, A Vision for Change: The Report of the Expert Group on Mental Health Policy (Department of Health and Children, 2006), which had recommended that services for people with intellectual disabilities be community-based and similar to those provided for members of the general population. The strategy envisaged specialist community based, multidisciplinary intellectual disability teams comprising psychiatry, psychology, nursing, social work and occupational therapy and offering a range of therapeutic interventions (Ramsey and Dodd, 2018). The drive for physically relocating people to community settings unfortunately, preceded the development of the community services, with challenges experienced in accessing services and obtaining, for example, timely mental health support (McCarron et al., 2018). These challenges remain and have seen the implementation of decongregation within intellectual disability services and the concurrent continuance of health and other provision with those services. This has resulted in the existence of a mixed mental health service provision. New mental health intellectual disability (MHID) and child and adolescent mental health (CAMHS-ID) service models (HSE, 2012, 2022) are slowly being set up, with community, in-patient and respite envisaged; as approved mental health services, these will likely fall within the regulatory remit of the Mental Health Commission. At the same time, disability services are addressing the otherwise unmet mental health service needs of people with intellectual disabilities; these services, though, operate within the regulatory remit of the Health Information and Quality Authority (HIQA).

The establishment of HIQA in 2007 ensured the development of standards and the regulation of health and social services. Designated centres for people with disabilities were registered with HIQA and inspected for compliance against the National Standards for Residential Services for Children and Adults with Disabilities (Health Information and Quality Authority, 2013). Included within these

standards are items supporting access to mental health care and appropriate medication review and management. In addition, thematic inspections were commenced, the initial focus being on physical and environmental restrictive practices (HIQA, 2022, 2023).

In the United Kingdom, concerns regarding the use of psychotropic use for people with intellectual disabilities or autism prompted the National Health Service (NHS) to instigate the work programme STOMP (Stop Overmedicating People with an Intellectual Disability) in 2015 (NHS, 2016; Royal College of Psychiatrists, 2021). The use of psychotropic medication in older adults with intellectual disabilities continues to receive attention and was recently highlighted in the EQUIP report (Gorman et al., 2023), which addressed the issue of high rates of psychotropic medication use in this population (Dwyer et al., 2016, 2017).

In the light of recent abuse, particularly affecting older people, the Social Care Division of the Health Service Executive issued a national policy in 2014 on safeguarding vulnerable adults, which included those with a disability; it does not, however, make specific reference to those with mental illness (HSE, 2014). Further guidance in this regard has followed, particularly the human-rights based guidelines issued jointly by Safeguarding Ireland and HIQA in 2019.

The provision of disability and health services for people with intellectual disabilities has been and remains in flux. This is the result of the realisation of new service policies, human rights expectations and changing legislation which seeks to respond to those policies and laws. In such a situation, there is a need for guidance which assists services and professionals to undertake necessary changes, and which provides clear information to people with intellectual disabilities, their family members and carers on what they should expect from those services and professionals.

Ramsey and Dodd (2018) note a commitment to intellectual mental health training in Ireland citing that psychiatry of learning disability is one of four specialty registers maintained by the Irish Medical Council for psychiatry and noting that most clinical psychologists have completed a training rotation with people with intellectual disabilities.

Rights and Legislative Responses

These changes in demographics and service approaches for people with intellectual disabilities took place during a period where there was an increased awareness of human rights. Disability rights, in particular, became more prominent in the late 20th Century, and focused largely on the rights of those persons with physical and certain sensory disabilities, driven by a desire to move away from a medical model and towards a social one. This grew through the Decade of Disabled Persons (1983-1992), leading to the adoption of Standard Rules on Equalization of Opportunities for Persons with Disabilities, culminating in the adoption of the Convention on the Rights of Persons with Disabilities

(CRPD) (United Nations, 2006). The CRPD arguably reset the benchmark and the context for understanding disability but was, for many countries, only a starting point in respect of those with intellectual disability and mental illness. In Ireland, for example, the Lunacy Acts of the 1800s remained in force, restricting realisation of the rights that were set out in the Convention. Thus, despite the existence of rights-based conventions, legislative change has typically lagged behind, and particularly for people with dual diagnosis. The result has been that historical restrictive legislation has tended to predominate, with a growing realisation of the need to modify that following the commitment to adopt rights conventions.

Over the past twenty years there have been concerted efforts in some jurisdictions to move away from the tendency towards custodial responses embodied in mental health legislation. That said, many countries, including Ireland (Mental Health Act 2001, Mental Health Act 2001 (Approved Centres) Regulations 2006) maintain legislation which allows for the involuntary admission of people with mental significant mental health concerns that pose a risk to self or others. Similar acts exist in, for example, the United Kingdom (Mental Health Act 1983), Queensland (Mental Health Act 2016) and New Zealand (Mental Health (Compulsory Assessment and Treatment) Act 1992). Whilst the approach underpinning such legislation was often incarceratory in nature, it is noted that modifications to acts have sought to address the unique issues associated with particular cohorts of people who fell outside the scope of such acts and were incarcerated under criminal law instead. This included those with problematic behaviours and intellectual disability. Thus, New Zealand enacted the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003 whilst a Joint Committee on the Draft Mental Health Bill (House of Commons and House of Lords 2023) has been examining the same issues in the UK.

The focus on human rights and particularly for those with disabilities has also raised questions on the rights afforded those who have been subject to involuntary assessment and/or treatment under mental health legislation. For this reason, modern mental health legislation demands that information on diagnosis, treatment and planning be made available to patients in accessible formats and/or through independent advocates or representatives. Furthermore, patients must have recourse to appeal in respect of detention, something that has been raised by the House of Commons and House of Lords Joint Committee (2023). It is in respect of these areas, and particularly the need for information in respect of decision-making and assessment of capacity, that legislation such as the Mental Capacity Act (England and Wales) 2005 and the Assisted Decision-Making (Capacity) Act 2015 have been so influential, as they have seen the enactment of rights embedded in international conventions such as the CRPD. A similar outcome has been witnessed in the United States of America, via the Americans with Disabilities Act 1990 (United States Department of Justice 1990). It should be

noted too, that ‘non-disability specific’ rights expectations are also extant in other legislative instruments, including the Equality Act 2010, the Health Act 2007 and the Disability Act 2005 and that, whereas there may be no reference to mental illness and intellectual disability, there is an implied conferring of rights to these people in terms of health and social service provision. The implications of these for mental health services are still being realised and will be discussed anon in the findings of this review.

The responsibility for regulating mental health services and for overseeing the implications of the above legislative changes falls under the remit of the Mental Health Commission (MHC), which was set up under the Mental Health Act 2001. The scope of this regulation is limited to services that are designated as 'approved centres’ under the Act and registered with the MHC. These are in-patient services which may be located in hospital of community settings. The MHC also has a remit to provide guidance in respect of quality mental health care and service provision. This is underpinned by the requirement for registered services to report in respect of specified safety and quality criteria (MHC, 2020). The MHC’s remit was extended, through the Assisted Decision Making (Capacity) Act 2015, to the establishment of the establishment of the Decision Support Service, which is a part of the Commission.

Overview of Rapid Review Approach

Review Aim and Objectives

The aims of this rapid review are to explore the literature pertaining to mental health services for people with a dual diagnosis intellectual disability and mental illness. The review is intended to form a basis for the development of guidance for providers of Irish mental health services to persons with intellectual disabilities.

Objectives

1. To undertake an in-depth literature review encompassing relevant peer and grey literature published in Ireland and internationally between 2018-2023. The review should specifically include the following:
    a. A comprehensive overview of current practice and policy regarding the treatment and care of persons with a dual diagnosis of mental illness and intellectual disability.
    b. A comprehensive overview of the key challenges faced by persons with a dual diagnosis of mental illness and intellectual disability in receiving quality care and treatment. In their review of evidence, tenderers should highlight strategies and best practice underscored in the literature as key enablers for service providers in mitigating those challenges.
2. To undertake a review of any legislative considerations and rights-based considerations that may impact the treatment and care of persons with a dual diagnosis of mental illness and intellectual disability.
3. To undertake a review of any Standards or Codes of Practice relating to the regulation of mental health services for persons with intellectual disabilities.
4. To make recommendations to the Mental Health Commission in respect of guidance for providers of mental health services for persons with intellectual disabilities.

Method

This rapid review was designed and undertaken based on the Cochrane guidance for conducting such reviews (Garritty et al., 2021). Although a systematic approach was employed, the methodology was adapted to meet the requirements of a rapid evidence review, “a…knowledge synthesis in which the steps of a systematic review are streamlined or accelerated to produce evidence in a shortened timeframe” (WHO, 2017). Rapid reviews serve to produce timely evidence to inform decision-making (Garritty et al., 2021), hence the decision to employ this approach for the task in hand. Each of the

objectives were scoped using the PEOS (Participants, Exposure, Outcomes, Study types) and the PICOS (Population, Intervention, Comparison, Outcomes, Study types) format as appropriate (Tables 1 to 4).

Table 1 Study selection criteria for objective 1a.

A comprehensive overview of current practice and policy regarding the treatment and care of persons with a dual diagnosis of mental illness and intellectual disability.	
Participants	Persons with a dual diagnosis of mental illness and intellectual disability, aged 5 years and older
Interventions	Mental health care, mental health treatments
Comparators	Different mental health care and treatments
Outcomes	Current practice and policy
Study Types	Research studies Published between 2018 and 2023 Scope Ireland, UK, USA, Canada, New Zealand, Australia. Some relevant sources from other jurisdictions were considered.

Table 2 Study selection criteria for objective 1b.

A comprehensive overview of the key challenges faced by persons with a dual diagnosis of mental illness and intellectual disability in receiving quality care and treatment.	
Participants	Persons with a dual diagnosis of mental illness and intellectual disability aged 5 years and older
Exposure	Mental health service
Outcomes	Barriers and challenges to accessing service
Study Types	Research studies Published between 2018 and 2023 Scope Ireland, UK, USA, Canada, New Zealand, Australia. Some relevant sources from other jurisdictions were considered.

Table 3 Study selection criteria for objective 2.

A review of any legislative considerations and rights-based considerations that may impact the treatment and care of persons with a dual diagnosis of mental illness and intellectual disability.	
Participants	Persons with a dual diagnosis of mental illness and intellectual disability aged 5 years and older
Exposure	Mental health service
Outcomes	Legislative and rights-based considerations
Study Types	Legislation, conventions Scope Ireland, UK, USA, Canada, New Zealand, Australia, EU, UN.

Table 4 Study selection criteria for objective 3.

A review of any Standards or Codes of Practice relating to the regulation of mental health services for persons with intellectual disabilities.	
Participants	Persons with a dual diagnosis of mental illness and intellectual disability aged 5 years and older
Exposure	Mental health service
Outcomes	Standards, codes and guidance for practice
Study Types	Standards, codes of practice, guidance. Scope Ireland, UK, USA, Canada, New Zealand, Australia. Some relevant sources from other jurisdictions were considered.

Search Strategy

Literature search strategies were developed by the research team in collaboration with a Subject Librarian. Initial scoping searches were run in Embase, PsychInfo, CINAHL and MEDLINE. These resulted in a list of synonyms using Emtree headings, PsychoInfo descriptors as well as MeSH and CINAHL subject headings.

Following this, comprehensive searches were conducted during the week of January 8th, 2024, in respect of each objective, using all identified keywords and index terms, across EMBASE, CINAHL, MEDLINE, PsycInfo and Web of Science. Further searches were conducted using Google, OpenGrey and GreyNet to identify standards, codes of practice, legislative and policy documents which may have been published outside of peer review publications. These searches focused on Ireland, United Kingdom, United States of America, Canada, New Zealand and Australia.

In respect of objective 1a, 'mental health services' was used as a proximity operator to increase the sensitivity of the search. This was designed to capture the variation of services and clinics applied in this area. In respect of objective 1b, 'mental illness' was used as a proximity operator to increase the sensitivity of the search. This was designed to capture the variation of manifestations of mental health and illness in this area.

Finally, reference lists of all identified reports and articles were searched for additional studies. Language restrictions were not applied to the search strategy, however, given the timeframe available and the nature of the review, selection of relevant papers was restricted to English language. Similarly, a final limitation was that the relevant papers would be available full-text and at no cost. A detailed account of the search strategy applied in each database, and results, is provided in Appendix 1.

Study Selection and Data Extraction

All recovered sources were uploaded to Covidence to facilitate screening. Initial screening comprised a review of titles and abstracts and was independently conducted by two reviewers. Any discrepancies were resolved through discussion. Full text screening of sources that remained were undertaken independently by two reviewers and any differences were again resolved through discussion or by decision of a third reviewer. Data extraction from included sources was undertaken by one reviewer, with a second reviewer carrying out independent random checking for accuracy in 10% of the extraction decisions made.

One reviewer carried out an independent rick of bias (ROB)/methodological quality assessment on all sources that were included for extraction. The ROB tools used are listed in Table 5.

Table 5 Risk of bias/quality assessment tools

Evidence Category	Risk of Bias/Quality Assessment Tool
Qualitative Descriptive Studies	CASP Qualitative
Cohort Studies	CASP Cohort Study
Cross-Sectional Studies	JBI Cross-Sectional
Systematic Reviews	CASP Systematic Review
Quantitative Studies	JBI Quasi-Experimental
Expert Opinion	JBI Expert Opinion

Data Analysis

Data from each of the four objective-led searches were analysed for emerging themes using the multiple case study approach advocated by Cresswell (2013). This encompassed an initial within-case analysis of each source leading to the identification of overarching themes. In order to conduct a meta-synthesis, a cross-case analysis was undertaken to note intersections, thus informing the refinement of thematic areas under which the findings could be discussed, and recommendations made (Noah, 2017). Extracted data were synthesised in research-objective specific evidence tables and narrative accounts were developed in relation to the aspects of mental health services for people with a dual diagnosis of mental illness and intellectual disability: current practice and policy; barriers and challenges to accessing service; legislative and rights-based considerations; standards, codes and guidance for practice.

Findings

The results (database and grey literature) yielded 11,566 records. Removal of duplicates, screening for title and abstract resulted in 10,950 records being excluded, with 616 remaining for full-text review. Of these, 498 were excluded, leaving 118 records. The main reasons for exclusion related to the type of publication (not research), non-mental health contexts/focus or wrong population (not dual diagnosis of mental illness and intellectual disability) (Figure 1).

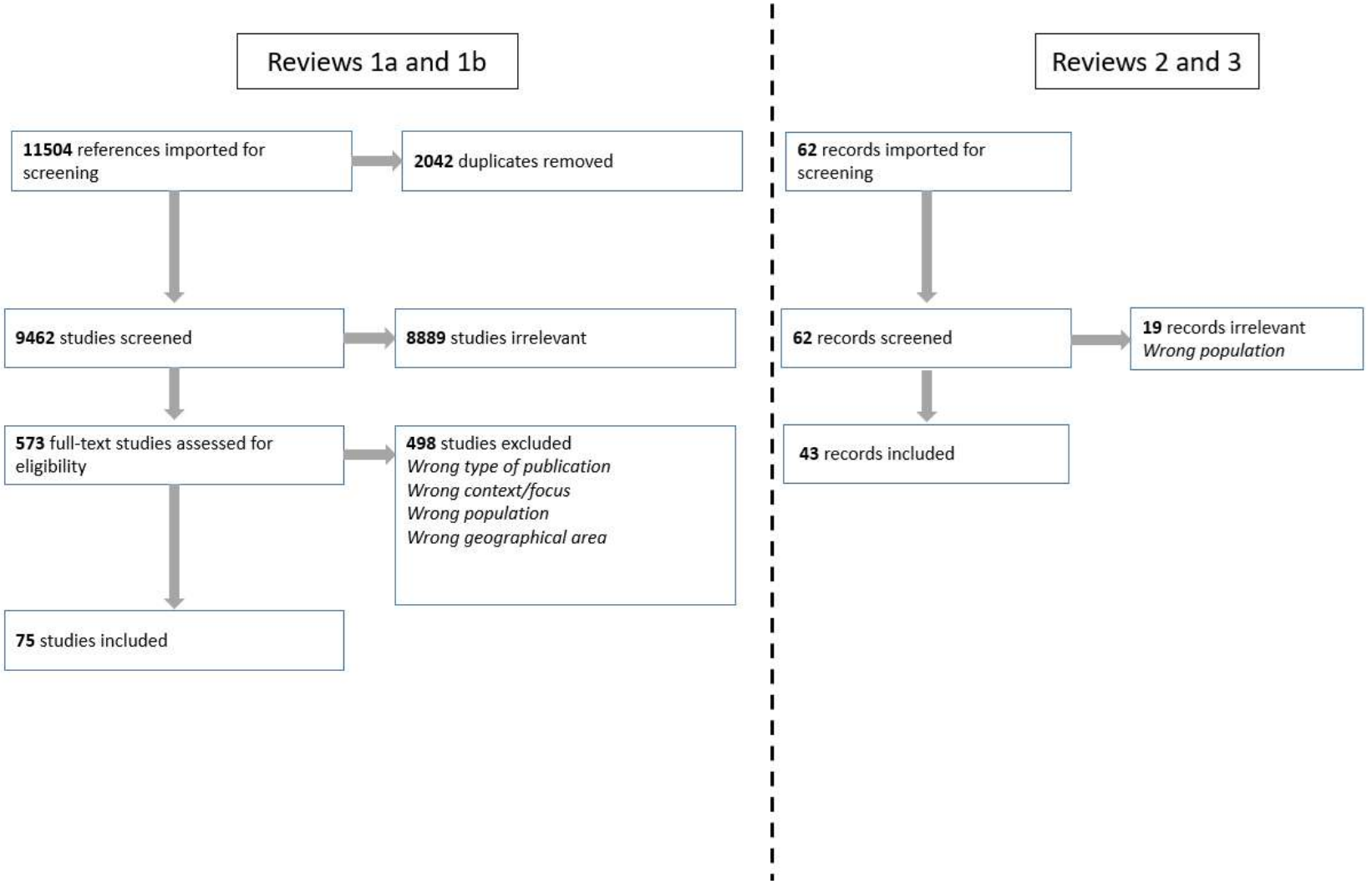

Figure 1 Combined PRISMA diagrams for the four reviews.

Review Summaries and Syntheses

Introductory paragraph for the section.

Objective 1a - Current practice and policy regarding the treatment and care of persons with a dual diagnosis of mental illness and intellectual disability.

The results from the five databases, grey literature, citation searching, and unspecified sources yielded 4515 records related to current practice and policy regarding the treatment and care of persons with a dual diagnosis of mental illness and intellectual disability. Removal of duplicates, screening for title and abstract resulted in 4,274 records being excluded, with 231 remaining for full-text review. Of these, 210 were excluded, leaving 31 records for inclusion in the review (Table 6). The main reasons for exclusion related to the type of publication wrong context or focus, wrong population, and wrong geographical area (Figure 2).

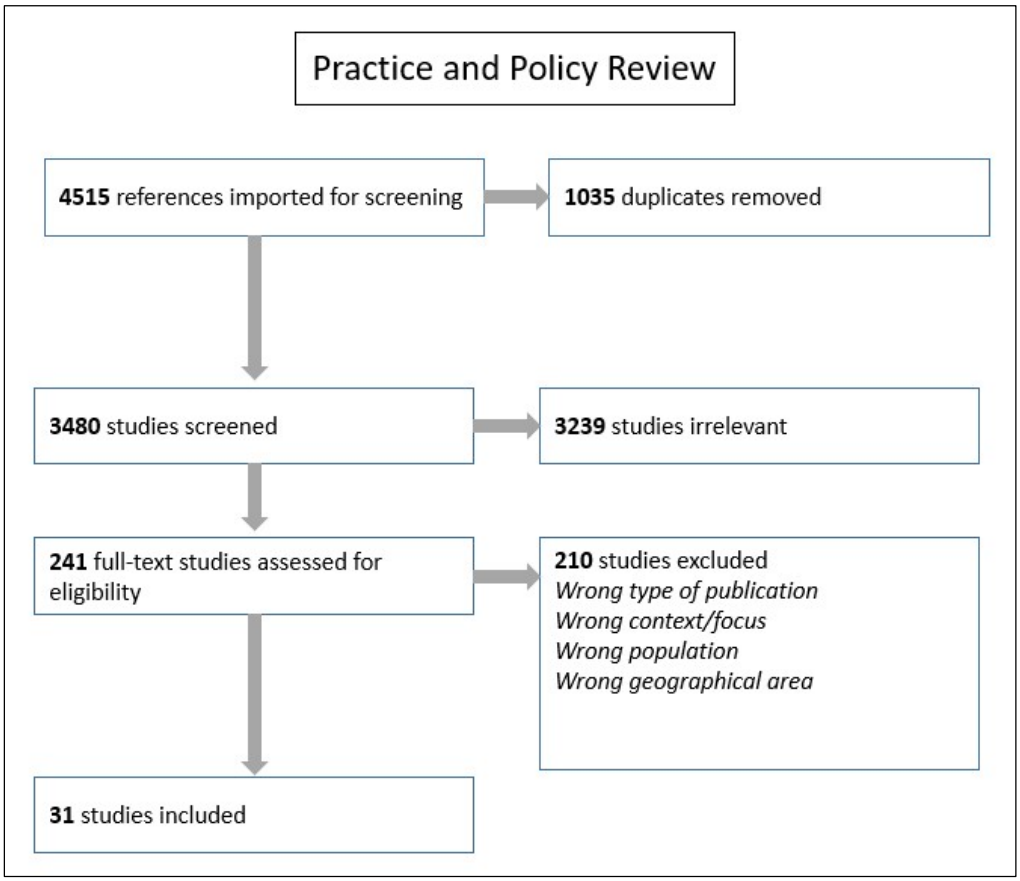

Figure 2 PRISMA diagram for the practice and policy review.

What was gleaned from these records is presented under five main areas that emerged during analysis. These are: pharmacological interventions; staff preparedness; development of services; Telehealth, eHealth and psychosocial interventions.

Table 6 Evidence on practice and policy regarding the treatment and care of persons with a dual diagnosis of mental illness and intellectual disability (for Quality Score/Risk of Bias, 'Good' implies good quality/low risk of bias; 'Poor' implies poor quality/high risk of bias').

Author (year) Country. Quality Score/ Risk of Bias.	Participant/ population.	Aim.	Tool / approach.	Findings.
Bond et al. (2021), Australia. *Good.*	53 experts completed all three survey rounds (67% retention rate)	To develop guidelines for how a family member, friend, concerned community member or disability worker without specialist mental health qualifications should give initial assistance (mental health first aid) to a person with an intellectual disability who may be experiencing mental health problems or in a mental health crisis.	Delphi approach.	These guidelines and the resultant course will provide clear information on recognising and addressing mental health problems in people with an Intellectual disability. Providing training on how to recognise and discuss mental health problems with people with an intellectual disability will empower them and those who support them to seek appropriate mental health care.
Bourne et al (2022), UK. *Good*	21 papers in the review (432 participants over the age of 18 years).	This review aimed to understand: 1. What forms of psychosocial groups interventions take place in community settings? 2. What groups are beneficial to adults with an intellectual disability and mental ill health? 3. What study designs are appropriate to evaluate community-based psychosocial interventions with this population? and 4. What priorities and adaptations are needed to make groups accessible?	Systematic review.	Limitations in study design, methods, outcomes, and follow-ups identified in several of the studies reviewed. The review highlights a lack of provision particularly for people with varying abilities, only one study included participants with profound intellectual disability. Positive results from the quantitative data were not sustained at follow-up suggesting that groups may need to run for longer periods to support learning and change behaviours. The best outcomes were seen in studies that adopted a creative element with multiple activities over a short period of time, with breaks and group rules.
Byrne (2022) Ireland. *Good.*	11 papers in the final review	To appraise the effectiveness of both cognitive behavioural therapy (CBT) and eye movement desensitization and reprocessing (EMDR) for PTSD and associated symptoms for both adults and children with mild, moderate, or	Systematic review.	Tentative findings suggest that EMDR and CBT are both acceptable and feasible treatment options among adults and children with varying levels of intellectual delay, but no firm conclusions can be drawn regarding effectiveness due to small sample sizes, lack of

		severe intellectual delay. Studies included 2010-2020.		standardized assessment, and a paucity of methodological rigorous treatment designs.
Caoili et al. (2023) USA. *Good.*	43 participants (19 prescribers, 13 non prescribing mental health clinicians, 5 family members, and 5 persons with intellectual disability and mental health service experience)	To develop Integrated Mental Health Treatment Guidelines for Prescribers in Intellectual and Developmental Disabilities for health care providers to use as a guide to address the complex needs of this patient population.	Mixed methods.	Recognises over prescribing of psychotropics within this population. Five domains: 1. Relationships, communication, and openness. 2. Understanding the person, their environment, and culture. 3. Importance of an integrated care and wellness approach. 4. Consideration of treatment modifications. 5. Recommendations from focus group participants regarding the guidelines.
Cooney et al. (2018) Ireland. *Good.*	24 adults who have intellectual disabilities and mental health needs.	To explore the experiences of adults with an intellectual disability who played a computerised cognitive behaviour therapy program.	Qualitative.	Five themes emerged: 1. Experience - overall experience of playing the game, positive, negative, and mixed reactions, reports that they gained from playing the game and expressing requesting wanting to play the game again. 2. Engagement - abilities to engage with the intervention, cognitively and physically. Participants reported elements that aided engagement and elements that interfered with Engagement. 3. Relationships - described their relationship to game characters, their therapist, other people in their lives and themselves. 4. Awareness - recognized and reported greater clarity of their thoughts, feelings and behaviours. Participants described discomfort around thoughts and emotions that they experienced when playing the game. 5. Novelty - novel experience of playing the game

				and using technology, the process of learning and a unique therapeutic environment.
daCosta et al. (2021), UK. *Fair.*	37 partici[ants, 6 from each of 5 consultant psychiatrist community teams and 7 others.	To discuss the application of the methodology of clinical audit within community learning disability mental health services to adapt interventions including optimising prescribing practice and behavioural interventions aiming to reduce behaviour that challenges in people with learning disabilities.	Quantitative. Review of electronic patient records.	A significant proportion of patients have prescribed medication in the absence of appropriate psychological or environmental interventions. Prescribing of psychotropic medication was within maximum British National Formulary limits. Evidence of consent, some attempts to deprescribe.
Deb et al. (2022), UK, Poland, Italy, Spain, Germany. *Good.*	32 articles selected for review.	To develop an evidence and consensus-based practice guideline for the assessment and diagnosis of major functional psychiatric disorders in adults with intellectual disabilities.	Systematic literature review.	A practice guideline like this is likely to be useful for psychiatrists and other related health care professionals and other people caring for adults with intellectual disabilities. This is particularly likely to be useful for psychiatrists who have very little training and experience in working in the field of intellectual disabilities.
Dew et al. (2018), Australia. *Fair to Good.*	37 mental health policy documents which met inclusion criteria.	To determine the current representation of people with intellectual disability and recommend strategies to enhance the inclusion of intellectual disability in mental health policy.	Policy analysis framework.	Only two documents identified specific strategies or measurable actions and targets to improve the access of people with intellectual disability and mental illness to mental health services.
Eagleson et al. (2022), Australia. *Fair.*	Mental health clinicians and non-mental health clinicians (managers, supervisors, and educators). 351 completed initial survey. 111 completed at 3 months. 78 completed at 12-months	To articulate the essential attributes the mainstream mental health workforce requires to meet the needs of people with intellectual disabilities and evaluate the framework's impact.	Quantitative survey.	The top five positive aspects of the framework were: 1. Provided comprehensive information. 2. Particularly beneficial sections included mental health interventions and care planning., 3. Easy to read and use. 4. Satisfying presentation structure. 5. Useful resource list.
Fodstad et al. (2024), USA. *Good.*	11 research studies.	The goal of this study was to identify via a rapid scoping review what	Rapid scoping review.	Treatments used for patients with Down syndrome most often included strategies

		strategies have been employed to clinically treat anxiety and anxiety-related disorders or the goal of this study was to identify via a rapid scoping review what strategies have been employed to clinically treat anxiety and anxiety-related disorders or behaviours in adolescents,		aligning with current standards for evidenced-based anxiety treatment, including (modified) CBT, behavioural strategies, and pharmacotherapy. While many of the studies reported positive treatment responses showing reductions in anxiety symptoms post-treatment, the available research was sparse, and the quality and generalizability of the studies was primarily poor.
Fynn et al. (2023), Australia. *Good.*	9 studies included.	To encourage awareness of the current literature around whether cognitive behaviour therapy (CBT) is appropriate and effective for individuals with intellectual disabilities and an anxiety disorder.	Systematic review.	All studies reported improvements in anxiety severity for some participants (25%–100%; N = 60) following CBT. Only three studies reported moderate effect sizes for CBT interventions on anxiety for individuals with intellectual disabilities.
Graser et al. (2022), Germany. *Good.*	22 studies included.	To quantitatively review the effectiveness of CBT for adults with intellectual disabilities by summarizing effect sizes for anxiety, depression, and anger.	Meta-analysis.	The meta-analysis showed significant effects of controlled trials regarding the efficacy of cognitive behavioural therapies for people with intellectual disabilities suffering from depressive symptoms and anger. The quality of the included studies was moderate, and heterogeneity was partially high. Indications for different levels of intellectual disabilities should be developed, as most of the available treatment options are focused on mild intellectual disabilities.
Hall (2023), UK. *Good.*	10 adults with intellectual disability who were on a waiting list for psychological therapy.	To explore how service users accessing a community learning disability team experienced waiting for psychological therapy.	Qualitative.	Provides evidence to understand the impact of waiting for therapy, may inform on the impacts of such waits, including the difficult emotional impact and psychological burden, the relief when screening appointments arrived, issue with accessibility of materials including apt. letters, and ways of coping. This project led to a range of recommendations to inform a psychology waiting list standard operating

				procedure, service developments and improve the waiting list experience for service users.
Hamers et al. (2018), Netherlands. *Good.*	15 research papers.	The aim of this review is to evaluate non-pharmacological treatments for adults with intellectual disabilities and depression.	Systematic review	Five different types of non-pharmacological interventions are identified in the included studies of this review: CBT, behavioural therapy, exercise Intervention, social problem-solving skills programme and bright light therapy (BLT). Concludes that CBT is an effective non-pharmacological intervention to decrease depressive symptoms in adults with mild or moderate intellectual disability.
Hamers et al. (2020), Netherlands. *Good.*	3 study groups (total n=41): Group I BLT 10,000 (n=12). Group II BLT dim light (n=15). Group III control (n=14).	To investigate whether BLT is effective in decreasing depressive symptoms in two BLT intervention groups compared to no-BLT (control group).	Randomised controlled trial.	In both BLT groups, a significant decrease in depressive symptoms was seen. No significant differences were found between 10,000 lux BLT and no-BLT ($p = .199$) and no significant differences between dim light BLT and no-BLT ($p = .451$). A minimum amount of side effects and no adverse events were reported.
MacHale et al. (2023) Ireland. *Good.*	5 research studies.	To collate the views and experiences of adults with intellectual disabilities accessing digital mental health interventions (DMHI).	Systematic review	Three major narrative themes were generated, each with sub-themes: 1. User experience with DMHI (personal experience, digital experience). 2. Relationships fostered through technology (interpersonal support, relating to virtual characters, computer as skilled helper). 3. Psychological benefits (new skills development, personal autonomy development).
Mayer et al. (2023), Switzerland & Germany. *Good.*	15 in total: Intervention group (n=7, 5 with intellectual disabilities), Control group (n=8, 5 with intellectual disabilities).	To provide initial evidence for the feasibility and effectiveness of Narrative Exposure Therapy (NET) adapted for persons with intellectual disabilities or severe chronic mental disorders suffering from PTSD.	Randomised controlled pilot.	No significant differences noted in NET group and control group, however, this study supports the feasibility of an RCT within this population.

Newman et al. (2023), Australia. *Good.*	49 participants across 4 sites: easy read users, health practitioners and staff from services providing mental health care.	To explore how easy read is used and the ways accessible information can address access barriers, with a focus on Australian mental health services.	Qualitative.	Most mainstream mental health staff did not use easy read or other accessible information and did not consistently offer people with intellectual disability opportunities to interact with mental health information. Staff at specialised sites had numerous strategies they used to make information easier to understand, including easy read, and people with intellectual disability valued flexible, tailored approaches to communication. Absence of ready-made or tailorable resources made creating resources time consuming for individual staff and required a level of skill, confidence, or expertise outside the capacity of many practitioners. This finding was reflected in the experiences of participants with intellectual disability who had not been offered easy read material in health service settings.
Oudshoorn et al. (2021), Netherlands. *Good.*	33 research studies.	To identify the characteristics of psychological eHealth interventions used during COVID, of participants and persons delivering the intervention.	Scoping review.	This review does not report on efficacy of eHealth interventions, rather all interventions that have been implemented. Many papers are focussed on behaviours. Provides a comprehensive description of psychological eHealth interventions which may be particularly relevant for mental health service and this population.
Panditaratne et al. (2022), Australia. *Good.*	8 mother-child dyads.	To provide the first qualitative evaluation of the Fearless Me! © (CBT) program by exploring participant experiences.	Qualitative.	Thematic analysis - 4 themes: 1. Reflections on features of the programme: overall a positive experience. Weekly sessions may have been a barrier. Importance of parents' role. 2. Interpersonal vs intrapersonal factors affecting participation: fears/anxieties re socialising, insects, sleep. Importance of strong therapeutic relationship. Intrinsic

				characteristics of the child - maturity and willingness. 3. Catering to the child's individual ability, language/communication, a lot of verbal communication in the programme, sufficient time for comprehension. 4. Characteristics of treatment outcomes - expectations for change, acquisition of new skills and information, treatment related changes.
Pouls et al. (2022), Netherlands. *Good.*	100 papers included.	To provide an up-to-date overview of the care provided by general practitioners (GP) to patients with intellectual disabilities and mental health disorders (MHD), identify knowledge gaps, and inform research, practice, and policy.	Scoping review,	The results show GPs' vital, diverse, and demanding roles in caring for patients with both intellectual disabilities and MHD. GPs experience problems in fulfilling their roles, and gaps are identified regarding effective GP training programmes, applicable guidelines and tools, optimal collaborative mental health care, and corresponding payment models.
Quevedo et al. (2021), Netherlands. *Good.*	10 patients from a tertiary clinical mental health treatment centre for patients with mild intellectual disability or borderline intellectual functioning (MID-BIF) and severe mental disorders	To evaluate the feasibility, safety, and effectiveness of eye movement desensitization and reprocessing (EMDR) therapy in patients MID-BIF suffering from PTSD and a comorbid psychotic disorder.	Case series.	Results were maintained at three-month follow-up. Furthermore, a significant decrease in general psychopathology (in five participants) and an improvement in general functioning was found, while in five of the six participants the severity of psychotic symptoms (hallucinations and delusions) decreased. No adverse effects found. The results suggest that EMDR therapy may be feasible, safe and effective in the treatment of PTSD of individuals with triple diagnosis residing in mental health care settings.
Roberts and Kwan (2018), Australia. *Fair to Good.*	13 participants.	To 1) describe how to implement cognitive challenging for adults with intellectual disabilities, 2) report results from a pilot evaluation of a manualized, modified CBT intellectual disability programme for anxiety, and	Pilot evaluation.	Majority of adults with mild intellectual disabilities were able to learn and implement key components of modified cognitive challenging skills, people with moderate intellectual disabilities struggled with aspects. Findings suggest that proficiency at components

		3) compare participants with mild versus moderate intellectual disabilities on post treatment cognitive challenging competencies.		of cognitive challenging is associated with the severity of intellectual disability, and training in cognitive components of CBT may be restricted to adults with mild, but not moderate, intellectual disabilities.
Sauter et al. (2023), Netherlands. *Good.*	Young people with Mild Intellectual Disabilities or Borderline Intellectual Functioning.	This paper presents the AAIDD framework as a way in which characteristics of MID-BIF youth can be integrated into a cognitive behavioural case formulation.	Framework development.	Presents a clear framework and guidelines for clinicians for adaptations, which allows for other studies to replicate and evaluate effectiveness against clear criteria.
Schwartz and Hwang (2022), USA. *Good.*	4 young adults with intellectual disabilities and mental health conditions who served as peer mentors to 5 young adult mentees.	To evaluate young adults with intellectual/developmental disabilities' ability to deliver a novel peer mentoring intervention with fidelity and the supports received	Qualitative.	Findings from this study suggest that, when provided with supports, young adults with intellectual disabilities and co-occurring mental health conditions can deliver a peer mentoring intervention.
Unwin et al (2023), UK. *Good.*	66 participants: 10 with intellectual disabilities; 4 with carers; 46 with therapists; and 6 with senior clinicians.	To presents the results of two feasibility studies: 1.To test the acceptability of a psychoeducation and stabilisation (PES), and EMDR intervention. 2. To examine the acceptability of remote or hybrid delivery of PES-EMDR, as a result of the COVID-19 pandemic and a move to a remote working model across the participating sites.	Mixed methods.	The majority of clients, carers and therapists interviewed reported that the intervention, whether PES alone or the full PES-EMDR package, had improved symptoms of PTSD and psychological well-being, and carers also reported decreases in challenging behaviour.
Vereenooghe et al. (2018), Germany, UK and Australia. *Good.*	5 studies included.	To evaluate the effectiveness of psychological and pharmacological treatments for mental health problems and their key symptoms in both children and adults with severe or profound intellectual disabilities.	Systematic review.	Lack of research in interventions that explicitly target mental health problems in people with severe and profound intellectual disabilities. The scope of this review was wide. However, only five studies were eligible for inclusion and the findings are inconclusive at best.
Walsh et al. (2021), Australia. *Fair.*	25 intellectual disability mental health experts.	To identify and reach consensus on the priorities and operation of an adult tertiary intellectual disability mental	Delphi approach.	1. People with complex needs, people identified as being at-risk and people aged 18-25 years experiencing difficulty transitioning to adult services were identified as specific targets of

		health service in New South Wales, Australia.		the service. The majority of participants (57%) indicated that the lower age limit should be 15 years. 2. Most participants (93%) agreed that a multidisciplinary team was essential to a tertiary intellectual disability mental health service. 3. Agreed clinical roles included providing short-term assessment, diagnosis and treatment of mental illness and severe challenging behaviours; consultation liaison and second opinions; high-level clinical advice including state-wide review at a quaternary level; and assistance in coordination of intellectual disability mental health services. 4. A list of principles and practical ways of work with people with intellectual disability and mental health concerns agreed - focus on rights, accessibility, inclusion, quality standards, adaptations to practice, building capacity, effective communication and collaboration.
Walton et al. (2022), UK. *Good.*	11 studies included.	To explore the current evidence for the organization, structure, and delivery of mental health services for people with mild intellectual disabilities.	Scoping review.	The available evidence suggested that despite higher levels of psychopathology there is not a corresponding consideration in care for individuals with mild intellectual disabilities 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 intellectual disability psychiatric services. Some evidence was found for intensive case management and assertive outreach for individuals with mild intellectual disabilities, but this was not replicated in further studies.

Witwer et al. (2022a), USA. *Good.*	52 treatment studies included.	To identify psychotherapy practices for adults with intellectual disabilities in the areas of treatment accommodations and outcome measures/treatment monitoring tools.	Scoping review.	This study summarizes common accommodations (e.g., visual supports, involvement of caregiver) included in psychotherapy research for adults with intellectual disability. It provides clinicians with accommodations and adaptations to consider using during informed consent, assessment, treatment and outcome evaluation and resources to assist in this process.
Witwer et al. (2022b), USA. *Good*	24 papers included.	To identify efficacious and effective treatment practices for individuals with intellectual disability and co-occurring psychiatric disorders.	Systematic review.	The value of practice and treatment guidelines in improving mental health care is well established; however, no such guidelines exist for the mental health treatment of adults with intellectual disability. An essential step in the composition of guidelines is broad and careful consideration of the relevant empirical literature. Details the weaknesses in research which considerers therapeutic intervention for people with intellectual disabilities and mental health concerns. Improving research rigour will inform practice and policy. Recommendations for future research protocols: 1. Adequate Participant Characterization. 2. Outcome measures, 3. Clinical rigour, 4. Statistical rigour.

Pharmacological Interventions.

Psychopharmacology is a specialist area and, in keeping with the NICE (2016) guidelines, the prescribing of psychotropic medication for persons with intellectual disabilities and mental illness should only be prescribed by a professional with expertise in treating the person with dual diagnosis.

Of the 31 sources reviewed under this objective, only four made specific reference to pharmacological interventions in the treatment and management of mental health disorders for the person with intellectual disability (Vereenooghe et al., 2018; da Costa, et al., 2021; Caoili et al., 2023; Fodstad et al., 2024).

The aim of Vereenooghe et al.'s (2018) systematic review was to identify and evaluate the effectiveness of pharmacological interventions in the treatment of mental health problems in children and adults with severe and profound intellectual disabilities. Three of the included studies evaluated pharmacological interventions for the treatment of mental disorders in this client group however, as the body of evidence was very limited with small sample sizes, it does not allow for generalisation of the findings. The challenges for clinicians prescribing for this client group are many, among which is the lack of an evidence base for the prescribing of medication for the person with severe and profound intellectual disability who cannot report their symptoms or the side effects of their medication (Vereenooghe et al., 2018) and the authors recommended that this inequality needs to be addressed.

In the UK, da Costa et al. (2021) conducted a clinical audit within a community intellectual disability mental health service finding that antipsychotics, followed by antidepressants, were the most frequently prescribed psychotropic medication. The majority of participants had moderate intellectual disabilities (51.4%; n=19/37) but the audit also included people with mild and severe or profound intellectual disabilities. Over half of the participants were prescribed antiepileptic medication as mood stabilisers. Polypharmacy was evident in up to three quarters of the study participants and atypical antipsychotics were more frequently prescribed than typical antipsychotics. While all audit participants were prescribed medication within British National Formulary (Joint Formulary Committee, 2024) limits, approximately half were prescribed medication for their co-occurring mental disorder, with the remainder prescribed medications off-label for challenging behaviour. Regardless of the indication for the prescribed medication, regular medication reviews occurred for 70% of the audit participants and medication reduction and or discontinuation was attempted for just over half of the audit participants. In keeping with the NICE (2015) guidelines specific behavioural support plans were in place for 20 of the 37 participants who had challenging behaviour.

Acknowledging the overprescribing of psychotropics for people with intellectual disabilities and mental health issues and the lack of training or guidance for healthcare practitioners on prescribing for this population, Caoili et al. (2023), in the USA, developed an evidence-informed, web-based, and

easy to use tool with links to best practice guidelines to help practitioners address the multifaceted needs for this client population. The people with intellectual disabilities who participated in the development of this tool identified the need for their clinician to talk directly to them using plain language, to be patient and to afford them the time to respond to questions. Long waiting times to see the doctor can be a source of stress for the individual and hence the need for shorter waiting times and longer duration of appointments was identified. Participants also noted that psychopharmacology interventions are not the only approach to treating mental health disorder and other non-psychopharmacology interventions should be considered. This received support from the clinicians and family members who participated in the study, and all identified the requirement for an integrated approach to healthcare. Such an approach acknowledges the biopsychosocial influences and needs of the person and is recognised as best practice by the American Psychological Association (2016) and the American Psychiatric Association Committee on Integrated Care (Druss et al., 2017) and when incorporated into practice, clinicians are more likely to consult with other professionals to identify the underlying cause of the person behaviour, in so doing identifying and developing holistic interventions for the person. The freely available tool is planned to be updated on a two-yearly basis, and it is envisioned that its use will reduce the possibility of over reliance on psychotropic medication prescription, facilitating incorporation of other multisystem interventions in the treatment mental health issues in this client group. Professional development and training programs about the tool guidelines have been designed for clinicians and the guidelines are being incorporated into medical training on the mental health treatment needs of the person with intellectual disabilities.

A scoping review by Fodstad et al. (2024) sought to determine the range and quality of treatments used to treat anxiety in adolescents and adults with Down syndrome, and how these treatments aligned with current evidence-based practices. Eleven studies met the inclusion criteria of which the majority (n=7) where case reports, with 2 randomized control trials, 1 non-randomized control trial and 1 case series. Of the 11 studies included in the review only 2 focused on pharmacotherapy (Howe et al., 2022; Hurley 2004). Selective Serotonin Reuptake Inhibitors (SSRIs) and Serotonin and Norepinephrine Reuptake Inhibitors (SNRIs) are usually the first line treatment for depression and anxiety in neurotypical individuals (Joint Formulary Committee, 2024). Buspirone an anxiolytic, is a serotonin 5-HT1A receptor agonist normally recommended as a second-line treatment however it has demonstrated to be effective is in the treatment of generalised anxiety disorder and has been recommended for the treatment of anxiety in persons with Down syndrome (Howe et al., 2022). Hurley (2004) reported on the use of SSRIs as first line treatment for a man with Down syndrome who had multiple phobias and agoraphobia, however they were discontinued as they did not result in a positive clinical outcome. Lorazepam, a benzodiazepine recommended for short term on an ‘as

needed' basis (as opposed to long term routine use), was then prescribed to help this man cope with his phobia specifically in relation to airport terminals. The interventions used in both studies aligned with evidence-based anxiety treatment guidelines but due to study design and small sample sizes are not generalisable.

These findings highlight the following issues:

- There is no evidence-base regarding the prescription of medications for persons with severe and profound intellectual disabilities who can report neither their symptoms nor the side effects of prescribed medication. Further research is required in this regard.
- Medications reviews should form a normal part of prescribing practice.
- Clear information on prescribing psychotropic medication, drawing on evidence-based guidelines, should be incorporated into medical programmes and be available to all prescribers.
- Psychotropic medication should only be prescribed as part of an integrated approach to care.
- It is important that the views of people with intellectual disabilities be elicited during all stages of the prescription process, with adequate time afforded to facilitate this. Information should be available in accessible formats and in plain language.

Staff Preparedness.

Ten of the 31 articles within this arm of the review contributed perspectives on staff preparedness (Dew et al., 2018; Vereenooghe et al., 2018; Bond et al., 2021; Deb et al., 2022; Eagleson et al., 2022; Graser et al., 2022**;** Pouls et al., 2022; Walton et al., 2022; Fynn et al., 2023; Newman et al., 2023).

Rights of the person.

The person with an intellectual disability who has a mental health disorder had the same right to mental health care as any other person with a mental health disorder (Bond et al., 2021) and this right should be embedded in the education and training of professionals as well as in the development of policies and guidelines for staff supporting the person with intellectual disability and mental health disorders (UNCRPD, 2006). It has been noted that there is a significant prevalence of mental health concerns among people with intellectual disabilities, yet many go undiagnosed.

Recognising Mental Health Disorders in this Population.

The risk factors for mental health disorders are the same for the person with and without intellectual disability, however for the those with intellectual disabilities, certain factors such as the person's phenotype, comorbidities and reduced coping skills may contribute to them having a higher incidence of mental ill health than that seen in the neurotypical population (Deb et al., 2022). Other factors may also have an impact, for example, the intellectual disability itself could mirror some of the symptoms of a mental health illness; differentiating between an intellectual disability and mental health disorder

can be complex and problematic, especially for the clinician who has not received specialist training or has little experience working with people with intellectual disabilities. Additionally, the side effects of antipsychotic medication, commonly used in this population, can trigger symptoms of mental disorders (Deb et al., 2022). It is also identified that, when compared to the general population, the symptoms of mental disorders may manifest differently in the people with intellectual disabilities, particularly in those with a moderate, severe or profound intellectual disability. There is, therefore, a need for clear and evidence-based guidelines to assist all clinicians, and particularly those in general practice, primary care, psychotherapy services, and non-specialist intellectual disability services, to identify and address these issues (Dew et al., 2018; Deb et al., 2022; Graser et al., 2022; Pouls et al., 2022). It cannot be assumed either that a change in a person's behaviour is indicative of a mental health issue and all efforts should be made to prevent diagnostic overshadowing (Bond et al., 2021).

Diagnostic challenges.

Diagnosing mental health disorders in people with mild intellectual disabilities can be achieved using the standardized ICD-11 (WHO, 2018) or DSM-5-TR (American Psychiatric Association, 2023) criteria, but for people with moderate to profound intellectual disabilities these standardised diagnostic instruments are not reliable and making a diagnosis can be challenging for the clinician. The use of specialised criteria such the DM-ID 2 (Fletcher et al., 2018) or DC-LD criteria (Royal College of Psychiatrists, 2001) to accurately diagnose and develop a treatment plan for this client is required. Failure to utilise these tools can lead to inaccurate diagnosis, inequality in care and ineffective treatment. The difficulties in accurately assessing and diagnosing mental health disorders in this client group has been identified (Vereenooghe et al. 2018) and includes, but is not confined to, how the mental disorder presents in the person with an intellectual disability, for example, it may present as challenging behaviour (Deb et al., 2022). Vereenooghe et al. (2018) has also noted that there is a lack of research specifically related to the people with severe-profound intellectual disabilities and mental health disorders. Deb et al. (2022) has pointed to the need to develop guidelines on the assessment and diagnosis of psychiatric disorders in adults with intellectual disabilities. Whilst there is some acknowledgement of the specific needs of people with intellectual disability who present with mental health disorders, current policy and approaches to care are inconsistent and need to be more inclusive to ensure that the needs of the person are met both in specialist disability and mainstream mental health services (Dew et al. 2018).

Facilitating Change to Address the Current Inequality in Services.

As identified, there is some evidence to suggest that the needs of some groups of people with dual diagnosis are being met, particularly those with mild intellectual disabilities, but this is not consistent across mental health and specialist intellectual disability services (Dew et al., 2018) and particularly for those with moderate to profound intellectual disabilities (Scott and Havercamp, 2014). It has also

been identified that generally general practitioners in primary care (Pouls et al., 2022), and adult psychiatrists in general mental health services (Deb et al., 2022) who do not have specialist training in working with this client group, face challenges particularly in relation to understanding how the risk factors for mental disorder may differ when compared to the non-intellectual disability population, and that recognising these differences is crucial for the assessment and diagnosis of mental health disorders (Deb et al., 2022). As a result, general practitioners and mainstream psychiatrists must rely on caregivers being able to recognise symptoms and manifestations of the disorder in the individual (Pouls et al., 2022). It is not just general practitioners and mainstream psychiatrists who lack training on supporting people with dual diagnosis; training programmes for psychiatric and psychotherapeutic practice do not always address how to support people with intellectual disabilities (Graser et al., 2022; Marrus et al., 2023). If such knowledge and understanding is absent and psychotherapy interventions are not modified/adapted for people with dual diagnosis, then they may be excluded from being able to avail of such therapies. To prevent this, more specialist training and education is required for therapists intending to work with people with intellectual disabilities (Graser et al., 2022; Fynn et al., 2023).

Staff training

Walton et al.'s (2022) scoping review on the organisation, structure and delivery of mental health services for people with mild intellectual disabilities in the United Kingdom found that an increase in staff training would make an impact on early referral to mental health services and promote suitable, timely treatment for the individual. Such training can be supported through the development of evidence-based guidelines.

Guidance is also important for other formal and informal caregivers and Bond et al. (2021), in their Australian study, developed guidelines to assist family members, caregivers and disability workers without specialist mental health qualifications to provide mental health first aid to people with intellectual disabilities, thereby supporting them as formal mental health care is arranged.

The need to develop practice guidelines to help general practitioners and general adult psychiatrists assess and diagnose psychiatric disorders in adults with intellectual disabilities is seen as crucial (Deb et al., 2022; Pouls et al., 2022; Caoili et al., 2023). Eagleson et al.'s (2022) evaluation of an intellectual disability mental health core competency framework identified that such a framework can be used to support the education and training of mainstream mental health workforce to assist them to meet the needs of the person with dual diagnosis and to inform policy. As previously identified (in the pharmacological theme), Caoili et al. (2023) in the USA developed an evidence-informed, web-based, easy-to-use tool, with links to best practice guidelines, to help practitioners address the multifaceted needs for this population. These guidelines, and those proposed by Deb et al. (2022), stress the

importance of the making reasonable adjustments, providing appropriate communicative aids, using plain language and flexibility in relation to waiting times and duration of appointments, so as to ensure that an appropriate assessment of the person's mental health can be conducted. Newman et al.'s (2023) Australian study identified the importance of providing accessible information to people with intellectual disabilities. They noted that specialist intellectual disability mental health services provided information for the person in easy read and other formats, whereas, despite guideline recommendations, generally mental health staff in mainstream services neither used easy read nor accessible approaches when supporting the person with intellectual disability, nor did they afford the person the opportunity to appraise and or understand the information provided to them.

Inclusive and equitable health care practices for the person with intellectual disability can be nurtured through, among other factors, the appropriate use of accessible information and reasonable adjustments across healthcare settings. People with intellectual disability have indicated the value and benefits of such adjustments (Newman et al., 2023).

The following key issues emerge from the above findings:

- Quality general practice care for people with intellectual disabilities and mental illness can be achieved by initiating close collaborations between care professionals, policymakers, and organisational managers.
- There is a requirement for the professional and clinical training of general practitioners, psychotherapists and psychiatrists to include the clear guidance on supporting the mental health of people with intellectual disabilities. This should include assessment, diagnosis and treatment options.
- Further research is required to provide guidance for diagnosing mental health disorders in people with severe-profound intellectual disabilities.
- Mental health information for people with intellectual disabilities should be provided in accessible formats.
- Reasonable adjustments are required to ensure the proper assessment of the mental state of people with intellectual disabilities.

Telehealth, eHealth and Digital Mental Health Interventions.

Three of the 31 articles reviewed discussed Telehealth or eHealth as a mode of delivery for delivering psychological interventions to people with intellectual disabilities and mental health disorder (Cooney et al., 2018; Oudshoorn et al., 2021; MacHale, 2023).

MacHale et al.'s (2023) qualitative systematic review on the experiences and views of adults with intellectual disabilities accessing digital mental health interventions found that the impetus for

accelerated use of technology in delivering mental health interventions was largely due to the COVID-19 pandemic. Oudshoorn et al.'s (2021) scoping review identified that eHealth affords new opportunities for the therapist to deliver psychosocial interventions, however, whilst it identified some of the benefits of using eHealth interventions to improve access to care, the review did not address the effectiveness of the intervention for persons with intellectual disabilities themselves. Such interventions can be delivered on an individual basis and can be accessed in the person's own home. In doing so, it can result in improved access to mental health supports. As it is delivered in the person's own living environment, they are not faced with the challenge of transferring their new skills to a new situation (Oudshoorn et al., 2021).

Whilst the use of technology can improve access to mental health care, this can only be achieved if the person has access to and the skills and cognitive function required to operate the digital devices required to engage in the therapy. Whilst most participants' feedback on the use of digital devices was positive, MacHale et al.'s (2023) review identified that for some participants the experience of engaging in such interventions was, from an emotional and cognitive perspective, negative; recognising the importance of building a therapeutic relationship they did not want a computer to replace the therapist and they required support from staff to help them to meaningfully engage with their therapist in the intervention.

Notwithstanding this, given the right opportunities, digital mental health interventions can support the person in their care and can also be used to complement face-to face therapeutic interventions (MacHale et al., 2023). MacHale et al., (2023:455) review also identified an observed increase in the self-confidence and skill development of the participants and that continued exposure to using digital interventions, with appropriate staff supports, helps to nurture the persons skills enabling them to move to 'digital empowerment'.

Cooney et al. (2018) explored the experiences of 24 adults who have a mild-to moderate intellectual disability and anxiety or depression, who took part in a computerised Cognitive Behaviour therapy (cCBT) programme over a 7-week period. A cCBT programme is a way of delivering cognitive behaviour therapy through a digital device in the persons home or healthcare setting, via phone or online. In this case, it was presented in the form of a game. Participants played the game alongside a clinical psychologist whose role was to, as required, explain the concepts to the person and support them in the completion of the programme exercises. Whilst participants experienced difficulties with some of the cognitive and physical demands (particularly for those participants who had physical disabilities) of playing the game and or completing the therapy related activities, the majority of participants found it to be fun and enjoyable, it helped them to recognise their thoughts, emotions and behaviours and to have more clarity around them. It is possible that this could have also been facilitated by the

development of the therapeutic relationship between the individual and the clinical psychologist, highlighting the importance of developing a therapeutic relationship between the person and their therapist.

The following key issues emerge from the above findings:

- Digital mental health interventions can promote access to mental health support but should not be seen as a replacement for face-to-face therapeutic interventions.
- In relation to the therapeutic setting, a blended approach that integrates the use of technology and staff support has been shown to be beneficial.
- As people with intellectual disabilities need access to digital devices to engage in digital interventions, there is a need for staff/caregiver training to provide supports during such sessions.

Psychological/Psychosocial Interventions.

Twenty of the 31 papers reviewed related to the theme psychosocial interventions (Hamers et al. 2018; Roberts and Kwan, 2018; Vereenooghe et al., 2018; Byrne, 2020; Hamers et al., 2020; Oudshoorn et al., 2021; Quevedo et al., 2021; Bourne et al., 2022; Graser et al., 2022; Panditaratne et al., 2022; Schwartz and Hwang, 2022;Walton et al., 2022; Witwer et al., 2022a; Witwer et al., 2022b; Fynn et al., 2023; Hall, 2023; Mayer et al., 2023; Sauter et al., 2023; Unwin et al., 2023; Fodstad et al., 2024).

As previously identified in the review, when compared to the general population people with intellectual disabilities are at greater risk of developing mental health issues. However, these conditions may go undiagnosed due to a number of reasons including diagnostic overshadowing, diagnostic challenges (particularly diagnosis for people with moderate to profound intellectual disabilities), and the inability of the person to self-report their symptoms due to their communication difficulties. Historically, when treating the people with dual diagnosis, the prescribing of medication was the first line of intervention. One of the factors influencing this was the assumption that other than behaviour therapy, non-pharmacological/psychological interventions, such as cognitive behaviour therapy (CBT) were not suitable for people with moderate to profound intellectual disabilities as their cognitive ability would hinder them in engaging with the therapy (Taylor er al., 2008). In recent years, however, there is a growing body of evidence to show that people with intellectual disabilities can, with the right supports and resources, acquire the basic skills required to engage in and benefit from adapted psychological interventions (Witwer et al., 2022b) as recommended by guideline 1.9.2 of the NICE guidance (NICE, 2016).

People with intellectual disabilities may require longer time to learn new skills and behaviours and this needs to be taken into consideration when planning and delivering the service (Byrne et al., 2021); this will also have a cost implication for service providers. People with intellectual disabilities identified that the long waiting times they experienced when accessing psychological services was particularly challenging (Hall, 2023) suggesting a need for shorter waiting times. There is a need for reasonable adjustments (Byrne et al., 2021) and accessible information to be made available for people with intellectual disabilities so that they can engage in therapies and services.

As identified in the previous theme, Telepsychiatry and eHealth interventions can help to overcome some of the barriers related to access (Oudshoorn et al., 2021), however other challenges to access exist, particularly in relation to children and the lack of suitable psychosocial interventions that take cognisance of the child's communication, social and cognitive ability. This may, consequently, exclude them from receiving psychotherapeutic interventions (American Psychiatric Association, 2013; Panditaratne et al., 2022). In relation to people with mild intellectual disabilities, Walton et al.'s (2022) scoping review revealed that, in comparison to the general population, higher levels of mental health disorders are seen in this group, however this is often not taken into consideration in the provision of mainstream mental health services. The National Collaborating Center for Mental Health (2019) emphasised the need to ensure provision of equitable mental health care for all. With regards to people with intellectual disabilities, the need for service providers to provide appropriate care, treatment and access to psychological services with reasonable adjustments has been identified (Walton et al., 2022).

Whilst acknowledging the barriers that may preclude people with intellectual disabilities from accessing suitable services and interventions, Fynn et al.'s (2023) systematic review identified a growing awareness of the need to develop suitable psychosocial interventions for this specific population, and these are discussed below.

Cognitive behavioural therapy is a form of psychotherapy that is recognised as the gold standard first line intervention for many mental health disorders (Panditaratne et al., 2022; Sauter et al., 2023, Fynn et al., 2023), so it is not surprising that the majority of papers reviewed in this theme refer to it and how it can be adapted or modified as an intervention for people with intellectual disabilities. Byrne (2022), in his systematic review, shows CBT to be a feasible intervention option for children and adults with intellectual disabilities. Adapted CBT has been shown to lead to treatment success in this population (Hamers et al. 2018; Roberts and Kwan, 2018; Bourne et al., 2021; Panditaratne et al., 2022; Sauter et al., 2023; Fynn et al., 2023). Adapting psychological interventions for people with intellectual disabilities should be informed by the following: a mental health assessment should be

undertaken; the timing and pace of the intervention should be specifically adapted to the person's needs; there should be caregiver involvement as appropriate; structured support should be provided to develop the new skills between the sessions; and the approach should be adapted to the communication needs of the person throughout treatment (Witwer et al., 2022a). Fynn et al.'s (2023) systematic review also identified adaptions such as the use of visual supports, plain language, and teaching aids such at storytelling and games.

Whilst the use of CBT has seen positive outcomes in the literature, there is some variance in the maintenance of intervention benefits at follow-up, with Hamers et al.'s (2018) systematic review reported that the benefits of the intervention were maintained in 6 of the 7 studies reviewed, whilst Bourne et al.'s (2021) more recent review identified that improvements were maintained in only 3 of the 5 studies they reviewed. People with intellectual disabilities may require longer time to learn the new skills and behaviours, but they may also need a flexible approach, with the timing and duration of the sessions adapted. This needs to be taken into consideration when planning and delivering the service (Byrne et al., 2021; Fynn et al., 2023) but will be associated with increased cost and a requirement for extra resources. There is a need for reasonable adjustments (Byrne et al., 2021) and accessible information to be made available for the person with an intellectual disability so that they can engage in these therapies and services.

Graser et al. (2022) undertook a meta-analysis on the effectiveness of CBT for adults with intellectual disabilities and noted that people with mild intellectual disabilities were the focus of the majority of the papers reviewed, with only one paper addressed the effectiveness of this intervention in respect of people with severe intellectual disabilities. Comparing post treatment cognitive competencies of participants with mild and moderate intellectual disabilities, Robert and Kwan (2018) identified the majority of adults with mild intellectual were able to learn and implement key components of these skills whilst people with moderate intellectual disabilities struggled with most of these skills. This would support Graser et al.'s (2022) recommendation that there needs to be indications developed in respect of CBT interventions for different levels of intellectual disability. Sauter et al. (2023) propose that the American Association on Intellectual and Developmental Disabilities (AAIDD) framework (Schalock et al., 2021) be used to inform decision making when planning and delivering CBT for youths with mild-borderline intellectual disabilities.

In a scoping review on the treatments used in the treatment of anxiety in adolescents and adults with Down syndrome, Fodstad et al. (2024) identified that 4 of the 8 studies reviewed used CBT approaches that were modified to meet the needs of the person. Modifications included assessment of the suitability of the persons for CBT, use of social stories, visuals, use of plain language and involvement of staff and care givers in the treatment of the person. Treatment outcomes resulted in a reduction in

the persons post-treatment anxiety symptoms but due to study design and sample sizes it was not possible to achieve generalisability.

Eye-movement desensitisation and reprocessing (EMDR) has also been proposed as a potentially helpful intervention for the treatment of post-traumatic stress disorder (PTSD) and may have application among people with intellectual disabilities. Compared to other treatments for PTSD it not as reliant on verbal skills and may be more beneficial than interventions that require verbal skills (Unwin et al., 2023). Tentative findings from Byrne (2021) suggest that EMDR is feasible intervention option for both adults and children with mild to severe intellectual disabilities. In a case series with 6 people with borderline and mild intellectual disabilities who received a maximum of 12 weekly EMDR sessions each lasting 90 minutes, Quevedo et al. (2021) reported a decrease in PTSD symptom severity for 5 participants with results maintained at 3-month follow-up.

Hamers et al. (2018), in a systematic review of non-pharmacological interventions, reported on the usefulness of Bright Light Therapy (BLT) as a treatment for people with profound intellectual disabilities and depression. Whilst positive effects on mood were found at the 3-week follow-up, these were, however, not maintained and increased depressive symptoms were seen at the 8-week follow-up. In a subsequent randomised controlled trial, Hamers et al. (2020) demonstrated that whilst BLT can show a decrease in depressive symptoms in adults with intellectual disabilities in a short space of time and is a promising treatment option, it is probably better as an add-on, rather than a standalone therapy.

Mayer et al. (2023) undertook a randomised controlled pilot study on the feasibility and effectiveness of Narrative Exposure Therapy (NET) for people with intellectual disabilities who have PTSD, finding that this approach can be successfully conducted when adaptations are made. Such adaptations include reducing the sessions from 120 minutes to between 50 and 60 minutes, adjusting the flexibility of the session to suit the concentration span of individual, and using plain language to therapeutically guide the person through the therapy process. A limitation of the study is that it did not specify the participants' levels of intellectual disability.

Bourne et al.'s (2022) systematic review found Narrative Therapy to be positive group experience for four people with mild intellectual disabilities, highlighting the benefit and importance of peer support and social connections.

Finally, when evaluating peer mentorship, Schwartz and Hwang (2022) found that young adults with intellectual disabilities and mental illness were able deliver a peer mentoring intervention, once appropriate supports were provided.

It is difficult to report clear findings in respect of psychological and psychosocial interventions, as this review explored research undertaken between 2018 and 2023, a period which included the COVID-19 pandemic. The rapid movement from in-person to online led to the development of solutions that were designed to meet a clinical need for individuals with intellectual disabilities. There are, therefore, a significant number of papers reporting on these, by way of case studies. There is evidence that such interventions provide positive outcomes for persons with mild and moderate intellectual disabilities (NICE, 2016), but it is clear that more work needs to be done in respect of those with more significant intellectual disabilities. Furthermore, there is a need for more cohort studies to be undertaken to provide further evidence of impact. That said, the value of psychological and psychosocial interventions is not questioned here and their role in the inventory of therapies for people with intellectual disabilities and mental illness is acknowledged by the Royal College of Psychiatrists (2020).

The following key issues emerge from the above findings:

- Psychological and psychosocial therapies play an important part in addressing mental health concerns for people with intellectual disabilities.
- There is a need for cohort studies to be conducted as many interventional studies identified, related to small sample sizes.
- More evidence is required on the use of psychosocial interventions with people who have profound intellectual disabilities; most related to people with mild-moderate disability.
- Longitudinal studies should be undertaken to provide clarity on how well the positive effects of psychotherapeutic therapies can be maintained.
- CBT has been demonstrated to produce positive therapeutic outcomes for specific groups of people with intellectual disabilities.

Development of Services

Five papers reviewed were pertinent to the development of services theme (Dew et al., 2018; Vereenooghe et al., 2018; Walsh et al., 2021; Walton et al., 2022; Newman et al., 2023).

In an Australian study, Dew et al. (2018) sought to determine the representation of people with intellectual in mental health policies and recommend strategies to enhance their inclusion. They found 37 documents that mentioned people with intellectual disability. Only two of those documents identified specific strategies to address the mental health needs of this group. Whilst the language used across the policies was consistent with the CRPD rights-based approach, with some recognition of the specific needs of this group, the approaches to care were not inclusive orientated and policies lacked specific detail on how the needs of people with intellectual disabilities could be met in specialist and mainstream mental health services. They recommended that an **i**nclusive human rights

based/framework approach to policy development be instigated. Policy development needs to be underpinned by a sound evidence base, focused on the needs of people with intellectual disability and dual diagnosis. This requires full cross-sector, government engagement with measurable actions and targets to ensure that workforce education and training on the needs of this client group across the lifespan of the individual are made available (Dew et al., 2018).

Acknowledging the higher prevalence of mental health disorders in people with mild intellectual disability, a United Kingdom scoping review (Walton et al., 2022) explored evidence for the organization, structure, and delivery of mental health services for this client group, finding that there is little agreement on how services for this group should be organised and structured. However, findings did suggest that people with mild intellectual disabilities benefited from improved staff training and integrated services. Evidence also pointed to relationship between poorer outcomes and experiences, lack of resources, and being from an ethnic minority group. In order to promote equitable and accessible services for this client group, a consultation-liaison model between general and specialist services is recommended, as is the use of a self-assessment checklist The Green Light Toolkit (National Development Team for Inclusion, 2017) to evaluate current provision of care.

In an attempt to identify the priorities and operation of an Australian adult tertiary intellectual disability mental health service, Walsh et al., (2021) found that people in the 18 to 25-year age group experienced problems transitioning to adult services. The majority of the intellectual disability mental health experts who participated in the study recommended that: 1) the age limit for adult services should be reduced to 15 years; 2) a multidisciplinary team was essential to the development of a tertiary intellectual disability mental health service; 3) there should be agreed clinical roles (for example, for assessment and diagnosis); consultation liaison and second opinions should be available; and 4) high level clinical advice and assistance should underpin the coordination of the services. The above should be underpinned by the principles of human rights, accessibility, inclusion, effective communication, practice adaptations, capacity building and collaboration.

Respondents to Eagleson et al.'s (2022) online survey-based evaluation of a mental health core competency framework on the key attributes required by the mainstream mental health workforce, reported that using the framework gave them the opportunity to explore the beliefs, emotions and attitudes towards people with intellectual disabilities, and in so doing this helped them to understand the human rights and policy obligations**.** The top five positive aspects of the framework related to the provision of comprehensive information, positive mental health interventions and care planning, useability, structure and the provision of a useful resource list.

A systematic review conducted by Vereenooghe et al. (2018), to evaluate the effectiveness of psychological and pharmacological treatments for mental health problems and their key symptoms in both children and adults with severe or profound intellectual disabilities, identified a lack of research on interventions that explicitly target mental health problems in people with such disabilities. Clinicians supporting and treating those with severe and profound intellectual disabilities have to rely on using mainstream mental health interventions which are inappropriate and, in the main, inaccessible for this group. This inequality in service delivery needs to be addressed in practice and policy development to ensure the rights to care for this group are upheld.

Newman et al.'s (2023) qualitative study explored how Easy Read is used in mainstream mental health services. They found that staff at specialised sites used numerous strategies, and tailored approaches to communication. Staff in mainstream services, on the other hand, did not use such approaches, or offer the person the opportunity to access information on their mental health. All people have a right to information and inclusive practices in a format they can engage with, but this right is not aways being upheld for people with intellectual disabilities. The use of and availability of Easy Read materials is seen as a first vital step in providing information to those who have alternative communication needs. Services are required to develop policies that uphold the right of the person to accessing information about their health and this requires that staff practices change so as to incorporate the development and utilisation of assessable formats across all settings.

The following key issues emerge from the above findings:

- The need for capacity building in primary health care, disability services and mental health services to identify, treat and support the person with dual diagnosis.
- The development of a consultation-liaison model between general and specialist mental health services.
- There is a need to improve mental health service access of people with intellectual disabilities and mental illness.
- A competency framework should be developed for the mainstream workforce to support first-line mental health supports.
- There is a lack of research on interventions for people with severe and profound intellectual disabilities.
- There is a need to modify service and staff practices in order to ensure that mental health and other information is available in Easy Read and assessable formats across all health settings.

Objective 1b - Key challenges faced by persons with a dual diagnosis of mental illness and intellectual disabilities in receiving quality care and treatment.

Introduction

The results from the five databases, grey literature, citation searching, and unspecified sources yielded 6,989 records related to current challenges faced by persons with dual diagnosis of mental illness and intellectual disabilities in receiving quality care and treatment. Removal of duplicates, screening for title and abstract resulted in 6,657 records being excluded, with 332 remaining for full-text review. Of these, 288 were excluded, leaving 44 records for inclusion in the review (Table 7). The main reasons for exclusion related to the type of publication, wrong context or focus, wrong population, and wrong geographical area (Figure 3).

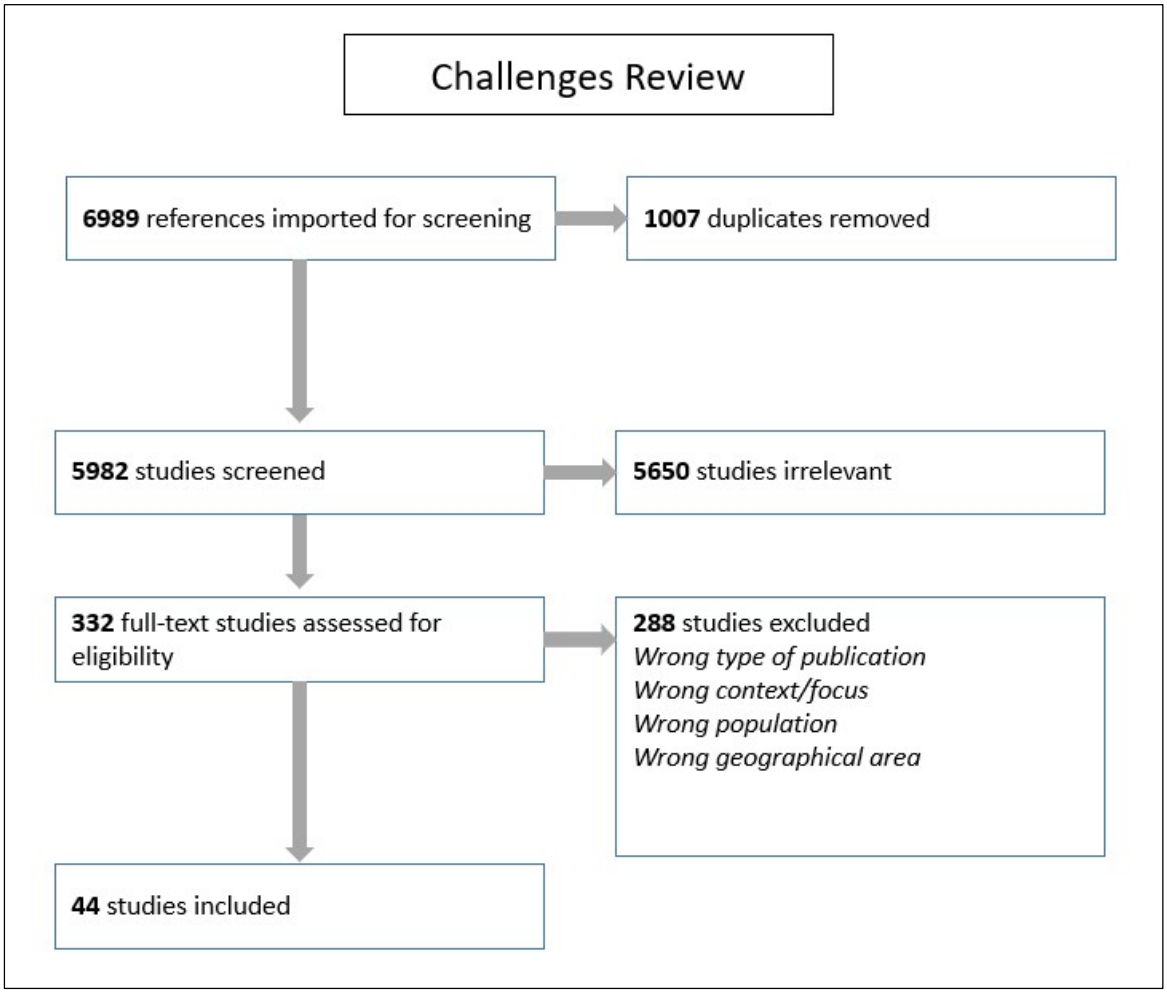

Figure 3 PRISMA diagram for the challenges review

What was gleaned from these records is presented under three main themes that emerged during analysis. These are: organisational challenges; access; and integrated working, education and training.

Table 7 Evidence on challenges faced by persons with a dual diagnosis of mental illness and intellectual disability in receiving quality care and treatment (for Quality Score/Risk of Bias, 'Good' implies good quality/low risk of bias; 'Poor' implies poor quality/high risk of bias.').

Author (year) Country	Participant/ population	Aim	Tool / approach	Findings
Adams and Jahoda (2019), UK. *Good.*	7 mothers of individuals with severe or profound intellectual disabilities and emotional difficulties.	To explore mothers' experiences of seeking mental health support for their offspring.	Qualitative.	Three themes emerged: a struggle to understand; challenges getting mental health support; a mother's approach to adapting therapy. Mothers faced challenges and discrimination accessing mental health services; felt their concerns were not taken seriously. Professionals perceived to lack the knowledge, skills and expertise especially for people with severe and profound intellectual disabilities. The therapeutic relationship is very important as is the need to involve carers.
Baxter et al. (2023), UK. *Good.*	7 individuals with intellectual disabilities.	To investigate the experiences of individuals with intellectual disabilities who had waited for psychological therapy in the context of a global pandemic.	Qualitative.	The absence of someone to talk to, made the wait more challenging. The uncertainty did not increase difficulties or heighten anxiety about future psychology appointments. Most were understanding about why they were waiting and did not notice a deterioration in their mental health. Services should contact those waiting longer than a specified wait time. Services should offer reassurance, validate difficult feelings, remind clients about pre-existing coping strategies and provide, albeit limited, self-help materials. Limiting session models can speed up speed of treatment thereby freeing clinicians.
Culnane et al. (2021), Australia. *Poor.*	81 in total: 1 young adult 18 carers 62 internal and external stakeholders (including paediatricians, general practitioners).	To understand the barriers to achieving effective transition and the supports required from the perspective of parents and carers, people with dual disabilities, and those who provide services, and to develop a model of shared care to	Mixed methods.	Carers report general practitioners lack adequate expertise in dual disability. Carers need support to navigate and negotiate services. The Fearless, Tearless Transition intervention introduced standardized clinical assessment tools and developed a process of shared care supported by dedicated transition manager.

		improve the transition of young people with dual disabilities.		Transition outcomes can be improved through early transition planning, consistent methods of assessing patient and carer needs, and shared care. Early engagement of general practitioners and paediatricians in shared care early during the transition process is essential.
Culnane et al. (2023), Australia. *Poor.*	Carers of adolescents with an intellectual disability and/or autism spectrum disorder with coexisting mental health disorders (99 pre-survey; 22 post-survey).	To describe carer perspectives of transition to adult care and the outcomes of a transition support intervention, Fearless, Tearless Transition, for adolescents with dual disabilities piloted at a tertiary children's hospital.	Cross-sectional survey.	Carers identified adolescents' emotional well-bring/mental health as their greatest concern and that there were significant unmet needs. The findings suggest this model has potential to improve transition outcomes for patients with dual disabilities and their carers through centralized transition planning.
Dagnan et al. (2020), UK. *Fair.*	6260 people with learning disabilities, people with other recorded disabilities and people with no recorded disabilities (national databases).	1.To describe how Improving Access to Psychological Therapies (IAPT) services record disabilities, and in particular record whether a person identifies themselves as having a learning disability. 2.To explore the differences in processes and therapy outcomes for people with learning disabilities compared with people with no disabilities and people with other disabilities. 3.To understand adaptations to IAPT processes and therapies that may make IAPT services more accessible to people with learning disabilities.	Cross sectional study.	National data from 2012–2013 to 2019–2020 demonstrates that people with and without disabilities experience broadly similar waiting times. People with intellectual disabilities are less likely to enter treatment and have poorer clinical outcomes although a broadly similar proportion finishing treatment. Improving Access to Psychological Therapies IAPT services can be adapted to make them more accessible to people with learning disabilities.
de Kuijper et al. (2024), The Netherlands. *Good*.	57 adults with intellectual disability attending a Dutch mental health care centre. 21 carers.	To investigate the perspectives of clients and their carers on clients' treatments with psychotropic drugs.	Cross-sectional, survey.	Importance of mental healthcare by a specialist mental healthcare centre with trained personnel to address shortcomings. Participants want more involvement in shared decision making on psychotropic drug treatments than they had received. General satisfaction with verbal information received and with contact with prescribers but improvements needed in provision

				of written information as content of even accessible information on psychotropics may be confusing. Consistent provision of accessible written information, structured medication evaluations and the meaningful involvement of clients would improve decisions about psychotropic medication. Recommends a personal approach with verbal explanations from carer's, doctors or nurses to help people with intellectual disability understand their healthcare interventions. Regular structured medication monitoring and review would provide opportunity to exchange information about treatment as part of an ongoing dialogue.
Delves et al. (2023), Australia. *Fair.*	46 carers who had attended the Intellectual Disability Mental Health Clinic to support clients.	To contrast the characteristics of clinic attendees assessed by telepsychiatry or in-person, assess the feasibility of care delivery by synchronous videoconference (telepsychiatry) or in-person; and assess acceptability to, and experiences of, participating carers (family members, non-government organisation workers or Community Mental Health Case Managers.	Cross-sectional, clinical records audit, quantitative carer survey.	Carers experienced telepsychiatry very positively reporting that it was acceptable, feasible and convenient. May allow for more equitable access to mental health services especially for those from disadvantaged and rural populations. Carers perceived clients engaged well and rapport was developed. May have limited application for assessing people with severe or profound intellectual disabilities or people with severe communication deficits.
Eaton et al. (2021), UK. *Good.*	13 research studies.	1.To identify which of the classic symptoms of depression, as captured in standardised diagnostic criteria (DSM and ICD), show a relationship with depression in individuals with severe and profound intellectual disabilities (behavioural indicators). 2.To identify whether behaviours not captured in standardised diagnostic criteria show a relationship with	Systematic review.	A relationship was found between two of the classic symptoms of depression (depressed affect and anhedonia) and depression in people with severe/profound intellectual disabilities. Other typical symptoms were easily observable and included irritability, sleep disturbance, psychomotor agitation, reduced appetite and fatigue. While challenging behaviours also showed a robust relationship with depression, authors advise against identifying these as "depressive equivalents". As challenging behaviours may

		depression/low mood in this population (behavioural correlates). 3.To assess which behavioural indicators and correlates index the depression profile in severe/profound intellectual disabilities across the greatest number of studies.		indicate the presence of depression or a risk of depression, clinicians could incorporate validated assessments of challenging behaviours into mental health assessments of individuals with severe intellectual disabilities.
Ee at al. (2022a), UK. *Good.*	14 research studies.	To explore how mental health professionals (MHPs) experience their work of providing services to adults with intellectual disabilities and mental health problems, and identify the challenges and facilitating factors that MHPs encounter which affect the care and treatment of adults with intellectual disabilities?	Systematic review.	Three main themes: 1. Understanding the person. 2. Relational interaction. 3. Organisational factors. Diagnostic overshadowing can lead to delay in treatment. Psychotropic medications may be used as first treatment in absence of adequate resources for complex problems. MHP working from medical model may view clients as untreatable if they struggle to make progress. MHP feel unsupported, and many experience negative emotions which can affect therapeutic relationships with their clients. Some MHPs supported development of specialist mental health services for people with intellectual disabilities, others advocated for more resources to make mainstream services mor accessible and responsive. Embedding specialist services within the community or co-locating in primary care services, could increase early detection and improve access to services and treatments.
Ee et al. (2022b), UK. *Good.*	13 research studies.	To investigate the attitudes and social care professionals towards people with learning disabilities and mental health problems.	Systematic review.	Some preferred that specialist mental health services cater for the specific needs of people with learning disabilities and referral pathway needs to be identified to access such services. Specialist mental health services should support mainstream services in community in collaboration with carers. Organisational work culture influences attitudes towards people with learning disabilities and

				mental health problems which may impact quality of service and safety of individuals. Formal and informal learning opportunities should be developed, more staff employed, and more time given. Mainstream clinicians need exposure in specialist settings in order that they may consider working with this client group thus improving recruitment.
Garcia-Dominguez et al. (2022), Spain. *Good.*	People ageing with intellectual disability.	To describe the mental health and behavioural problems presented by aging people with intellectual disability, as well as the type of psychotropic medication they use; and analyse the factors that predict a greater intake of psychiatric drugs in older people with intellectual disability.	Cross sectional survey.	More than half the sample exhibited mental health conditions in previous year; almost 40% of whole sample some type of psychotropic medication. Many of the individuals taking medication had no mental or behavioural problems. Being older, having mild intellectual disability, living in a residential setting, having mental health conditions, and exhibiting behavioural problems increased the likelihood of being prescribed 2 or more psychotropic drugs. Psychotropic medication may be being used because public health professionals are inadequately trained and lack understanding of chemical restraint, its side effects, and alternatives. Certain behavioural problems, resulting from stressors, may be being interpreted as psychiatric disorders.
Gregson et al. (2022), UK. *Good.*	12 qualified psychologists.	To understand the experiences of psychologists delivering psychological services to people with learning disabilities during the COVID pandemic, and the impact of COVID on the wellbeing of people with learning disabilities from the perspective of psychologists.	Qualitative.	Clinicians reported issues around remote working including technological issues and the limitations of virtual or telephone consultations. Barriers also emerged in the effective use of therapeutic tools particularly around non-verbal communication including drawing together on paper, using picture cards, using subtle nuances to interpret feelings, modelling, and use of physical movement. Virtual therapies may disempower and disadvantage people with learning disabilities, however there is potential for more flexibility and

				choice in the way services can be delivered in the future.
Hinde and Mason. (2020), Australia. *Good.*	93 Primary health practitioners (psychologists; mental health practitioners, and alternative therapists).	To investigate and report current Australian health practitioner knowledge and confidence levels; and to pilot the use of the Mini Psychiatric Assessment Schedules for Adults with Developmental Disabilities (MPAS-ADD) to examine Australian practitioner symptom knowledge of common mental health disorders in persons with an intellectual disability.	Cross sectional survey.	Australian health professionals demonstrated confidence, but low knowledge, in the diagnosis and treatment of mental health disorders in people with intellectual disabilities. A positive significant correlation was found between knowledge of depression and knowledge of three other common mental health disorders, psychosis, anxiety and hypomania. Training programmes are required to address specific deficits in knowledge of mental health symptoms, assessment, and assessment-based communication is recommended to improve outcomes for this population.
Hronis et al. (2018), Australia. *Fair.*	152 psychologists and counsellors.	To identify how confident Australian clinicians are when working therapeutically with people with intellectual disabilities; and identify factors that may be associated with increased confidence.	Cross-sectional survey.	Clinicians were more confident about being empathic, listening to concerns and working with caregivers, but were least confident about using assessments, explaining assessment results, identifying therapeutic approaches, and using knowledge of the most effective mental health interventions to use. Training, professional development and prior experience result in significant increase in confidence. Clinicians using more than one type of therapy were more confident indicating that greater confidence may be associated with greater flexibility and more tailored treatment.
Kaushal et al. (2020), UK. *Fair.*	107 psychiatrists from two mental health trusts working in general adult, forensic, and older adult services.	To gather information about the levels of knowledge and skills amongst mainstream psychiatrists in managing patients with intellectual disabilities and comorbid mental health disorders, to assess their perception of the quality and accessibility of psychiatric services for people with intellectual disabilities and	Cross-sectional survey.	Risk of clients falling through gap due to lack of collaborative working and shared care protocols between mainstream and specialist services. Staff becoming overwhelmed due to limited resources. Lack of intellectual disabilities specific resources. Communication is impeded by organisation issues and boundaries.

		to establish the local implementation of the Green Light Toolkit.		Additional training and sharing of skills and knowledge across intellectual disabilities and mainstream services is needed, and this requires strong and explicit leadership.
Lewis et al. (2020), Australia. *Good.*	6,260 adults with intellectual disability.	To establish whether receipt of disability support services was associated with mental health service usage (specifically psychiatric admissions and community mental health service) in people with intellectual disability and a co-existing mental illness.	Data linkage from four databases.	Persons in receipt of disability support services had a higher rate of utilising community mental health services but not of psychiatric admission. Usage was not associated with social disadvantage, sex or age; there was a greater use of community mental health services and fewer psychiatric admissions in rural areas compared to inner city areas. Receipt of disability services was associated with greater community mental health, but not psychiatric hospital utilization in people with intellectual disability and co-existing mental illness.
Lines et al. (2020), UK. *Good.*	50 psychiatry trainees.	To explore whether psychiatry trainees in the Maudsley Training Programme (MTP) feel adequately skilled to support individuals with intellectual disabilities.	Cross-sectional, survey.	Experience of working in specialist intellectual disability teams is positively associated with greater confidence and skills among trainees in the care of people with intellectual disabilities; this is beyond what would be expected based on seniority alone. UK policy asserts the right of people with intellectual disability to access mainstream psychiatric care, where possible. The care given could be improved if psychiatry trainees were given practical experience in the care of people with intellectual disabilities and in specialist intellectual disability services.
Lineberry et al. (2023), United States. *Good.*	532 people with intellectual and developmental disabilities who used state-funded disability services in Virginia	To explore and describe different patterns of mental health diagnosis and reported behavioural support needs based on demographic and disability characteristics, service usage, and assessed support needs.	Cross sectional study of two datasets	People with severe and profound intellectual and developmental disabilities are more likely to only have identified behavioural support needs in the absence of any mental health diagnosis. Conversely, people with mild or moderate intellectual and developmental disabilities showed

				a tendency toward having mental health diagnoses, either with or without behavioural support needs. Case managers, community mental health professionals and service planners may tend to identify and plan around mental health supports around behavioural needs for people with severe or profound intellectual and developmental disabilities. This may be a result of clinician bias.
Marrus et al. (2023), United States. *Good.*	78 child and adolescent psychiatry and general psychiatry program directors.	To evaluate the state of psychiatry residency training in autism spectrum disorder/intellectual disability as of 2019.	Cross-sectional survey.	Psychiatry training in autism spectrum disorder/intellectual disability is insufficient possibly associated with diminished future interest in serving these patients, perpetuating significant barriers to mental health care for them. Educational resources are required to strengthen training and engage the next generation of psychiatrists to serve this growing, underserved population. Minimal apparent improvements in autism spectrum disorder/intellectual disability training over the past decade. An urgent need exists to advance psychiatry training in this field through dissemination of resources.
Mattock et al. (2020), UK. *Fair.*	5 adult service users with intellectual disabilities and co-occurring mental health problems.	To add to the knowledge base in this under-researched area, creating a space for individuals with intellectual disabilities to share their experiences within a mental health setting of what they found helpful, and to feedback to service providers and service users to improve the quality of service for them, as well as maintaining communication and keeping them involved in the service.	Qualitative.	Service users can be involved in their own care and valued being listened to and having control. Both peer support and supportive staff qualities were helpful in this regard. Conversely, they experience uncertainty and distress when they didn't know what was happening especially around medication, living situations and loss. Although service users could identify many of their mental health symptoms and were aware of the link between mental and physical health there was less awareness about the behaviours that would impact their well-being, positively or negatively.

Mills et al. (2023), UK. *Good.*	1,392 individuals aged 18 years and over who accessed specialist community intellectual disability services from January to December 2019.	To understand the characteristics of adults with intellectual disability accessing specialist community intellectual disability services and to examine whether there were differences in the provision of non-pharmacological interventions based on the level of intellectual disability and on the presence or absence of autism.	Cross sectional study, primary and secondary data analysis.	In the absence of appropriate access to psychological interventions (as per NICE guidelines), adults with intellectual disabilities are manged with psychotropic medications, are on them for longer and at higher doses. Limited evidence exists for the effectiveness of psychological interventions based on the NICE guidelines in adults with intellectual disability with most of the evidence relating to those with mild disability. The adaptations made for those may not meet the needs of those with autism and intellectual disability.
Newman et al. (2023), Australia. *Good.*	49 participants across 4 sites: easy read users, health practitioners and staff from services providing mental health care.	The research explored how easy read is used and the ways accessible information can address access barriers, with a focus on Australian mental health services.	Qualitative research.	People using mainstream mental health services were not offered easy read of accessible mental health information. Staff at specialised sites had numerous strategies they used to make information easier to understand, including easy read, and people with intellectual disability valued flexible, tailored approaches to communication. Respectful relationships between people with intellectual disability, service providers and family / carers significantly supported interaction with health information. Access to information is a right not a favour but significant change is required to create an inclusive culture of supportive relationships to implement a diverse array of communication options.
O' Dwyer et al. (2018), Ireland. *Good.*	677 participants in Wave 2 of the IDS-TILDA study with available medicines data.	To examine the prevalence and patterns of antipsychotic use and their associations with problem behaviours and reported mental health conditions in a representative population of older adults with intellectual disability in Ireland.	Cross sectional survey (from longitudinal study).	Four in ten older adults with intellectual disability were taking antipsychotics; of which only one quarter had a reported psychotic condition. Most frequently reported combination was a diagnosis of another (non-psychotic) mental health condition, with anxiety being most common and one or more problem behaviours. Problem behaviours were independently associated with

				antipsychotic use, indicating that they may be being used for behaviour management. Regular review of appropriateness, usefulness and impact of antipsychotics required especially where no psychotic indication exists. National audit programme required on treatments for behaviours. National campaign on issue potentially inappropriate use of antipsychotics for problem behaviours recommended.
Ramerman et al. (2018), Netherlands. *Good.*	11 psychiatrists, intellectual disability physicians and behavioural scientists.	To explore the barriers and facilitators that clinicians experience in implementing and using guideline recommendations on antipsychotic drugs prescription in mental health care for people with an intellectual disability.	Qualitative.	Although intellectual disability physicians were aware antipsychotic prescribing guidelines, they had their own views and preferences. Identified barriers included lack of collaboration across disciplines, inappropriate monitoring of side effects and treatment effects. Physicians suggested developing clearer diagnostic tools to differentiate between psychotic symptoms and challenging behaviours. Physicians and behavioural scientists should be involved in the translating of recommendations into organisation guideline recommendations to enhance ownership. Enhanced awareness and involvement of care staff may improve guideline implementation.
Rauf et al. (2021), UK. *Good.*	7 people with intellectual disability and/or autism spectrum disorder, within a community intellectual disability service.	This study aimed to estimate if COVID restrictions were associated with a change in number of total consultations carried out by psychiatrists and prescription of psychotropic medication in people with intellectual disability and/or autism spectrum disorder, within a community intellectual disability service.	Quantitative.	COVID-related lockdowns resulted in an increase in medication interventions, total consultations, and involvement of multidisciplinary teams to manage mental health and behavioural issues in people with intellectual disability and/or autism spectrum disorder. Regular multidisciplinary team reviews should be conducted to support reduction or withdrawal of any medications commenced/increased during the COVID period without clear agreed diagnostic justification. Improved monitoring of side-effects of psychotropics required.

				Development of appropriate behaviour support plan could reduce reliance on medication. Development of effective remote video consultations for routine appointments; availability of adequate PPE for in-person contact. Adequate community support including from psychiatrists may prevent placement breakdowns and hospitalisation.
Ross and Dodds. (2023), UK. *Fair.*	7 adolescents with an intellectual disability and caregivers of a young person with an intellectual disability.	To identify risk factors for admission to inpatient intellectual disability services for children in the North-East of England.	Qualitative.	Key identified themes: 1. Behaviours which challenge. 2. Comorbid difficulties. 3. Isolation. 4. Insufficient crisis planning. 5. Care coordination. 6. Familial stressors. 7. Availability of community service provision and school placements. The risk of inpatient intellectual disability hospital admission may be impacted by a range of pathological, interpersonal, social and educational factors.
Rodhouse et al. (2022), UK. *Fair.*	National dataset.	People with learning disabilities within IAPT have poorer key clinical outcomes than people who do not identify as having a learning disability. During the global COVID pandemic remote consultations have accounted for nearly 90% of all contacts in IAPT services; this paper aims to report the effects of these on outcomes for people with learning disabilities.	Cross-sectional.	Clinical recovery in people with learning disabilities is very much lower than general population despite that they differ little on several key process and outcome variables. Following the shift to remote therapy delivery, outcomes for people with learning difficulties were not differently affected. IAPT practitioners now have extensive experience and knowledge about adapting remote therapy techniques for people with learning difficulties and about how much collaboration was possible with local leaning disability services.
Seidel and McLennan. (2023), Canada. *Good.*	149 caregivers of new referrals to a clinic.	To identify caregiver concerns, clinical characteristics, and the relationship between these two constructs for	Mixed methods.	Two overarching categories of caregiver concerns: 1. Aspects of clinic service, especially medication questions.

		referrals to a clinic specializing in psychiatric care for persons with intellectual disabilities.		2. Specific emotional, behavioural, and diagnostic concerns, especially regarding emotional states. Caregivers of persons with autism had higher odds of medication concerns, but few other significant relationships were found. Early access to information about the mental health services may benefit caregivers. Caregivers should be offered additional information about psychotropic medications. Mental health services could potentially expand services to address the social interaction needs of this population.
Siddel,P. (2022), UK. *Fair.*	7 clinical psychologists working within community-based services for adults with intellectual disability.	To understand and explore the views of clinical psychologists working therapeutically with people with both autism spectrum disorder and intellectual disabilities, particularly in regard to the accessibility and effectiveness of psychological interventions for this client group.	Qualitative.	1. Accessibility: barriers include the difficulty clients may have in articulating their distress; difficulties in diagnosis the physical environment; the best service. 2. Effectiveness: participants felt that therapy can be beneficial but maybe only with appropriate adaptations and adjusted expectations (therapists and service expectations). 3. Multidisciplinary team is key. Therapist challenges and opportunities: professional challenges; service level inflexibility; clinician innovation and use of intuition; future directions; importance of clinicians sharing experience. 4. Services need to become more flexible and focussed on the needs of this group of service users.
Sommerstad et al. (2021), Norway. *Good.*	10 inpatients with co-occurring intellectual disabilities and mental illness.	To enhance the understanding of ward atmosphere for inpatients with co-occurring intellectual disabilities and mental illness by exploring patients' experiences from a specialised mental health inpatient unit.	Qualitative.	Relationships with ward staff is central to patients' experience. Also important was feeling safe, contained, and validated. Patients have little influence on treatment choices and did not report participating in shared decision-making. Results suggest that admission to a specialist ward may be feasible for individuals with intellectual disabilities and co-occurring mental illness when

				necessary, and that individuals' experience of their relationships with ward staff is a central aspect of their experience of such admissions in general.
Son et al. (2019), Australia. *Good.*	126 service providers caring for youth aged 14 to 24 years with a dual diagnosis.	To identify gaps and challenges in care delivery, identify bridges for young people with intellectual disabilities and mental health problems and identify what works well in existing services.	Qualitative.	Youth with dual diagnosis living in regional areas require integrated models of care and services that are timely, easy to access and have the expertise to meet their needs. Six themes identified: access to information and services; communication between service providers and with clients and carers; the mental health and intellectual disability divide where intellectual disability interfaces with mental health; capacity building of service providers; early intervention and health promotion; capacity building of clients and carers. Suggests approaches to break down silos and to facilitate including increasing specialised dual diagnosis services and building the capacity of current disability and mental health service providers.
Statham and Beail. (2018). UK. *Fair.*	10 People with intellectual disability who were attending, or who had attended, psychodynamic psychotherapy (PP).	To understand out how individuals with intellectual disabilities experience attending a service to receive PP, and what their perceptions are of how accessible the service was, how acceptable therapy was, and how effectively it could reduce their distress.	Qualitative.	Most participants identified problems that had been improved through therapy and were unhappy that it had ended though struggled to share what they had learned. Most understood how they had accessed the therapy, though some found the travel to the sessions to be difficult. Clinicians should ensure that service users understand the nature of PP before starting sessions and identify clear goals. Support traveling to sessions may improve attendance. The importance of planning the ending of therapy was highlighted.
Verma et al. (2022), United States. *Poor.*	5 autism spectrum disorder/developmental disability clinics.	To assess the rates of telepsychiatry appointment attendance pre- and post-lockdown.	Cross-sectional survey.	1. Barriers: secure telehealth platforms; technical expertise, access to video-enabled devices; internet stability (particularly for disadvantaged communities). Difficulty for non-English speakers

				and integrating live interpreter service. Distractions within home. 2. Clinician difficulties: vital signs and physical examinations not possible; management of acute behavioural dysregulation or suicidality were especially challenging; merging of clinical space with home space could lead to boundary breaches. 3. Positives: more frequent appointments, flexibility of scheduling; time and travel costs; familiar setting; clinician insight into home environment; more sustained interactions; capacity for multidisciplinary involvement. A hybrid in-person/tele-psychiatry model, in which the patient primarily accesses care by tele-psychiatry, interspersed by in-person appointments when clinically indicated, or at least annually, can be a cost-effective, safe, and efficient treatment delivery model.
Watfern et al. (2018), Australia. *Good.*	36 participants: 13 people with lived experience of intellectual disability; 9 support workers; 5 allied health professionals; 9 advisory group members.	To examine the feasibility and acceptability of Healthy Mind, an e-mental health program for adults with an intellectual disability, focusing on the design and implementation of the website.	Qualitative.	Findings across 3 domains: 1. User experience. 2. Design dilemmas. 3. Reconceptualising 'self-help'. Website feasibility is dependent on capacity to support the individual needs of each user and ability to meet differing requirements of information presentation and access.
Weise et al. (2018), Australia. *Good.*	28 family members and paid and non-paid supporters of people with an intellectual disability and co-occurring mental ill health.	To determine what family members and paid and non-paid supporters of people with an intellectual disability and co-occurring mental ill health thought makes an effective generalist mental health professional for people with an intellectual disability and co-occurring mental ill health.	Qualitative.	4 domains identified: 1. Approaches to clinical practice. 2. Working with people with an intellectual disability. 3. Clinical competence. 4. Quality improvement and professional development. Generalist mental health professionals should have attributes across all areas of clinical work and

				require a broad skill set. Many of the identified attributes complement those identified by intellectual disability mental health experts but also identified novel attributes including the importance of mental health professionals being able to infer meaning, acknowledging professional limitations, and maintain professional boundaries and self-care.
Weise and Trollor. (2018), Australia. *Good.*	566 mental health professionals.	To determine mental health professionals' attitudes, confidence, and training needs in the area of intellectual disability mental health; and to gain an understanding of what would need to be included in an intellectual disability mental health workforce development strategy to adequately equip them to work in public mental health services.	Cross-sectional survey.	Mental health professionals agreed that treating people with intellectual disability was part of their role and that people with intellectual disabilities should have the same access to their service as others and have a right to good quality care. However, lack adequate resources, appropriate training and report low confidence in key clinical areas. A comprehensive workforce development strategy is required to facilitate the engagement and capacity of public mental health professionals to treat people with intellectual disabilities.
Weise et al. (2020), Australia. *Fair.*	42 family members and support persons of people with intellectual disabilities.	To determine and reach consensus on the key priorities and resource requirements of a state-wide tertiary intellectual disability mental health service in New South Wales (NSW), Australia for adults with an intellectual disability and co-occurring mental ill health.	Cross-sectional, survey.	Most participants (family and support persons) supported the provision of a tertiary intellectual disability mental health service. Such a service would be located within the public health system and would be delivered by psychiatrists and psychologists, provide face-to-face clinical contact and advice. Key service areas included behaviours of concern, self-harm, assessments, and interventions. The findings indicate support for a tertiary intellectual disability mental health service.
Weise et al. (2019), Australia. *Good.*	33 participants from key workforce stakeholder groups including: psychiatry, psychology, occupational therapy, social work and	To gain an insight into the current capability of the mental health workforce across Australia and to determine what workforce development strategies are required to meet the recommendations	Qualitative.	Results indicate that workforce capability would be enhanced by: 1. The development and implementation of intellectual disability mental health career pathways and best practice guidelines.

	nursing, policy makers, and relevant advocacy groups.	of the National Roundtable and to uphold the rights of people with an intellectual disability to quality mental health care.		2. The articulation of intellectual disability-related clinical and communication skills. 3. Research into the fears of mental health professionals that they are not providing people with intellectual disabilities appropriate care. 4. The current capability of the mental health workforce may be a barrier to people with intellectual disabilities achieving their right to the highest attainable standard of mental health and wellbeing.
Weise et al. (2021), Australia. *Good.*	14 participants: 12 mental health, health and disability professionals; 2 intellectual disability health advocates.	To explore the delivery of mental health services over the last 50 years to people with intellectual disabilities in New South Wales (NSW), Australia, and identify the key lessons from the delivery of mental health services for people with intellectual disabilities and co-occurring mental ill-health over the last 50 years	Qualitative.	Key lessons from the historical perspective indicate a need for: specialized intellectual disability mental health services; clear policy and governance; including people with intellectual disabilities in the design and delivery of services; holistic and collaborative services; an appropriately equipped workforce; quality assessment and treatment; and ongoing research.
Whittle et al. (2018), Australia. *Good.*	12 research studies.	To scope recent empirical evidence related to the barriers and enablers for accessing mental health services for people with an intellectual disability.	Scoping review.	1. Barriers: lack of skilled workforce, diagnostic overshadowing, and lack of service integration. 2. Facilitators to better access, treatment and outcomes were collaborative working and multidisciplinary approaches.
Whittle et al. (2019), Australia. *Good.*	41 participants: 7 people with intellectual disability; 11 carers and support people; 13 disability service providers; 7 mental health service providers; 3 other service providers.	To explore people with intellectual disabilities', carers' and service providers' lived experiences of barriers and enablers in relation to accessing mental health services.	Qualitative.	Barriers and enablers were identified at both systemic and personal level and across the key dimensions of service availability, barriers to access (e.g., financial barriers), personal barriers (e.g., mental health disorder, violence and challenging behaviour), organisational barriers (e.g., having dual diagnosis) and advocacy. Most central themes were collaboration and relationship building. The one-size-fits-all approach does not work reinforcing the need for specialist services or specialist streams within mainstream services.

Wigham et al. (2024), UK. *Fair.*	34 research studies.	To identify factors that may contribute to the lack of identification of mental health conditions among adults with learning disabilities in primary care.	Scoping review.	Six broad themes identified: 1. Mental health screening in primary care. 2. Education, training and awareness raising for primary care staff. 3. Increasing access to psychological therapies (IAPT) through improved mental health condition case recognition in primary care and IAPT practitioner confidence. 4. Health checks and continuity of care. 5. Specialist support for primary care providers. 6. Awareness raising among adults with learning disabilities. Increased availability of appropriate mental health screening measure in primary care is required. As are training opportunities across health and social care professions the mental health needs of people with a learning disability.
Wise et al. (2022), United States. *Good.*	1652 clients of the START programme.	To assess age-related differences in the mental health presentations of adults with intellectual and developmental disabilities.	Cross-sectional, database analysis.	Older adults were more likely to be taking psychiatric medications than younger adults despite having fewer psychiatric conditions. This may be because of a reluctance to remove medications even when their efficacy has not been established. Older people with intellectual disabilities are a vulnerable group exposed to polypharmacy and are at risk of adverse events; more attention should be paid to their healthcare needs.
Witwer et al. (2024), United States. *Good.*	28 participants: 15 mental health clinicians who provide direct care to adults with intellectual disability; 13 adults with intellectual disability.	To identify opportunities, successes, and challenges through the perspective of adults with intellectual disability who have received mental health treatment and clinicians providing psychotherapy.	Qualitative.	1. People with intellectual disability cited structural barriers (access to therapy), involvement of support people, difficulties with group therapy contexts, and therapists not understanding their disability. They also referred to lack of flexibility in treatment approach and lack of an individualised approach. 2. Clinicians cited structural barriers including access, insurance and funding, and the

				involvement of support people. They considered there to be too few therapists trained to deliver mental health services to the intellectual disability population and identified a complicated separation between intellectual disability and mental health service delivery systems. Lack of confidence and willingness to treat this population are significant barriers to detection and effective treatment of mental health. Reasons for this include a lack of trained professionals and therapists' doubts about the efficacy of psychotherapy for adults with intellectual disability.

Organisational Challenges

The historical approach to supporting the mental health of persons with intellectual disabilities in Ireland has been discussed earlier in this report. It is worth reiterating that such support was an integral part of the disability service's multidisciplinary team, thus allowing for timely assessment and intervention. This was a mental health service led by a psychiatrist specialised in intellectual disabilities supported by other professionals who had significant knowledge and experience in intellectual disability service provision. This approach was usually underpinned by a holistic philosophy and maintained its health care role due to the challenges of accessing generalist health services. Whereas there were advantages to having a mental health service 'on-site', it often existed as a distinct entity to mainstream mental health services, leading to what Weise et al. (2021:78) described as the 'idiosyncratic delivery of intellectual disability mental health services', with significant variability in provision, approach and quality across disability services.

27 of the articles made reference to organisational issues that had the potential to impact negatively on accessing mental health services (Ramermann et al., 2018; Weise and Troller, 2018; Whittle et al., 2018; Son et al., 2019; Watfern et al., 2019; Whittle et al, 2019; Kaushal et al., 2020; Lewis et al., 2020; Mattock et al., 2020; Weise et al., 2020; Culnane et al., 2021; Sommerstad et al., 2021; Weise et al, 2021; Ee et al., 2022a, 2022b; Rodhouse et al., 2022; Siddell, 2022; Verma et al., 2022; Baxter et al., 2023; Culnane et al., 2023; Delves et al., 2023; Marrus et al., 2023; Newman et al., 2023; Ross and Dodds, 2023; Seidel and McLenna, 2023; Wigham et al., 2024; Witwer et al., 2024). These spanned three principle sub-themes, namely organisational structure and approach, access, and integrated working.

Many of the challenges which impact on the access to and quality of service provided to people with intellectual disabilities are related to organisational issues, both at national and service levels, These pertain to governance and policy and, ultimately leadership, and play out in the creation of barriers which exclude some people and (Whittle et al., 2018) or the provision of services that are not tailored to individuals' needs (Whittle et al., 2018; Witwer et al. 2024). Whittle et al. (2018), in their qualitative study which engaged with carers and service providers identified that there was often a failure to design services around, and in consultation with the key stakeholders: people with intellectual disabilities and carers. This, they suggested, led to the likelihood that the services would not meet the needs of the individual and was just another form of mainstreaming, something which was also found by Whittle et al. (2019) in their separate scoping review of research related to access. This is further supported by Weise et al.'s (2021) interpretative descriptive study, in which 14 mental health professionals and advocates from health and disability backgrounds took part in semi-structured interviews. A key finding was that mental health services will fail to achieve their potential for service

users if clear policy and governance structures are not in place. Indeed, when this is absent at regional or state levels, it inevitably leads to inconsistency in availability and delivery of services (Whittle et al., 2018). This was noted to extend even to the criteria governing who can or cannot access a given mental health service, with evidence pointing to the possibility that people with moderate-profound intellectual disabilities and mental health issues may be excluded (Whittle et al., 2018). Unfortunately, the only recourse for those who cannot access service due to unavailability of exclusion is the general mental health service or the disability services; the presence of intellectual disability may be another exclusionary factor for the former whilst the mental illness may be likewise for the latter. This 'silo-ing' of services (Whittle, 2018:81) leaves the real risk that many people with dual diagnosis could fall through a gap in service (Whittle et al., 2018; Kaushal et al., 2020; Mills et al., 2023; Witwer et al., 2024).

Whittle et al. (2018, 2019) and Kaushal et al. (2020) call for strong leadership to be demonstrated through the development of mental health service models that are tiered with a stepped approach to care, with entry points that are determined by the intensity of issues presenting or of intervention required (Whittle et al., 2018, 2019; Culnane et al, 2021, 2023; Rodhouse et al., 2022). This is likely to include Improving Access to Psychological Therapies (IAPT) (Dagnan et al., 2020), an approach advocated by NICE (2016) and the Royal College of Psychiatrists (2020), though it should be noted that the latter report referred only to those with mild-moderate intellectual disability in this regard. A stepped approach may also have the potential to address another challenge in respect of accessing service, specifically the logjam that may result from having only one point of contact/treatment. Verma et al. (2022), in their US-based national survey of appointments during COVID-19, identified the need for lengthy waiting times to be addressed, advocating for an alternative model which incorporated Telepsychiatry as part of a stepped approach to care. They found that such an approach could relieve the pressure on specialist services, thus improving access (Verma et al., 2022). This was also proposed by Delves et al. (2023) in their survey of carers in Australia. They proposed that it could also make mental health services accessible in a timely manner for those who lived in rural areas. Weise et al. (2021) suggested there to be a number of core characteristics that should underpin any specialist intellectual disability mental health service model, namely that: they have a footprint in mainstream mental health services; are available across the country; and are co-created alongside people with dual diagnosis. Ee (2022a, 2022b) supports this concept, particularly in respect of developing community mental health supports. The importance of such supports is highlighted by Ross and Dodds (2023) who note their role in reducing the risk of unwarranted inpatient admissions. The role of the general practitioner as a key entry point for support in any stepped approach is

important (Whittle et al., 2018; Culnane et al., 2023) and, indeed, was considered to be essential in the roll-out of Culnane et al.'s (2021) 'Fearless, Tearless Transition' model.

In any stepped approach, there is a need for clear communication lines between the various professionals, service providers and agencies., as the absence of this can lead to fragmentation in service provision (Weise et al., 2020). This includes the development of protocols, guidelines and training to support the identification of mental health concerns in people with intellectual disabilities particularly in non-specialist services (Ramerman, 2018; Kaushal et al., 2020; Eaton, 2021; Wigham, 2024) Lewis et al. (2020) also identified the need for clear lines of communication between mental health and disability services. In their multiple database analysis of mental health service usage in Australia, they found that use of community mental health services was higher among those in receipt of disability services (Lewis et al, 2020). Whereas they were unable to apportion causality in this regard, they did suggest that inter-agency collaboration was important, something also identified by other authors (Rodhouse et al., 2022), particularly in respect of transitions between child and adult mental health services (Son et al., 2019; Culnane et al., 2021, 2023; Siddel, 2022).

It has been previously noted that people with a dual diagnosis of mental illness and intellectual disabilities risk falling 'through the cracks' (Whittle, 2018:94), thereby being excluded from specialist mental health services (Kaushal, 2020) and having to access mainstream mental health services which are unable to meet their needs (Weise et al., 2020). Moreover, mothers of people with intellectual disabilities, seeking mental health support for their children, have stated that they faced discrimination (Adams and Jahoda, 2019). This is a human rights issue as it potentially precludes the receipt of quality mental health services, a fundamental right under the CRPD (2006) and Irish law (Government of Ireland, 2005, 2006, 2007). It is crucial that the development and running of specialist mental health services include the perspectives of those who will be using those services, and their carers/families (Ea et al., 2022b; Seidel and McLennan, 2023). Such an approach should involve co-creation, an approach that is person-centred and empowering. People with intellectual disabilities and their advocates, where necessary, should also be involved in decisions related to their mental health care (Sommerstad et al., 2021; de Kuijper et al., 2024), something that has been advocated for in many of the legislative, rights and policy documents to be discussed anon. This can also help to inform services that are inclusively designed (Watfern et al., 2018; Newman et al., 2023) and holistic in nature (Weise et al., 2021), while ensuring that they are flexible enough to meet individual person's needs (Whittle, 2018; Weise et al., 2021), including an acknowledgement that pre-defined time slots are often unhelpful and extra time is often needed (Lines et al., 2020; Ee et al., 2022a, 2022b; Siddell, 2022).

The following key issues emerge from the above findings:

- There is a need for clear governance and leadership in mental health services for people with intellectual disabilities and mental illness.
- A tiered or stepped approach to mental health service provision, enlisting primary care, mainstream mental health, disability services and specialised intellectual disability mental health services is proposed as the best practice approach.
- A tiered or stepped approach should incorporate access to a range of therapeutic interventions that are tailored to the needs of the person with intellectual disabilities and mental illness.
- In order to attain a quality mental health service model for those with dual diagnosis, there needs to be collaboration and shared guidelines to support a seamless service.
- It is crucial that any mental health service have, as core values, person-centeredness and engagement with all stakeholders.
- Cognisant of the historical reality that the voices of people with intellectual disabilities have often not been heard/listened to, and of the challenges of redressing this, mental health services must ensure that reasonable accommodations are provided, and that appropriate means are made available to support communication.

Access

Access to mental health services featured as a theme in 10 reviewed sources (Stratham et al., 2018; Whittle et al., 2018; Son et al., 2019; Mattock et al., 2020; Gregson et al., 2022; Verma et al., 2022; Baxter et al., 2023; Delves et al., 2023; Witwer et al., 2024). Whittle et al, (2018) conducted a comprehensive scoping review on barriers and enablers to accessing mental health services for people with intellectual disabilities were based on data gathered from 32 published items. Their findings set the baseline and covered many recurrent themes which were further developed in more recent research. Access to mental health services was often difficult as these specialist services were scarce, this being exacerbated by added geographical or logistical issues. Many organisational barriers were identified such as competing, conflicting and siloing of services, difficulties with referral pathways, inconsistent eligibility criteria and transition planning. Diagnostic overshadowing and difficulties in diagnosing mental health disorders in this population were noted. Access was also frustrated by increasing levels of intellectual disabilities and psychosocial determinants. Rectifying these challenges was advised through innovative models of care, clear referral pathways to a single point of access and clear eligibility criteria and inter-agency working, education of service providers and the building of capacity in services.

The lived experience of people with intellectual disabilities, their carers and service providers in accessing/providing mental health services was discussed by Whittle et al. (2019). In addition to the

challenges presented in their scoping review (2018), costs, both upfront and hidden such as loss of earnings, were considered a significant challenge. This work demonstrated the complex and multidimensional nature of access to mental health care for such a marginalised population. Collaboration between services themselves and those attending them was seen as vital to ensuring the best outcomes for the individual requiring care. Education was noted to be crucial for health care professionals to avoiding diagnostic overshadowing, in particular, differentiating 'challenging behaviour' from mental health symptomatology. Advocacy was recommended as an important enabler to support the person with intellectual disabilities and to coordinate access across services.

The issue of advocacy and self-determination also featured in work by Witwer et al. (2024). Focus groups with adults with intellectual disabilities and mental health clinicians were conducted, these aiming to identify the successes and challenges in provision of psychotherapy services. Key emergent themes concerned being partners in communication to build a respectful rapport whilst ensuring confidentiality. Supporting people though the therapeutic process by making the necessary accommodations to set treatment goals was valued. Barriers included the therapist not understanding the person's disability, the difficulty in finding a therapist to support a person with dual diagnosis, high staff turnover and coping with the dichotomy between mental health and disability services. Many of these themes echo those identified in the Whittle's scoping review (2018) and in a qualitative study undertaken by Mattock et al. (2020), which explored the experiences of people with intellectual disabilities accessing services. One emergent theme was the need for person-centred practices such as advocacy and empowerment.

Travelling to mental health services featured as an issue for both people with intellectual disabilities and their carers (Son et al., 2018; Delves et al., 2022; Verma et al., 2022). Cost, both direct, relating to the time and cost of travel, and indirect cost due to missed work opportunities, placed an extra burden on often already stretched systems. Another angle was raised by Stratham and Beail (2018) who reported on the views of 10 people with mild intellectual disabilities regarding their experiences of psychodynamic psychotherapy. Travelling to the clinic while anxious was identified as the most challenging issue associated with accessing therapy, whereas the referral process, and positive therapist interactions were positives. The therapy itself was acceptable, however, some reported that, although an explanation of the therapy was given in advance of commencing sessions, their experience was different to their expectation. Most participants reported benefits from therapy with some finding this improvement short-lived once therapy finished. Recommendations from this study included: screening for suitability, providing an explanation and assessing the understanding of an individual prior to commencing therapy, which should include discussion on surfacing difficult emotions or thoughts. Concluding therapy may prove difficult, however, being clear about the

duration of therapy and gradually reducing frequency or offering periodic follow up appointment may ease this concern.

Challenges in providing mental health care for youth with intellectual disabilities, aged 14-24 were identified by Son et al. (2018), following focus groups with service providers in a region of New South Wales, Australia. Service providers surveyed commented on difficulties navigating complexities of the system due to lack of clear information on which services were available and their varied eligibility criteria. Once an appropriate service was identified, long waiting lists were encountered due to the shortage of specialists in mental health care. Access to services was further complicated by costs, transport, cultural and linguistic challenges. Positive experiences were recounted when interagency and collaborative case management were used. Concern was raised, however, regarding the divide between intellectual disability and general mental health services with the risk of youth with intellectual disabilities and mental health concerns falling between the cracks of services. Diagnostic over-shadowing was identified as an issue, with difficulties in differentiating treatable mental health issues from 'challenging behaviour'. Participants considered that increased training, capacity and integration in services, early intervention and health promotion would go some way towards providing better services to those youths with a dual diagnosis.

Rapid adoption of alternative means of conducting assessments and therapy were required with the onset of COVID-19 restrictions in March 2020. Concerns regarding the accessibility, acceptability and effectiveness of remote communications were evident in literature published during the pandemic.

Verma et al. (2022), compared telepsychiatry appointments for children, with autism spectrum disorder and/or intellectual disabilities before and during COVID-19 restrictions. The onset of these restrictions rapidly pushed in person appointments to a virtual setting, with appointment numbers returning to pre-pandemic levels within months. They identified challenges with the use of technology including the availability of video-enabled devices, quality of connection, the ability of the person or their carer to use the new system, confidentiality, language barriers, lack of ability to perform tests requiring physical examination and the breaching of home/clinic boundaries. Many of these challenges could be overcome with planning, education and interpreter services. Added benefits were a decrease in time and travel costs, virtual sessions were less anxiety provoking for people with autism spectrum disorder and improved multidisciplinary team working.

A similar study but focusing on adults with intellectual disabilities accessing psychiatry services in rural Australia before and after COVID-19 restrictions was reported by Delves et al. (2022). The characteristics and experiences of people with intellectual disabilities, assessed in-person or by a Telepsychiatry clinic in rural Australia over a 33-month period were contrasted. Their findings

demonstrated that videoconferencing was feasible and acceptable to both the patients and their carers. Challenges to the application of Telepsychiatry were mitigated by ensuring health centre hubs had high-quality audiovisual equipment and staff were experienced in its use and in establishing rapport over remote links. A further shift to using telepsychiatry occurred with the onset of COVID-19 restrictions in March 2020, this highlighting the paucity of internet and appropriate devices in family and group homes. This impacted negatively on the quality of assessment and increased reliance on collateral information. Recommendations arising from this work called for access barriers to be removed through ensuring increased capacity in videoconferencing equipment and training staff in its use. Benefits noted by carers were that timely assessment could occur while expense and time associated with travel were minimised. Caution was noted in using video technology when assessing people with severe to profound intellectual disabilities or people with communication difficulties. Overall, though, Telepsychiatry was noted to be feasible and acceptable in addressing challenges to accessing mental health care for people with intellectual disabilities while minimising the cost in time and travel expense.

Gregson et al. (2022), in their exploration of psychologists' perspectives on providing therapies during the COVID-19 pandemic, noted how the use of technologies was adopted and the challenges that they presented for clinicians and people with intellectual disabilities. Many of these were rooted in users' lack of knowledge and confidence in using such approaches, and whilst they noted the potential benefits of their use, particularly in respect of equitable access to service, they pointed to the need for training to support its ongoing usage.

Time on a waiting list can be difficult to tolerate, this being exacerbated during the COVID-19 pandemic. Enquiring on this subject, Baxter et al. (2023), drew on the experience of 7 adults with intellectual disabilities who waited for psychological therapies during the pandemic. It was intended to use the gathered data to better inform the support of individuals while on a waitlist. Four themes were identified following qualitative analysis: waiting was 'painful' as the individuals continued to struggle with their underlying issue while also dealing with negative effects of the pandemic, this being exacerbated by the lack of someone to talk to; the wait, however, was more tolerable when understanding the reason for the wait; the use by individuals of internal and external coping strategies was a positive; support from the intellectual disability team was helpful when given, although some participants felt they lacked this support. To reduce the burden of waiting, it was suggested the services contact the individuals on the wait list once a target wait time is breached, this call validating their difficult feelings, assuring them regarding their wait and suggesting the employment of already known coping strategies, as appropriate, or directing them to other resources. Service strategies on

waiting list management should formalise a response model noting the need to change session arrangements or employing a stepped approach to care.

The following key issues emerge from the above findings:

- Waiting list times can be mitigated by explanation and meaningful contact advising on helpful strategies to manage the wait.
- Travelling to and from appointments can be difficult and not only stressful for the person with intellectual disabilities, but also costly to them and their accompanying person.
- Telehealth approaches have been proven to be acceptable and effective in supporting individuals in need to services and overcomes the above issues. Care must be taken to ensure that good quality technology is available at both ends and that training appropriate to what is required for a video conference is given to both the therapist and the person with intellectual disabilities.
- The lack of specialists in dual diagnosis was a recurring theme, and when they are available there was confusion regarding how to access them. There were also challenges navigating the variable eligibility criteria and dichotomy between disability and mental health services. Communication and collaboration were suggested vital to ensure the best outcome for the individual, this being consistent with person-centred care.

Integrated Working, Education and Training

In what has been presented above it will be noted that none of the best practice approaches and models advocated by the various authors can come at no cost. The design of any specialist mental health service is predicated on the availability of resources, both financial and human. Furthermore, the resource need must be viewed across all tiers of the service, from general practice to specialist care. Whilst some of these issues have been already been identified, that of resourcing staff education, and training is one which needs special mention, and it arguably underpins the ability to provide the other aspects of the service. Furthermore, there is a need to consider the importance of integrated working, particularly across sectors and agencies. This is in line with the concept of integrated care which is increasingly being acknowledged as a facilitator in meeting complex support needs. Integrated approaches arise often in intellectual disability literature, given the complexity and multifaceted requirements of this population (Ramerman et al., 2018; Whittle et al., 2018; Whittle et al., 2019; Kaushal et al., 2020; Lewis et al., 2020; Culnane et al., 2021; Ee et al., 2022a, 2022b; Siddel, 2022; Wigham et al., 2024).

The failure of services to provide an integrated approach was one of the key barriers identified in Whittle's (2018) scoping review alongside a lack of skilled workforce and diagnostic overshadowing. They also noted that collaborative working is fundamental to improving access and outcomes for

people with intellectual disabilities and mental health disorders. In an Australian study (Lewis et al., 2020), it was reported that whereas people with intellectual disabilities and mental health issues were more likely to access community mental health services, they were less likely to be admitted to a mental health hospital bed. The authors recommended collaboration between disability and mental health services as being key to enabling good mental health care. There is, however, evidence that those working in mainstream mental health services may not have the skills to meet the needs of people with intellectual disabilities.

In its report on Mental Health Services for Adults with Mild Intellectual Disability, the Royal College of Psychiatrists (2020) that placement in an intellectual disability psychiatric area is not a requirement for core psychiatrist trainees in the United Kingdom. This is the case in Ireland too (College of Psychiatrists of Ireland (2023) and it is also noted that such placements are also not mandatory in the Nursing and Midwifery Board of Ireland's Standards and Requirements for general and mental health nursing education and training programmes (NMBI, 2023). This is concerning, considering the role that these professional groups have in provision of mental health services envisioned in the HSE's service models (2021, 2022b). Whilst general practitioners' training does include a module on intellectual disabilities (Irish College of General Practitioners, 2020), the absence of such a focus in general psychiatry and general nursing is concerning as the emergency department may be a first contact for some individuals with intellectual disabilities and mental health concerns.

In their survey of child and adolescent psychiatry and general psychiatry programmes across the United States, Marrus et al. (2022) explored the education and training components related to autism spectrum disorder and/or intellectual disabilities. From the responses of 78 programme directors (representing 83 of approximately 248 programmes), they found that such content was limited, particularly in respect of intellectual disabilities. Furthermore, they noted a correlation between quantity of content and perception of competence to work with this client group. Marrus et al. (2022) highlight the need for greater resourcing of psychiatric training, and particularly of placements to enhance that profession's ability to respond to the needs of children and adolescents with intellectual disabilities. This need is also stated in Lines et al.'s (2020) examination of the training of psychiatrists in the United Kingdom. Their online survey was responded to by 50 doctors across core and higher trainees taking part in the Maudsley Training Programme in London. Findings suggest that there is an association between clinical experience with people with intellectual disabilities who have mental health concerns and having the confidence and skills to meet the mental health needs of this population. The authors recommend that rotational and other opportunities should be made available to psychiatric trainees to address what was described as a training gap.

The specific challenges posed by transition between child and adult mental health services were explored by Culnane et al. (2022) in their research reporting on the experience of carers assisting in this transition. They noted the need for co-ordination between mental health, disability and social services in this regard and stressed that transition outcomes were improved in a shared care model including the person's general practitioner and/or paediatrician, using a stepped, planned approach involving specific transition appointments.

It is concerning that, in a review of the literature on health professionals' attitudes and perceptions of people with intellectual disabilities and mental health problems, it was found that those outside of intellectual disability services had little knowledge and lacked training in understanding the needs of people with intellectual disabilities (Ee et al., 2022a). This lack of knowledge was compounded by a lack of available resources in mainstream settings to redress this imbalance. A further review noted that collaboration between community services, primary care settings and the multidisciplinary mental health team was considered a positive factor in providing integrated care (Ee et al., 2022b), though there was no clear consensus on the need for specialist mental health teams for people with intellectual disabilities. Those in favour of having only mainstream mental health services for all, however, advocated for more resources to ensure education and adaptation of services to be more responsive to the needs of people with intellectual disabilities.

A number of studies have focused on the challenges in diagnosing mental illness in people with intellectual disabilities (Weise et al., 2018, 2019; Hinde and Mason, 2020; Kaushal et al., 2020; Hronis et al., 2021). Hinde and Mason's (2020) conducted a survey of 93 health professionals regarding their knowledge of mental disorders among people with intellectual disabilities. These professionals were drawn from primary care, psychology, mental health and alternative therapies across Australia. Whereas the study found that many of the professionals rated themselves as confident in diagnosing and addressing mental health concerns in this population, their knowledge of mental health symptoms was low. Kaushal et al. (2020) surveyed mainstream psychiatrists across two NHS Trusts in the United Kingdom to ascertain their knowledge, assess the quality of services and to institute a self-audit tool, The Green Light Toolkit (National Development Team for Inclusion, 2017), an approach that was introduced by the United Kingdom's Department of Health in 2004 to improve access to mental health services by people with intellectual disabilities through ensuring the use reasonable adjustments. Their findings mirror those noted previously regarding the limited resources and access to of training in support people with intellectual disabilities who presented with comorbid mental health problems, but also revealed that many psychiatrists reporting that they felt unprepared to treat patients with dual diagnosis. Of particular concern was that most participants had not heard of the Green Light Toolkit. Noting frustration with 'organisational boundaries' and difficulties in ensuring that

communication across services was maintained, participants in this study called for additional education and training, as well as the development of protocols and clear pathways of care which would include integrated working between services. It was noted that clear organisational leadership would be required to ensure that this could occur.

An insufficiency in education and training was also noted by respondents to Weise and Troller's (2018) survey of 566 public health professionals across Australia who noted that mainstream mental health services could not adequately meet the mental health needs of people with intellectual disabilities. More than fifty percent of respondents also noted that they lacked confidence in their ability to do so. It was reported that many had received some content on intellectual disability mental health during their initial education programmes, but that this was not sufficient to prepare them meet the needs of this population. The authors, whilst acknowledging the limitations of their study in terms of representativeness, concluded that there is a need for a clear workload strategy to underpin mental health services which takes into account the educational, training and attributes that are required in a workforce that can meet the needs of people with dual diagnosis. This spans all aspects, tiers or steps of the service, from primary care, through mainstream and to specialist mental health services. This must take account of integrated, inter-sector and inter-agency working, with sharing of skills, and competencies amongst professionals in all aspects of the service. Hronis et al. (2021) also advocated that treatment protocols be developed and likewise disseminated. Many of the above recommendations are also identified in Weise et al.'s (2019) earlier qualitative study, which engaged the perspectives of 33 mental health intellectual disability experts, as well as in findings from their study of family members and support persons' views (Weise et al., 2018), though this particularly highlighted the need for their engagement in determining workforce attributes.

Weise and Troller (2018) note a particular need for education and training in relation to psychotropic medication prescription and usage, and area that has received much attention in recent years, through the Stopping Over-Medication of People with a Learning Disability and Autistic People (STOMP) initiative in the United Kingdom (NHS, 2015) and, in Ireland, through the work of IDS-TILDA, which has highlighted a significant disparity whereby, of those prescribed anti-psychotics only a quarter had been diagnosed with a relevant mental illness (O'Dwyer et al., 2018). Moreover, similar findings were reported in García-Domínguez et al.'s (2022) survey of professionals and family members which gathered information on mental health conditions, behavioural concerns and medication use in 353 adults with intellectual disabilities in Spain. The authors attributed some of the over-reliance on psychotropic medication to inadequate training of public health professions, as well as to the difficulties in separating challenging behaviour from mental illness. Furthermore, they pointed to other potential instances of diagnostic overshadowing that can be presented by the early onset of

dementia, something also noted by Wise et al. (2022) in their examination of mental health and medication usage in older adults with intellectual disabilities. Such issues can present significantly challenging behaviour and the usage of psychotropic medications in such instances, and in the absence of mental illness, could be considered as chemical restraint and should, rather, be addressed through person-centred approaches, such as positive behaviour support (García-Domínguez et al., 2022), a position which is also advocated by Rauf et al. (2021), Lineberry et al. (2023).

Ramerman et al.'s (2018) study of healthcare professionals in intellectual disability and their adherence to antipsychotic medication guidelines reveals further insight into medication management. A lack of multidisciplinary working was noted to cause potential issues with respect to the understanding of roles regarding the monitoring of medication effects and side-effects. It was proposed that positive collaboration between those supporting an individual, with a key person to coordinate treatment - both medication and other modalities - could result in better, more streamlined care. It was also considered important to embed guidelines into organisation policy, thereby setting out roles and responsibilities more clearly and maximising the benefits of collaborative working. Siddel's (2022) study engaging with clinical psychologists working with people with intellectual disabilities and mental health needs recommended the fostering of good relationships with allied health and social care agencies to decrease barriers to access and improve integration of care.

The following key issues emerge from the above findings:

- A clear workload strategy is required to identify the knowledge, skills, competencies and that are required of staff and carers in all parts of a stepped mental health intellectual disability service.
- Education and training programmes for health professionals should include education on intellectual disabilities and require clinical placement supporting the health needs of people with intellectual disabilities.
- All professionals working within the context of a mental health service, as proposed above, should be required to have knowledge, skills and competencies pertinent to mental health and intellectual disabilities, commensurate with the role that they are expected to play within that service.
- Inter-professional, inter-agency and inter-sector working, alongside collaboration should be the norm in meeting both the education and training needs of professionals, and quality mental health service outcomes for people with intellectual disabilities and their families/carers.

- Monitoring in respect of the use of psychotropic medications among people with intellectual disabilities should be considered as well as enactment of a national awareness campaign advocated for by O'Dwyer et al. (2018).

Objective 2 - Legislative considerations and rights-based considerations impacting the treatment and care of persons with a dual diagnosis of mental illness and intellectual disability.

Introduction

A manual and grey literature search was conducted to identify legislative and rights-related sources that pertained to the treatment and care of persons with mental illness and intellectual disability. This was conducted across six jurisdictions, Ireland, United Kingdom, United States of America, New Zealand, Canada and Australia, with state exemplars taken from the latter two countries. The aim was to obtain a broad perspective on legislative and rights approaches outside Ireland, and to use this to contextualise Irish legislation and the embodiment of rights therein. Through this it was possible to identify how Irish legislation affecting those with dual diagnosis has responded to developments in respect of decision-making, capacity which have flowed from the ratification of, in particular the UNCRPD. The scope of documents reviewed was broadened though, to include consideration of other policy developments in the areas of decongregation, restrictive practices, safeguarding and proposed models for providing services to persons with a dual diagnosis of mental illness and intellectual disability.

42 records were returned by the searches were initially tagged as being potential contributors to addressing this objective. These are included in Figure 4 which also included records from the standards and codes of practice review. Following full-text review, 19 records were found to be irrelevant, leaving 23 records for inclusion (Tables 8 and 9). Some of these records were used to form this report's earlier introduction on rights and legislative responses.

What was gleaned from these records is presented under five main areas that emerged during analysis. These are: values underpinning service; governance; service provision; mental health interventions; and consultation.

It should be noted that findings are only those that have relevance to mental health service provision to people with a dual diagnosis of mental illness and intellectual disability.

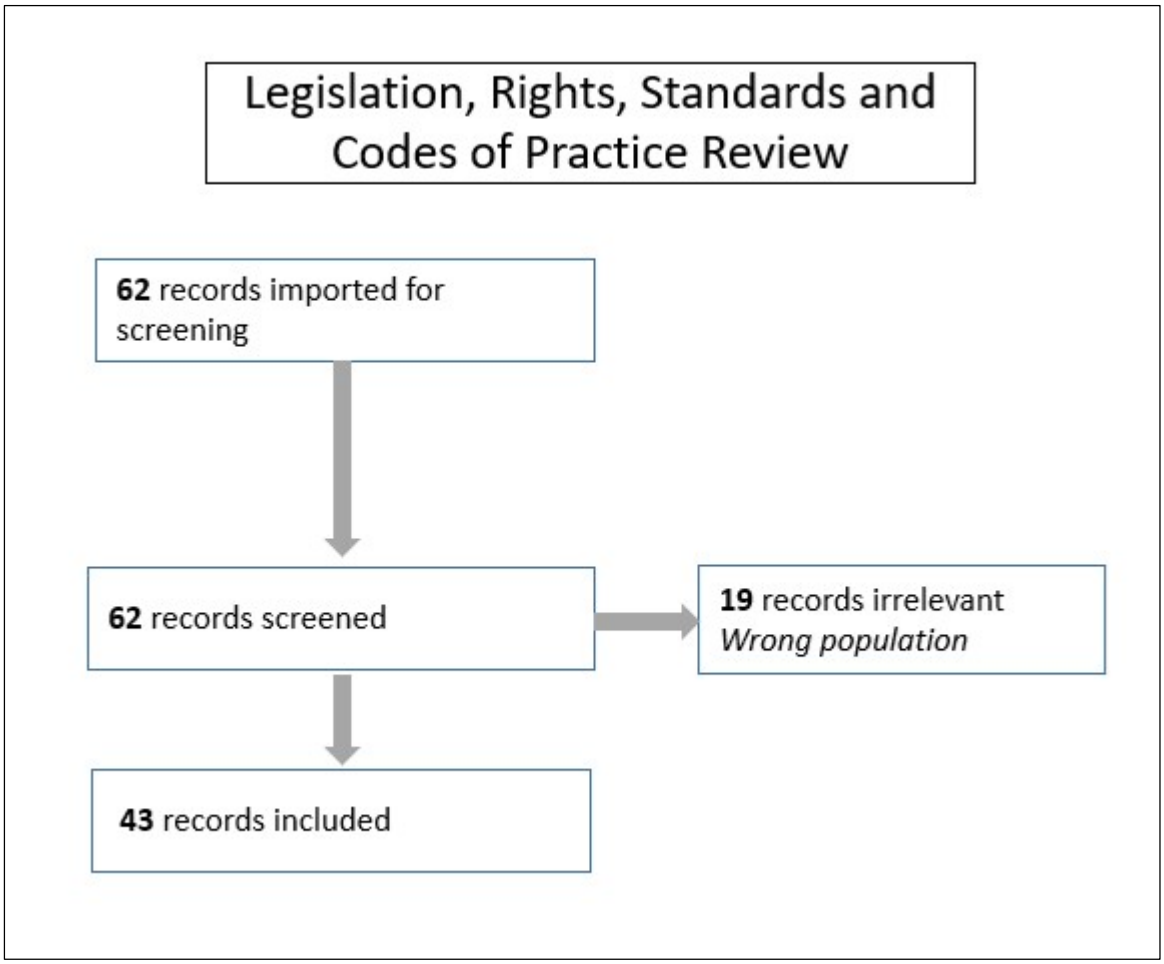

Figure 4 PRISMA diagram for the legislation, rights, standards and codes of practice reviews.

Table 8 Evidence on legislative and rights-based considerations.

Author (year) Country	Document	Scope	Content Relevant to this Review
Government of Ireland (2001), Ireland.	Mental Health Act 2001.	All people, including people with intellectual disability, where mental illness poses a risk to self or others. Also, those with significant intellectual disability who could benefit from treatment.	Provides for involuntary admission of persons with mental illness to 'approved centres' on the bases of risk to self or others, and/or for therapeutic reasons. Established Mental Health Commission.
Government of Ireland (2005), Ireland.	Disability Act 2005.	All people with disabilities.	Commits to provision of an assessment of needs and enablement of provision to meet those needs. Identifies the requirement for Universal Design to underpin provision of services that are accessible, inclusive and equal.
Government of Ireland (2006), Ireland.	Mental Health Act 2001 (Approved Centres) Regulations 2006.	All people, including people with intellectual disability, where mental illness poses a risk to self or others. Also, those with significant intellectual disability who could benefit from treatment.	Sets out regulation of approved centres under the Mental Health Act 2001.
Government of Ireland (2007), Ireland.	Health Act 2007.	Addresses service quality and the setting up of 'designated centres' for persons with disabilities.	Provides for registration and inspection of designates centres for persons with disabilities, under the remit of the Health Information and Quality Authority (HIQA).
Government of Ireland (2013), Ireland.	Health Act 2007 (Care and Support of Residents in Designated Centres for Persons (Children and Adults) with Disabilities) Regulations 2013.	Addresses the setting up of 'designated centres' for persons with disabilities.	Sets out regulation of designated centres under the Health Act 2007.
Government of Ireland (2015), Ireland.	Assisted Decision-Making (Capacity) Act 2015 (as amended).	Applies to all people and the provision of health and social care. Addresses decision-making supports, assessment of capacity,	Recognises ability of person to take part in decisions about mental health treatment planning, including decision to reject treatment, as well as representation in this regard.

		assignment of representation and advance healthcare directives.	Linked to Mental Health Act 2011 in respect of capacity. Extended the remit of the Mental Health Commission regarding decision-support.
New Zealand Government (1992), New Zealand.	Mental Health (Compulsory Assessment and Treatment) Act 1992.	Applies to all people where compulsory psychiatric assessment and treatment is warranted.	Implication of this was that those with intellectual disability and behaviour concerns (not mental health) were diverted to the justice and forensic services.
New Zealand Government (2003), New Zealand.	Intellectual Disability (Compulsory Assessment and Treatment) Act 2003.	Applies to people with intellectual disabilities who are charged with or convicted of an offence.	Enables compulsory care and treatment in a hospital setting of supervised/secure community facility. Addresses shortcoming of Mental Health Act 1992.
Queensland Government (2016), Australia.	Mental Health Act 2016 (Queensland).	All people including those with intellectual disabilities, who have a mental illness that led to a criminal act, or which posed risk to others. Diverts from criminal justice system.	Provides for involuntary admission of persons for treatment where they lack capacity or are of 'unsound mind'.
United Kingdom Government (2005), UK.	Mental Capacity Act (England and Wales) 2005.	All persons who lack capacity to make decisions due to impairment of, or a disturbance of in the functioning of the mind or brain. Includes intellectual disability.	Supported assessment of capacity and assignment of representation.
United Kingdom Government (2010), UK.	Equality Act 2010.	Scope included all public sector agencies, including those responsible for mental health.	Set out the requirement for reasonable adjustments to be enacted in services.
United Nations (2006), International.	Convention on the Rights of Persons with Disabilities.	Applies to all persons with impairments/disabilities.	Identifies the right of the person with disabilities including: 1. Right to enjoy highest standard of health with the full range, quality and standard of free or affordable health care.

			2. Right for health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons. 3. Right for children to express views on all matters affecting them. 4. Right to be free from torture, cruel, inhuman or degrading treatment or punishment. 5. Right to freedom of expression, opinion and consent. 6. Right to access information pertaining to oneself. 7. Right for privacy of self and of health information.
United States Department of Justice (1990), USA.	Americans with Disabilities Act 1990.	Broad scoped federal act addressing disability in its widest understandings.	Requires that states deliver services in integrated settings, maximising independence and participation.

Table 9: Evidence on policy and models

Author (year) Country	Document	Scope	Content Relevant to this Review
Department of Children and Youth Affairs (2015), Ireland.	National Strategy on Children and Young People's Participation in Decision-Making 2015-2020.	Children and young people, including those with experience of growing up in care, living with disabilities, being in detention or interacting with the health, mental health, child protection or homelessness services.	Calls for children and young people's voices should be heard in respect of services they receive. They should be facilitated to be active participants in decisions that affect them, in accordance with their age and maturity.
Department of Health (2011), Ireland.	Towards a Restraint Free Environment in Nursing Homes.	Nursing homes for older persons but is often referred to in respect of health and disability service expectations.	Defines restraint and sets out various types. Sets out the rights and legal contexts for the use of restraints. Commits to the elimination of restraint usage in nursing homes and person-centred care.
Department of Health (2020), Ireland.	Sharing the Vision – A Mental Health Policy for Everyone.	Provides a framework for a modern, responsive mental health service for all persons.	Provides basis for setting up a national model of mental health service for people with intellectual disabilities. Identifies the need for mental health intellectual disability (MHID) teams, as well as a tiered approach to the provision of mental health services to people with intellectual disabilities. Commits to the setting up of baseline teams in advance of MHID teams being set up. Plans for the development of acute and day hospital services for MHID as well as acute and respite mental health services for children and adolescents with intellectual disabilities. Notes the need for data from prison service in respect of forensic service need.

Health Service Executive (2021), Ireland.	Mental Health Services for Adults with Intellectual Disabilities: National Model of Service.	Adults with intellectual disabilities and mental health needs.	Proposes the development of multidisciplinary Mental Health of Intellectual Disability (MHID) teams on a catchment area-basis. These should be but closely linked to the multidisciplinary teams in Intellectual Disability Services, who provide health and social care service for people with intellectual disability. Sets out the core multidisciplinary team membership. Identifies the importance of planned transition of care between child and adult MHID services.
Health Service Executive (2022), Ireland.	National Consent Policy.	All actions conducted by or on behalf of the Health Service Executive, with people in all locations.	Sets out the responsibilities of healthcare workers and or organisations regarding consent. Identifies the processes of giving, refusing, and withdrawing consent. Iterates the bases for considering decision-making capacity: risk to self or others; uncharacteristic or inconsistent decision; lack of clarity in communicating a choice; apparent irrationality of a decision. Sets out the processes for undertaking a capacity assessment. Notes the role of a decision-making representative in relation to involuntary admission under s.3.1a and s.3.1b of the Mental Health Act 2001. Sets out enactment of consent in respect of children receiving mental health services and the roles of legal guardians and of Tusla.

Health Service Executive (2022), Ireland.	Specialist Child and Adolescent Mental Health Services for Children with Intellectual Disability: National Model of Service.	Children and adolescents with intellectual disability and mental health needs.	Proposes the development of multidisciplinary Child and Adolescent Mental Health of Intellectual Disability (CAMHS-ID) teams on a catchment area-basis. These should be closely linked to the interdisciplinary Children's Disability Network Teams (CDNT), which provide health and social care service for children with intellectual disability. Sets out the core multidisciplinary team membership. Identifies the need for transition of care between child and adult mental health intellectual disability services to be planned and coordinated in conjunction with the child and family, beginning six to twelve months prior to transfer. This model outlines the referral pathway and details of the child's journey though the CAMHS-ID service.
National Association for Dual Diagnosis (*no date*), USA.	Including Individuals with Intellectual/Developmental Disabilities and Co-Occurring Mental Illness: Challenges that Must Be Addressed in Health Care Reform.	Adults with intellectual disabilities and co-occurring mental health needs.	Sets out workforce competencies and training requirements, emphasising specialised skills in respect of diagnosis and treatment. Notes the importance of community living and role of families in supporting people with dual diagnosis.
National Health Service (2015), UK.	Building the Right Support.	People with intellectual disabilities and/or autism who display behaviour that challenges, including those with a mental health condition.	Proposes a new community-based mental health service model based on nine principles: 1. A good meaningful life. 2. Support for family and paid staff. 3. Choice of where to live and with whom. 4. Access to mainstream health services.

			5. Access to specialist multidisciplinary health and social support in the community. 6. Access to hospital care. 7. Person and family/carers at the centre.
New South Wales Government (2016), Australia.	Intellectual Disability Mental Health Core Competency Framework.	People with intellectual disabilities and mental health needs.	Provides a framework for mental health professionals to provide mental health services to people with intellectual disabilities. Notes the importance of services being rights-based, grounded in respect and person-centeredness. Identifies the importance of accessibility and choice/decision-making supported by advocacy. Services should be recovery-focused, strengths-based and empowering, encompassing collaboration with the person and across agencies.
Western Australia Council of Social Service (2015), Australia.	A Core Capability Framework for Working with People with Intellectual Disability and Co-Occurring Mental Health Issues.	People with intellectual disabilities and mental health needs.	Sets out a framework for those working with people with intellectual disabilities and co-occurring mental health issues. Comprises five domains, addressing: organisational culture and values; person-centeredness; workforce development; collaborative practice; and provision of quality care. Underpinned by guiding principles of rights, inclusion, holism, recovery-oriented practice as well as evidence-based service.

Some Principles Underpinning Service

Person-Centeredness

It has been noted above that human rights have increasingly become a key benchmark in respect of the provision of mental health services to people with intellectual disabilities. The central focus of human rights is the person, and in this regard, it is notable that person-centeredness, whether in terms of care or support, is an expectation of health service provision in Ireland, underpinned by the Health Act 2007 (Care and Support of Residents in Designated Centres for Persons (Children and Adults) with Disabilities) Regulations 2012 (Government of Ireland, 2013). Whereas these regulations do not relate specifically to services which fall under the Mental Health Act 2001, they do support individualised assessment and the development of a personal plan which is determined in consultation with the person around his or her needs and preferences. This is in line with the concept of integrated person-centred care inherent in the Health Service Executive's models for mental health intellectual disability services (HSE, 2021, 2022) as well as recommendations presented by the National Association for Dually Diagnosed (NADD, *no date*). The concept of person centeredness is far-reaching and has implications for all aspects of service organisation, funding, provision and delivery (Sheerin et al., 2024). An Australian intellectual disability competency framework (New South Wales Government, 2016) highlights the importance of a person-centred approach for supporting human dignity and maximising the therapeutic relationship. The National Quality Framework (MHC, 2023) notes the value of key workers in supporting co-creation of care pathways as well as personalisation of services.

Capacity and Decision-Making

Person-centeredness derives from recognition of the inherent dignity and worth of each human being and that fact that they have equal and inalienable human rights (United Nations, 2006). It is incumbent on mental health services to ensure that these rights are realised in the lives of patients despite the challenges that may present when intellectual disability and mental illness co-occur (MHC, 2009). The main issue that arises here relates to balancing the right for self-determination and the risks associated with operationalising that right. This has been the focus of legislation in several countries, and centres on the issue of decision-making capacity. Whereas the UK's Mental Capacity Act (England and Wales) 2005 (United Kingdom Government, 2005) offered limited decision-making supports and linked capacity to a medical diagnosis, the recently enacted Assisted Decision Making (Capacity) Act 2015 (Government of Ireland, 2015) has avoided this and arguably provided a stronger basis for the assumption of capacity to be realised, in line with the CRPD (Davidson, 2022). Assumption of capacity is particularly important in respect of mental health service provision as people may enact their right to refuse treatment with potentially negative consequences for them or others. The Assisted Decision Making (Capacity) Act 2015 provides for assessment of capacity and decision-making supports in such situations. Under the Mental Health Act 2001 (Government of Ireland, 2001), involuntary admission

may occur on either risk or therapeutic grounds. The latter ground provides a basis for decisions to be made by a decision-making representative, if appointed, to give consent for treatment under the Assisted Decision Making (Capacity) Act 2015. The Mental Health Act 2001 allows for reviews and appeal, something which has also been recommended for inclusion in the upcoming UK Mental Health Bill (House of Commons and House of Lords, 2023).

Provision of Information

Decision-making is premised on the availability of clear, accessible, and comprehensive information. The Mental Health Act 2001, Health Act 2007 Regulations 2013, Mental Health Act 2016 (Queensland Government, 2016) and the two Health Service Executive mental health intellectual disability service models (HSE, 2021, 2022) state that information related to diagnosis, treatment and advocacy supports communication should be provided by services and professionals to patients, family and carers, as appropriate. This assists decision-making but also enhances the therapeutic relationship ensuring that care can be planned in a collaborative and inclusive manner.

Accessibility

The provision of information notes the requirement for it to be in an accessible format. This relates to a key principle of the CRPD (UN, 2006) and is relevant to all aspects of health and social service provision. This is particularly highlighted in the National Quality Framework which also notes the importance of including the voices of all stakeholders in achieving service quality (MHC, 2023). T Disability Act 2005 (Government of Ireland, 2005) alludes to this too in its call for all services to adhere to the 'universal design' concept. The UK Equality Act 2010 (UK Government, 2010) specifically refers to the need for reasonable adjustments in services to make them more accessible and/or effective for protected groups (including those with intellectual disabilities). The Mental Health Act 2001 and Health Act 2007 Regulations 2013 also note the importance of those in approved and designated centres having access to a full range of professionals across the health service. This requires collaboration across services and agencies (New South Wales Government, 2016; Western Australia Council of Social Service, 2015; NAAD, *no date*).

Service Governance

Mental health services in Ireland are provided under the Mental Health Act 2001. This brought mental health law into alignment with the European Convention on Human Rights (Council of Europe, 1950). It also provided for the establishment of the Mental Health Commission to 'promote, encourage and foster high standards and good practices…protect the interests of people who are detained in approved…centres and regulate inpatient mental health services' (Citizens Information Board, 2024). The development of mental health services for people with intellectual disabilities, under the HSE models of service, is creating a largely community-based service, separate from but liaising with disability services. Whereas mental health support has heretofore been provided with the designated

centres for persons with disabilities, under the remit of the Health Information and Quality Authority, any new approved centres will fall under the regulation of the Mental Health Commission.

Service Model

The National Quality Framework: Driving Excellence in Mental Health Services (MHC, 2023) highlights the importance of achieving quality and recovery-oriented services. Given the fact that so many people with intellectual disabilities have lived with mental health concerns throughout their lives, it is vital that the concept of recovery is embodied in mental health intellectual disability services (HSE, 2022; New South Wales Government, 2016; Western Australia Council of Social Service, 2015). In the UK, recent remodelling of mental health services for people with intellectual disabilities has seen a move away from inpatient facilities and towards community-based services (National Health Service, 2015), something that is embedded in the Americans with Disability Act 1990 (United States Department of Justice, 1990) which calls for services to be delivered in community-based integrated settings. These two sources also note the need for inpatient care but advise that clear transition pathways to community and to disability services must be provided for (Royal College of Psychiatrists, 2020). This is identified in the two HSE national models, as is the importance of transition pathways between CAMHS-ID and adult MHID services. Underpinning transition is the requirement for integrated care pathways facilitated by inter-agency and inter-service collaboration (United States Department of Justice, 1990; Royal College of Psychiatrists, 2020; HSE, 2022).

Mental Health Interventions

People with intellectual disabilities are entitled to mental health care of a high standard with access to a full range of treatments and supports (United Nations, 2006; Government of Ireland, 2007). Sharing the Vision (Government of Ireland, 2020), which preceded publication of the mental health intellectual disability service models, commits to a tiered approach to mental health support and treatment and the development of a national service with specialist teams comprising psychiatrists, psychologists, clinical nurse specialists, speech and language therapists and administrative support. This is in keeping with international sources which clearly note the need for such services to be staffed by individuals who have the knowledge, skills and competencies to meet the needs of people with dual diagnosis (Royal College of Psychiatrists, 2020; New South Wales Government, 2016; Western Australia Council of Social Service, 2015; NADD, *no date*), and was reiterated in the recent National Quality Framework (MHC, 2023) This expectation extends to those who will deliver mental health support as part of the broader multidisciplinary team (Government of Ireland, 2013; Western Australia Council of Social Service, 2015; Royal College of Psychiatrists, 2020; HSE, 2021, 2022).

Provision of mental health service should be premised on the conducting of a holistic assessment which takes into account the perspectives of the person, family members and carers. As such it should

be consultatory in nature and support the voice of the person with intellectual disability (Government of Ireland, 2013; Department of Children and Youth Affairs, 2015; Government of Ireland, 2015). Engagement of the person, their supporters and/or representative, is not just crucial in respect of assessment, but also in planning or co-creating the treatment path. This is in line with the requirements in Assisted Decision Making (Capacity) Act 2015 and the Health Service Executive's National Consent Policy (HSE, 2022).

Evidence presented earlier in this report notes the role that medication has played in the management of mental illness and other concerns in people with intellectual disabilities. It has identified that challenges in diagnosis may have led to psychotropic medications being prescribed outside defined indications, whereas in other situations they may have represented a form of restrictive practice. Polypharmacy was a significant concern. As such, they may have served as a form of management rather than treatment. Treatment, as noted above, should be recovery oriented (HSE, 2022; New South Wales Government, 2016; Western Australia Council of Social Service, 2015). Medications do, however, have a place in the management of mental illness, but they are just one line of treatment and should adhere to the guidelines on delivering pharmacological interventions (for example, NICE, 2016). The full range of appropriate interventional options should be available to people with intellectual disabilities as they would be for their peers of regular cognitive ability (HSE, 2021, 2022).

Restriction, by way of involuntary admission to a mental health service, is at the core of many mental health acts, but it has seen more widespread usage in mental health and intellectual disability services. The use of medication as a form of chemical restriction has been mentioned, but restriction can also be physical and environmental (Government of Ireland, 2013), including the use of solitude (HIQA, 2023). Many of the standards and codes of practice that will be referred to anon, clearly call for reduction of restriction as an intervention and invariably refer to the 'least restriction'. Whereas this will be addressed in more detail at that point, it may be important to consider this in the context of the CRPD and the right for persons with disabilities to be 'free of torture, cruel, inhuman or degrading treatment' (UN, 2006; Department of Health, 2011).

The following key issues emerge from the above findings:

- Policies and models that are designed to support people with intellectual disabilities and mental illness must embody a person-centred approach and this must be demonstrated in all of their elements.
- Presumption of decision-making capacity must be enshrined in policies and models whilst acknowledging the possibility that individuals may not have capacity in respect of specific

decisions at specific times. In this case, the principles of assisted decision- making and decision support must be applied.

- Decision-making, collaboration and enactment of choice are premised on the provision of clear, understandable and accessible information.
- Service models should provide a tiered or stepped approach, preferencing the provision of mental health support in community settings but offering clear referral and transitioning pathways to more specialised or intensive services if required.
- Services should ensure that people with intellectual disabilities and mental illness have access to a full range of mental health services, offered according to assessed need and provided by teams of specialists, comprising psychiatrists, psychologists, nurse specialists, speech and language therapists and administrative personnel.

Conclusion

This review seeks to provide information on legislative and rights-based considerations that have emerged since the MHC (2009) guidelines were issued. Rights conventions remain unchanged though ratification of the CRPD took place in March 2018 with an expectation that services will be enhanced to ensure that people with disabilities are guaranteed the same human rights as others in society. Prior to ratification of the CRPD, there was a requirement for the repeal of certain historical acts/regulations with the consequent introduction of modern capacity legislation. This was achieved through the introduction of the Assisted Decision Making (Capacity) Act 2015. This act was fully commenced in April 2023 and requires health services to support decision-making and maximise a person's capacity to make decisions. This has implications for services at a governance and provision level but also in how mental health interventions are decided upon, with a requirement for information to be provided and consultation carried out, things that are evident in the new HSE MHID and CAMHS-ID service models. Many of these implications, however, were predicted by the previous MHC (2009) guidance but there are differences in respect of the concept of best interests and this should be highlighted in any new iteration.

Objective 3 - Standards or Codes of Practice relating to the regulation of mental health services for persons with intellectual disabilities.

Introduction

A manual and grey literature search was conducted to identify evidence pertinent to standards and codes of practice. This took place alongside that which focused on legislative and rights-related sources. It was also contributed to by sources from the database search for evidence on policy and practice as well as from the manual and grey literature search. Following full-text review, 16 records were considered relevant to this review (Table 10). These included records which provide guidance related directly or indirectly to the provision of mental health services to persons with dual diagnosis of mental illness and intellectual disability. There were few records which presented formal standards or codes of practice. Instead, most information came from guidance documents.

What was gleaned from these records is presented under two main areas that emerged during analysis. These are: values underpinning service; and service provision.

Table 10 Evidence on standards and codes of practice

Author (year) Country	Document	Scope	Content Relevant to this Review
Government of Ontario (2008), Canada.	Joint Policy Guideline for the Provision of Community Mental Health and Developmental Services for Adults with a Dual Diagnosis.	Services for adults with dual diagnosis of intellectual disability and mental illness.	Provides a framework for planning, coordinating and delivering community mental health services. Highlights the importance of coordinated cross-agency integrated care. Proposes three lines of intervention: 1. First Line: prevention, assessment and treatment by frontline providers with referral onwards. 2. Intensive: mental health assessment, treatment and support in community/ hospital-based mental health services. 3. Specialised: specific mental health programmes for complex mental illnesses, inpatient/outpatient or forensic with outreach as necessary.
Health Information and Quality Authority (2013), Ireland.	National Standards for Residential Services for Children and Adults with Disabilities.	Designated centres for children and adults with disabilities.	Not under the remit of the Mental Health Act 2001 and so outside that of the Mental Health Commission. Identifies the importance of timely access to health services, including assessment and treatment. Reiterates the requirement for inclusion of the person in decision-making and consultation with all stakeholders. Recognises the importance of safe medication management, including review of medications.
Health Information and Quality Authority (2023), Ireland.	Guidance on Promoting a Care Environment that is Free from Restrictive Practice.	Registered providers of designated centres for people with disabilities and staff therein.	Recognises the infringement of the constitutional right liberty that restrictive practices represent, and the need to reduce or eliminate their usage.

			If employed, such practices must be underpinned by consultation with the person/their representative, a comprehensive assessment, and planned discontinuation and review. Staff must be properly trained in techniques to prevent the need for restrictive practices, and in alternative approaches. There must be clear governance in place with policies addressing use of restrictive practices and reporting of any such usage to HIQA.
Decision Support Service (2023), Ireland.	Code of Practice for Healthcare Professionals.	Healthcare professionals providing service.	Identifies the importance of maximising the person's capacity and uphold decision-making. Describes how need for decision-making support may be ascertained. Sets out approach to assessment of capacity. Identifies process for making decisions in emergency situations.
Mental Health Commission (2009), Ireland.	Code of Practice: Guidance for Persons working in Mental Health Services with People with Intellectual Disabilities.	Persons working with people with intellectual disabilities in mental health services.	Provides guidance to mental health and other health professionals. Although predating the Assisted Decision-Making (Capacity) Act 2015, it anticipates much of what was to be set out in that act. The 'best interests' principle is applied, though this was to be replaced by the concept of 'will and preferences' in the later act. Identifies the importance of a person-centred approach focused on participation and inclusion in society.

			States the need for a least restrictive approach to interventions underpinned by a presumption of capacity.
Mental Health Commission (2020), Ireland.	Guidance on Quality and Safety Notifications.	Mental health services, including approved centres and community health services.	Sets out the quality and safety notifications that services are required to make: 1. Child admissions and discharges. 2. Deaths. 3. Reporting of incidents. 4. Overcapacity. 5. Operational bed capacity. 6. ECT notifications. 7. Restrictive practices.
Mental Health Commission (2022a), Ireland.	The Use of Restrictive Practice in Approved Centres.	Mental health services.	Reports on the use of restrictive practices over a three-year period. Notes general decline in use of restrictive practices. Seclusion use increased but less people experienced seclusion.
Mental Health Commission (2022b), Ireland.	Rules Governing the Use of Mechanical Means of Bodily Restraint.	Mental health services.	Defines mechanical means of bodily restraint and sets out the principles for its use: 1. Governance. 2. Staff training. 3. Scope of usage. 4. Ordering of restraint. 5. Informing the person. 6. Monitoring. 7. Recording. 8. Ensuring dignity and safety. 9. Ending of restraint. 10. Supporting the person.
Mental Health Commission (2022c), Ireland.	Rules Governing the Use of Seclusion.	Mental health services.	Defines seclusion and sets out the principles for its use: 1. Governance. 2. Staff training.

			3. Scope of usage. 4. Seclusion facilities. 5. Ordering of seclusion. 6. Informing the person. 7. Monitoring. 8. Recording. 9. Ensuring dignity and safety. 10. Ending seclusion. 11. Supporting the person.
Mental Health Commission (2022d), Ireland.	Code of Practice on the Use of Physical Restraint.	Mental health services.	Defines mechanical means of bodily restraint and sets out the principles for its use: 1. Governance. 2. Staff training. 3. Scope of usage. 4. Ordering of restraint. 5. Informing the person. 6. Monitoring. 7. Recording. 8. Ensuring dignity and safety. 9. Ending of restraint. 10. Supporting the person
Mental Health Commission (2023), Ireland.	The National Quality Framework: Driving Excellence in Mental Health Services.	Persons (including families and representatives) availing of mental health services in the public, voluntary and independent sectors.	Sets out what people should expect from mental health services in terms of best practice. Focuses on the importance of governance and leadership in services, ensuring that staff have the knowledge, and skills to provide an accessible recovery-focused service. Identifies the rights-based priorities that services must be inclusive and non-discriminatory, with co-production and collaboration to ensure excellence.
National Health Service (2024), UK.	Culture of Care Standards for Mental Health Inpatient Services.	Providers of mental health inpatient care.	Identifies core commitments: 1. Valuing the lived experience.

			2. Ensuring that people feel safe. 3. Supporting relationships based in rights and trust. 4. Supporting staff through training, education and emotional support. 5. Valuing diversity, inclusivity and equity. 6. Avoiding doing harm and acknowledging when this happens. 7. Guided by people's individual and unique needs. 8. Supporting choice. 9. Ensuring a positive, inclusive and accessible environment. 10. Facilitating choice in what people do. 11. Providing choice of therapies. 12. Being honest and transparent.
National Institute for Health and Care Excellence (2016), UK.	Mental Health Problems in People with Learning Disabilities: Prevention, Assessment and Management.	People with intellectual disabilities who have mental health concerns.	Provides guidance on service provision, noting the importance of communication and collaboration between people with intellectual disabilities, family members and caregivers, particularly during assessment. Identifies the importance of assessment, review, particularly in respect of pharmacological and non-pharmacological interventions. Recognises the need for accessible and acceptable services with reasonable accommodations. Highlights the need to plan for the transition between child and adult mental health services advising that this start at age 14. Advocates for clear care pathways for quality service provision, setting out

			responsibilities and staff knowledge/skill training. Notes the need for staff to have knowledge of the person too.
Safeguarding Ireland (2019), Ireland.	Guidance on a Human Rights-Based Approach in Health and Social Care Services.	All health and social care services staff and organisations providing service to adults.	Uses the FREDA principles to set out a rights-based approach to service: 1. Fairness: provision of information; consent; supporting decision-making; minimising restrictive practices. 2. Respect: person-centred care and support; communication; relationships; property; participation. 3. Equality: quality care and support; presuming capacity; participation in society; representation. 5. Dignity: meeting needs; privacy; sensitivity; supporting preferences; minimising restriction. 6. Autonomy: consent; respecting preferences; supporting capacity; independent living; minimising restrictive practices.
Selick et al., (2023), Canada.	Supporting Alternative Level of Care (ARC) Patients with a Dual Diagnosis to Transition from Hospital to Home: Practice Guidance.	Services supporting people with intellectual disability and mental illness to transition from hospital to community.	Identifies the principles and core components for transition. Identifies the importance of information sharing and communication with the person, family and community service providers. Notes the need for assessment and review as part of a clear transition pathway, including medication reviews. Sets out the need for staff and carer education and training. Links to the need for housing, funding and community support.

United Kingdom Government (2022), UK.	Building the Right Support Action Plan.	People with intellectual disabilities and autism who have mental health needs.	Relates to the Mental Health Act 1983. Notes the need for early diagnosis of mental health issues and referral to mental health services (community and hospital), as well as regular treatment reviews. Seeks to engage a mental health advocate to those who are inpatients in a mental health hospital. Calls for the provision of safe and effective care using least restrictive practices. Identifies the importance of staff having the correct skills and training to meet the needs of patients. Notes the need to divert those with mental health illness and intellectual disability away from the criminal justice system.

Values underpinning service.

Person-centeredness

In line with what has been noted previously, many of the sources which provide guidance to organisations and professionals note the importance of having the person with intellectual disabilities central to provision of service, whether this related to personal development (HIQA, 2013), person-centred transition (Selik et al., 2023) or, more generally, to person-centeredness (MHC, 2009; NHS, 2024). This is linked to other related concepts such as accepting the diversity or uniqueness of the person, inclusion and holism (MHC, 2023). These all, in turn, speak to the importance of service being underpinned by human rights.

Human Rights

Valuing a person for their innate humanity and personhood, brings with it an expectation that they will be afforded fundamental human rights and, more specifically, the rights embodied in disability-related conventions such as the CRPD. These are set out in the Guidance on a Human Rights-Based Approach in Health and Social Services (Safeguarding Ireland, 2019) using the FREDA Principles of fairness, respect, equality, dignity and autonomy (Curtice and Exworthy, 2010). As these relate closely to the European Convention on Human Rights (Council of Europe, 1950), they provide an important benchmark for assessing how a mental health service is adhering to its requirements. Thus, they form a vital benchmark when any rights are required to be curtailed (MHC, 2022a, 2022b, 2022c, 2022d). They also play an important role in ensuring that the culture of such a service is rights-based and are clearly embedded in the recent Culture of Care Standards for Mental Health Services issued by the UK's National Health Service (NHS, 2024).

Capacity and Decision-Making

Person-centeredness and human rights-based approaches recognise the autonomy of the person and, in turn, progress from a point of presuming that a person has capacity to make decisions in respect of their life. Whereas the legal basis for this has been addressed already, this presumption of the person's ability to make decisions is present in many of the reviewed guidelines, including those issued by the Mental Health Commission in 2009 and implicitly in the 2016 NICE guidelines. More recent guidance, from the National Health Service (NHS, 2024) and the Decision Support Service's (2023) Code of Practice for Healthcare Professionals clearly recognise the importance of recognising and maximising capacity while, where necessary, supporting decision-making.

Consultation and Communication

Decision-making can only take place when one is in position of information relevant to those decisions. Thus, it is important that the including the person with dual diagnosis is provided with information to allow them to consent to, or refuse a given treatment or interventions (NICE, 2016). This supports relationships between organisations, professionals and those who are in receipt of their services,

positively impacting the culture (MHC, 2023; NHS, 2024) and involving the person, family and carers in treatment planning (NICE, 2016; MHC, 2022b, 2022c, 2022d; HIQA, 2023; Selik et al., 2023). HIQA (2013) and MHC (2023) also highlight the importance of communication with all stakeholders (internal and external), including the multidisciplinary team and others who may be engaged in supporting the person's health, providing for an integrated approach to care and timely access to services.

Service Provision

Several of the sources reviewed address the importance of strong governance in ensuring the delivery of quality mental health services (HIQA, 2023; MHC, 2022a, 2022b, 2022c, 2022d; MHC, 2023). Such governance includes demonstrating external accountability in respect of regulatory requirements (MHC, 2020), but also internal accountability, characterised by transparency and responsivity, actively engaging the opinions of stakeholders, particularly those availing of the service (Safeguarding Ireland, 2019; MHC, 2023; Selik et al., 2023; NHS, 2024). Responsivity implies that mental health services should be accessible to people with dual diagnosis. HIQA (2013) highlights this in respect of achievement of health outcomes, noting that there should be timely access to screening, assessment and mental health treatment. This is also noted by the National Institute for Health and Care Excellence (NICE, 2016) which points to the need for reasonable adjustments, where necessary. NICE (2016) considers accessibility and responsivity in the context of mental health services that have clear and integrated care pathways, providing a full range of interventions, and supported by appropriately qualified and skilled intellectual disability and mental health professionals, including those who have knowledge of the person. Care pathways incorporate planned transitions, something that is evident in The Government of Ontario's (2008) Joint Policy Guideline on the Provision of Community Mental Health and Developmental Services for Adults with a Dual Diagnosis. In this, the care pathway involves cross-sector collaboration with services provided by frontline health, mental health or specialist professionals, depending on the nature and severity of the mental health concern, with referral pathways between each group. NICE (2016) notes the importance of transition planning as part of the pathway between child and adult mental health services, recommending that this should start when the child is 14 years of age.

It has been noted that the models of service identify the specific professional roles that should be represented on mental health intellectual disability teams (HSE, 2021, 2022). The sources herein, however, focus on the importance of staff having the proper education, training and competencies and, in particular, the values that need to underpin their practice (MHC, 2022a, 2022b, 2022c, 2022d). Thus, person-centeredness and human valuing are emphasised across many of the reviewed sources (NHS, 2015; HIQA, 2023; MHC, 2023; NHS, 2024).

Conclusion

There was limited evidence available which spoke expressly to standards or codes of practice in relation to provision of service to people with a dual diagnosis of mental illness and intellectual disabilities. There were, however, sources which provided guidance to services and to professionals working in them. A principal finding which emerged from these relates to the approach that should underpin service, particularly person-centeredness, human rights and consultation in the context of decision-making capacity. This is in line with legislation and policy across jurisdictions, particularly as embodies in models of service. There was also further endorsement of an integrated approach to mental health service provision that is accessible and consultative. This, again, is something that has been a feature of the earlier reviews. These form important intersections across the reviews which will be explored in the following integrated discussion, and which will inform recommendations for inclusion in the guidance for those providing mental health support to people with mental illness and intellectual disabilities.

Summary and Recommendations

This rapid review sought to explore the literature pertaining to mental health services for people with a dual diagnosis of intellectual disability and mental illness. Searches were conducted focussing on current practice and policy regarding treatment and care of persons with intellectual disabilities and mental illness, and the key challenges faced by such persons in receiving quality care and treatment. Legislative and rights-based considerations were also reviewed along with standards and codes of practice pertaining to service regulation. This final section draws together the key findings from these reviews and synthesizes recommendations for consideration in respect of updating the MHC guidance for providers of mental health services for persons with intellectual disabilities. Three main areas for emerged, namely service model, service delivery and interventions, and these are contextualised by a number of key value-based underpinnings, such that services should be human rights based, person-centred, focused on the individual's capacity and consultatory (Figure 5).

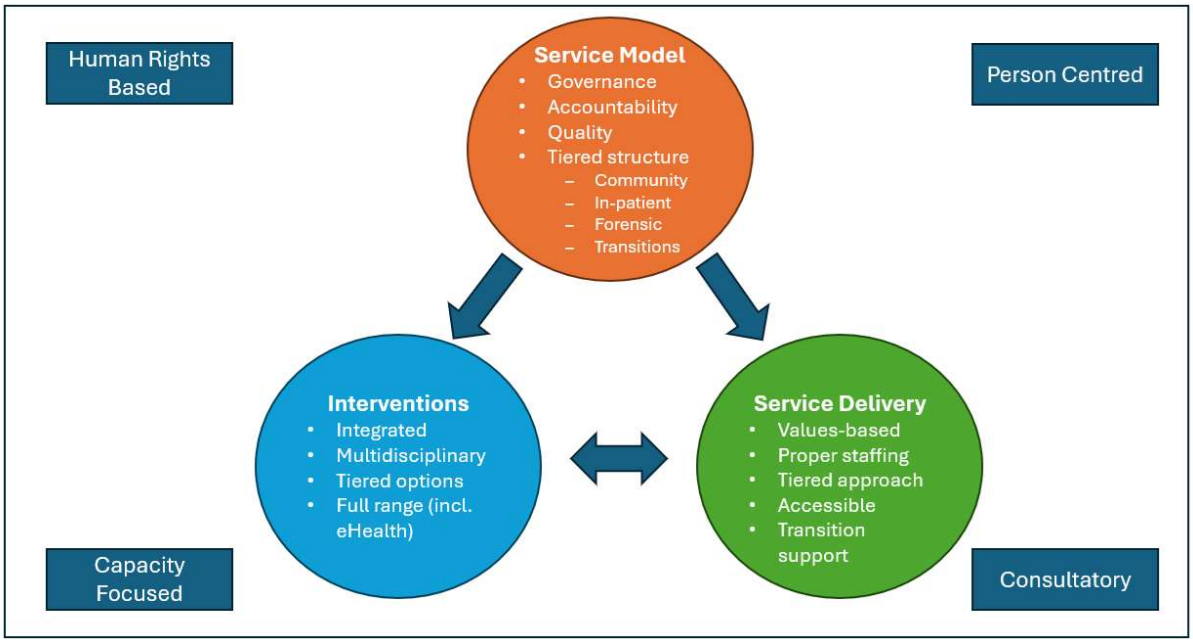

Figure 5 Priorities for service delivery to persons with intellectual disabilities and mental illness.

Service Model

The HSE has issued service models for meeting the needs of adults and children with intellectual disability and mental health concerns (HSE, 2021, 2022). These present proposals for how such services should be structured as well as identifying governance, accountability and monitoring. It is not clear, however, what role individuals with intellectual disabilities and other stakeholders have in such governance at local and national levels. It has been noted that the regulation of mental health services falls within the remit of the MHC. As it currently stands, most services have their mental health intellectual disability (MHID) teams integrated within the wider intellectual disability service

and these have, to date, fallen outside MHC regulation, as they were located in HIQA-regulated designated centres. This is likely due to the fact that intellectual disability service decongregation has preceded the development of the MHID service models, creating a service hiatus which has been filled by existing intellectual disability service providers. It is noted that newly established MHID teams are largely under HSE governance, but that the only approved intellectual disability beds are located in one HSE-run intellectual disability service; these are not admission beds, though, as envisaged in the service models.

Across the literature, there was widespread agreement that a quality service model should encompass a tiered approach, with community, in-patient and forensic components. It is envisaged that the first point of contact may be the individual's general practitioner or other healthcare professional, with the possibility of referral to more specialised personnel or teams, as required. The preference is for health care to be provided, where-ever possible, on a primary care basis. Where there is a need to move between service tiers or to other services, as well as back to community, this should be preceded by timely and inclusive transition planning. The provision of a seamless service, with inter-professional and inter-service collaboration, based on shared guidelines, should help to maximise service quality and impact positively on the user's experience.

Recommendation 1: The national service model for supporting the needs of people with dual diagnosis of intellectual disability and mental illness should demonstrate inclusive governance with clear external and internal lines of accountability.

Recommendation 2: The service model should provide a tiered approach to service delivery, with a preference for addressing the mental health need of people with intellectual disabilities in primary care settings.

Recommendation 3: The Irish Government and HSE should ensure that funding is provided to realise all aspects of the MHID service models.

Recommendation 4: All mental health services for people with intellectual disabilities, whether community, hospital or forensic based, should fall solely under the regulation of the Mental Health Commission.

Service Delivery

Much of the information extracted from professional literature and best practice documents highlighted the importance of service delivery being underpinned by key values, such as, person-centeredness, human rights, recognition of capacity and consultation. It was evident that these are considered central to all aspects of service including the point of contact, the approach to assessment and diagnosis, the decisioning regarding treatment, the delivery of therapeutic interventions and the

transition between tiers of mental service or, indeed, out of service. Staff are key in this regard, as they are the mediators for service delivery. There is a requirement that staff have the education and training required to provide quality mental health service, consummate with their position in the tiered structure. Clear guidelines and inter-professional collaboration should also ensure that there is a continuum or service, rather than fragmentation. This knowledge and skillset extends beyond assessment, diagnosis and treatment and includes the ability to provide information to people with intellectual disabilities in accessible formats, to support communication and to apply reasonable adjustments in how service delivery is provided. These adjustments also extend to the potential for incorporating eHealth or telehealth approaches, thus reducing stress brought on by travel and cost.

Recommendation 5: The HSE should develop a workforce strategy to identify the staffing needs, in terms of knowledge, skills and competencies, that are required to realise the MHID service models.

Recommendation 6: A competency framework should be developed to mainstream health and social care workers to meet front-line mental health support needs.

Recommendation 7: Higher education institutes and bodies responsible for the regulation of healthcare professionals in Ireland should require that education and training programmes provide content on intellectual disability (including mental health), as well as clinical placements supporting the needs of people with intellectual disabilities.

Interventions

The expectation that service models and service delivery should be guided by a tiered structure was also evident in how mental health interventions should be approached in respect of people with intellectual disabilities. Whereas medication has historically formed the first line approach to treatment, it is acknowledged that it forms just one part of a range of interventions, alongside psychological, psycho-social and digital health options. It is widely noted that people with intellectual disabilities should have this full range of interventions available to them, and their use should be based on assessed need.

Together, these may all be part of an integrated approach to care, which includes inter-disciplinary perspectives as well as those of people with intellectual disabilities and, where appropriate, those of carers or family members. This broader engagement in decision making brings with it a requirement for making information regarding treatment choices available in accessible formats. All therapeutic interventions should be evidence-based and underpinned by clear and agreed guidelines. Much of the literature and documents reviewed note that medication reviews should be instigated as a normal part of practice, and that psychotropic medication usage, in particular, should be closely monitored.

Recommendation 8: Services should ensure that a full range of interventions are available to meet the mental health needs of people with intellectual disabilities. Their usage should be based on assessed need.

Recommendation 9: Services should employ an integrated and consultatory approach in assessing the needs of people with dual diagnosis of intellectual disabilities and mental illness; this should extend to decisions regarding interventions.

Recommendation 10: Medication reviews, particularly in respect of psychotropic medications, should be enacted as a normal part of prescribing practice.

Research

It is acknowledged that this review was limited to a specific period of time and that it sought to identify recent research, policy and practice. Despite this, a number of evidence gaps were identified which require further examination. Some of these pertain in particular to those people with more significant and complex intellectual disabilities. Others relate to interventions other than pharmaceutical ones. These are presented here by way of recommendations for research.

Recommendation 11: Ongoing research is required in respect of the diagnosis of mental illness in people with severe and profound intellectual disabilities.

Recommendation 12: Research should be conducted regarding the prescription of medications for persons with severe and profound intellectual disabilities, particularly where symptoms and side effects can be self-reported.

Recommendation 13: Research is needed to explore the useability and usefulness of psychological and psychosocial Interventions for people with severe and profound intellectual disabilities.

Recommendation 14: Research into the effectiveness of non-pharmaceutical therapeutic interventions for people with intellectual disabilities and mental illness should be conducted, to include cohort and longitudinal studies.

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Appendices

Appendix 1: Inclusion and Exclusion Criteria for Objective 1 Searches

Review	Inclusion Criteria	Exclusion Criteria
Practice and Policy		
Population:	Persons with a dual diagnosis of intellectual disability and mental illness; aged 5 years and older.	Persons who do not have a dual diagnosis of intellectual disability and mental illness; persons age less than 5 years of age.
Intervention/Exposure:	Legislation; rights; national and international policy; practice guidelines; service strategy; standards.	
Context:	Mental illness; mental health crisis; mental health services; mental health intervention; mental health recovery.	Physical illness
Outcome:	Quality and service regulation.	
Study Characteristics:	Published between 2018 and 2023.	Published outside the years of 2018 and 2023; conference abstracts, posters.
Other:	Full text at no cost	Full text not readily available
Challenges		
Population:	Persons with dual diagnosis of intellectual disability and mental illness; persons with intellectual disability who use mental illness services; aged 5 years and older.	Children aged under 5 years; persons who do not have a dual diagnosis of intellectual disability and mental illness; challenging behaviour in absence of mental illness; autism and mental illness in the absence of intellectual disability.
Intervention/Exposure:	Mental health services; mental health care; mental health support; mental health crisis.	Provision of physical health services
Context:	Barriers; access; unmet need; challenges; best practice; equality	
Outcome:	Quality care; quality treatment	
Study Characteristics	Published between 2018 and 2023; research studies; studies from UK, Ireland, USA, Canada, NZ, Australia	Published outside the range 2018 – 2023; conference abstracts, posters; opinion and discussion articles.
Other:	Full text at no cost	Full text not readily available

Appendix 2: Intellectual Disability & Mental Health Practice and Policy Search Strategy

Concept 1: Intellectual Disability
Embase: 'mentally disabled person'/exp OR 'mental deficiency'/exp OR 'intellectual impairment'/exp
Medline: (MH "Mentally Disabled Persons") OR (MH "Intellectual Disability+") OR (MH "Learning Disorders+") OR (MH "Mental Retardation, X-Linked+") OR (MH "Developmental Disabilities")
CINAHL: (MH "Developmental Disabilities") OR (MH "Intellectual Disability") OR (MH "Mentally Disabled Persons") OR (MH "Mental Retardation, X-Linked+")
PsycINFO: DE "Intellectual Development Disorder" OR DE "Down's Syndrome"
WoS: Keywords on topic only

Embase Keywords(TI/AB): 'Intellectual Disabil*':ab,ti OR 'Intellectually disabled':ab,ti OR 'mentally disabled':ab,ti OR 'mental disabil*':ab,ti OR 'Intellectual Development Disorder*':ab,ti OR 'mental handicap*':ab,ti OR 'mentally handicapped':ab,ti OR 'mentally impaired':ab,ti OR 'mental impairment*':ab,ti OR 'intellectual impairment*':ab,ti OR 'developmental disabil*':ab,ti OR 'mental defici*':ab,ti OR 'intellectual retard*':ab,ti OR 'mental retard*':ab,ti OR 'mentally retarded':ab,ti OR 'intellectually challenged':ab,ti OR 'intellectually deficient*':ab,ti OR 'intellectually handicapped':ab,ti OR 'intellectually impaired':ab,ti OR 'intellectually retarded':ab,ti OR 'mentally challenged':ab,ti OR 'mentally defici*':ab,ti OR 'cognitive disab*':ab,ti

EBSCO Keywords: TI ("Intellectual Disabil*" OR "Intellectually disabled" OR "mentally disabled" OR "mental disabil*" OR "Intellectual Development Disorder*" OR "mental handicap*" OR "mentally handicapped" OR "mentally impaired" OR "mental impairment*" OR "intellectual impairment*" OR "mental defici*" OR "intellectual retard*" OR "mental retard*" OR "mentally retarded" OR "intellectually challenged" OR "intellectually deficient*" OR "intellectually handicapped" OR "intellectually impaired" OR "intellectually retarded" OR "mentally challenged" OR "mentally defici*" OR "cognitive disab*") OR AB ("Intellectual Disabil*" OR "Intellectually disabled" OR "mentally disabled" OR "mental disabil*" OR "Intellectual Development Disorder*" OR "mental handicap*" OR "mentally handicapped" OR "mentally impaired" OR "mental impairment*" OR "intellectual impairment*" OR "mental defici*" OR "intellectual retard*" OR "mental retard*" OR "mentally retarded" OR "intellectually challenged" OR "intellectually deficient*" OR "intellectually handicapped" OR "intellectually impaired" OR "intellectually retarded" OR "mentally challenged" OR "mentally defici*" OR "cognitive disab*")

Concept 2: Mental Health

Concept 2 Mental Health Services
EMBASE: (('health service'/exp OR 'health care facilities and services'/exp) AND ('mental health'/exp OR 'mental disease'/exp)) OR 'mental health care'/exp OR 'mental health service'/exp

Medline (MH "Mental Health Services+") OR (MH "Mental Health Recovery") OR (MH "Emergency Services, Psychiatric+") OR (MH "Counseling+") OR ((MH "Health Services+") OR (MH "Women's Health Services+") OR (MH "Health Services for the Aged") OR (MH "Preventive Health Services+") OR (MH "Rural Health Services+") AND ((MH "Mental Health") OR (MH "Mental Disorders+"))

CINAHL: (MH "Mental Health Services+") OR (MH "Counseling+") OR ((MH "Health Services+") OR

PsycINFO: DE "Preventive Mental Health Services" OR DE "Mental Health Services" OR DE "Psychological First Aid" OR DE "School Based Mental Health Services" OR DE "Community Mental Health Services" OR DE "Community Counseling" OR DE "Community Mental Health Centers" OR DE "Mental Health Disparities" OR DE "Mental Health Parity" OR DE "Mental Health Programs" OR DE "Crisis Intervention Services" OR DE "Deinstitutionalization" OR DE "Hot Line Services" OR DE "Suicide Prevention Centers" OR DE "Psychiatric Hospital Programs" OR DE "Preventive Mental Health Services" OR DE "Behavioral Health Services"

WOS: Keywords run on topic

EMBASE Keywords: (Health* OR care OR nurs* OR medic* OR clinic* OR support* OR service*) NEAR/2 (mental* OR psych* OR wellbeing* OR anxiet* OR depress* OR vulnerab* OR suicid* OR crisis*)
EBSCO Keywords: (Health* OR care OR nurs* OR medic* OR clinic* OR support* OR service* OR counsel*) N2 (mental* OR psych* OR wellbeing* OR anxiet* OR depress* OR vulnerab* OR suicid* OR crisis*)

Concept 3: Policy & Practice
EMBASE: 'policy'/exp OR 'best practice'/exp OR 'framework'/exp OR 'law'/ OR 'Convention on the Rights of Persons with Disabilities'/exp
Medline: (MH "Legislation as Topic+") OR (MH "Policy+") OR (MH "Public Policy+") OR (MH "Health Policy+") OR (MH "Policy Making+") OR (MH "International Law") OR (MH "Practice Guidelines as Topic") OR (MH "Guidelines as Topic+")
CINAHL: (MH "Guideline Adherence") OR (MH "Legislation+") OR (MH "Hospital Policies+") OR (MH "Rules and Regulations") OR (MH "Public Policy+") OR (MH "Organizational Policies+") OR (MH "Legislation, Medical+") OR (MH "Legislation, Nursing+") OR (MH "Practice Guidelines") OR (MH "Parliamentary Practice") OR (MH "Guideline Adherence") OR (MH "Professional Regulation") OR (MH "Government Regulations+") OR (MH "Conceptual Framework")
PsycINFO: DE "Disability Laws" OR DE "Americans with Disabilities Act" OR DE "Laws" OR DE "Abortion Laws" OR DE "Affordable Care Act" OR DE "Disability Laws" OR DE "Discrimination Laws" OR DE "Drug Laws" OR DE "Law (Government)" OR DE "Civil Law" OR DE "Criminal Law" OR DE "Discrimination Laws" OR DE "Best Practices" OR DE "Clinical Practice" OR DE "Professional Boundaries" OR DE "Clinical Governance"
Web of Science:

EMBASE: 'best practice*':ab,ti OR policy:ab,ti OR policies:ab,ti OR 'service strateg*':ab,ti OR standard*:ab,ti OR guidance*:ab,ti OR guidelines:ab,ti OR 'service* framework*':ab,ti OR 'codes of practice':ab,ti OR 'convention on the rights':ab,ti OR legislat*:ab,ti OR ‘pathway*’:ab,ti

EBSCO Keywords title and abstract: “best practice*” OR policy OR policies OR “service strateg*” OR standard* OR guidance* OR guideline* OR “service* framework*” OR “code* of practice” OR “convention on the right*” OR legislat* OR pathway*

Appendix 3: Intellectual Disability and Mental Health Challenges Search Strategy

Concept 1: Intellectual Disability

Embase: 'mentally disabled person'/exp OR 'mental deficiency'/exp OR 'intellectual impairment'/exp

Medline: (MH "Mentally Disabled Persons") OR (MH "Intellectual Disability+") OR (MH "Learning Disorders+") OR (MH "Mental Retardation, X-Linked+") OR (MH "Developmental Disabilities")

CINAHL: (MH "Developmental Disabilities") OR (MH "Intellectual Disability") OR (MH "Mentally Disabled Persons") OR (MH "Mental Retardation, X-Linked+")

PsycINFO: DE "Intellectual Development Disorder" OR DE "Down's Syndrome"

WoS: Keywords on topic only

Embase Keywords(TI/AB): 'Intellectual Disabil*':ab,ti OR 'Intellectually disabled':ab,ti OR 'mentally disabled':ab,ti OR 'mental disabil*':ab,ti OR 'Intellectual Development Disorder*':ab,ti OR 'mental handicap*':ab,ti OR 'mentally handicapped':ab,ti OR 'mentally impaired':ab,ti OR 'mental impairment*':ab,ti OR 'intellectual impairment*':ab,ti OR 'developmental disabil*':ab,ti OR 'mental defici*':ab,ti OR 'intellectual retard*':ab,ti OR 'mental retard*':ab,ti OR 'mentally retarded':ab,ti OR 'intellectually challenged':ab,ti OR 'intellectually deficient*':ab,ti OR 'intellectually handicapped':ab,ti OR 'intellectually impaired':ab,ti OR 'intellectually retarded':ab,ti OR 'mentally challenged':ab,ti OR 'mentally defici*':ab,ti OR 'cognitive disab*':ab,ti

EBSCO Keywords: TI ("Intellectual Disabil*" OR "Intellectually disabled" OR "mentally disabled" OR "mental disabil*" OR "Intellectual Development Disorder*" OR "mental handicap*" OR "mentally handicapped" OR "mentally impaired" OR "mental impairment*" OR "intellectual impairment*" OR "mental defici*" OR "intellectual retard*" OR "mental retard*" OR "mentally retarded" OR "intellectually challenged" OR "intellectually deficient*" OR "intellectually handicapped" OR "intellectually impaired" OR "intellectually retarded" OR "mentally challenged" OR "mental defici*" OR "cognitive disab*") OR AB ("Intellectual Disabil*" OR "Intellectually disabled" OR "mentally disabled" OR "mental disabil*" OR "Intellectual Development Disorder*" OR "mental handicap*" OR "mentally handicapped" OR "mentally impaired" OR "mental impairment*" OR "intellectual impairment*" OR "mental defici*" OR "intellectual retard*" OR "mental retard*" OR "mentally retarded" OR "intellectually challenged" OR "intellectually deficient*" OR "intellectually handicapped" OR "intellectually impaired" OR "intellectually retarded" OR "mentally challenged" OR "mental defici*" OR "cognitive disab*")

Concept 2 Mental Health Services

EMBASE: (('health service'/exp OR 'health care facilities and services'/exp) AND ('mental health'/exp OR 'mental disease'/exp)) OR 'mental health care'/exp OR 'mental health service'/exp

Medline (MH "Mental Health Services+") OR (MH "Mental Health Recovery") OR (MH "Emergency Services, Psychiatric+") OR (MH "Counseling+") OR ((MH "Health Services+") OR (MH "Women's Health Services+") OR (MH "Health Services for the Aged") OR (MH "Preventive Health Services+") OR (MH "Rural Health Services+")) AND ((MH "Mental Health") OR (MH "Mental Disorders+"))

CINAHL: (MH "Mental Health Services+") OR (MH "Counseling+")

PsycINFO: DE "Preventive Mental Health Services" OR DE "Mental Health Services" OR DE "Psychological First Aid" OR DE "School Based Mental Health Services" OR DE "Community Mental Health Services" OR DE "Community Counseling" OR DE "Community Mental Health Centers" OR DE "Mental Health Disparities" OR DE "Mental Health Parity" OR DE "Mental Health Programs" OR DE "Crisis Intervention Services" OR DE "Deinstitutionalization" OR DE "Hot Line Services" OR DE "Suicide Prevention Centers" OR DE "Psychiatric Hospital Programs" OR DE "Preventive Mental Health Services" OR DE "Behavioral Health Services"

Wos:

EMBASE Keywords: (Health* OR care OR nurs* OR medic* OR clinic* OR support* OR service*) NEAR/2 (mental* OR psych* OR wellbeing* OR anxiet* OR depress* OR vulnerab* OR suicid* OR crisis*)

EBSCO Keywords: (Health* OR care OR nurs* OR medic* OR clinic* OR support* OR service*) N2 (mental* OR psych* OR wellbeing* OR anxiet* OR depress* OR vulnerab* OR suicid* OR crisis*)

Concept 3: Barriers

EMBASE: 'health care access'/exp

Medline: (MH "Health Services Accessibility+")

CINAHL: (MH "Health Services Accessibility+") OR (MH "Access to Primary Care")

PsycINFO: (DE "Health Care Access" OR DE "Treatment Barriers" OR DE "Accessibility (Disabilities)" OR DE "Health Service Needs")

Wos:

Keywords in title and abstract: (attitud*:ab,ti OR barrier*:ab,ti OR challeng*:ab,ti OR hinder*:ab,ti OR hindr*:ab,ti OR bias*:ab,ti OR discriminat*:ab,ti OR gap*:ab,ti OR inequalit*:ab,ti OR disparit*:ab,ti OR unequal*:ab,ti OR restrict*:ab,ti OR stigma*:ab,ti OR percept*:ab,ti OR exclu*:ab,ti OR fear*:ab,ti OR anxiety*:ab,ti) AND (access*:ab,ti OR use*:ab,ti OR usage*:ab,ti OR utilis*:ab,ti)

EBSCO Keywords: (attitud* OR barrier* OR challeng* OR hinder* OR hindr* OR bias* OR discriminat* OR gap* OR inequalit* OR disparit* OR unequal* OR restrict* OR stigma* OR percept* OR exclu* OR fear* OR anxiety*) AND (access* OR use* OR usage* OR utilis*)