Mental Health Services for Adults
with Intellectual Disabilities

National Model of Service

HSE Mental Health Services

Seirbhís Sláinte Níos Fearr á Forbairt | Building a Better Health Service

Contents

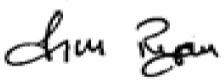
Foreword

This document proposes a framework for providing specialist mental health services for people with an intellectual disability. It recognises the strengths of existing services while acknowledging the challenges that must be faced.

Extensive consultation with clinicians, service users, families and service providers informed this policy. A number of vignettes help to provide clarity and a template advises on the delivery of a person-centred approach to managing some of the service boundary issues. Service providers highlighted their priorities too, articulating a clear need for adequate resources to enable them to respond to the full medical, psychological and social needs of service users and their families.

This model also proposes that solutions for people with intellectual disability and mental health needs lie in establishing effective partnerships between healthcare providers, service users and their carers, in a community-wide context. Furthermore, it looks at the comprehensive range of interventions provided, including the use of inpatient settings where necessary.

The document was led on by the offices of the National Mental Health of Intellectual Disability (MHID) Clinical Developmental Lead and Service Improvement Lead, involving significant consultation as outlined.



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Acknowledgement and thanks go particularly to the service users and their families and carers who engaged in consultation with us to help shape this report.

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Executive summary

People with intellectual disability should access support from mental health services in the same way as the general population, within a framework which is multi-disciplinary and catchment area-based. Team members should have appropriate training and expertise, and teams should be suitably resourced. Recommendations for the mental health of intellectual disability (MHID) model of service follow similar international models. It is imperative that MHID services capture the work they do, and use evidence-based practice. Guidance in this model is provided to work towards service provision which is person-centred, integrated and with a clear governance structure.

There are a number of challenges in delivering mental health services for people with intellectual disability. Recruitment is a significant issue, as is the interface between mental health and social care, and intellectual disability and general adult services. Local and national leadership fostering a person-centred approach which ensures that service users are appropriately assessed and treated in a timely manner are key aspects in the provision of these services.

Summary of key recommendations

1. Mental health services for people with intellectual disability should be provided by a specialist mental health of intellectual disability (MHID) team that is catchment area-based. The multidisciplinary MHID teams should be provided on the basis of two per 300,000 population for adults with intellectual disability.
2. These services should be distinct and separate from, but closely linked to, the multidisciplinary teams in Intellectual Disability Services, who provide a health and social care service for people with intellectual disability.
3. The core multidisciplinary team to deliver mental health services to adults with intellectual disability and a mental health problem and or challenging behaviour (where there is some suspicion of mental illness) should comprise key individuals from the disciplines of psychiatry, psychology, nursing, social work, occupational therapy (OT) and speech and language therapy (SaLT), in addition to an administrator.
4. Transition of care between child and adult MHID services is vital.
5. Model of service should be reviewed and updated where appropriate, within a two year timeframe.
6. Although this model provides national guidance, it is not a prescriptive approach but rather a flexible guide. Teams should decide how best to encompass national standards, but also how to adopt the model as necessary, based on local requirements and geography.

1. Introduction

1. Introduction

This introductory section provides the context and background to provide an up-to-date understanding of MHID and this report's purpose and structure. It provides an overview of the relationship between intellectual disability and mental health, current MHID services in Ireland and how they have developed from de-institutionalisation to the HSE's Vision for Change framework.

1.1 Purpose

The purpose of this report is to detail a national model of service which will improve the mental health provision for people with intellectual disability, by advancing the development of specialist mental health services for adults with such a disability nationally, and the standards of care provided to service users and their families.

This specialist service is provided by community MHID teams. Our model is designed to be a guide for MHID management and teams, but is also for supporting partners in the care of people with intellectual disability, including disability services, voluntary agencies and mainstream mental health services.

This mental health model of service represents a 'One Stop Shop' to bring together all the different strands of information that are needed to better understand how to improve MHID services in Ireland. Specifically it has drawn on relevant information from:

- Strategic HSE and mental health policy documents and reports
- Service users, family members, carers, staff and subject matter experts
- Innovation and best practice reviews

1.2 Report structure

To comprehensively address the remit of this report, it has been divided up into nine key sections, as follows:

Section 1: Introduction – provides the context and background to the model of service and the development of specialist mental health services for adults with intellectual disability.

Section 2: Model of service overview – provides details on the specific aims of the model, its benefits, who the model is for and how the model was developed.

Section 3: MHID specialist service – focuses on specific details of an MHID service and why a specialist service is needed.

Section 4: Integrated care – outlines the importance of collaborative working between the MHID team and other services that may provide care for service users.

Section 5: Service user's journey through an MHID service – details the four main stages of care a service user can expect to experience as he or she journeys through the service.

Section 6: Specialist populations – outlines the specific mental health requirements of service users who may have a mild intellectual disability, be on the autism spectrum disorder (ASD) and or who need forensic supports, and where applicable, the degree of support MHID teams can provide.

Section 7: Governance – details the governance structures for MHID teams, including clinical responsibility, key workers, continuous professional development and metrics.

Section 8: Team supports and resources – provides an overview of additional supports and resources an MHID team will require, including suitable facilities.

Section 9: Legal and ethical considerations – outlines key pieces of relevant legislation and national guidance from overseeing bodies, within which MHID teams need to operate.

1.3 The relationship between mental health and intellectual disability

People with an intellectual disability experience very poor mental health compared to the general population (Deb et al., 2001), with common mental disorders occurring around two to three times more often. Four in every ten people with intellectual disability experience a mental illness in their lifetime (Cooper et al., 2007). Psychosis, bipolar disorder and neurodevelopmental conditions such as attention deficit hyperactivity disorder, are all more commonly experienced by people with an intellectual disability, than in people without, and emotional disorders are at least as common.

Vulnerability of people with an intellectual disability to mental health problems may be underpinned by:

- Communication difficulties, for example social communication disorders or being non-verbal
- Reduced coping strategies and social skills
- High prevalence of neurodevelopmental disorder – notably autism spectrum disorder and attention deficit hyperactivity disorder
- Increase in physical health problems, for example, epilepsy, sleep disorders and cerebral palsy
- Increase in genetic conditions, including rare syndromes
- Socioeconomic deprivation and poverty
- Difficult educational experiences and insufficient supportive services
- Increase in rate of adverse life events
- Reduced opportunities to engage in a range of life choices, and restricted social networks
- Carer fatigue and burnout, which can impact on the quality of support available to people with an intellectual disability.

The presentation of mental disorders in people with an intellectual disability

The presentation of both physical and mental health problems can be influenced by a person's level of intellectual disability and the presence of any associated communication difficulties. People with milder intellectual disability and good communication skills are usually able to describe what they are experiencing, and typically present in a manner familiar to most mental health professionals.

However, presentation is often atypical in those with more severe intellectual disability or in people with communication difficulties. This can mean that mental disorders mainly present behaviours which are problematic for the person or their support system. Therefore, individuals showing behavioural changes require careful assessment for a range of potential contributing factors, including underlying mental or physical health conditions. Such complex presentations highlight the importance of a multidisciplinary approach to assessing behavioural changes in people with intellectual disabilities.

It is vital for all those working with people with intellectual disabilities, to understand the phenomenon of 'diagnostic overshadowing'. Diagnostic overshadowing means that symptoms of mental ill-health are misattributed to the intellectual disability rather than being recognised as part of the manifestation of a mental disorder.

Section 3 of this report outlines in more detail why a specialist mental health service is needed for people suffering from an intellectual disability, but these specific clinical challenges highlight why people with such disabilities are best cared for and supported by mental health professionals who have specialised in this area.

1.4 De-institutionalisation and normalisation

In nineteenth-century Ireland, asylums were developed in line with the United States, the United Kingdom and other countries. These initially were developed as 'moral treatment' centres for people with psychiatric disorders which were potentially curable, but developed into crowded institutions which were unable to provide quality of care. The deinstitutionalisation movement's main aim was to replace asylums with community services and coincided with the advent of effective new treatments in the 1950s. During the latter decades of the twentieth century, general mental health services in Ireland changed considerably, mirroring changes in other countries such as our nearest neighbours in the United Kingdom. Starting with the *Planning for the Future* initiative from the Department of Health in 1984, services have increasingly moved away from inpatient treatment to a community-based model.

Social care provision for people with intellectual disability in Ireland has also changed significantly over time. In line with psychiatry services, for a period of 100 years from the 1850s onwards, special residential centres for children and adults with intellectual disabilities were set up in Ireland, mainly by religious orders. However, from the 1950s, the development of community-based services began to emerge, spearheaded by parents and friends groups. From the 1980s onwards, the thrust of policy and practice has been moving steadily towards community inclusion for people with disabilities.

Public policy in Ireland over the past twenty years has favoured the development of community-based services and *Needs and Abilities,* the policy for people with intellectual disabilities, published in 1990, made detailed recommendations for discontinuing residential provision that is not domestic in scale.

In June 2011 the report *Time To Move On From Congregated Settings – A Strategy for Community Inclusion* was published. That report identified that in 2008 approximately 4,000 individuals with disabilities lived in congregated-type settings and made thirty-one recommendations for enabling individuals in congregated settings to transition to homes in the community. By 31 December 2016 there was a reduction to 2,579 people who remained living in congregated settings in Ireland, and these numbers are gradually decreasing.

Day services for people with intellectual disabilities have also changed. *New Directions* was published by the HSE in 2012. That report set out a new approach to day services that envisaged all the supports available in communities would be mobilised so that people with disabilities would have the widest choice about how to live their lives and how to spend their time. The *National Disability Strategy* (NDS), which was launched by the Irish Government in 2004, represented a fundamental shift towards social inclusion and full citizenship for people with disabilities, and made specific legal provision for the mainstreaming of access to public services. The main objective of the *National Disability Strategy* is that people with disabilities should be supported to be active and contributing members of society. The Disability Act 2005, which is a core element of the NDS, places a duty on six key government departments to prepare and publish sectoral plans.

1.5 Development of mental health services for people with intellectual disability

Internationally, service planners and providers assumed that mental health problems for people with intellectual disability would substantially reduce when community care programmes were put in place following de-institutionalisation. Overall, people with such disabilities and their families have benefitted from this policy change and have experienced improved quality of life and opportunities. However, as increasing numbers of institutions closed in the United Kingdom and the United States, the needs of people with intellectual disabilities who have mental health problems became more evident. It became clear that when service users moved to community settings, services were required from both the intellectual disability network and the mental health system.

The expectation in some countries has been that health services, including mental health, would seamlessly assume responsibility for treating the mental health problems experienced by people with intellectual disabilities living in the community. However mainstream psychiatric services were unprepared to respond to the needs of this population, due to significant caseloads, and the fact that service users with learning disabilities sometimes required specialist input in relation to their communication needs and the interpretation of atypical symptoms and signs.

Historically, services for people with intellectual disabilities in Ireland have been provided primarily through the voluntary sector, often religious orders (Holt et al., 2000) and therefore evolved to include mental health service provision separate from general psychiatry services. These services have mainly been provided by psychiatrists employed through the voluntary bodies, funded by the HSE.

There has been a notable commitment to intellectual disability mental health training in Ireland in recent years. Psychiatry of Learning Disability has long been recognised as a distinct psychiatric specialty in Ireland, provided through the Royal College of Psychiatrists up to 2009, and the College of Psychiatrists

of Ireland from its foundation in 2009. Indeed psychiatry of Learning Disability is one of four specialty registers maintained by the Irish Medical Council for psychiatry and most specialists in intellectual disability psychiatry are dual trained, both in that discipline and in general adult psychiatry. There is therefore a core body of psychiatrists with specialist training in MHID in Ireland. In addition, high-quality training in clinical psychology in Ireland generally includes rotations in intellectual disability placements. This support for training in that area has also been reflected in the long-standing existence (since 1974) of a special interest group in intellectual disability with the Psychological Society of Ireland.

However, mental health services for people with intellectual disabilities in Ireland remained limited and extremely variable by geographical area and social care service. Irish practice has been studied in the context of other European countries (Holt et al., 2000). That review found that, in common with other European services in Greece, Spain and Austria, access to specialist MHID services in Ireland was patchy and primarily based in larger urban centres.

1.6 A Vision for Change and mental health of intellectual disability

Mental health services in Ireland have been evolving over the last several years in line with *A Vision for Change* (2006) and the more recent, *Sharing the Vision, A Mental Health Policy for Everyone* (2020), both of which were published as blueprints for future mental health services.

Chapter 14 of *A Vision for Change* (2006) set out the roadmap for developing MHID services. The underlying principle is that the process of service delivery of mental health services to people with intellectual disability should be similar to that for every other citizen. Mental health services for people with Intellectual disability should be provided by a specialist MHID team that is catchment area-based.

These services should be distinct and separate from, but closely linked to, the multidisciplinary teams in intellectual disability services who provide a health and social care service for people with intellectual disability. The multidisciplinary MHID teams should be provided on the basis of two per 300,000 population for adults and one per 300,000 for children with intellectual disability.

A Vision for Change and *Sharing the Vision* also advised that the training, skills and experience of all members of the multidisciplinary MHID teams are crucial. All team members should have dual training or equivalent, and experience of treating mental health problems in people with intellectual disability.

The composition of each MHID team should ensure that an appropriate mix of skills is available to provide a range of best practice therapeutic interventions. A range of therapeutic expertise should be available within each team according to the needs of service users. Other mental health professionals and other health professionals like creative therapists, should be brought in as required to address these needs. Section 3.4 of this report outlines the mental health professionals that are recommended to comprise each core multidisciplinary MHID team, and it details their specific roles and responsibilities.

It is important to note that *A Vision for Change* mental health policy is in line with the World Health Organisation Mental Health Action Plan (2013–2020), which promotes 'Community-based service delivery for mental health needs to encompass a recovery-based approach that puts the emphasis on supporting individuals with mental disorders and psychosocial disabilities to achieve their own aspirations and goals.' The guiding principles of this report, see Section 2.5, affirm this policy.

The process of developing the MHID teams in Ireland has begun, with the formation of several small teams around the country. However, there is a need for ongoing investment and integration between primary care, intellectual disability and mental health services.

At time of writing this document the teams were (for adults with intellectual disability) at 33 per cent capacity of the required service levels outlined in *Vision for Change*. Within the mental health services of the HSE this has been highlighted and a service improvement project was initiated to continue to develop community MHID teams nationally.

Sharing the Vision highlights the importance of prioritising investment in mental health services as developed through the HSE MHID service improvement programme. It also advocates for innovative acute treatment services, including therapeutic respite. Its implementation roadmap may provide a pathway for further development of MHID services.

1.7 Overview of current MHID services

'We would love to have our own community team and have those relationships.' – family member

'Have a nurse that knows me. I need to be supported by someone I trust and know'. – service user

(Extract from focus group with service users, family members and carers)

Despite the over-representation of mental health problems in people with intellectual disability as referenced in Section 1.3, access to mental healthcare in Ireland may fall short of what is required to meet the needs of individuals who may be at increased risk. As mentioned above, MHID services are at 33 per cent of the required service levels outlined in *Vision for Change*. There are currently twelve partial adult MHID teams nationally (September 2020) whereas *A Vision for Change* recommends 29 adult MHID teams in Ireland, based on two teams per 300,000 adult population.

The National Disability Authority published a detailed report reviewing the access to mental health services for people with intellectual disability in 2003. The report noted that: 'Persons registered with a mainstream intellectual disability service provider find it more difficult or impossible to gain access to appropriate mental health services for assessment, treatment or continuing care. The same situation still currently exists, with many people encountering significant barriers which prevent timely access to appropriately skilled mental health supports and services'.

People with intellectual disability, their families and carers, along with professionals from mental health, disability and other services, all agree that improvement in access to mental health supports and services is required. One fundamental barrier is the difficulty of securing admission to a service provider for assessment by mental health clinicians. Early detection of potential mental health problems along with timely referral from primary care service providers to necessary community or acute services is needed to effectively understand and meet the service users' needs.

'It's very difficult to access services', 'Getting services is so hard', 'No-one wants us'

(Extract from focus group with service users, family members and carers)

This document aims to provide a model of service for the emerging multidisciplinary MHID teams around the country, to promote early intervention with evidenced-based treatments and to support a recovery-oriented mental health service recovery, in line with the HSE's *The National Framework for Recovery in Mental Health,* (2017).

Ireland ratified the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD) in March 2018 and this affirms that all persons with a disability must enjoy the same fundamental human rights and basic freedoms as do those without a disability. Families and service users in our consultation for this document stressed this point and told us that they were not understood, felt invisible and were not given dignity and respect.

'Not seen as a real person', 'People with ID seen as separate, invisible.'

(Extract from focus group with service users, family members and carers)

Achieving health equity for people with intellectual disability includes provision of better mental health services which recognise the changing face of mental health and disability services in Ireland.

2. Model of service overview

2. Model of service overview

This section of the report provides greater detail on the specific aims of the model, its benefits, who the model is for and how the model was developed, based on guiding principles, consultation and international research.

2.1 Aim and objectives

This model of service was developed to provide a national vision and strategic direction for the implementation of specialist MHID teams within an integrated system of care. The need for the model was based on an acknowledgement that previously there had been a standards vacuum, with no nationally agreed framework which would enable existing and future MHID teams to deliver services in a consistent and co-ordinated manner across the country.

This model addresses that vacuum, and provides national guidance on how to deliver integrated, person-centred services consistently across the country. The model also represents the HSE's commitment to improve standards and quality in the provision of mental health services to people with intellectual disability.

The primary aim of the model is to improve the mental health service experience and outcomes for people with an intellectual disability and their supporters, by providing national guidance and clarification on:

- How MHID services can be delivered in line with best practice standards, while defining what a good MHID service should look like.
- The roles and responsibilities of the different MHID team members.
- How to work collaboratively with other mental health, disability and primary care services to ensure all services are working together and enabling joined-up thinking, to achieve the best care for service users.
- Detailed care pathways for service users as they journey through the service, and information on the type and level of care that can be expected by a service user when entering a modelled care service.
- The considerations needed for specialty populations of service users.
- Recommended governance for MHID teams.
- The support infrastructure and resources needed for an MHID team.
- Legal and ethical considerations under which an MHID team needs to operate.

Important note

- Although this model provides national guidance, it is not a prescriptive approach but rather a flexible guide. Teams should decide how best to encompass national standards, but also how to adopt the model as necessary, based on local requirements and geography.
- This model of service relates to adult MHID teams, with at least a baseline minimum team, consisting of a consultant psychiatrist, psychologist and clinical nurse specialist (CNS) along with administration support.

2.2 Who is the model of service for?

The primary audience for this model of service is MHID management and team members. However, based on the model's whole system and person-centred approach, it is of use to multiple users in helping them understand what an MHID service can offer.

Overall this model of service is of value for:

- **MHID specialist teams** – to clearly show how local staff and teams can deliver an MHID service in line with best practice and core principles.
- **Service users and their families** – outlines what service users and their families can expect from their MHID service. It can also provide them with important information on their care and how to better understand how MHID teams and other services should work together.
- **Mental health management, both HSE and voluntary agency** – provides an overview of how to deliver and plan for MHID services and what is needed to ensure that quality and safety standards are met.
- **Child and adolescent mental health (CAMHS) and intellectual disability teams** – helps CAMHS-ID staff to understand what to expect for their service users as they progress into adult services and therefore how best to plan for and manage that transition.
- **Disability services** – outlines how disability services and mental health services can work together to help service users and their families. It clearly defines roles and responsibilities for all services and staff and what supports they can expect from an MHID team.
- **Community general adult HSE mental health teams** – outlines how general adult mental health services can work together to help services users and their families, and how MHID services can support their colleagues in their provision of care.
- **Other professionals and trainees** – acts as a useful resource for professionals and student trainees who have little experience of the mental health needs of adults with a learning disability.

2.3 Benefits of the model of service

The model will also help to improve the mental health service experience and outcomes for people with an intellectual disability and their supporters by:

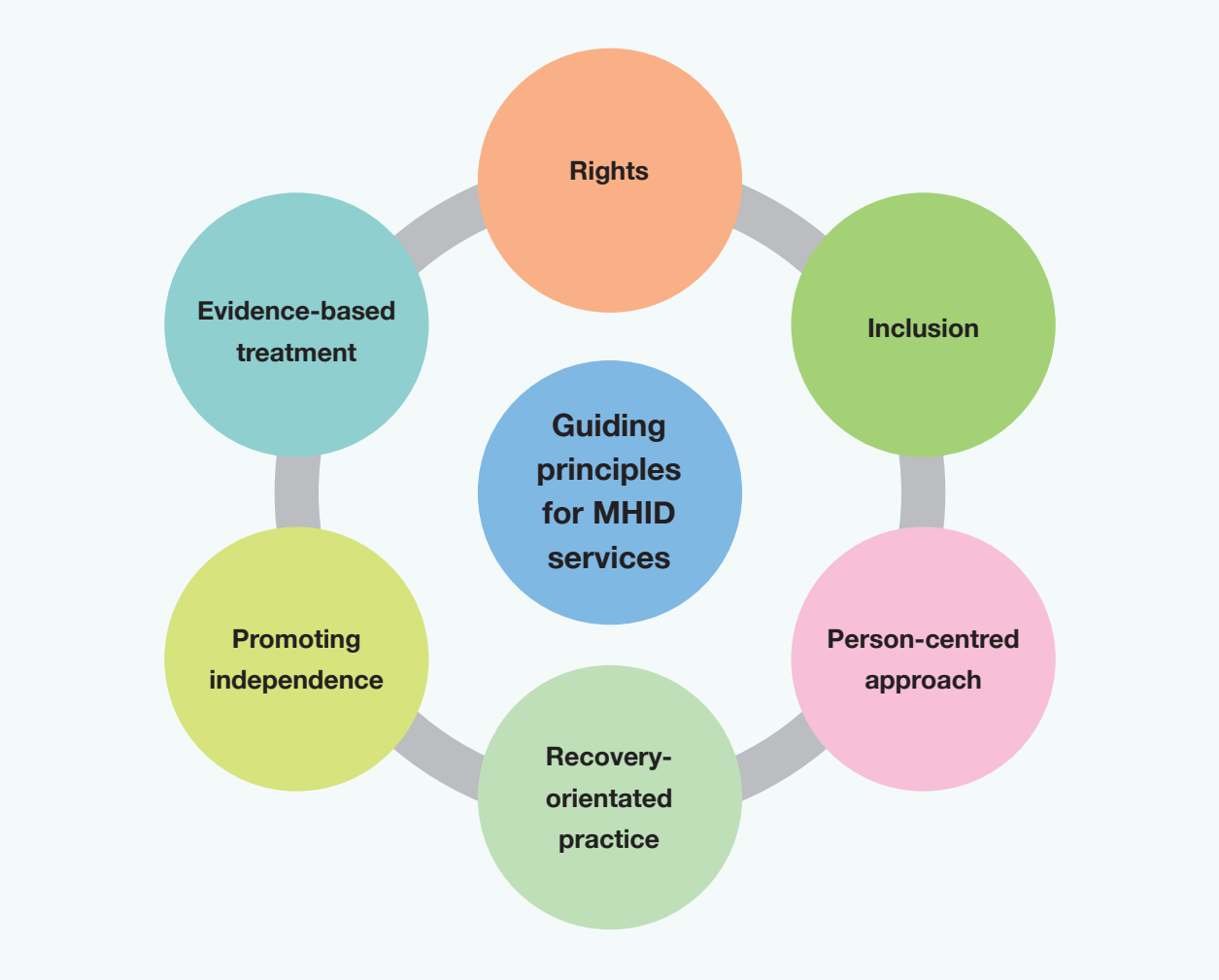
- Facilitating collaboration within the existing system in a way that enables a whole-system approach, achieving better services and outcomes for service users and their families.
- Facilitating partnership in working with service users, family members and carers.
- Facilitating partnership in working with other care providers. For example, by developing consensus in care planning, joint working protocols and greater liaison and communication.
- Providing better support and understanding for clinical staff members.
- Advising staff on expected and acceptable levels of care and service.
- Providing a foundation for improved design and delivery of training and education programmes for specialist staff, service users and mainstream mental health and disability staff.
- Assisting planning for MHID service delivery, including efficient utilisation of resources and future workforce development.

When implemented, this model of service will help service users and their families to achieve their best clinical outcomes and meaningful recovery. This will be achieved by enhancing the ability of all Irish service providers of mental health services for adults with intellectual disability, both HSE and voluntary agencies, to deliver accessible and safe services to a high quality and standard.

2.4 Guiding principles for MHID services

The model of service is based on six guiding principles – see Figure 1 below. These guiding principles provide a pathway for the development of this model and for its subsequent recommended care.

Figure 1: Guiding principles for MHID services



Human rights

A human rights framework in healthcare identifies people with a disability as having a right to health and healthcare. In relation to health services, *The United Nations Convention on the Rights of Persons with Disabilities* (CRPD), which was ratified by Ireland in 2018, commits to ensuring the right of people with disability to the highest attainable standard of health, without discrimination.

Inclusion

People with intellectual disability have the right to full participation in all aspects of community life, including being able to access all components of mental health services in a timely fashion. This will often require accessible information and other reasonable accommodations to assist this full participation.

Person-centred approach

A person-centred approach to mental health maximises the involvement of the person with an intellectual disability in decision-making, rather than viewing such a person as a passive recipient of care. In a person-centred approach, the individual is central to their care plan and to any decisions made with respect to their mental health. Such an approach seeks to understand the situation from the person's own perspective, discovering what is important, and taking into account age, community and culture.

The person with an intellectual disability should be provided with choices about their mental healthcare, in keeping with their age and capacity. While the person is the focus, family and carers should be consulted where appropriate. Service providers in both health and disability networks can be viewed as partners in this approach, working together to provide a cohesive system of person-centred mental health supports.

Recovery-orientated practice

Recovery-orientated care is a strategic priority for the Irish mental health service and has been set out in *A Vision for Change* national mental health policy. It has also underpinned a number of quality requirements for mental health services including *The Judgement Support Framework* (2017) and *Best Practice Guidance for Mental Health,* also in 2017. In 2018 *A National Framework for Recovery in Mental Health* was published by the HSE in consultation with service users, family members, carers, professionals and service user support services such as GROW, Mental Health Reform and Mental Health Ireland, among others.

A National Framework for Recovery in Mental Health defines recovery-orientated services as an inclusive concept which is built on a culture of hope and expectation that a person can recover from their mental health challenges and build a fulfilling life of their choosing. Adopting a recovery-oriented approach for people with an intellectual disability may require additional effort and resources because of the complexity of supports needed.

Promoting independence

Mental healthcare for people with intellectual disability should recognise the autonomy of individuals with such a condition, while acknowledging their age and capacity, and work in a manner that maximises their independence.

Evidence-based treatment

Professionals should continually seek to enhance their knowledge of new and existing interventions. Sources of evidence can include clinical research in the areas of assessment and management of mental illness in people with an intellectual disability. If there is no specific information available, best practice can include interpreting results of studies in the general population and applying them where appropriate.

2.5 Development of the model of service

As mentioned in the introduction, this model of service was developed in collaboration with clinicians, managers, service users, family members and other mental health and disability service providers. The following section outlines this approach and provides an overview of the research conducted on evidence-based services and international models of service.

2.5.1 Staff and subject matter expert consultation

In developing the model of service and the previously issued 'Interim Guidelines', it was important to fully engage with MHID staff, who have first-hand experience of working within the service. The core part of staff consultation was the formation of the National Model of Service Working Group. The working group was made up of staff directly involved in the provision of mental health and disability services. The model and associated document was therefore written and developed directly by staff.

The national working group was tasked with developing a model of service that drew on:

- The experience of service users, family members and carers.
- The experience of staff and subject matter experts.
- Innovation and best practice experience from across the country and internationally.
- Existing HSE policies and strategic documents, such as *A Vision for Change*.

The working group was comprised of multidisciplinary clinicians with experience of working within MHID services, professionals from disability and general adult mental health services (from both the HSE and the voluntary sector), and service user advocates.

It included representation from:

- Psychiatry
- Psychology
- Nursing specialists
- Social work
- HSE disability services
- HSE adult mental health operations
- Voluntary agencies
- Inclusion Ireland

Each member received drafts for review and revision, which they were actively encouraged to share with their colleagues from within their own disciplines and teams to obtain their feedback and input. Recommendations for inclusion in the document were based on group consensus.

Further advice and quality assurance was sought from individual experts and professional bodies and included representation from:

- Speciality population experts such as CAMHS-ID
- The College of Psychiatrists of Ireland
- Allied health disciplines including occupational therapy, speech and language, psychology and nursing
- A United Kingdom MHID expert *(for external quality assurance and international benchmarking)*

General oversight was provided by the HSE's national MHID steering committee, which includes senior mental health and social care managers and clinicians. Final revisions to the guide were made by the working group's chair and the steering group.

2.5.2 Service user, carers and family member consultation

In order for the model of service to provide guidance on best practice in service delivery, it was vital that the views, needs and wishes of service users, their carers and family members, were understood and actively shaped the final recommendations. To enable co-production between staff and service users, several different approaches were adopted.

- **Service users were represented on the national working group** – by a representative from Inclusion Ireland, whose responsibilities were to ensure that service users and their families' needs and wishes were considered at each stage of the model and to help write and edit the overall document.
- **Inclusion Ireland-facilitated focus group** – was held in partnership with Inclusion Ireland and the HSE. Attendees at that focus group included family members, carers and service users. Attendees were asked what worked well and where improvements could be made for each of the main care pathway stages. Quotes from that session are referenced in Section 1.7.
- **Previous service user consultations** – had occurred with existing MHID teams and the service user feedback from those sessions was also reviewed.
- **Best practice literature review** – highlighted different articles and reports that outline research into service user needs.

2.5.3 Evidence-based services

In addition to consultation, members of the working group benchmarked the development of the model of service against a review of international and Irish research. The following section provides a brief summary of that review.

As previously mentioned in Section 1.3, international and Irish studies provide evidence that people with intellectual disability have a higher overall prevalence of mental health problems (Cooper et al., 2007). These problems are more complex and show differences to the general population, with much higher rates of co-existing autism spectrum disorder (Matson and Shoemaker, 2009) and multiple medical and psychiatric conditions occurring together (multi-morbidity) (Cooper et al., 2015).

The mental health needs of people with intellectual disability are also changing over time. Increasing numbers are living into older age (Kelly and Kelly, 2011). In Ireland, it is estimated that 26 per cent of the general adult population (over 15 years) experience psychological distress at any given time (Central Statistics Office, 2015), while 47.5 per cent of adults with intellectual disability over 40 years in Ireland had emotional, nervous or psychiatric conditions (McCarron et al., 2011). In addition to elevated rates of dementia, particularly in those with Down Syndrome (McCarron et al., 2017), the intellectual disability supplement to the Irish longitudinal study on ageing (IDS-TILDA) project also found that older adults with intellectual disability have particularly high rates of complex multi-morbidity (McCarron et al., 2013).

Evidence on the precise interventions designed to meet the specific needs of individuals with intellectual disability is limited (Koslowski et al., 2016; Sheehan and Paschos, 2013). However, despite an absence of well-designed trials of services, existing research suggests that providing general psychiatric services without extra intellectual disability-specific input is insufficient to meet the needs of people with intellectual disability and mental health problems (Chaplin, 2009). Such people need specialist services to meet their needs, and these should be built around effective multidisciplinary community teams (Slevin et al., 2008).

Such multidisciplinary teams may be beneficial in reducing prolonged hospital inpatient stays and high rates of re-admission (Lohrer et al., 2002). Evans et al. (2012) considered how best to integrate a human rights approach into mental health service delivery for people with intellectual disability in Australia. Among the strategies they recommended were public health services and access to services and changes to policy development. The key intervention was regular evaluation of services.

Consultations with principal stakeholders, including people with intellectual disability, their carers and clinicians, have identified a number of key features of mental health services for people with intellectual disability (Hemmings et al., 2009; Hemmings and Al-Sheikh, 2013; Hemmings, 2008).

These included:

- Clear care pathways
- Joint working
- Accessible information
- Flexibility
- Multidisciplinary team makeup
- Provision of a personalised service

This is consistent with Irish research findings that highlighted the importance of aligning MHID services with intellectual disability services and working closely with these services (O'Leary et al., 2018). The provision of mental health services for people with intellectual disability also needs to consider factors that increase service need. For example, an area with economic deprivation is associated with an increased need for mental health service support (Nicholson and Hotchin, 2015).

2.5.4 Service models from an international perspective

A review of service models from around the world was conducted, to benchmark the development of the model of service against other mental health services for people with an intellectual disability and to determine worldwide trends.

Appendix 1 provides a detailed summary of this review. The level of service provision in the following countries was highlighted in more detail:

- Switzerland
- Germany
- Norway
- Netherlands
- United States of America
- Australia
- New Zealand
- England

In the initial developmental stages of the model of service, several members of the steering and working groups conducted a site visit to Tower Hamlets in London, to study the Community Learning Disability Service (CLDS) there. Through the work of their Mental Health and Challenging Needs team, integrated working has been developed within health and social care services. The aim of that visit was to learn from the existing integrated model of service in London.

Appendix 2 provides a summary of the key lessons learnt from that visit.

The following elements provide an overview of the key features contributing to an effective MHID service for the Tower Hamlets community learning disability service:

- **A whole systems approach has been taken** – examined all aspects of service from beginning to end and how they interact with others.
- **Incremental gains are focused on service users** – continually addressing every aspect of the service and focus on how best to improve a person-centred approach.
- **Good clinical leadership is needed** – need to recruit and develop good clinical leaders from all disciplines.
- **Good multidisciplinary teamwork is important** – working at moving towards a meaningful multidisciplinary model across psychology, psychiatry, nursing, occupational therapy and speech and language therapy.
- **Integrated working between health and social services is essential** – both health and social services work in joint teams and have developed strong working relationships, are co-located and run joint clinics.
- **Focus on early assessment and prevention** – strong focus on identifying mental health problems and challenging behaviour early.
- **Open access referrals are in place** – they operate a single point of entry called the *Front Door Team.*
- **Communication and training are key components** – training for users, carers and staff, all designed from their individual perspectives.
- **Provide support to families and local providers to prevent and reduce mental health needs** – this includes supports for families through social work input and psychoeducation at all stages. It is the family that can make the most difference.
- **Clear governance is in place** – one provider for all local MHID services.
- **Active discharge planning** – working closely with inpatient services, featuring early involvement with social care and actively planning for discharge from the beginning of stay.

3. MHID specialist service

3. MHID specialist service

This section details the specialist mental health service provided by MHID teams. It gives an overview of the purpose of the MHID team, why it is needed, its scope and the roles and responsibilities of team members.

3.1 Purpose

The purpose of developing MHID teams in line with *A Vision for Change* (2006) is to provide:

- Good quality mental healthcare to service users with *moderate, severe and profound intellectual disability* and mental health problems.
- Some adults with mild intellectual disability and mental health problems will already be receiving mental healthcare from MHID teams or psychiatrists in disability services due to historic arrangements. It is appropriate for these service users to continue to access this mental healthcare from the MHID team for continuity of care, unless arrangements have been agreed locally with general adult mental health services to take over the management of their care.
- Access to consultations and second opinions from the MHID team to general adult community mental health teams (CMHTs) for people with mild intellectual disability and more complex mental health problems, within available resources. New referrals of people with mild intellectual disability and moderate to severe mental illness should be made to general adult mental health services.

Mental health services for people with an intellectual disability, which are person-centred and multidisciplinary, are in line with current *Best Practice Guidance for Mental Health Services* (HSE, 2017). MHID teams provide recovery-oriented care which promotes service user rights, working in partnership with individuals, respecting diversity and striving to provide safe and effective care.

3.2 Why are specialist MHID services needed?

The knowledge of both intellectual disability and mental health problems is crucial to assessment and treatment, in order to avoid diagnostic overshadowing (where a presentation is deemed secondary to a disability without exploring other factors), as mentioned in Section 1.3. Specialist training and the development of practice expertise with this service user group are therefore important.

For MHID teams to provide specialist assessments in a timely fashion and to be flexible to the needs of service users, they need to support a smaller caseload of complex individuals. This also has been shown to allow teams to tailor services to individual needs and levels of ability. The literature supports the idea that specialised services are best suited to:

- Service users with moderate, severe and profound intellectual disability.
- Service users with limited or no verbal communication.
- Complex medical or psychiatric needs which present challenges to diagnosis and assessment.

3.3 Scope of the service

The MHID team is a specialist adult mental health service that aims to complement the services provided by primary care, disability services and community mental health teams. Individuals living with mental illness are usually supported by the MHID team for limited periods of time to provide specialist mental health assessment and intervention. As the person's mental health improves the MHID team will plan discharge back to primary care with a recovery plan for staying well and how to access the team again if needed.

3.3.1 The MHID team provides

a. Diagnosis and treatment of mental health problems which significantly impact on everyday functioning to a degree that requires specialist MHID input

b. Development of individualised mental health care plans

c. Provision of multidisciplinary team interventions for MHID service users as needed to support their mental health diagnosis

d. Provision of appropriate and specific staff and carer mental health education and training

e. Development of discharge and after-care planning

f. Mental health medication management (if required)

g. Liaison with intellectual disability services and mental health services

h. Working with acute mental health inpatient services where appropriate. (The scope of the MHID team to perform inpatient services will depend on local service level agreements and governance arrangements within the mental health service).

3.3.2 The MHID team does not provide

a. An alternative clinical team to the primary care team or disability teams.

   If a person with an intellectual disability is attending a clinical service in a primary care team or disability team, they should not be discharged from that clinical service as the MHID team will not be in a position to provide for all the clinical needs of the person with an intellectual disability. The MHID team will not duplicate the work of the clinician on the primary care or disability team, but aims to complement their input with a specialist mental health service. Furthermore, MHID team members should not provide interventions such as behaviour analysis to bridge a service gap or vacancy.

b. Access or cannot allocate or arrange day or residential services or respite for people with an intellectual disability.

   (However, if it is identified that a service user attending MHID services needs such day or residential services, it is appropriate for the team to advocate for such services, which are usually provided through disability services).

c. A service which establishes the presence or absence of intellectual disability or autism. Referrals coming into the service need to be accompanied by psychometric and social communication assessments or reference to assessments which establish this prior to referral.

3.4 What professionals work in MHID teams and what do they do?

The MHID team will consist of multidisciplinary team members with training and experience of supporting individuals with intellectual disability and mental health problems. The range of mental health professionals should include a core multidisciplinary team to deliver mental health services in line with other community mental health teams.

As previously mentioned in Section 1.6, *A Vision for Change* (2006) and *Sharing the Vision* (2020), have advised that the community MHID team should comprise of the following:

- A consultant psychiatrist
- A non-consultant hospital doctor (NCHD)
- Two psychologists
- Two clinical nurse specialists (CNS)
- Two social workers
- An occupational therapist
- A speech and language therapist
- Administration support

Important: Not all teams will come into existence with full membership. The current national MHID programme is working towards establishing baseline teams in all areas, consisting of a consultant psychiatrist, a senior psychologist, a clinical nurse specialist and administration support.

The following sections provide more detail on the recommended role and responsibilities of each discipline.

Consultant psychiatrist

Consultant psychiatrists are medical doctors who choose to train and specialise in psychiatry. The College of Psychiatrists of Ireland provides a comprehensive competency-based training which consists of basic and higher specialist training. Clinical and written examinations are carried out while trainees work in mental health services to gain a wide breadth of experience in psychiatry which is urban and rural, community and hospital-based.

Learning disability psychiatry is one of four specialities currently recognised by the Irish Medical Council, and consultant psychiatrists on the specialist register for learning disability psychiatry are deemed by the college to be competent in that speciality. Following 3–4 years of basic specialist training, higher training usually includes two years in an intellectual disability setting and another two years in general adult psychiatry. The College of Psychiatry of Ireland has close links with the Royal College of Psychiatrists in the United Kingdom. Consultant psychiatrists have mandatory continuous professional development (CPD) training.

The role of the consultant psychiatrist on the MHID team includes but is not limited to:

- Providing assessment, diagnosis and treatment of mental health illness in those with a moderate, severe or profound intellectual disability. The assessment process involves a number of elements, with a mental state examination forming a crucial central aspect of the assessment process.
- The provision of information to and liaison with the families and other carers of service users and people with an intellectual disability who have developed significant mental health problems.
- As medical doctors, psychiatrists are responsible for prescribing medications and liaising with primary care.
- Where appropriate, liaison and inter-agency working with statutory and voluntary organisations involved in the care of people with mental health problems and those who have an intellectual disability.
- Clinical supervision of trainee psychiatrists and often involvement in medical student training.

Other roles include:

- Management of the complexity, severity and risk to the service user or to others in the context of mental illness.
- Research, audit and innovation.
- Exemplifying values, challenging stigma and discrimination.
- The implementation of the relevant parts of the Mental Health Act 2001, where appropriate.

Non-consultant hospital doctor (NCHD)

The role of the NCHD, overlaps with that of the consultant psychiatrist, and includes but is not limited to:

- Providing assessment, diagnosis and treatment of mental health illness in those with a moderate, severe or profound intellectual disability, under the supervision of the consultant psychiatrist.
- The provision of information to and liaison with the families and other carers of service users and people with an intellectual disability who have developed significant mental health problems.
- As medical doctors, NCHDs are responsible for prescribing medications and liaising with primary care.
- Research, audit and innovation.
- Exemplifying values, challenging stigma and discrimination.

Clinical nurse specialist (CNS)

The National Council for the Professional Development of Nursing and Midwifery (2008) states that a CNS must be a registered nurse in the division of which the application is being made, have extensive clinical experience (a minimum of five years post-registration experience) and have the ability to practise safely within their scope of practice (An Bord Altranais 2000). They must also engage in continuous practice development and hold a Level 8 or above on the NQAI framework post-registration education.

Through clinical focus, education, training, audit, research, advocacy and consultancy the clinical nurse specialist works to provide person-centred support to the individual and their support network.

The role of the CNS on the MHID team includes but is not limited to:

- Completing a mental health assessment of the service user being referred, using evidence-based tools such as the mini PAS-ADD (psychiatric assessment schedule for adults with developmental disabilities).
- Formulating an individualised mental health care plan in collaboration with the service user, their family or carers and the multidisciplinary team.
- Using recovery-focused initiatives such as the wellness recovery action plan (WRAP), and working collaboratively with the service user, primary and secondary care and voluntary agencies in the pursuit of best health outcomes for the service user.
- Managing a caseload of service users and having responsibility for organising home visits, supporting families and carers on management strategies, psycho-education and liaising with respite and day services as required.
- Monitoring the mental health of the service user, organising reviews by consultants at outpatient clinics if required, submitting requests for additional supports, or facilitating admission to the approved centre if deemed necessary.

- Working as a team member to complete referrals to other disciplines as deemed appropriate and working jointly with other members of the team in the delivery of specialist, client-specific mental healthcare.
- Working collaboratively in the development of policies, operational procedures and delivering specific training to staff in the approved centre on caring for the mental health needs of someone with an intellectual disability.

Psychologist

Psychologists working in MHID teams have undertaken undergraduate, postgraduate, and doctoral training in psychology in line with the requirements of the Psychological Society of Ireland.

The role of the psychologist on the MHID team includes but is not limited to:

- Delivery of a psychology service to meet the mental health needs of individuals with an intellectual disability, in line with best practice in psychology, mental health and intellectual disability treatment.
- Provision of psychological assessments appropriate to the mental health needs of individuals, based upon the interpretation and integration of information from a variety of sources with service users, family members and or carers. This information can contribute to the differential diagnosis of individuals who present with complex difficulties.
- Formulation and development of plans for psychological interventions.
- Delivering individual therapy, group therapy, and development of psychologically informed models of care to meet the mental health needs of the person (cognitive behavioural therapy, schema, psychodynamic, family therapy, group and so on). Psychologists work from a range of psychological models and consider what is most effective to understand and meet the needs of the person. They can work across community and inpatient settings.
- Contributing a psychological perspective to care planning, and working in co-operation with team members and others to ensure an integrated service provision.
- Representing and advocating for the psychological needs of service users.
- Research and audit.
- Psychologists in MHID can provide clinical supervision to other psychology staff members and provide specialist placements in MHID in line with supervision requirements.

Occupational therapist

The ethos of occupational therapy is directed by a client-centred perspective throughout all aspects of the occupational therapy process. It is considered that occupational therapy can act as a valuable asset to the emerging MHID services nationally throughout Ireland.

An occupational therapist within the MHID team works with the service user and his or her support network (family, professional supports etc.) in their own homes, in the community and in other settings (for example in acute and residential mental health approved centres), to identify how occupational therapy assessment, interventions and the therapeutic use of occupation therapy can influence the following areas:

- **Mental health symptom management** – both in community settings and inpatient settings, through anxiety management, managing challenging behaviours, support in managing the environment, addressing roles and routines and strategies to support same.
- **Daily living skills** – working with service users and their families to achieve optimal functioning (as defined by the service user) in their home environment, providing assessments and interventions that affect their mental health needs, including liaison with primary care services and other relevant services.
- **Community integration and social inclusion** – working with service users to identify meaningful community roles and to promote active engagement in community-based activities. This is coupled with working collaboratively and providing support to community agencies in ensuring accessibility to service users who have mental health difficulties and an intellectual disability.
- **Educational and vocational pursuits** – working with individuals to achieve personal goals in the area of education and employment, and enabling vocational participation through tailored use of community resources and specialist services.
- **Leisure pursuits** – working with individuals to identify personally meaningful values and interests which can be facilitated through active leisure pursuits.
- **Sensory-based interventions** – evaluating the person's sensory experiences and identifying if sensory issues are impacting on their everyday functioning and quality of life. This involves working with the individual to develop an understanding of their sensory needs, aversions and preferences.
- **Recovery-oriented occupational participation** – working with the service user to develop a greater understanding of their personal recovery and specifically, how occupation can be utilised to enhance and maintain health and well-being throughout the recovery journey. This may involve exploration of coping strategies that are occupation-focused and or promote occupational engagement.
- **Community living and placement support** – working with the service user to identify their personal strengths and needs in formulating an accurate support profile. This is with a view to promoting independence and personal values as matched within placement environments. This can inform identification of how to optimise the person's living situation or home environment, day services and or vocational and educational placement options.

- **Healthy lifestyle promotion** – building awareness and understanding of the use of occupations to achieve healthy lifestyle goals. Occupational therapists work to empower individuals within their communities to access and avail of occupations which promote health and well-being. This is in line with the goals and implementation themes of the Healthy Ireland Framework (Department of Health, 2013).
- **Promoting health and wellbeing through occupation across all life stages** – understanding the challenges and ever-increasing barriers service users face as their lives progress, including friendships, relationships and sexual health, as well as meaningful engagement and vocational aspects of their lives. This is particularly relevant for older adults considering the increased health vulnerabilities and risk of marginalisation for older adults with intellectual disability and mental health difficulties.

Social worker

Mental health social workers are social workers who work and specialise in the area of psychiatry. Mental health social workers are registered practitioners with CORU. They must also engage in continuous practice development and hold a Level 8 or above on the NQAI framework. Through clinical focus, education, training, audit, research, advocacy and consultancy, the mental health social worker provides person-centred support to the individual and their support network.

Social work in mental health and intellectual disability seeks to address the social and environmental factors connected to the mental illness, working in partnership with the person and their family.

The role of the social worker on the MHID team includes but is not limited to:

- **Family-focused practice and mental health services** – involving families and carers in the delivery of care for the service user. Social work seeks to address the social and environmental factors that contribute to the mental health problem. Family-focused care is widely acknowledged as a crucial aspect of effective mental healthcare delivery (NSW Health 2010). Its aim is to provide a 'whole-of-family' approach, assessment of family members and family functioning, provision of psychoeducation and emotional and practical support, family care planning and liaison and advocacy (Foster et al., 2016). Targeted and specific family interventions include;
  - Generic carer/family support work.
  - Psycho-educational work with carers and families.
  - More specialised family work with families with more complex needs.
  - Group work and or development of family support programmes.
  - Parenting work.
- **Clinical case management** – responsibility for coordinating care for a caseload of service users, organising home visits, supporting families and carers on management strategies, psychoeducation and liaising with respite or day services and inpatient mental health staff, as required.

- **Recovery-orientated interventions** – this necessitates working systemically with service users and families, carers, staff and significant others at a micro level and with the wider community – both the statutory and voluntary sectors – at a macro level. Recovery interventions range from wellness recovery action programme (WRAP), involving service users and carers, behavioural family therapy, peer support and psychoeducation that applies recovery principles.
- **Mental health assessments** – mental health social workers may also train as an authorised officer (S.9 of Mental Health Act 2001). This involves mental health assessment and managing care in the community or making a recommendation for an involuntary admission.
- **Role of advocate/ inter-agency work/mobilisation of resources** – encouraging individuals to advocate for themselves and or acting as an advocate where needed at times, in conjunction with national advocacy services and other statutory advocacy services. Social workers aim to build on people's strengths and skills. This incorporates advocating with other service providers in the area of day care, housing, social welfare and voluntary groups, to ensure that service users and their families obtain maximum resources and services where possible, to improve their quality of life, to foster participation in education, employment, social and leisure activities and ultimately to support the recovery of services users' mental health difficulties.
- **Personalising safeguarding of adults** – safeguarding of adults is an increasingly important role in adult social care services. There is an emerging policy and legislative framework underpinning safeguarding work in adult social care that stems from a human rights perspective. Personalisation is about enabling people to lead the lives that they choose and achieve the outcomes they want in ways that best suit them. It is important in this process to consider risks, and keeping people safe from harm. Work in the area of safeguarding adults can range from:
  - Assessment of abuse of a physical, emotional, sexual or financial nature, together with other members of MHID and other relevant services.
  - Supported decision-making models in care planning; replacing best interest assessments with will and preferences through advanced healthcare directives.
  - Dignity of risk, risks need to be weighed up alongside benefits. Risk should not be an excuse to restrict people's lives.
- **Trauma-informed care practice** – helps service users who have experienced abuse to 'develop their capacities for managing distress and for engaging in more effective daily functioning' (Gold 2001). Trauma-informed care incorporates:
  - Supportive counselling for vulnerable parents
  - Mobilisation of extra resources
  - Psychoeducation of courses that look at healthy relationships and sex education
  - Psychoeducation for carers that look at healthy relationships and sex education

Speech and Language Therapist (SLT)

Sharing the Vision, A Mental Health Policy for Everyone (2020) includes speech and language therapists as core members of MHID teams. It recognises that the presence of a speech and language therapist can significantly enhance the service user experience by supporting and enhancing communication to ensure the service user's voice is central to the engagement.

The Irish Association of Speech and Language Therapists (IASLT) scope of practice (2016) states: 'Speech and language therapy includes the screening, assessment, diagnosis, management and prevention of speech, language and communication disorders and feeding, eating, drinking and swallowing disorders (FEDS), also known as dysphagia.'

'SLTs in mental health are required to see beyond the diagnostic label and formulate each service user's language and communication support needs from a broad perspective, incorporating considerations at the personal, environmental and community levels'. *Speech and Language Therapy in Mental Health Services; A Guidance Document* (2015).

The role of the SLT on a MHID team covers three key areas:

1. **Working with the service user** – key responsibilities include but are not limited to:
    - Assessment and diagnosis of communication support needs resulting from both mental health illness and intellectual disability. This is of particular note in MHID services when there is interplay between mental health difficulties and communication difficulties. Difficulties with communication (as a result of the intellectual disability or the mental health illness), can make differential diagnosis a challenge.
    - Providing direct therapy individually and in groups.
    - Taking a lead role in dysphagia assessment and management (when this is related to mental health diagnosis and or mental health medications).
    - Supporting the service user, using services that ensure their voice is heard through:
        - Development of personal communication passports
        - Support for advocacy systems
        - Developing the role of the peer support worker
        - Supporting the development of coproduction
    - Working with service users in distress, in conjunction with the MHID team, to help uncover the meaning of the service user's distress.
    - Providing service user specific supports such as;
        - Mindfulness
        - Wellness Recovery Action Planning (WRAP)
        - Creative writing

2. **Working with the service user's environment** – key responsibilities include but are not limited to:

    - Identification of communication barriers and seeking to provide alternative and additional means of communicating with people who access this service. Communication difficulties can determine how people with mental health illness access their mental health services (which are largely provided through verbal and written language), and thus participate in their own recovery.
    - Providing training and practical resources to help with communication and or eating and drinking difficulties to anyone living with, working with or providing a service to the service user and their family.
    - Supporting other MHID team members in determining and adapting the most appropriate forms of mental health assessment and intervention in relation to the service user's individual communication support needs.

3. **Working with the service user's wider community** – key responsibilities include, but are not limited to:

    - Working towards recovery with the service user and supporting access to their local community.
    - Working with the local community to improve communication access for people with communication support needs.
    - Working with national organisations to raise awareness of the communication support needs and dysphagia needs of people with both mental health difficulties and an intellectual disability.

Creative art therapist

Creative or arts therapies such as visual art and music are an established clinical intervention recognised as an effective treatment in working in the area of mental health and intellectual disability and are acknowledged as such in *A Vision for Change* and *Sharing the Vision*.

Everyone has the ability to respond to music, visual art and or drama, and creative art therapists use this connection to facilitate positive changes in emotional wellbeing and communication through such engagement.

Creative art therapies are a non-verbal medium that allows the direct voice of the service user to be heard, even when the service user has difficulty using language. It allows the individual to express and act out feelings and sensations without using words.

Non-verbal psychological therapy interventions have been identified as a key treatment on a mental health team. Creative art therapies offer an unique opportunity to achieve this, and have demonstrated effectiveness with service users who have been poor candidates for traditional verbal psychological therapy.

MHID teams should be able to access these therapies based on service user needs. Creative therapists play an important role within the MHID team and their therapies should be offered as part of a range of an MHID team's services.

4. Integrated person-centred care

4. Integrated person-centred care

People with intellectual disability living with mental health problems may need support from a specialist mental health service, but also at various points or simultaneously from all community services (primary care, disability, mental health and inpatient services) during their illness, treatment and recovery. See Figure 2 below for an overview of the integrated care needed for service users with an intellectual disability and mental health problems.

This model of service supports the best practice principle of joint and collaborative working of the MHID team with primary care, community mental health services, disability services and if required inpatient units, in order to provide integrated person-centred care. This is in line with the recommendations of the *Sláintecare 10-year plan* published by the Department of Health in 2019.

Figure 2: Integrated person-centred care for people with an intellectual disability and mental health problems.

People with intellectual disability have the right to full participation in all aspects of community life and should be able to access all components of mental health services, including mainstream and specialised mental health services. People of all ages and with all levels of intellectual disabilities can be affected by mental health issues in a similar way as all members of Irish society. However, if a person has difficulties being understood or in expressing their distress or when they have coexisting physical health problems, the mental health issues can be more complex to identify. As with all mental health problems, the earlier that issues are identified and a person is adequately supported and receives appropriate treatment, the sooner their recovery can occur.

Integrated care promotes ways of working together to improve the quality of care delivered by those who work in the healthcare system. Community healthcare services place a strong emphasis on working with communities and individuals to maintain and improve health and social well-being. The aim is an integrated, interdisciplinary, high quality, team-based and user-friendly service. 'Deliver the right service, at the right time, in the right place, by the right team.' (HSE 2014).

What matters most to people with an intellectual disability and their families and carers is that their care is better planned, better coordinated, better delivered, is easy to access and is inclusive of their views and opinions.

4.1 Primary care services

A primary care team (PCT) is a multidisciplinary group of health and social care professionals who work together to deliver local, accessible, health and social services to a defined population of between 7,000–10,000 people at 'primary' or first point of contact with the health service. The population to be served by a team will be determined by geographical boundaries and or the practice population of participating general practitioners (GPs).

General practitioners and primary care teams provide the first point of contact for all people living with mental health problems. There are services to treat social, psychological and mental health problems from a range of primary care and community service providers which are available to all individuals. Primary care teams are, however, in various stages of development around the country.

The role of the general practitioner is central for an individual with intellectual disability who is experiencing a mental health problem. A meeting with their general practitioner is usually their first point of contact when seeking help.

This initial primary care contact can be the key to a timely and successful resolution of their mental health problem, if the problem is identified and treated by the GP or where appropriate, the person is referred on to the specialist mental health services. There is also recognition that well integrated and best-fit primary care services result in better adherence to treatment regimes, leading in turn to better treatment outcomes (DoHC, 2006). The family context and carer needs are also often well recognised by GPs.

General practitioners also have knowledge of the individual from a developmental and medical perspective. From the mental health team's perspective it is important to be fully aware of any medical issues, as these may be important in the differential diagnosis and management strategies, so timely communication between the MHID team and GP is essential. *A Vision for Change* (DoHC 2006), outlines as one of its key recommendations the enhancement and formalisation of links between specialist mental health services and primary care. Service users who are identified as requiring the intervention of the sector mental health or MHID team should be given access to these services in as seamless a manner as possible.

It is also important to ensure that the physical health needs of people with intellectual disability who have mental health problems are properly met. Clear processes for referral to MHID services and discharge back to primary care are outlined in Section 5 of this document.

4.2 Disability services

People with intellectual disability often also access care from disability services, either through the HSE or voluntary or independent sector organisations. Within disability services, multidisciplinary teams provide person-centred care that is focused very much on the social, vocational, educational and residential needs of the individual (*A Vision for Change,* 2006). Through these disability services, early detection and intervention for a range of mental health problems can be provided to individuals with an intellectual disability.

The HSE's disability services have service-level agreements negotiated with the voluntary agencies to provide care to service users with a disability. As referenced in Section 1.5, when *A Vision for Change* was published in 2006, the majority of the mental health services for people with intellectual disability was provided by the voluntary and non-statutory sector (such as by religious orders and parents' associations). To establish greater partnerships between HSE and voluntary mental health services, two partnership approaches are currently in effect and or in development for each community healthcare organisation (CHO).

Partnership or in-reach service delivery model

Figure 3: In-reach service delivery model

Over the last ten years some MHID teams have been set up within HSE areas where there is less voluntary agency involvement. In such areas, service users attend either HSE-run disability services (day, respite or residential) or voluntary agencies' disability services and HSE MHID teams provide an ***'in-reach'*** mental health service, to service users attending those services. See Figure 3 above. This service includes assessment and treatment of mental health issues and is in line with *A Vision for Change*, which advocates for catchment-based mental health service provision.

Partnership or out-reach service

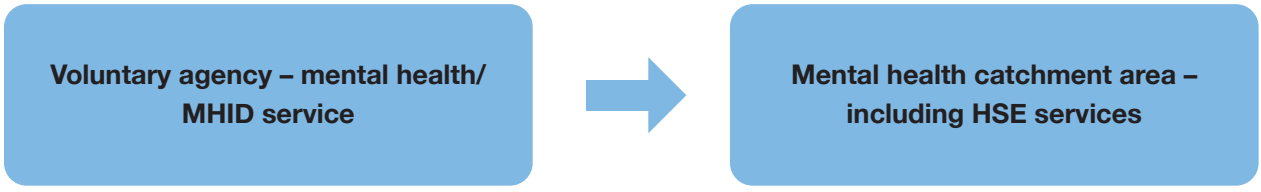


Figure 4: Out-reach service delivery model

For people with an intellectual disability attending services within the voluntary sector, as referenced in Section 1.5, their mental healthcare has in some organisations been supported by a relatively small number of consultant psychiatrists with a special interest in the psychiatry of intellectual disability. Many of these psychiatrists work in voluntary agencies, without the support of resourced multidisciplinary MHID teams, and do not have access to the range of facilities required for comprehensive mental health assessment, treatment and care. They have worked alongside their multidisciplinary disability colleagues within the voluntary agency but not specifically as an MHID team.

The multidisciplinary disability organisation staff may include similar disciplines to those found in MHID teams. However, the focus within social care organisations (unless an MHID service is developed within it) is on supporting the service user in relation to their disability rather than their mental health. For example, occupational therapists may support an individual with aids and appliances and a speech and language therapy staff member may support the individual in relation to dysphagia. The staff members usually report to the heads of disciplines within the disability organisation and ultimately to the director of services. There is no clinical governance structure linking these staff members with mental health colleagues and hence they do not provide an MHID service structure.

What has worked well for service users – where psychiatrists work in a voluntary agency – is that they have easy access to psychiatric assessment, medication treatment and outpatient follow-up and in some cases have limited, but good support from a range of therapists and clinical nurse specialists. Being based in an agency which service users attend is very familiar for themselves, staff and families, and they are included in the development of multidisciplinary care plans and discussions regarding their on-going assessment and treatment.

However, the links with general mental health services have been challenging, with no clear pathways to assist when a service user suffers an acute episode and requires admission to an acute mental health unit. Other service priorities can mean that multidisciplinary support is not always available or specific to the mental health needs of the service user, and that MHID support may not always be available to service users supported by other voluntary agencies in the same catchment area.

To overcome these challenges some voluntary organisations have more recently developed MHID teams that are supported by funding from the HSE's mental health services. This is done on the basis of service level agreements to provide the service in a way that is broadly accessible within a mental health catchment area. This is an 'out-reach' mental health service that is a partnership between HSE and voluntary agencies. See Figure 4 above.

As part of the 'Transforming Lives' strategy, service users in disability services who currently live in large congregated settings within the voluntary sector will soon de-congregate to community living. It is therefore timely that there is a commitment to developing an MHID service as described in *A Vision for Change* (2006) which is catchment area-based.

There may be circumstances where psychiatrists or an interdisciplinary team working in a disability service have a caseload which for example, for historical reasons includes cases outside of the MHID inclusion criteria as set out in this document. As the service develops an MHID framework, it is important for those individuals falling outside of the framework to continue to access services until appropriate signposting has taken place, which will be discussed later in this document.

Where the disability provider hosts a growing MHID service, it is important for appropriate infrastructure in terms of premises and information technology resources to develop with it.

4.3 Adult community mental health services

Community (sometimes referred to as 'generic' or 'mainstream') mental health services refer to existing mental health services available to the general population. These services may be quite broad in scope, such as psychiatric consultation or medication follow-up services offered through a local community mental health team (CMHT) or a psychiatric inpatient unit in a general hospital. Other mainstream services may focus on a particular category of diagnosis, such as eating disorders or early intervention psychosis programmes or a particular demographic such as perinatal mental health services. They may also provide specific types of intervention, such as home-based intensive community treatment to reduce admission to hospital.

Mainstream general adult mental health services in Ireland are not designed specifically for people with an intellectual disability. They are developed in line with *A Vision for Change* policy, based on one mental health team per 50,000 of the general population. Mainstream mental health services can, however, be a good option for people with mild intellectual disability because, in addition to being community based, they also have the advantage of larger capacity and choice of service.

Some studies also suggest such services may be less stigmatising for some service users. However, limitations of this model can include a lack of MHID-specific training and expertise within the teams and inadequate resources to adapt the available supports to the needs of service users with an intellectual disability.

4.4 Specialist community MHID services

As detailed in Section 3, *A Vision for Change* (HSE, 2006) emphasises the importance of specialist, community, multi-disciplinary mental health teams in delivering appropriate mental health services for people with an intellectual disability.

These specialist community MHID services tend to be smaller in size and have a higher staff to service user ratio. Therefore they can be more client-focussed and can tailor services to adapt to the cognitive and communication capacity of service users. This in turn can mean a lower caseload capacity.

Well-integrated models of care for MHID teams have key elements which facilitate good practice, including training in intellectual disability for staff in mainstream mental health services, clear care pathways, interdisciplinary teams and close links to community services. All clinicians in mainstream services should receive some training in intellectual disability to become more comfortable working with people with such disability. The MHID team is well placed to act as a bridge between mainstream mental health services and disability-specific services.

Currently most of the MHID teams nationally do not all have the entire multidisciplinary team members available as outlined in *A Vision for Change*, see Section 3.4, but the aim of the national HSE MHID service improvement programme is to continue to develop multi-disciplinary MHID teams. Priority has initially has been given to the psychiatry, psychology and clinical nurse specialist posts (to provide baseline teams) and the remaining team members should be prioritised with subsequent phases of funding.

4.5 Inpatient treatment

The aim of inpatient psychiatric admission is to diagnose, observe and treat severe acute mental illness. As previously outlined in this document, people with intellectual disability have a higher rate of co-morbid mental health issues, and therefore are at greater risk of inpatient admission. Similarly, as in the general population, only a small proportion of individuals with intellectual disability will require inpatient services, leaving most individuals receiving care on an outpatient basis. However, there will be a need for some admissions where a person with intellectual disability is experiencing a mental disorder and the risks are high (risk of harm to self or others and risk of deterioration without treatment).

Development of MHID teams in the community will help to play a significant role in improving integrated care within inpatient units, in helping to support inpatient staff with identifying and treating acute psychiatric illness. The MHID multidisciplinary teams can also play a significant role in addressing the issue of the frequently unrecognised and unmet mental health needs of people with an intellectual disability. Some admissions for people with intellectual disability to hospital have resulted from the cumulative effects of unrecognised and unmet needs. So MHID teams can work with a person to develop an understanding of the nature of that person's complex needs and to provide necessary recommendations and interventions to meet such needs.

In addition, lack of access for families to home support or therapeutic short breaks or respite or residential services can result in inappropriate admissions to acute mental health units. Chronic poor supports for families and service users can result in the family placement becoming untenable, and difficulties in the interactions between service users and families – sometimes leading to a crisis inpatient admission.

Inappropriate admissions can have a traumatic effect on an individual with an intellectual disability and compound their difficulties. These types of situation are detrimental to the service user, family and mental health services and should be avoided if at all possible. There can be risks of prolonged admission and therefore the social care sector needs to be engaged early to prevent these sometimes foreseeable problems. It is also imperative that service users in the social care sector receive recognised evidence-based assessments and interventions in a timely manner to meet their needs within social care services. This requires the development of the necessary resources, including multidisciplinary teams within social care services to meet the needs of service users.

As mentioned in Section 1.5, it should be noted that social care services for people with intellectual disability have moved in large part to a de-congregated model of residential service provision and there are statutory requirements for residential services outlined and inspected by the Health, Information and Quality Authority (HIQA).

Partly as a result of de-congregation and issues over quality and safety, there are now no national specialist acute admissions units for people with intellectual disability in Ireland and therefore people with such disabilities have to access general acute psychiatric units for treatment of their mental health problems, as do the rest of the population.

In 2010, the Mental Health Commission (MHC) published a very helpful code of practice for staff working in mental health services treating people with intellectual disabilities. Four guiding principles were highlighted which it was felt were particularly important when delivering care and treatment to that group – best interests, person-centred approach, the presumption of capacity and least restrictive intervention. The MHC code of practice, which was developed in consultation with service users and multidisciplinary team members, also includes useful vignettes to help staff in mainstream services with likely clinical scenarios.

Future service planning for inpatient services for people with intellectual disabilities

Further consideration regarding the future of emergency mental healthcare for individuals with an intellectual disability is required. Studies show that people with such disability in specialised inpatient settings consistently document greater clinical improvement than those in mainstream settings. However, this may be in part related to the clinical characteristics of the populations studied. A study in the United Kingdom examining three specialised and seven mainstream services (Longo and Scior, 2004) described positives and negatives for each type of service. While specialised units were described as positive, caring and practical, such units left some patients feeling isolated. Mainstream wards were described as supportive of peer relationships, but left patients feeling disempowered and vulnerable. It is therefore important for Irish mental health services to learn from these studies and the qualities that work well in both types of service, so that service users are able to benefit from inpatient admission when they are required.

In the United Kingdom a number of integrated service models of care have started to emerge (Alexander et al 2002; Hall et al 2006; Davidson and O'Hara 2007; Chaplin 2009). These services enable mental health services to work collaboratively with intellectual disability services, to deliver care which is effective for individuals with intellectual disability. Key elements of successful integrated programmes include those which incorporate staff training in intellectual disability, interdisciplinary teams, clear care pathways and close links with community services for people with intellectual disability, such as residential, vocational and respite services.

People with intellectual disability should be consulted and considered when developing and improving acute psychiatric units, so that there are accommodations made for physical, sensory and cognitive issues. Funding should be therefore be channelled to existing approved centres for upgrading or providing additional beds and planned new units should include additional beds for people with intellectual disability, based on population size and characteristics.

Ultimately how integrated or separate the intellectual disability admission beds should be is a decision which can be made locally. Similarly, addressing key issues such as:

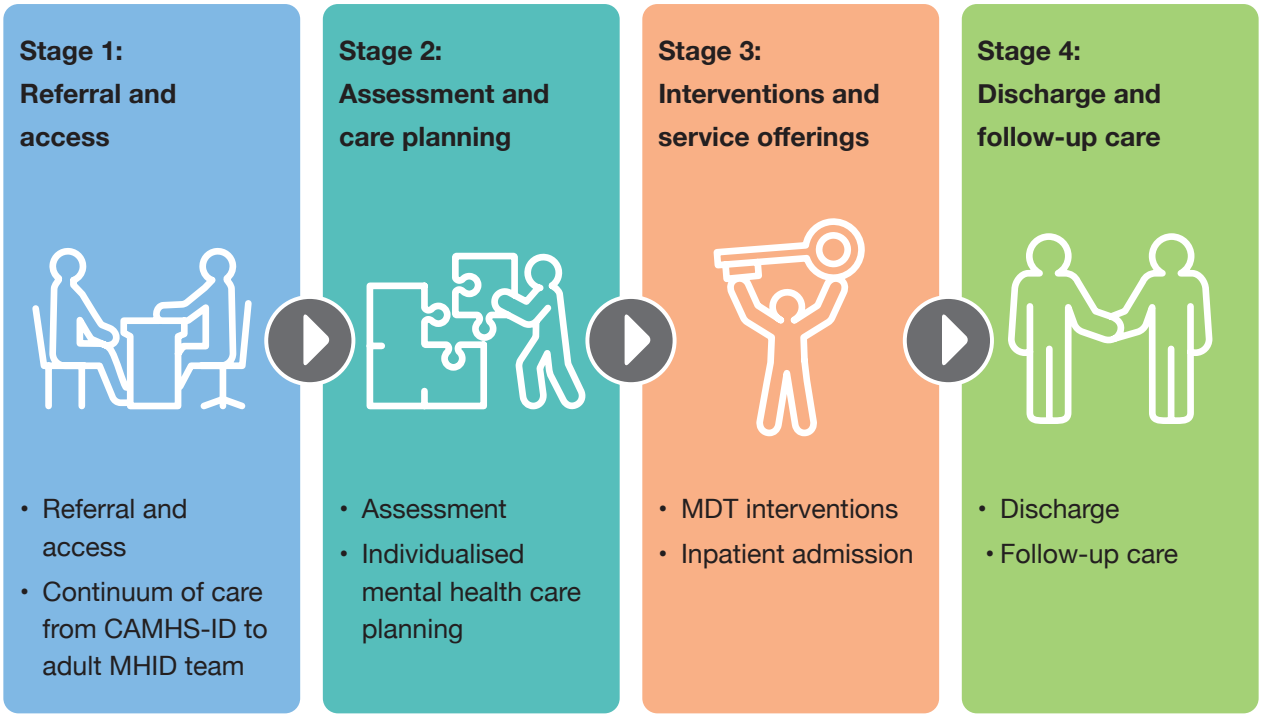
- Ring-fencing beds which can be accessed by the population when required.
- Staff that are trained and familiar with how to support the population.
- Providing an environment which is suited to specific issues such as potential vulnerability or a need for a low stimulus environment.

5. Service user journey through an MHID service

5. Service user journey through an MHID service

The following section provides details of a service user's journey as he or she progresses through the four key stages of care within an MHID service and their associated processes. See Figure 5 below. Additionally for each stage, key actions are highlighted, which would directly improve the care experience for service users and their families.

Figure 5: Key stages of a service user's journey through an MHID service



The four stages of the service user's journey are:

Name	Title
Stage 1: Referral and access	• Being directed appropriately to, and gaining entry to the MHID service • Transitioning from a CAMHS-ID team
Stage 2: Assessment and care planning	• Assessment: evaluation and identification of condition • Care planning: agreeing programme of care with service user
Stage 3: Interventions and service offerings	• Intervention and service offerings: activities for remedial treatment or prevention
Stage 4: Discharge and follow-up care	• Discharge: completing care programme • Follow-up care: with relevant service providers • Re-referral – after discharge (if needed)

5.1 Stage 1: Referral and access

People with an intellectual disability should have equal access to mainstream mental health services. However, people with complex needs, such as a moderate, severe or profound degree of intellectual disability or those whose vulnerability cannot be managed in mainstream services, may require specialist support and benefit from accessing a specialist service. The aim of this section is to assist the latter group of service users, their families or other clinicians to best navigate the mental health system in terms of gaining access to required mental health services for people with an intellectual disability. This section aims to ensure that the referral criteria and process pathway are clear.

5.1.1 Referral criteria

Referral inclusion criteria

The referral criteria for the MHID team are as follows:

- Referrals are considered for a person who presents with evidence or suspicion of mental illness or disorder
- The person is aged 18 years or older
- With a level of intellectual disability in the moderate, severe or profound range. Referrals should include the most recent psychological assessment as an adult
- Living in the agreed catchment area of the team
- Impact of the mental illness or disorder on the person's wellbeing is such that the person needs the support of mental health treatment at a specialist level
- It is recommended that all referrals are accompanied by a recent medical (GP) physical health assessment. Medical problems such as pain or delirium, for example, may present, resembling mental illness or disorder in people with intellectual disorder. Medical health diagnoses and medication also affect treatment choices.
- New presentations of people with intellectual disability over the age of 65 can occur occasionally and it would be preferred that an arrangement exists between psychiatry for older persons and MHID teams to consult with each other to ensure an integrated care approach is provided. Those with more severe intellectual disability require specialist cognitive assessment, without which diagnosing dementia can prove difficult.

Referral exclusion criteria

The exclusion criteria used by the MHID team are as follows:

- The MHID teams cannot provide autism diagnostic assessments routinely. However, referral for treatment of co-morbid mental illness is appropriate in people with moderate-profound intellectual disability and autism spectrum disorders.
- Primary presentation may indicate alcohol or drug dependency, but referral for treatment of comorbid mental illness in people with moderate-severe Intellectual disability is appropriate.
- Acquired brain injury occurring after the development period (see definition of intellectual disability).

5.1.2 Referral agents

The primary source of referral to the MHID service is the general practitioner. This will often be prompted by family members or staff working with a person with intellectual disability. Consent and capacity issues need to be considered (see referral process below).

If another referrer wishes to send a referral, they should also consult with the service user's general practitioner. Other possible sources of referral are consultant psychiatrists (or members of community mental health teams via consultant psychiatrist) and hospital consultants.

5.1.3 Further information

Further information may be requested at point of referral e.g. further medical tests, outcome measures, previous psychological assessments i.e. assessment of cognitive and adaptive functioning, behavioural assessments, medical or service information. This information is used to assist with understanding the needs of the service user and how best to carry out an assessment with the service user.

5.1.4 Referral process

The referral process is as follows:

- A completed MHID referral form or a detailed letter of referral should be sent to the MHID teams.
- This should contain consent from the person with intellectual disability or from their decision-making representative, if the person lacks capacity to consent, in line with the Assisted Decision-making (Capacity) Act 2015[1]. The referrer should comment on the service user's engagement with the referral process, and where possible provide a statement in relation to their capacity to consent, and when the 2015 Act is commenced, the decision-making assistance supports that they have registered with the decision support service.
- In order to promote consent for the referral process, accessible information (see definition Section 10) should be made available.

1. At the time of writing the 2015 Act has not been fully enacted but is in the planning stage

- Referrals to the MHID team should be discussed by multidisciplinary professionals at the MHID team meeting and prioritised as appropriate. At that stage, the team decides whether assessment is warranted and how it should proceed.
- Where a referral is not accepted, the referrer and service user will be advised in writing, giving clear justification, with appropriate recommendations, including signposting to the most appropriate services to meet their individual needs.
- Where a referral is accepted, the referrer and service user will be advised in writing, outlining the next steps and an appointment for an assessment with the MHID team.

5.1.5 Improving the service user's experience

Based on liaison with service users and their advocates, the following outlines key aspects of stage 1 service delivery that will improve the experience for service users:

- Clear communications from the referrer and the MHID team about access to services.
- Consent and capacity evaluation to ensure that a collaborative approach is used as much as possible.
- Family and carer support throughout.
- Timely decision by the MHID team in relation to progressing to the next stage.
- If referral is not accepted, good communication with all stakeholders to ensure signposting to the appropriate services.

5.1.6 Transition from CAMHS-ID to adult MHID

Transition from child to adult services is a normal development but can be particularly stressful for adolescents with intellectual disability who often face multiple transitions with changes of school, disability, social service support and network disability team. It also brings the loss of key support figures, such as the community paediatrician and the teacher.

- It is recommended that at least six months prior to the 18th birthday of those adolescents requiring transfer from CAMHS-ID to adult MHID, the MHID key worker (See section 7.3) should begin the communication process between services, to ensure that the transition takes place with minimum disruption to the young person or their family.
- For the most complex cases a joint handover meeting may be appropriate. This meeting should:
  - Involve clinicians from both the CAMHS-ID and adult MHID teams, in addition to other practitioners providing support to the young person and their family or carers, such as the general practitioner.
  - Involve the young person if considered appropriate, and their family or carers.

- The MHID teams should provide information to the young people and their families or carers about what to expect from adult mental health services and what support is available to them. This information should be provided early enough to allow young people and their families time to reflect and discuss with practitioners their concerns about transition, in addition to hopes and goals for their future.
- A transition plan and its supports should be developmentally appropriate and tailored to the individual's needs, taking into account the young person's:
  - Maturity
  - Cognitive abilities
  - Mental health needs
  - Psychological status
  - Needs in respect of long term conditions
  - Social and personal circumstances
  - Caring responsibilities
  - Communication needs
  - Other plans the young person has in respect of their care and support
- CAMHS-ID teams should hold an annual meeting with adult MHID teams to identify children transitioning from child to adult mental health services and to plan for a smooth transition of care between services.

5.2 Stage 2: Assessment and mental health care planning

If the MHID service is appropriate to their needs, people with an intellectual disability will have timely access to a comprehensive mental health assessment and care plan. The aim of the mental health assessment is to gather information about the presenting problems and background history from the person themselves and those closest to them in as efficient and inclusive a manner possible and to assess the individual's mental state. In complex presentations, more than one assessment appointment may be necessary, and assessment in more than one setting should be considered.

This section outlines the recommended guidelines for:

- The assessment process
- Conducting a mental health assessment for a person with an intellectual disability
- Further assessment
- Assessment tools
- Risk assessment and risk management plans
- Mental health assessment during a crisis

Also included in this stage is individualised mental health care planning, the aim of which is to develop an individual (mental health) care plan (ICP) with each service user, based on an assessment of their mental health.

5.2.1 Conducting the assessment process for a service user with an intellectual disability

A member of the MHID team will coordinate the mental health assessment, and conduct it with:

- The person with the mental health problem
- The family members, carers and others that the person wishes (and has consented to be present)
- Two members of the MHID team (ideally)

The person with intellectual disability who has been referred should receive support to prepare for their assessment by receiving understandable information about the assessment and reasonable accommodations should be made for them to be able to participate in their assessment. These include some of the following:

- Providing extra time for the consultation to adjust for possible complexity.
- Arranging appointments which accommodate the person's preference and facilitate accessibility such as time, location or any other health considerations. The location of the assessment could be at the team base, but may take place at the individual's home if more appropriate or comfortable for the individual.
- Avoiding long waiting times in high stimulation environments.
- Identifying other physical support needs such as those arising from physical or sensory needs and preparing for the person's communication needs. For example, ensuring that their preferred communication system such as Lámh or PECS, is available during the appointment, and where necessary, arranging an interpreter.
- Privacy for the service user is important when choosing an assessment setting. It is also important that the person with an intellectual disability has the opportunity to be seen alone and that appropriate confidentiality is maintained by all involved in the assessment.
- If the service user cannot self-advocate in the assessment process, service user nominated advocates such as a family member or carer can support the service user to communicate with the MHID team and ensure that the service user's point of view and wishes are always at the centre of any discussions. This person may be best placed to provide a comprehensive history, baseline information and any current changes to a presentation.
- Following the team assessment, an MHID key worker will be assigned from within the MHID multidisciplinary team, if resources allow, to each case, based on the unique needs of each service user. See Section 7.3 for detail on the role of the key worker.

5.2.2 Key aspects of a mental health assessment for service users with an intellectual disability

Confidentiality is very important and therefore the professional should speak to the service user on their own to find out if they have any concerns (including safeguarding concerns) that they do not want to talk about in front of their family members, carers or care workers.

For additional detail on each stage of conducting a mental health assessment and associated additional assessments, please see Appendix 3 for full details on:

- Preparations before a mental health assessment
- Key considerations during a mental health assessment
- Developing a formulation
- Further assessment
- Assessment tools
- Risk assessment and management plan
- Mental health assessment during a crisis

5.2.3 The individualised mental health care plan

It is recommended that the MHID team develop an individualised mental health care plan with the central involvement of each service user and their family members, carers or care support workers (as appropriate). Copies of the mental health care plan can be provided to carers, with the service user's consent, in order to integrate it with other care plans which are in place.

Individualised mental health care plans should include:

- Goals agreed with the service user and the steps to achieve them.
- These goals should be recovery-focused. See guiding principles Section 2.5, for definition of recovery.
- Treatment decisions.
- Agreed outcome measures that are realistic and meaningful to the service user, to monitor and evaluate progress.
- Early warning signs of relapse or exacerbation of symptoms, if known.
- Risk management and crisis plans, if needed, with steps to minimise future problems.
- A clear pathway and plan for discharge from the MHID service.

The individualised mental health care plan sets out the roles and responsibilities of everyone involved in delivering it, including:

- The service user can access all interventions and services in the plan.
- It is communicated to everyone involved, including the service user and their family members, carers or care workers (as appropriate) with the consent of the service user.
- Where possible the MHID team will encourage the service user and their supporters to discuss their goals, choices and support needs with relevant primary and social care agencies and services.
- When necessary, and with consent, the MHID team will have a role in advising and consulting with primary and social care services in relation to service user's needs as part of their mental health care plan.
- There is an agreement on when the plan will be reviewed.
- Care planning is an on-going process throughout a service user's journey with MHID.
- A letter to the service user's general practitioner, where appropriate.

Clinical scenario

Denise is a 29-year-old lady with a moderate intellectual disability and schizophrenia. When unwell she can present with paranoid delusions and agitation. Her main motivation in terms of treatment is to resume day centre attendance. A collaborative approach is taken to ensure timely treatment leading to improvement, with minimum side effects. Warning signs leading to risk of day service breakdown include irritability towards others. Crisis planning is documented, including time-limited day service reconfiguration, one-to-one support and medication review. Once she sufficiently improves she returns to the day service and is discharged from the MHID service with a stable medication regimen and clear guidance to the general practitioner in relation to therapeutic drug and side effect monitoring.

5.2.4 Improving the service user's experience

Based on liaison with service users and their advocates, the following outlines key aspects of stage 2 of service delivery that will improve the experience for service users:

- Consent and capacity evaluation to ensure that a collaborative approach is applied to the process as much as possible.
- Family and carer support throughout the process.
- Comprehensive multidisciplinary assessment in a timely fashion. A full multidisciplinary biopsychosocial assessment ensures that a balanced approach is applied to treatment, which prevents an overemphasis on certain aspects, such as medications and the risk of polypharmacy.
- Timely decision by the MHID team in relation to admission into the service
- Mental health care plan to be developed, and key worker to be identified

- Liaison with service user's primary care supports (if needed).
- The service user and their supporter(s) will:
  - Have an opportunity to indicate who they would like to support them in the process of sharing information about their mental health distress and making decisions about how best to address this distress.
  - Feel that they have been listened to and heard.
  - Have begun to get information about what is happening to them in a way that will help them to understand and make decisions about how to address their situation.
  - Make decisions about where they would like to be supported, for example, indicating a preference to be treated at and to remain within their home.

5.3 Stage 3(a): MHID multidisciplinary team interventions

The aim of stage 3 is to provide each service user with the necessary interventions and supports to promote recovery. Specifically this stage of care aims to:

- Promote the recovery of the service user in a way that best meets their needs by providing them with the interventions and supports agreed in their individualised mental health care plan.
- Provide access to multidisciplinary interventions and supports to meet mental health needs.
- Ensure a coordinated approach to meeting the goals of the service user.
- Monitor the effectiveness of interventions and supports in promoting recovery.
- A biopsychosocial approach, including medication and overall health review, psychological mode of engagement, and social interventions.

5.3.1 Interventions process

Each service user of the MHID team will be provided with access to multidisciplinary interventions and supports, based on an assessment of their initial and on-going mental health needs.

- Evidence-based interventions will be delivered in a stepped care approach (ranging from the least complex to the most complex interventions) in line with best practice for all individuals who experience mental illness.
- The service user's strengths, preferences, and support needs will be taken into account in the delivery of interventions.
- Adaptations and flexibility will be required to facilitate access to and engagement with interventions. The team can work in partnership with the service user's family and or supporters (with consent from the service user) to aid understanding and enable them to provide necessary supports across environments.

- A range of multidisciplinary interventions should be available within each team according to the needs of service users. A full description of the role and specific expertise of core team members can be found in section 3.4.
- Interventions will be monitored and reviewed to ensure that they are effective in meeting the service user's mental health needs and recovery goals.
- Any changes to interventions required to support the service user's mental health needs will be discussed with the service user and their family or carer (where appropriate) and their mental health care plan will be updated.
- There may be occasions where the MHID team may decide it is necessary to seek access to other mental health professionals and other health professionals to meet the service user's mental health needs.

5.3.2 Decision-making and mental healthcare

A person with an intellectual disability cannot be treated without the evaluation of consent. Inclusive practice will engage the service user in decisions about their mental healthcare to the greatest extent possible.

Mental health professionals must be able to evaluate the service user's capacity to consent to treatment, and must engage the person, along with their delegated decision-maker (see legal considerations Section 9) where appropriate, to the fullest extent possible.

Capacity is situation and decision-specific. A person may be able to consent to simple but not complex treatments, and may be more able to consent in a calm, unhurried situation. It should be recognised that consent is often an emerging process (rather than a single event at a given point in time), as the person gains experience with the assessment and treatment process. With this in mind, it is important for mental health professionals to regularly revisit consent throughout their involvement with the person, and to allow for changes in the person's capacity and in their views.

5.3.3 Improving the service user's experience

Based on liaison with service users and their advocates, the following outlines key aspects of stage 3 service delivery that will improve the experience for service users:

- Having access to a range of different interventions that can be provided by the MHID team and interventions that the service user can do themselves to improve their own mental health.
- Learning about how these (evidence-based) interventions have helped other people.
- Being supported to make choices and decisions about what actions might work best for them.
- Having regular opportunities to review how helpful these actions are for them.
- Being able to access inpatient support if needed.

5.4 Stage 3(b): Inpatient admission

The aim of inpatient psychiatric admission is to diagnose, observe and treat severe acute mental illness. Development of MHID teams in the community will help to identify and treat acute psychiatric illness, and as in the general population, only a small proportion of individuals with intellectual disability will require inpatient services, with most individuals receiving care on an outpatient basis.

However, there will still be a need for some admissions where a person with intellectual disability is suffering from a mental disorder and the risks are high (risk of harm to self or others and risk of deterioration without treatment). When required, MHID team members can be involved in developing plans for admission, treatment and care planning, and discharge. It will be important for MHID and social care services to establish clear understanding of the admissions processes, mental health legislation and requirements.

5.4.1 Inpatient process

Service users should be assessed for admission to inpatient units in the same way as other mental health service users, and admission pathways should be the same as for general adult community. The same rules and regulations for all under the Mental Health Act 2001 should apply.

- Following referral by GP, the service user is seen by consultant/MHID team, and a mental health disorder which requires admission to hospital is diagnosed.
- In a situation where the MHID consultant psychiatrist has rights to admission to approved beds within local arrangements, the consultant should liaise with the clinical director of the approved centre to arrange admission to hospital.
- For situations where MHID teams work across a number of community sectors and approved centres and or local arrangements require admission arranged directly through the sector community mental health team, the MHID consultant needs to liaise with the team to arrange an admission.
- During out of hours, admission should be arranged via accident and emergency departments or by arrangement within normal hours of service.
- If there are concerns about admission, the clinical director and if necessary the executive clinical director (ECD) should be involved in discussions about planning for the admission.
- MHID teams have an important liaison and support role with their colleagues in general adult psychiatry to assist in the diagnosis, care planning, treatment and discharge planning of patients with intellectual disability admitted to hospital (depending on local arrangements). This would be based on weekly input from the MHID team. See Section 5.4.2 for more details.
- Discharge back to MHID team following discharge planning meeting.

5.4.2 Integrated inpatient care

Developing a collaborative approach between the general adult psychiatry team and the MHID team is important to ensure integrated care in the areas of diagnosis, care planning, treatment and discharge planning of patients with intellectual disability admitted to hospital. An integrated approach is beneficial both for the patient and the hospital staff, because MHID teams members can:

- Often have developed long-term relationships with the service user, family, local disability services and carers and have specialist knowledge of the presentation of mental and physical illness in people with intellectual disability.
- Advise on best practice treatment options, taking into account consent and capacity.
- Provide a multidisciplinary approach. Psychiatry, nursing, psychology, social work and speech and language are recommended to help assess and develop the individual care plan with the person in line with best practice guidance in mental health.
- Provide extra staffing support (if available), as most individuals with intellectual disability can be more vulnerable in a hospital setting and may need extra supports, such as increased staffing support levels at particular times such as during personal care and feeding, to access occupational therapy or outside day services, or when displaying behaviours which challenge.
- Support in consideration, assessment and planning of least restrictive approach to interacting and supporting individuals who present with behavioural distress.
- Support risk assessment and management plans, to protect the individuals whose vulnerability may be increased in the context of an acute mental health unit and who at times may need additional support to ensure the safety of all concerned.
- Ensure that safeguarding issues are identified and that safeguarding plans are in place to address concerns.

This integrated care can be achieved by:

- A member of the MHID team being invited to weekly planning meetings and or attending weekly ward rounds. If this is not possible, by arranging separate weekly linkages.
- Lead MHID clinicians developing working relationships with the local clinical directors and executive clinical director and developing a written care pathway and protocols for people with intellectual disability which could be in place before admissions arise. Disability and mental health managers for the local area should also be involved in this process.
- Establishing a policy to activate a wider discharge planning meeting early in the admission process – for example by including the social care sector if discharge is likely to be problematic due to higher levels of support being required post-discharge.
- The MHID team being informed of any unexpected admission and being able to see the service user on the admission ward as soon as possible.
- The psychologist on the MHID team contributing to the assessment, formulation and treatment approaches and advising on psychological supports for the patient while in hospital, including inputs as part of mental health care plan.

- The MHID clinical nurse specialist can assist hospital staff throughout the patient's stay in terms of diagnosis, care planning, treatment and discharge planning.
- Social worker on the MHID team assisting with the liaison with families and social services.
- The speech and language therapist on the team liaising with staff to provide communication support and advice on feeding issues, which are more prevalent in people with intellectual disability. Communication support can be extremely helpful in overcoming issues with consent and capacity and assists staff on the ward with day-to-day support of the individual with intellectual disability.
- Occupational therapist developing recovery plans and working on improving adaptive skills and functioning which can decline during a period of illness and hospitalisation in people with intellectual disability.
- Members of the MHID team, working with hospital staff to provide them with training in relation to care for patients with an intellectual disability and best practice guidance.

5.3.4 Improving the service user's experience

Based on liaison with service users and their advocates, the following outlines key aspects of stage 3 service delivery for inpatient care that will improve the experience for service users:

- Access to an admission if required, without undue delay related to the person's disability and or concerns about generic inpatient services being unsuitable to meet the person's needs.
- Community MHID team to support the individual as soon as possible following admission, to ensure continuity of care.
- Access to MHID team expertise at inpatient weekly care planning meetings.
- Involvement of key stakeholders at the outset is vital. An example is disability services, which may be involved in delivering the inpatient's residential service.

5.5 Stage 4: Discharge and follow-up care

The aim of the final stage of a service user's journey through an MHID is to ensure that service users are discharged from the service at the right time for their recovery, and to ensure the appropriate follow-up care is in place. At the heart of the discharge stage is the focus on recovery and the need to work with the service user to build a discharge plan that enables them to live a full life, without the continuing presence of mental health symptoms.

5.5.1 The discharge process

This works as follows:

- Discharge is discussed and planned throughout the service user's path with the MHID team. This is achieved through regular care planning with all members of the team.
- Discharge from this team occurs when the service user has experienced a recovery from their mental illness. This is through a process of ongoing discussion and consultation with the service user.
- Discharge also occurs from an MHID team when the service user's mental health is stable and an aftercare plan is in place to ensure the service user is supported to stay well.
- Discharge is a clinical decision by the consultant psychiatrist, which is discussed and agreed at a multidisciplinary team meeting.
- The service user is discharged to the care of their general practitioner and or adult intellectual disability services and parents and carers will be notified. Disability services will continue to meet the needs of the service user in relation to all other aspects of their care. Figure 6 summarises the discharge options for service users from an MHID service.
- The MHID team adheres to good practice by ensuring all agencies or individuals who need to know the recommendations of the team for aftercare are communicated within an appropriate and timely fashion, with the consent of the service user.
- If there is a transfer to another service, the team has a duty to ensure there is clear handover of information and that all parties are aware of the plan, including the service user, carers and the general practitioner.

On completion of care, the service user will be discharged to the care of the general practitioner, with advice on:

- Ongoing management of their mental illness (if required).
- Links to other non-mental health services in place or those recommended for consideration by the general practitioner.
- Guidance on how to refer the service user back to the MHID team if this is required in the future.

Figure 6 below highlights the different service options a service user can avail of for their follow-up care.

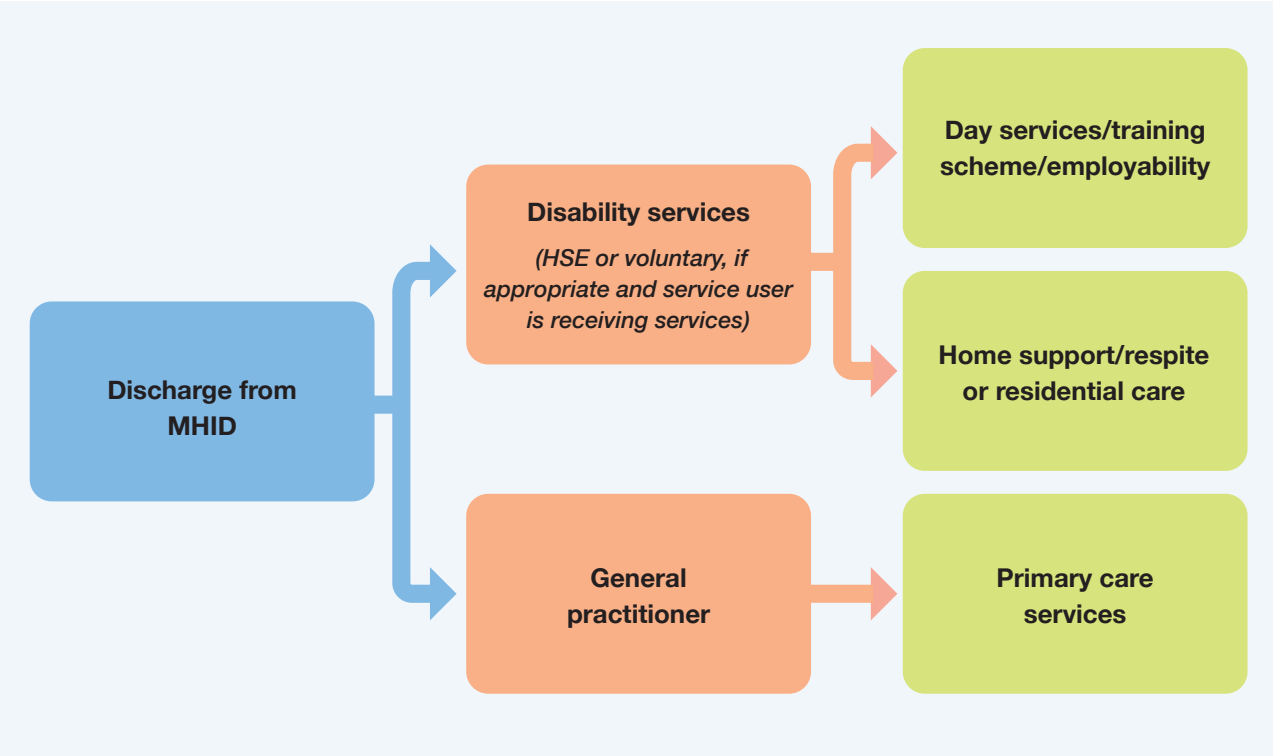


Figure 6: Follow-up options for MHID service users post discharge

5.5.2 Improving the service user's experience

Based on liaison with service users and their advocates, the following outlines key aspects of stage 4 service delivery for inpatient care that will improve the experience for service users:

- Service user has recovered from the mental health issue that led to the referral.
- The service user has an aftercare plan and access to psychoeducation and other resources that will help the person and their carers or supporters to continue and sustain their recovery.
- Access to the MHID service in the future, if required.

6. MHID specialist populations

6. MHID specialist populations

The following section outlines the specific mental health requirements of service users who may have a mild intellectual disability, be on the autism spectrum disorder (ASD), and or who need forensic supports, and where applicable the circumstances and degree of service and support MHID teams can provide for them.

6.1 Mild intellectual disability

Many people with mild intellectual disability currently attend general adult community mental health teams, as they can access specialist therapies for specific illnesses and have more continuity of care through acute care in hospital than to ongoing care by local community teams.

People with mild intellectual disability cannot access many intellectual disability services at present (for example, respite or day services) as there is a cut-off at moderate level of intellectual disability. It is proposed that progressing disabilities will be rolled out to adults in the coming years, which will be a more needs-based approach to service delivery.

There are also a group of service users with mild intellectual disability who already receive mental health services from MHID teams and these service users should continue to receive these mental health services unless it is in their best interests to attend general adult psychiatry teams and when the transfer of care has been agreed by the general adult team.

Service users with low mild intellectual disability and with significant support needs on adaptive functioning in at least two areas of need, which cannot be adequately managed solely by general adult psychiatry teams (estimated to be around one-third of those with mild intellectual disability), as defined in *A Vision for Change*, may need the support of an MHID team. Examples of additional support needs would include communication (where there is some suspicion of mental illness), behaviours with significant risk issues and developmental disorders. The MHID teams need to develop further before being in a position to work jointly with general adult psychiatry teams to deliver a fully-integrated service for people with mild intellectual disability. It is important to provide integrated care pathways for all people in this category and to supply continuity of care.

This model of service therefore proposes that MHID teams where possible offer:

- A consultative framework to adult mental health teams for service users with mild intellectual disability attending their services where specialist input is required (for example in relation to communication).
- General advice in the area of specialist mental health assessment tools.
- Advice on individual care plans and treatment strategies.
- Specific case conferences for complex cases to provide the best outcome for the service user.

Clinical scenarios of joint working – general adult community mental health services and MHID team

The following two clinical scenarios highlight examples of how the mental health needs of service users with a mild intellectual disability can be addressed jointly between general adult community mental health services and MHID teams if applicable or appropriate, and where the MHID team is sufficiently developed and resourced:

1. Diane is a 45-year-old lady with mild intellectual disability and a long-term diagnosis of Schizoaffective disorder. Her background history includes trauma and family breakdown and she has received support from disability services for many years. She attends an MHID psychiatrist for her mental state monitoring and medication management and a psychologist for adapted cognitive behaviour therapy to help manage her symptoms.

   When Diane has a relapse of her illness she is admitted to the local acute psychiatric unit for treatment. A member of the MHID team attends her weekly reviews with the treating inpatient team in hospital. As she has treatment-resistant psychosis, a decision is made with Diane to commence Clozapine therapy, which is initiated in hospital. Following discharge Diane attends the Clozapine clinic locally, under the care of the general adult mental health team (assisted initially by the nurse on the MHID team) and her MHID team for ongoing care. The two teams liaise regularly about Diane's management.

2. Mark is a 23-year-old man with mild intellectual disability and autism spectrum disorder. He also has epilepsy. When Mark experiences a psychotic episode, he has an urgent assessment by his local general adult mental health team. The psychiatrist liaises with the MHID team for help with how best to communicate with Mark and his family about his care plan and which medications would be most useful in terms of his psychosis because of his epilepsy. The MHID team provide advice about his care plan but do not take over his care.

6.2 Autism spectrum disorder

For adults with an intellectual disability, the presentation of which is for assessment of a developmental disorder or an autism spectrum disorder (ASD) with no comorbid moderate to severe mental illness or disorder, their condition should be assessed through disability teams. The needs of adults with autism and intellectual disability are diverse and need specific inputs from the educational system or supported occupational environments, in addition to clinical supports. Their main support needs are in the areas of language and communication programmes, social skills and self-care training programmes, specific educational interventions, vocational advice and training, family support, access to respite care, support and education for their family.

Adults with an intellectual disability and an autism spectrum disorder should not be referred to an MHID team unless there is concern about a comorbid moderate to severe mental health illness or disorder. It has become increasingly evident that adults with autism spectrum disorder are at higher risk of experiencing psychiatric disorders, particularly if they have an additional intellectual disability (Bradley et al., 2014; Lai et al., 2013; Underwood et al., 2010). The role of MHID teams in the area of autism can be defined as consultation on difficult diagnoses with specialist episodic treatment of acute mental illness or disorders. The prevalence of psychiatric disorder in adults with ASD is shown to be at rates of 16-35 per cent (Royal College of Psychiatrists, 2014).

Conducting a comprehensive mental health assessment of a person with ASD

The treatment of an underlying mental illness is important in terms of reducing further impairment in functioning and improving the quality of life of the individual with ASD. Making the correct diagnosis is critical, as people with ASD may not respond to treatment in the same way as those without ASD, so the clinician needs to decide if lack of response is due to treatment resistance or an incorrect diagnosis of mental illness. For further details on how best to conduct a mental health assessment on a person with ASD, please see Appendix 3.

Continuum of care for service users with mild intellectual disability and or ASD

Service users with mild intellectual disability and or autism spectrum disorder with no comorbid mental illness, amongst other groups, often receive services from disability providers. Within this context they may also be in receipt of mental health support, possibly from multidisciplinary colleagues within the voluntary agencies, but not specifically as part of an MHID team.

It is important in such circumstances that the ongoing need for mental health supports by this population is accounted for if they are on psychotropic medication. The following clinical scenario highlights an example of continuum of care for a service user with mild intellectual disability and autism spectrum disorder, following a change in presentation.

Clinical scenario

Darragh is a 29-year-old man with mild intellectual disability and autism spectrum disorder. He is supported by a local disability provider and sees a psychiatrist quarterly. He does not have a formal mental illness diagnosis, but has significant restrictive and repetitive behaviours which impact on his quality of life and cause him distress. These behaviours have responded well to a small dose of a selection serotonin reuptake inhibitor (SSRI), a commonly prescribed antidepressant, recommended by prescribing guidelines.

When a change in Darragh's routine leads to an increase in repetitive behaviours, he has an urgent assessment by his psychiatrist. The psychiatrist is of the view that a review of his antidepressant dose is required temporarily, as well as discussions with his support network about reinstating his original routine, as per Darragh's wishes.

Darragh improves in due course and does not require other interventions, including a referral for consultation or otherwise to his local MHID or general adult team.

6.3 Forensic issues

There can be confusion as to whether people with intellectual disability who are convicted of criminal offences should be dealt with by health or criminal justice systems (or both). A recent study by Mears and Cochrane suggests that the relationship between offending is curvilinear, whereby those in the borderline or mild range of intellectual disability have higher rates of offending but those in the IQ range below 85 have lower rates than the average. When people with intellectual disability do access the criminal justice system there are significant dangers that their specific needs will not be recognised and therefore not met.

The first intellectual disability forensic psychiatrist in Ireland was appointed in November 2015 and there is a small multidisciplinary team in place in the Central Mental Hospital in order to begin to address the needs of offenders with mental health problems and intellectual disability. This team is named the forensic mental health intellectual and developmental disability team (FMHIDD), and they work in conjunction with the general forensic psychiatry teams to manage inpatients and outpatients. They have also to date provided assessments about fitness to plead and risk management to the criminal justice system, mental health and intellectual disability services.

In line with international experience, the current inpatients in the Central Mental Hospital are mainly in the mild range of intellectual disability. Many people in the moderate to severe range of intellectual disability are managed by intellectual disability services and are not charged under the criminal justice system. This group of service users are often regarded as having severe behaviour which challenges and needs significant input from clinicians and high levels of staffing support.

Forensic psychiatry referrals should be made through the clinical director in the Central Mental Hospital and are discussed at a weekly meeting. Referrals should be comprehensive and include details of any offences or severe behavioural incidents, background history of the individual and the setting and support system, risk assessments and what outcome is expected or hoped for from the assessment.

It is recognised that the needs of people with intellectual disability who offend in Ireland is greater than the current provision in forensic psychiatry services. Plans for a new forensic psychiatry hospital will increase the bed numbers from the current nine beds to approximately twenty. There is also a need for forensic community facilities for people to move on from the hospital who have completed the acute phase of treatment but who are not ready for ordinary community facilities. For the subset of offenders with intellectual disability, this should be integrated with the developments for all forensic psychiatry patients. Multidisciplinary team membership also needs to increase with regional multidisciplinary provision in order to provide greater assessment and treatment options.

7. Governance

7. Governance

This section of the model of service outlines all the different areas of governance for MHID teams, covering accountability, communication and monitoring.

The following is a summary of the key features of the governance structure:

- The governance of MHID services will be configured within current mental health service governance structures, alongside other community mental health services such as general adult, CAMHS and psychiatry of old age.
- The executive clinical director and head of service for mental health for the catchment area in which the MHID service operates have responsibility for the clinical and management governance and performance of the MHID team.
- This clinical and management governance may be managed through a service level agreement with a voluntary or other agency, if the MHID service is provided by such an agency, on behalf of the HSE.
- The governance of MHID teams should be underpinned by good inter-agency working relationships and included under regional integrated management structures, as envisaged by Sláintecare.
- When a service user of an MHID team is admitted to an approved centre the clinical governance arrangements are those of the approved centre.

7.1 Team governance

- Each head of discipline (for example area director of nursing, principal psychologist) holds responsibility for ensuring that each team member operates to the highest clinical standard.
- Each MHID team will have a defined catchment area.
- Voluntary agencies that have designated local governance agencies will have their terms agreed through the service level agreement with the HSE.
- Each team may also consider the appointment of a team coordinator to facilitate the smooth running of the team as outlined in *A Vision for Change,* Chapter 9.

7.2 Clinical responsibility

In keeping with *A Vision for Change*, each member of the MHID team takes responsibility for the delivery of care in a collaborative and respectful manner, always adhering to a sense of parity of esteem. Clinical governance will be seen as a multidisciplinary activity requiring collaboration across disciplines, supported by the local professional management structures.

In addition, all members of the team must adhere to their individual professional code of ethics, and the level of individual clinical responsibility associated with their job description, and their scope of practice.

7.3 Role of the MHID key worker

This document recommends that each service user attending the MHID team be allocated an MHID key worker from within the MHID multidisciplinary team, following the team assessment, if resources allow. It also recommends that MHID key workers are allocated in a manner that relates to the primary focus of the intervention, based on the training and skills of the individual team members, with the agreement of team members.

The key worker will function collaboratively with service users throughout their stay and will:

- Ensure that the pathway from referral to discharge is followed in the most efficient and service user-friendly way possible, keeping the service user central to all discussions and interventions.
- Work in partnership with service users and their family to inform them of each stage of their journey through the MHID service.
- Help support service users in communicating their wishes and preferences.
- Coordinate all stages of the service user's journey while attending the MHID team.
- Be the main point of contact of the service user and their family.
- Address the service user's treatment goals and needs.
- Support the service user to attend appointments and in some cases facilitate where an appointment occurs.

7.4 Continuous professional development

All MHID clinicians should engage with the level of continuous professional development (CPD) required by the individual's professional code of practice and should be supported by their local management to maintain CPD, which should align with the team's overall service objectives.

Supervision is seen as an important part of continuous professional development. In keeping with best practice, and given the complex nature of the work of the MHID team, all clinicians are advised to seek an appropriate level of clinical supervision for their work, in order to maintain a safe, effective and high quality service.

7.5 Clinical metrics

Previously within the HSE, clinical metrics about MHID were not collated at a national level, unlike other specialties in mental health. This meant that the work carried out by teams could not be fully appreciated. Collecting clinical metrics is in line with *Best Practice Guidance for Mental Health Services* (HSE, 2017).

To address this, from 2020, MHID teams have been requested to record clinical metrics which are similar to those collated by other mental health teams.

These monthly metrics will include:

- Whole-time equivalents (WTEs)
- Accepted and non-accepted referrals
- Number of new cases seen, by level of intellectual disability
- Waiting times for cases to be seen
- Number of cases closed or discharged

In addition, MHID teams will – on a quarterly basis – collect data on 'open active cases'. This metric has been designed to better differentiate the various levels of care, service users attending an MHID service may require.

Teams will record their open caseload based on the service user's:

- Level of intellectual disability
- Living situation, either community or residential
- Level of support required, either:
  - **Level 1:** *Intensive intervention* – when a service user is acutely unwell and or highly complex and or with enduring needs, and will require an intensive level of support.
  - **Level 2:** *Ongoing intervention* – when a service user has significant needs but is stabilised, and will require a high or medium level of support.
  - **Level 3:** *Ongoing support* – when a service user needs ongoing monitoring of progress and will require a low level of support.

8. Team supports and resources

8. Team supports and resources

The capacity of a team to work effectively and provide a high quality service for their service users is impacted by the supports, resources and facilities made available to them. This section outlines additional supports and resources required by MHID teams.

8.1 Education and training

It would be beneficial for MHID team members to have a tailored training and education programme made available to them on an ongoing basis, including initial induction training. To develop an effective programme, a training needs analysis would provide valuable feedback for the team, service managers and individual staff, along with service users, family members or carers.

When carried out regularly, a training needs analysis provides systems audits used to review incidents and key performance indicators, such as complaints, and the developing needs of the service.

Team training plans should be reviewed regularly to assess their relevance and identify gaps. Staff should have access to education and training resources such as internet, HSEland and journals.

During the development of this model of service, it was identified that to continually support MHID team members and to attract other professionals into the area, collaboration with universities and colleges is essential to develop and further expand educational courses and or modules that promote multidisciplinary training within the MHID specialism.

Records should be maintained of all training undertaken and all education and training programmes delivered should be evaluated and reviewed for relevance. Staff should be supported in undertaking courses of education and training. This will ensure their capacity to meet the assessed needs of the service user and continuous professional development.

All staff should be provided with mandatory training in areas such as fire safety and Children First, and other areas identified as essential to their role.

8.2 Integration with other mental health services and staff

Integration of the MHID team with other mental health services may prove a challenge and this has been the experience of some established MHID teams. Consideration should be given to having representation on the management team, quality and safety committee and other groups, with opportunities to interact with mental health staff from other mental health services.

The following will also have an impact on integration with other mental health services:

- Clinical supervision
- Joint working in areas such as care plans
- Involvement of lead for service user engagement in the wider mental health organisation
- Ensuring staff in other mental health services fully understand MHID services.

8.3 Facilities

An MHID team should be accommodated in premises that provide space for the entire team. This ideally should be in the same premises as another mental health team.

The MHID service should be located in accessible premises that comply with the following regulations and legislation:

- Part M, Building Regulations (2000) Access for people with disabilities
- Safety Health and Welfare at Work Acts 1989–2005
- Employment Equality Acts 1998–2004
- Equal Status Acts 2000–2004
- Disability Act 2005

In addition to physical access and the requirements of those with impaired mobility, the building must include accessibility for those with sensory, communication and cognitive difficulties. Therefore, providing accessible premises should include the following:

- **Physical access** – provision for wheelchair users, walking aids, handrails, ramps, lifts and lowered counters.
- **Sensory access** – for people with hearing and visual impairment, tactile markings, signs and labels, hearing augmentation listening system, audio cues for lifts and lights.
- **Communication access** – for people who have difficulties with the written word, vision, speech and language problems or non-English speakers, ideally with the support of a speech and language therapist.
- **Accessible systems** – detailed service information should be provided. This may include information on services on notice boards and the HSE website, documents in plain English, easy read and video formats and digital accessibility tools.

Service users and or family members should be consulted where possible on building design and layout and on the facilities that ensure maximum accessibility.

The premises should be fully equipped to provide clinical and therapeutic services. The following resources will also be required:

- Information and communications technology (ICT), vital in enabling teams to collect data.
- Photocopying facilities
- Storage of records
- Porter and security officer
- Service user transport

9. Legal and ethical considerations

9. Legal and ethical considerations

The development of the model of service should also be in keeping with relevant national guidelines and key legislation. This section outlines key pieces of relevant legislation and national guidance from overseeing bodies, within which MHID teams need to operate.

9.1 Convention on the Rights of Persons with Disabilities

Irish government policy has been informed by international standards, including the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD). The CRPD states that health services for those with intellectual disabilities should be equal to those provided to others but should also address the specific needs of people with an intellectual disability (United Nations, 2006). Overall the CRPD does not outline a prescriptive model of service delivery and allows for flexibility to suit the local context. However, it does recommend that services should be provided 'as close as possible to people's own communities'.

Ireland ratified the CRPD in March 2018, though work remains to be done to give full effect to its principles, particularly with regard to legal capacity and deprivation of liberty. Capacity legislation has been passed but not fully implemented (see below), while legislation on deprivation of liberty is currently being advanced with ongoing public consultation on a draft Heads of Bill.

9.2 Assisted Decision-Making Capacity Act

A person whose decision-making capacity is in question should be as free as anyone else to make decisions. The current legal starting point is a presumption that every person has the capacity to make decisions about their resources and personal affairs free of intervention, until the contrary is shown. This approach is set out in law in the Assisted Decision-Making Capacity Act that was passed by the Oireachtas at the end of 2015. It places a legal requirement on service providers to comprehensively enable a person make a decision through the provision of a range of supports and information appropriate to their condition.

This act will introduce far-reaching changes to the way supports are provided to adults who have difficulties with their decision-making and will impact on MHID teams in the areas of consent to assessment and treatment. The act outlines three levels of decision-making assistance by 'interveners': 'decision-making assistant', 'co-decision-maker' (joint decision-maker) and 'decision-making representative' (substitute decision-maker). All interveners must endeavour to ascertain and give effect to the person's will and preferences. The guiding principles of the act emphasise minimal intervention, and due regard to a person's right to bodily integrity, privacy and autonomy.

Informed consent is one important practical example of the principle of autonomy. To 'give consent' to a medical treatment or a service means to give permission. The definition of consent provided by the National Consent Advisory Group's National Consent Policy specifies the importance of communication and information sharing in the consent process. The purpose of communication is to ensure that before giving consent, people using services have sufficient information to understand the care, support, or treatment to which they are agreeing, and to understand the associated potential risks or benefits.

For people with intellectual disability this includes supports to assist with communication difficulties, such as easy-read information and the use of alternative forms of communication such as Lámh and pictorial and other augmentative communication aids. In terms of consent to treatment, when there is not full capacity present, consideration needs to be given as to whether it would be possible to improve decision-making capacity by supporting the person's abilities to consent. This could be achieved by both offering support and education about the decision to be made and simplifying the decision if possible. If there is nobody with legal authority to make decisions on the person's behalf (as under the Assisted Decision-Making Capacity Act) it is also good practice to consult more widely with those people close to the person who may be familiar with his or her preferences, beliefs and values as per the Irish Medical Council Guidelines, as well as weighing up which treatment option would give the best clinical benefit.

9.3 National guidance from the Mental Health Commission

The Mental Health Commission (MHC) was established in 2002 as an independent body to promote high standards in the delivery of mental health services and to protect the interests of patients who are involuntarily admitted (Oireachtas, 2001). The MHC has published an overall quality framework for mental health services in Ireland (Mental Health Commission, 2007), as well as a more specific code of practice for people working with people with an intellectual disability and mental health problems (Mental Health Commission, 2010). Guiding principles in this code of practice include the best interests of the person being the principal consideration; a person-centred approach; the assumption of full capacity; and interventions taking place in the least restrictive environment. The MHC has also published a number of other key documents relevant to evolving mental health services for people with intellectual disability, including guidance on effective multidisciplinary team working (Mental Health Commission, 2006b) and on forensic service needs (Mental Health Commission, 2006a).

9.4 Health Information and Quality Authority

The Health Act (2007) (Oireachtas, 2007) established the Health Information and Quality Authority (HIQA), which is legally responsible for monitoring, inspecting and registering designated centres for adults and children with a disability. HIQA has developed standards and guidance for those providing services to people with disabilities. For example, HIQA standards for residential services (Health Information and Quality Authority, 2013) require a personal plan, detailing needs and outlining supports required to maximise personal development and quality of life. In the case of mental health needs, this suggests a need for clear assessment of those needs and a care plan approach to meeting those needs, similar to that advocated by the Mental Health Commission (Mental Health Commission, 2012). HIQA has also published guidance on use of restraint, including chemical restraint (Health Information and Quality Authority, 2016), which is of significant relevance to mental health teams.

10. Definitions

Mental health

The World Health Organisation defines mental health as not just the absence of mental illness but as 'a state of well-being in which the individual realises his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community'.

Mental health and well-being are fundamental to our collective and individual ability as humans to think, emote, interact with each other, earn a living and enjoy life. On this basis, the promotion, protection and restoration of mental health can be regarded as a vital concern of individuals, communities and societies throughout the world (WHO April 2016).

Mental health problems, mental illness and mental disorder

Mental health problems: the full range of mental health difficulties that might be encountered from the psychological distress experienced by many people, to serious mental disorders and illnesses that affect a smaller population (Source: *A Vision for Change,* 2006).

Mental illness: means a state of mind of a person which affects the person's thinking, perceiving, emotion or judgement and which seriously impairs the mental function of the person to the extent that he or she requires care or medical treatment in his or her own interest or in the interest of other persons (Source: Section 3, Mental Health Act, 2001).

Mental disorder: *The Diagnostic and Statistical Manual of Mental Disorders (DSM)* is the American Psychiatric Association (APA) standard reference for psychiatry, which includes over 450 different definitions of various mental disorders.

The International Classification of Diseases (ICD) currently at ICD-11 published by the World Health Organisation (WHO) is the international standard system for classifying all medical diseases. It also includes a section on mental and behavioural disorders.

The APA has defined mental disorder as 'syndrome characterised by clinically significant disturbance in an individual's cognition, emotional regulation, or behaviour that reflects a dysfunction in the psychological, biological or developmental processes underlying mental functioning' (American Psychiatric Association, 2013).

Examples of mental disorders defined in these reference guides include: mood disorders, psychotic disorders such as schizophrenia and anxiety disorders. See DSM-5 and ICD-11 for more details.

Mental disorder also has a particular definition under Irish mental health law and relates to those requiring admission to an approved centre for treatment.

'Mental disorder' means mental illness, severe dementia or significant intellectual disability where:

(a) because of the illness, disability or dementia, there is a serious likelihood of the person concerned causing immediate and serious harm to himself or herself or to other persons, or

(b) (i) because of the severity of the illness, disability or dementia, the judgement of the person concerned is so impaired that failure to admit the person to an approved centre would be likely to lead to a serious deterioration in his or her condition or would prevent the administration of appropriate treatment that could be given only by such admission, and

(ii) the reception, detention and treatment of the person concerned in an approved centre would be likely to benefit or alleviate the condition of that person to a material extent.

Source: Mental Health Act 2001

Mental state examination (MSE)

An MSE is a full psychiatric examination of signs and symptoms, which takes place during a psychiatric interview and should apply only to signs and symptoms elicited at that time. It should not take into account historical information. The examination is usually divided into the following subheadings: appearance and behaviour, speech, mood, affect, thought and perception, insight, and orientation. Usually it also includes a risk assessment.

Concise Medical Dictionary (8) Oxford.

National Institute for Healthcare Excellence (NICE), Guidelines on Mental Health Problems in People with a Learning Disability (2016)

Intellectual disability

National and international definitions of intellectual disability generally share three key criteria. These are:

1. A significant impairment of adaptive behaviour (social functioning);
2. a significant impairment of intellectual functioning,

with

3. both impairments arising before adulthood.

Intellectual disability (ID) is the presence of a significantly reduced ability to understand new or complex information and to learn new skills, with a reduced ability to cope independently, which starts before childhood and adolescence and has a lasting effect on development. However, the presence of low intelligence (IQ below 70) is not, of itself, a sufficient reason for deciding whether an individual requires health and social care support. An assessment of social and adaptive functioning and communication skills should also be taken into account when determining need. The terms 'mild', 'moderate', 'severe' and 'profound' are used to describe different levels of intellectual disability. These terms correspond to different IQ levels. (*A Vision for Change*, Chapter 14.)

- In order to determine whether a person meets the criteria for an intellectual disability, individual standardised assessment of cognitive and adaptive functioning will be completed by suitably qualified psychologists. As with any diagnosis, the psychologist needs to make a clinical judgement about the information gathered and how it contributes to the overall opinion and diagnosis of intellectual disability. (Source – British Psychological Society, 2015).
- These criteria are in line with internationally recognised diagnostic classification systems namely, The International Classification of Diseases – Eleventh Edition (ICD-11), Diagnostic and Statistical Manual of Mental Disorders – Fifth Edition (DSM-5) and American Association on Intellectual and Developmental Disabilities – Eleventh Edition (AIDD-11). (British Psychological Society, 2015).
- Individuals who meet the criteria for a moderate, severe or profound intellectual disability in line with current diagnostic classification systems can be referred to MHID services.

Intellectual disability is characterised by significant limitations in intellectual (i.e., reasoning, problem solving, planning, abstract thinking, judgement, learning from experience) and adaptive behaviour as expressed in conceptual, social, practical adaptive skills. The disability originates in the developmental period before 18 years of age.

There are four levels of intellectual disability determined by standardised and clinical assessments of cognitive and adaptive abilities, the results of which are more than two standard deviations below the mean. See diagnostic criteria in ICD 11 section 6A00.0 and DSM 5 pages 33–38.

- **Mild:** the person may require minimal and intermittent support with social, practical and conceptual domains of adaptive functioning, with cognitive and or adaptive ability two to three standard deviations (SDs) below the mean (approximately 0.1–2.3 percentile) – (Usual corresponding IQ level 55–69).
- **Moderate:** the person typically requires additional support in relation to adaptive functioning, with cognitive and or adaptive ability three to four SDs below the mean (approximately 0.003-0.1 percentile) – (Usual corresponding IQ level 35–54).
- **Severe:** the person typically requires extensive support in relation to adaptive functioning, with cognitive and or adaptive ability four SDs below the mean (less than approximately the 0.003rd percentile) – (Usual corresponding IQ level 20–34).
- **Profound:** the person typically requires pervasive support in relation to all domains of adaptive functioning, with cognitive and or adaptive ability four or more SDs below the mean (approximately less than the 0.003rd percentile) – (Usual corresponding IQ level under 20).

Communication support and accessible information

Accessible information: information which is able to be read or received and understood by the individual or group for which it is intended. This could include at a minimum plain English or Easy to Read information formats.

Communication support: support needed to enable effective, accurate dialogue between a professional and a service user to take place such that they are not put at a substantial disadvantage in comparison with persons who are not disabled (when accessing health and social services).

Accessible information and communication support enables individuals to:

- Make decisions about their health and wellbeing and about their care and treatment
- Self-manage conditions
- Access services appropriately and independently
- Make choices about treatments and procedures, including the provision or withholding of consent

Easy-to-read documents: are made up of short, simple sentences that will communicate the most important messages you need to convey. These are usually accompanied by pictures that will aid understanding (Inclusion Ireland – see resources section below).

Service level agreements and arrangements

Service level agreements and arrangements are documents which explicitly describe the nature of the service being provided to the HSE by an external agency. The HSE funds a range of service providers under either Section 38 or Section 39 of the Health Act, 2004. The Health Acts empower the HSE to enter into an arrangement with the provider to deliver health and personal social services.

Section 38 arrangements involve organisations that are funded to provide a defined level of service on behalf of the HSE, while under Section 39 the HSE grant-aids a wider range of organisations – to a greater or lesser extent. The employees of agencies that are funded under Section 38 agreements are classified as public servants. The employees of agencies that receive grant-aid from the HSE under Section 39 are not public servants. (Source: Best Practice Guidance for Mental Health Services and Department of Public Expenditure and Reform).

11. Resources

Guides to accessible information and communication

National Adult Literacy Agency (NALA) www.nala.ie

Make it easy: a guide to preparing easy-to-read information is available on: http://www.inclusionireland.ie/sites/default/files/attach/basic-page/1193/makeiteasyguide2011.pdf/. Developed by the Accessible Information Working Group.

Information for all: European standards for making information easy to read and understand. Published by Inclusion Europe. Produced in the framework of the project: Pathways to adult education for people with intellectual disabilities.

http://easy-to-read.eu/wp-content/uploads/2014/12/EN_Information_for_all.pdf

The National Disability Authority has produced an online accessibility toolkit. This includes practical guidelines on accessible information and inclusive communication.

http://nda.ie/Resources/Accessibility-toolkit/Make-yourinformation-more-accessible/

Accessible Information for All was produced by the Citizens Information Board in 2009. http://www.citizensinformationboard.ie/downloads/accessibility/Accessible_Information_For_All.pdf

Accessible Information Standards NHS England- https://www.england.nhs.uk/ourwork/accessibleinfo

Other useful information

Mental health problems in people with learning disabilities: prevention, assessment and management NICE (NG54) https://www.nice.org.uk/guidance/ng54

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Appendix 1

Service models from an international perspective

Overall background worldwide trends for people with intellectual disability

According to Inclusion International, there are 130 million people with intellectual disabilities around the world and the vast majority live in poverty. Regardless of where they live – in the populous countries of the Asia Pacific Region, in North America, Central, East or West European countries, the Caribbean, Central and South America, Africa, or the Middle East – they tell a remarkably similar story. People are excluded from education, employment, healthcare and other services, and from belonging in their communities. Parents and siblings advocating for their relatives face barriers to employment, adequate income, community services and community acceptance. People find their rights are denied. They feel invisible in development and poverty reduction strategies.

According to a report by the United Nations in 2010, children with intellectual disabilities are disadvantaged in three ways in healthcare. Not only do they have greater health needs, they also experience greater barriers in accessing appropriate healthcare, and when treated, are at high risk of receiving poor care. Key barriers include poor knowledge and training of health professionals on disability issues, communication difficulties (poor patterns of communication with the child), negative attitudes, poor intersectoral collaboration and the lack of reliable health monitoring data for this population. These complex and multiple factors lead to negative outcomes in access to healthcare and inclusion in programmes that target preventive healthcare and health promotion but also in morbidity and mortality levels.

Placing children and adults with severe or profound intellectual disabilities in institutions has been a traditional practice in almost all the countries in the European region. In the western part of the region, the number of places in institutions for people with intellectual disability increased rapidly from 1945 to 1970. The process of deinstitutionalisation became the focus of disability policy in many countries in the western part of the region in the early 1970s. It entailed the closure of large residential institutions, replacing them with networks of community-based alternative services. Research into the process of deinstitutionalisation has shown clearly that outcomes are better overall in the community than in institutional care.

Some countries, including Italy, Norway and Sweden, have gradually closed all large-scale residential facilities while developing community-based alternative services provided in families, including substitute families, family-like settings, group homes and home-based care, through personal assistance. This process took three decades in those countries. In some other countries, including Belgium, Germany, Greece, the Netherlands and Spain, community-based services have been developed as alternatives to institutional care, although existing service structure remains dominated by institutional models.

Deinstitutionalisation has progressed less quickly in the countries of central and Eastern Europe and the Baltic countries. The number of children being placed in institutions actually increased in these countries during the 1980s and 1990s. This is in part because those countries were struggling with worsening economic conditions and political instability, while some experienced war and ethnic conflict. Families with vulnerable members, including children with disabilities, were all too often trapped in chronic poverty and forced to abandon vulnerable family members to institutions, which were undergoing a parallel process of deterioration. Poverty drove parents to leave their children in institutions that had no rehabilitation or exit route.

Europe

A review of practice in Europe in 2000 indicated that provision of specialist services varies with geography and local historical development. The BIOMED-MEROPE project review of studies in England, Ireland, Greece, Spain, and Austria found that while there was broad access to specialist intellectual disability mental health services in England, other countries tended to have patchy specialist services based in larger population centres (Holt et al., 2000).

It was found that normalisation was taking effect across all five countries, with deinstitutionalisation and integration into communities becoming more common. However, although the mental health needs of people with intellectual disabilities were being recognised, there was often a failure to implement recommended guidelines because of unclear policies and a lack of planning.

The journal *Advances in Mental Health and Intellectual Disabilities* much more recently published a special edition in July 2018 which described the models of care from six countries in Europe with the aim of learning from each other. This is a summary of the findings (excluding Ireland and the United Kingdom which are described separately). A theme in the papers is the move from institutional care to community services over the recent forty years that has led to fragmented care.

In Switzerland the process of de-hospitalisation of people with intellectual disability has been completed, so that people who resided there have moved into intellectual disability services. However ‘treatment guidelines and care standards are implemented in hardly any of the facilities for people with intellectual disability and many provide only basic medical care. This has led to widespread over-medication, as well as a lack of psychiatric-psychological assessment.’

Although new diagnostic and therapeutic approaches and concepts have been introduced (especially from Germany) in recent years, this has been sporadic and implemented locally rather than nationally. Few mental health organisations have developed services tailored to the needs of intellectually disabled patients. Most of them still provide only crisis intervention and no specific psychotherapy. The authors

estimated that it will likely take at least another decade for appropriate outpatient and inpatient treatment options to be implemented on a national scale, as there are still too few specialised professionals and training programmes for doctors and psychologists in this area.

The current situation of MHID in Switzerland shows a mixed and sometimes even contradictory picture. On the positive side are the numerous, well-funded, well-staffed and well-equipped facilities for people with intellectual disability. These facilities have highly trained special education teachers and social education workers. Legislation, the insurance system as well as the policies and strategies on a national level are basically in line with people's intellectual disability needs. On the other hand, the psychiatric care, the specialist training and the medical and psychological research in this field are insufficient. (Georgescu , D. and Styp von Rekowski, A., 2018).

In Germany there is a highly developed healthcare infrastructure but healthcare for people with intellectual disability is not co-ordinated or universal. Mental healthcare for people with intellectual disability is predominantly provided within in-patient services. Only in recent years, out-patient services for such people have been developed. There is a little emphasis in medical education on the healthcare needs of people with intellectual disability.

In healthcare, there are many barriers to people with intellectual disability amongst health providers, with few specialised services and little knowledge and understanding of the issues affecting people with intellectual disability due to insufficient funding of services. Moreover, organisational barriers sometimes prevent people with disabilities from benefiting from adequate healthcare compared to persons without disability. To counteract this anomaly, a law for special out-patient centres for people with intellectual or other severe disabilities was enacted in June 2015.

The centres are known as "Medizinische Behandlungszentren für Erwachsene mit geistiger Behinderung oder schweren Mehrfachbehinderungen" (MZEB), which are medical treatment centres for adults with intellectual or severe multiple disabilities. These centres are available to people with intellectual or other severe disabilities who have difficulties in securing adequate healthcare in the common out-patient system. The MZEBs provide integrated care through multi-disciplinary work, providing in-patient and out-patient services that include a range of specialist care – for example in physical healthcare and mental healthcare. They are run by physicians and organised by private companies of residential homes or hospitals. The healthcare providers employ physicians from different medical fields and other therapists such as psychologists, physiotherapists and others. The MZEBs are funded by health insurance.

It is too early to conclude the success of MZEBs in caring for people with intellectual disability in Germany but with their integrated, multidisciplinary nature of organisation, improvement is likely. For some critics of the MZEB model, they represent a retrograde step for inclusion by separating people with intellectual disability from general health services. In spite of this, medical expertise in intellectual disability treatment is growing. (Elstner, S. and Theil, M. 2018)

Norway

The general psychiatric services in Norway have over the last thirty years been transformed to some extent from being predominantly in-patient services, to being predominantly out-patient services. People with intellectual disability were returned to their home municipalities during the early 1990s following de-institutionalisation. According to the intentions of the reform to decentralise care for people with intellectual disability, which was enacted by law in Norway in 1990, mental health should be taken care of in the general psychiatric services. However, since then patients with intellectual disability have only had limited access to these services. In particular people with intellectual disability and mental health problems have poor access to inpatient services. There is also a lack of specific training in mental health and intellectual disability for both psychiatrists and psychologists in Norway.

The main finding of a literature review and survey by Baaken et al, in 2018 is that mental health services for persons with intellectual disability are still fragmented in Norway, although efforts have been made both in building up clinical services and initiating and conducting research projects. There are several reasons for this fragmentation. The first is the lack of a common health policy in this area, with no national policies, especially for this patient group. Second, mental health services are provided in three different categories: generalised psychiatry, specialised psychiatry and specialist rehabilitation services (which provide some disability services).

Netherlands

Wieland and ten Doeschaate (2018) described that in the Netherlands, curative mental healthcare and supportive care for people with an Intellectual disability are organised in separate domains Some mental healthcare organisations have departments specialising in the dual diagnosis of a mental disorder and intellectual disabilities, but waiting lists are long and this type of specialised mental health care is not readily available everywhere in the country. A new development is the realisation of a ‘quality standard of care’ (QSOC) on mental healthcare for people with borderline intellectual functioning or mild intellectual disability. This QSOC describes what comprises good integrative multidisciplinary care from the perspective of the patient during the complete care continuum and the patient journey.

United States of America

People with intellectual disability in the USA have found it difficult to access mental health services because of a long-standing division between mental health and intellectual disability services (Hackerman et al, 2006). Administrative distinctions left some people with intellectual disability and a mental health condition trapped in the gap between mental health and intellectual disability services. In 1999, the Developmental Disability Assistance and Bill of Rights Act led to the development of university centres for the treatment of people with intellectual disability and a mental health condition.

Mental health services for people with intellectual disability are usually offered by consultants, university-affiliated programmes and out-patient clinic services. The Rochester Model, in which a specialist out-patient team provides mental health support as part of a generic mental health team or a developmental disability service, is also implemented in some areas. The state of North Carolina also devised an

integrated and coordinated care system across services for those with a dual diagnosis of intellectual disability and mental illness. The Greater Boston START Model has also been developed. However, overall mental health services for people with intellectual disability in the United States are fragmented and there are very few 'centres ' and complex insurance cover systems cause problems with access for service users.

Australia

Overall, mental health services for adults with an intellectual disability in Australia are regarded as unsatisfactory (Trollor, 2014). This is due to problems with limited psychiatric input, negative attitudes and a lack of education among professionals around the mental health needs of patients with intellectual disability (Einfeld et al, 2006). Mental health conditions in those with intellectual disability often go undetected because of a number of barriers, such as general practitioners being unaware of the mental health needs of this group and carers and families being unable to relay psychiatric symptoms to professionals.

Efforts to address these deficits have been rolled out in New South Wales by the publication of *The Guide – Accessible mental health services for people with an ID.* This is a national framework of understanding and action for frontline mental health service providers with respect to people with an intellectual disability. It provides an overview of intellectual disability mental health, why accessible services are important, principles that should guide service delivery, practical strategies for inclusive and accessible services, and the implications for the service system. *The Guide* was developed in consultation with key national stakeholders, and was funded by the Australian Government's Department of Health.

The Department of Developmental Disability Neuropsychiatry (3DN) in Sydney was instrumental in developing this guide and in producing e-learning modules which are available to staff working in primary care, disability services and mental health, in order to up-skill the workforce on mental health in people with intellectual disability. They also provide some specialist clinical services for people with intellectual disability.

Service development across Australia has, however, been poorly coordinated and varies widely between states (Queensland Centre for Intellectual and Developmental Disability, 2002). In Victoria the Gippsland Dual Disability Evolution Project was implemented to conceptualise and analyse a model of service delivery for adults with dual diagnosis (Chesters et al, 1999). Victoria also has a statewide psychiatric service specifically for those with a dual diagnosis. In some states, such as New South Wales, there are research centres for intellectual disability such as the 3DN service that also provide general health clinics for patients. Yet several states, for example Tasmania and Western Australia, do not have any specialist services specifically for those with a dual diagnosis.

A model of interest is based in the Australian Capital Territory (ACT). A dual disability service (DDS) (recently renamed the Mental Health Service for People with ID – MHS-ID), has been in operation since 2002. Some of the results of ten years of a specialist team for assessment and treatment of mental health problems have been described by Wurth and Brandon (2014).

The ACT covers an area of 2,400 square kilometres, with a population of approximately 367,000. This MHS-ID service is unique in Australia in providing a comprehensive mental health assessment and treatment service to this population in a defined catchment area. In 2001 a memorandum of understanding between ACT health and disability services proposed the establishment of a specialist mental health service to work within DACT (disability services). This initiative was driven by recognition of the numbers of individuals with intellectual disability presenting to emergency departments and the crisis assessment and treatment team (CATT), or occupying inpatient psychiatric beds. Funding was to be provided by both agencies.

The aim was to provide clinical expertise to patients with intellectual disability and mental health problems and their carers, and consultation-liaison services to staff from disability services and other agencies. A psychiatrist with specific expertise was to be appointed as a visiting medical officer (VMO), together with three mental health workers. Administrative support was to be provided by disability services. By 2012, staffing consisted of four full-time clinicians, filled with three psychologists and one registered nurse, and a 0.5FTE administrative support officer. One of the psychologists had the combined roles of team leader and clinician. Two psychiatrists visited for a total six hours per month.

The service expanded from initially providing services only to those patients known to either mental health services or living in disability services accommodation to also providing services to those living with family or in accommodation run by NGOs. They have shown reductions in the use of acute psychiatric admission beds and reduced requirement for the involvement of the crisis assessment and treatment team.

MHS-ID reviews historical information from a multidisciplinary perspective, including developmental history, medical history, including detailed medication history and specialist reports, plus reports from school, psychologists and other sources. Contact is made with all relevant stakeholders including family, support workers, general practitioners, specialists and allied health professionals. Valuable historical information, of critical importance in the clinical formulation, is often discovered. Team psychologists may administer psychometric tests.

Assessment includes a review of the shared mental health electronic record (MHAGIC). Many patients have had years of involvement with a range of mental health services. This is often the first time that a comprehensive longitudinal review has occurred, and is crucial in addressing the shortcomings of the cross-sectional approach frequently taken with this population. Following diagnosis, a treatment plan is developed and implemented. Not infrequently, recommendations by other treating specialists are found to have been neglected, and implementation is expedited and monitored by the team. Regular psychiatrist reviews are held until the situation is stabilised. This can take years in some instances. The patient is then discharged for follow-up by their general practitioner or a community mental health team. Post-discharge, contact can be made with MHS-ID team for advice and or re-referral.

New Zealand

Aotearoa New Zealand has both a private and a public healthcare system, the latter of which is managed under the Ministry of Health. The government-funded public healthcare system works on a community-oriented model and includes district health boards that are funded by the government and are responsible for providing or funding health and disability services in their district, including mental health and addiction services. (Mc Carthy, J. and Duff, M. 2018).

The New Zealand representation of the Section of Psychiatry of Intellectual and Developmental Disabilities in consultation with members of the Royal Australian and New Zealand representation of College of Psychiatrists from Australia have recently put forward a number of key recommendations to improve outcomes for people with intellectual disability and mental health needs (RANZCP, 2018):

- Consideration of the mental health needs of adults with neurodevelopmental disabilities in relevant policy development and implementation.
- Review of training and support for all frontline health staff across all disciplines. It is critical to ensure that training in neurodevelopmental disorders is part of both undergraduate and postgraduate courses for all health disciplines.
- Development of clear clinical pathways with broader intake criteria in secondary mental health services for patients with neurodevelopmental disorders.
- Development of multidisciplinary specialist mental health teams, with the specific functions of managing the mental health needs of people with intellectual disability and autism who also present with comorbid mental illness.
- Development of centres of excellence in this area with strong links to academic institutions, leading to the expansion of leadership in regard to training and research.

A key issue in developing specialist services is the availability of a workforce with sufficient expertise to deliver such services. Recent analysis of workforce data for New Zealand and Australia showed that there are up to eighteen psychiatrists working in intellectual developmental disability mental health (IDDMH) services on the North Island and seven psychiatrists on the South Island. There is no approved specialist training programme in the psychiatry of intellectual disability, although The Royal Australian and New Zealand College of Psychiatrists are currently developing a curriculum for a specialist training programme. A focus on workforce planning and training over the coming years will be important in ensuring a critical mass of expertise across professional groups, which must include psychiatry, psychology, nursing, occupational therapy, and speech and language therapy. (Mc Carthy, J .and Duff, M. 2018).

England

It is estimated that nearly 1.1 million people in England have an intellectual disability. Of these, nearly 200,000 are children and 930,000 are adults. Around 830,000 of them are aged 18–64 (Learning Disabilities Observatory, 2015). Nearly £8 billion is spent annually by the government through local authorities on care for people with intellectual disability in England, divided into 60 per cent on social care, 30 per cent on welfare benefits and 10 per cent on specialist intellectual disability health services (Department of Health, 2017). Healthcare is provided by the National Health Service (NHS) and social care by local authorities. Health and social care services in intellectual disability have been well-established for many years and continue to evolve according to demand and political changes.

Meeting the needs of people with intellectual disability in the United Kingdom has evolved from institutional care to more community-oriented services for children and adults with intellectual disability. It has been due to changes in public policy and the actions of parents that have led to the greatest changes in service provision. Services are well developed but face certain challenges as they seek to support people moving out of hospitals to live meaningful lives in the community with the right support. There is also the challenge of meeting health and social care needs of people within a finite budget. Providing high quality care, inclusion, improved quality of life and parity of care are some of the main targets for services. (Perera, B. and Courtenay, K. 2018).

Mental health services in the community are usually provided through multidisciplinary teams either as stand-alone services or alongside physical health services. In some services, social care for people with intellectual disability is integrated with health care. Even within the best available services, in the United Kingdom, service delivery differs, with only some regions reporting well-established community intellectual disability teams providing a range of mental health and or behavioural services to individuals in their own homes or in the community. Currently there is no consistent ‘model’ of what a community intellectual disability team should look like. Services differ in their professional make-up, referral criteria and or care pathways to reflect and meet locally identified needs. There is clearly therefore a need for more research on service models.

The models adopted depend on local preference and can be broadly divided into three main categories: NHS healthcare teams; Social care teams and unintegrated teams where social and NHS employed staff work within one team and under one management structure.

Appendix 2

Learning from an integrated model of service in the UK

Members of the model of service working group and the steering group for the MHID service development project travelled from Dublin to Tower Hamlets in London to visit the community learning disability service (CLDS) which has developed a mental health and challenging needs team which has integrated working within health and social care. They are one of four teams (the others being: community health and well-being, complex physical health and transition) which are integrated with CLDS services. They met with the lead clinician, Dr Ian Hall and his multidisciplinary team and heard about their experience of developing their service and what works well and how this was achieved. Their emphasis is on: *Getting it right for patients.* Proof that their services and systems are working is in their outcomes: None of the service users they see have needed specialist assessment and treatment beds for five years and their general psychiatry admissions are very short.

The following is a summary of what has worked well in Tower Hamlets:

1. **A whole systems approach has been taken**

   There is a need to examine all aspects of service from beginning to end and how they interact with others.

2. **Incremental gains are focused on service users**

   There is a need to address every little aspect of the service and focus on how best to improve the interaction from a service user's perspective and services are person-centred.

   - Every step looked at how the process can be more person-centred and how to really meet people's needs in a way that they want.
   - Person-centred planning that genuinely incorporates choice and promotes independence.

3. Clinical leadership is needed

- There is a need to recruit and develop good clinical leaders from all disciplines
- You need leaders that:
  - promote innovation and innovative community solutions.
  - actively build trust with other services and develop strong working networks.
  - develop strong clinical networks with mainstream services (across all disciplines).

4. Multidisciplinary teamwork is important

- For people with mental health problems and with challenging behaviour, they provide direct psychology, psychiatry, nursing, occupational therapy and speech and language therapy. They also offer family therapy and counselling to service users and their families, to help address problems early on.
- They have worked at moving towards a meaningful multidisciplinary model. As a team they problem-solve together, support each other, share information and networks, rotate responsibilities and are flexible. If there are not enough resources, team members work across disciplines to address the need.
- Multidisciplinary team includes – 1 consultant psychiatrist, 1 specialist registrar and 1 other junior doctor, nursing, social work, psychology, speech and language, occupational therapy and art therapy. All disciplines are co-located in the same building.
- A case management system is in place – the most appropriate discipline for each service user takes the lead and this is adjusted as needs change.
- The role of consultant psychiatrist is to support the work of the team and go where the team feels they are most needed, such as complex assessments, demanding cases and discharges.
- Team leads are actively involved with service users.
- Speech and language is essential for complex cases.
- Team leads report to clinical lead but obtain supervision from within their individual disciplines.

5. Integrated working between health and social services is essential

- Both health and social services work in joint teams and have developed strong working relationships and are co-located and run joint clinics.
- They invest significant time and energy in developing these close integrated working relationships with other adult mental health services and social services.
- Pooled budgets and joint commissioning are in place.
- Flexible social care provision is regarded as essential to achieve truly personalised care plans.
- For service level agreements between social care and mental health there is joint commissioning with quality monitoring officers, to ensure standards are met by contracted agencies.

6. There is a focus on early assessment and prevention

- Strong focus on identifying mental health problems and challenging behaviour early.
- Integration and joint intervention helps achieve early assessment and prevention.
- Working together also helps identify and remove perverse incentives to keep people in hospital, such as funding.

7. Open access referrals are in place

- They operate a single point of entry, the Front Door Team.
- This starts with an initial screening and assessment phone call, which.
  - Collects all background and history, supported by one IT system this means the service users and or carers do not need to repeat their story.
  - At this call they look at eligibility for the service. Assessment criteria are strictly audited by senior management.
  - The service user is then signposted to the team that best addresses their needs.
  - Sub team follows up with more detailed multidisciplinary assessment.

8. Communication and training are key components

- Training for users, carer and staff which is designed from their perspectives.
- They conduct awareness programmes designed to engage (educate?) staff using short videos, accessible information, on-line learning modules.
- Service user training on self-advocacy for target groups.
- Accessible communication officers (people who have training and or can provide training in and promote accessible communication).
- Promoting intellectual disability awareness is important.

9. Support to families and local providers to prevent and reduce mental health needs is provided

- Include supports for families through social work input and psychoeducation at all stages. It is the family that can make the most difference.
- Engage with local providers in independent sectors, such as training, developing relationships, knowing which service users may present.

10. Clear governance is in place

- One provider for local MHID services – work in process, clear path of trust and intellectual disability and autism strategy.
- Joint lines of accountability for both social care and mental health.

11. Active discharge planning

- There has been a big government emphasis on discharging service users from hospitals and specialist units where admissions have in some cases been prolonged and out of area. These service users often have high needs and placements are very costly and the service users can experience high levels of anxiety around this, so proactive work is important.
- They work closely with in-patient services.
- Senior clinical psychologist or psychiatrist is present at all reviews.
- Early involvement with social care, actively planning for discharge from the beginning of stay.
- Focus on keeping patient within their local community.
- Work with local services for bespoke community services to support discharge.

Appendix 3

Conducting a mental health assessment for an adult with intellectual disability

The following details key considerations and actions required for each stage of a mental health assessment and associated assessments, including risk, crisis and for an adult with autism spectrum disorder:

Before mental health assessments

- It is important to be prepared and make reasonable adjustments.
- Agree a clear objective, and explain it to the person, their family members, carers or care workers (as appropriate), and all professionals involved.
- Read all documentation, charts, assessment materials and referral form.
- Explain the nature and duration of the assessment to everyone involved.
- Explain the need to ask certain sensitive questions.
- Address any queries or concerns that the person may have about the assessment process.
- Make any reasonable adjustments such as booking an extended consultation to accommodate possible complexity; avoiding long waiting times in high stimulation environments; arranging appointments which accommodate the person's preference and facilitate accessibility, such as time, location or any other health considerations. Identify and accommodate other physical support needs such as those arising from physical or sensory needs.
- Avoid cancelling appointments at short notice and where possible, prepare the person for change.
- Prepare for the person's communication needs, for example, ensuring that their preferred communication system is available during the appointment, and where necessary, arranging an interpreter. A person with an intellectual disability may use specific augmentative and alternative communication strategies such as gestures or signing (Irish Sign Language, Lamh or other sign languages), or aided communication through the use of specific devices or picture communication systems.

During mental health assessments:

- Establish specific areas of need to focus on.
- Assess all potential psychopathology, and not just the symptoms and signs that the person and their family members, carers or care workers first report.
- Describe the nature, duration and severity of the presenting mental health problem.
- Take into account the person's cultural, ethnic and religious background.
- Review psychiatric and medical history, past treatments and response.
- Review physical health problems and any current medication, and refer to other specialists for review if needed.
- Review the nature and degree of the intellectual disabilities, and if relevant the person's developmental history.
- Assess for problems that may be associated with particular behavioural phenotypes, for example, anxiety in people with autism so that they can be treated.
- Assess the person's family and social circumstances and environment, and recent life events.
- Assess the level of drug or alcohol use as a potential problem in itself and as a factor contributing to other mental health problems.
- Establish or review a diagnosis using:
  - A classification system such as DSM-5 or ICD-11, or those adapted for people with intellectual disability (for example the Diagnostic Manual – Intellectual Disability [DM-ID] or Diagnostic Criteria for Psychiatric Disorders for Use with Adults with Learning Disabilities/Mental Retardation [DC-LD]) **or**
- Assess whether a risk assessment is needed.
- Assess recent changes in behaviour using information from family members, carers, staff or others involved in the assessment, as well as information from relevant records and previous assessments. Take into account the nature, quality and length of their relationship with the person.

When conducting mental health assessments it is useful to be aware that:

- An underlying physical health condition may be causing the problem.
- A physical health condition, sensory or cognitive impairment may mask an underlying mental health problem.
- Mental health problems can present differently in people with more severe intellectual disability.

It is also important when conducting mental health assessments to take into account the person's:

- Level of distress.
- Understanding of the problem.
- Living arrangements and settings where they receive care.
- Strengths and needs.

Develop a formulation

Use the results of the mental health assessment to develop a written statement (formulation) of the mental health problem, which should form the basis of the care plan and cover:

- An understanding of the nature of the problem and its development.
- Precipitating and maintaining factors.
- Any protective factors.
- The potential benefits, side effects and harms of any interventions.
- The potential difficulties with delivering interventions.
- The adjustments needed to deliver interventions
- The impact of the mental health problem and associated risk factors on providing care and treatment.

Provide the person, their family members, carers or care workers (as appropriate), and all relevant professionals with a summary of the assessment:

- In an agreed format and language that sets out the implications for care and treatment.

Give the person and their family members, carers or care workers (as appropriate) another chance to discuss the assessment after it has finished – for example at a follow-up appointment.

Further assessment

Consider conducting a further assessment that covers any areas not explored by the initial assessment, if:

- New information emerges about the person's mental health problem or
- There are significant differences between the views of the person and the views of their family members, carers, care workers or staff about the problems on which the assessment has focused.

Assessment tools

During any mental health assessment, consider using tools that have been developed or adapted for people with learning disabilities, as this will improve the quality of the assessment. If using tools that have not been developed or adapted for people with learning disabilities, take this into account when interpreting the results.

When conducting an assessment with a younger adult with intellectual disabilities, consider using tools such as the Developmental Behaviour Checklist – parent version (DBC-P) or the Strengths and Difficulties Questionnaire (SDQ).

When assessing depressive symptoms in an older adult with an intellectual disability, consider using a formal measure of depression to monitor change over time, such as the Glasgow Depression Scale (the self-report for people with milder intellectual disabilities or the carer supplement for people with any degree of intellectual disabilities).

Other assessment tools which are commonly used in practice are:

- PAS-ADD (checklist, mini-PAS-ADD, structured clinical interviews).
- Glasgow Scale for Anxiety.
- MONASH Depression Checklist.
- CORE – LD.
- Lancaster and Northgate Trauma Scale for Intellectual Disability.
- HONOS-LD.
- Assessments of adaptive behaviour may be completed as part of an overall assessment.
- Assessments typically used include the Vineland and Adaptive Behaviour Assessment System-3.

Risk assessment and management plan

When conducting risk assessments with people with learning disabilities and mental health problems, assess:

- Risk to self.
- Risk to others.
- Risk of self-neglect.
- Vulnerability to exploitation.
- Likelihood and severity of any particular risk.
- Potential triggers, causal or maintaining factors.
- Whether safeguarding protocols should be implemented.

If indicated by the risk assessment, develop a risk management plan with the person and their family members, carers or care workers (as appropriate).

Risk management plans should:

- Set out individual, social or environmental interventions to reduce risk.
- Be communicated to family members, carers or care workers (as appropriate) and all relevant staff and agencies.

Risk assessments and resulting risk management plans should be reviewed regularly and adjusted if risk levels change.

Mental health assessment during a crisis

Conduct an initial assessment for people who are experiencing a mental health crisis, which should include:

- An assessment of the person's mental health.
- A risk assessment.
- Identification of interventions to:
  - help address the problem that caused the crisis.
  - minimise any associated risks.
  - bring stability to the individual and their immediate environment.
- A crisis plan that sets out (using the least restrictive options possible) how to reduce the likelihood of further crises, and what to do if the person has another crisis.

Conducting a comprehensive mental health assessment with a person with autism spectrum disorder

The treatment of an underlying mental disorder is important in terms of reducing further impairment in functioning and improving the quality of life of the individual with autism spectrum disorder. Making the correct diagnosis is critical as people with such conditions may not respond to treatment in the same way as those without that condition, so the clinician needs to decide if lack of response is due to treatment resistance or an incorrect diagnosis of mental illness. The criteria of DSM-5 and the ICD-11 should aid clinicians to make more informed diagnoses of psychiatric illness using evidence-based diagnostic tools for those with autism spectrum disorder (Underwood et al, 2015).

To aid correct diagnosis, a comprehensive assessment should:

- Be undertaken by professionals who are trained and competent.
- Be multidisciplinary team-based and draw on a range of professions and skills.
- Where possible involve a family member, partner, carer or other informant or use documentary evidence (such as school reports) of current and past behaviour and early development.

At the beginning of a comprehensive assessment, discuss with the person at a developmentally appropriate level the purpose of the assessment and how the outcome of the assessment will be fed back to them. Visual aids may be needed to assist in communication with the person. Feedback should

be individualised, and involve a family member, partner, carer or advocate, where appropriate, to support the person and help explain the feedback.

During a comprehensive assessment, enquire about and assess the following:

- Core autism signs and symptoms (difficulties in social interaction and communication and the presence of stereotypic behaviour, resistance to change or restricted interests) that have been present in childhood and continuing into adulthood.
- To aid more complex diagnosis and assessment for adults with an intellectual disability, consider using a formal assessment tool, such as: the ADOS-G, the ADI-R or the DISCO.

Assess for possible differential diagnoses and coexisting disorders or conditions, such as:

- Other neurodevelopmental conditions
- Mental health disorders (for example, schizophrenia, depression or other mood disorders, and anxiety disorders, in particular, social anxiety disorder and obsessive-compulsive disorder).
- Neurological disorders (for example, epilepsy).
- Physical disorders.
- Communication difficulties (for example, speech and language problems, and selective mutism).
- Hyper- and/or hypo-sensory sensitivities.

During a comprehensive assessment, assess the following risks and develop a risk management plan if needed. :

- Self-harm.
- Rapid escalation of problems.
- Harm to others.
- Self-neglect.
- Breakdown of family or residential support.
- Exploitation or abuse by others.

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