Connecting for Life

Specialist Child and Adolescent Mental Health Services for Children with Intellectual Disability (CAMHS-ID)

National Model of Service

Contents

Foreword

This model of service document proposes a framework for providing specialist mental health services for children and adolescents with a moderate to profound intellectual disability, affording them for the first time equitable access to specialist mental health services as their peers of normal cognitive ability.

This document aims to provide better clinical outcomes for children and adolescents with an intellectual disability by standardising mental health provision nationally. The model of service document is in line with national mental health policy as outlined in a Vision for Change 2006, which is the precursor to Sharing the Vision - A Mental Health Policy for Everyone 2020, recommending geographically distinct, catchment area based multidisciplinary teams, per 300,000 of the population. This also complements the recently published CAMHS Operational Guidelines 2019, extending equitable mental health access, assessment and intervention to children with a moderate to profound intellectual disability.

The model of service document provides a comprehensive framework for service development and the resourcing requirement of the new specialist CAMHS-ID teams. The publication of this document coincides with reconfiguration of disability services into the Children's Disability Network Teams. The CAMHS-ID teams provide a specialist mental health service that is separate and distinct but aims to complement the work done by the CDNT who adopt a health and social care approach to treat the child's disability. In line with the recovery model, CAMHS-ID teams provide discrete, episodic specialist intervention to treat the child's mental disorder, and to enhance their quality of life and optimise functioning.

Extensive consultation with clinicians, service providers and users of the services informed this document. Collectively they highlighted their priorities, articulating a clear need for adequate resources to enable mental health services to respond to the needs of children and adolescents who present with a moderate to profound intellectual disability and comorbid moderate to severe mental disorder.

This model of service supports the best practice principle of joint and collaborative working of the CAMHS-ID team with primary care, community mental health services, developmental paediatrics, 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 ten-year plan* published by the Department of Health in 2019.

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. Mental Health Operations welcome this new development and endeavour to continue to improve services for children with intellectual disability and mental disorder.

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Executive summary

Children and adolescents with an intellectual disability should have access to mental health services in the same way as those of normal cognitive ability, 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 services for children and adolescents with an intellectual disability (CAMHS-ID) model of service follow similar international models.

It is imperative that CAMHS-ID 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 has a clear governance structure.

Summary of key recommendations

1.0 Mental health services for children and adolescents with a moderate to severe to profound intellectual disability should be provided by specialist Child and Adolescent Mental Health of Intellectual Disability (CAMHS-ID) teams that are catchment area-based. These multidisciplinary teams should be provided on the basis of one team per 300,000 population.

2.0 These specialist mental health services should be distinct and separate from, but closely linked to, the interdisciplinary Children's Disability Network Teams (CDNT), who provide a health and social care service for children with intellectual disability. The core multidisciplinary team to deliver mental health services to children with intellectual disability and a mental disorder and or challenging behaviour (where mental illness is an aetiological factor) should comprise key individuals from the disciplines of psychiatry, psychology, nursing, social work, occupational therapy (OT) and speech and language therapy (SLT), in addition to an administrator.

3.0 Transition of care between child and adult mental health intellectual disability services needs to be planned and coordinated in conjunction with the child and family. Ideally the transition process should begin six to twelve months prior to transfer.

4.0 This model outlines the referral pathway and details of the child's journey though the CAMHS-ID service.

5.0 It is anticipated that this model of service will be reviewed and updated within a five-year period.

6.0 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 within their own resources, and how to adopt the model as necessary, based on local requirements and geography.

1. Introduction

Introduction

This introductory section outlines the context and background of CAMHS-ID services in Ireland and how they have developed under 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 children and adolescents with intellectual disability, by advancing the development of specialist mental health services nationally and standardising the care provided to service users and their families. These children traditionally have not had equal access to services as their peers of normal cognitive ability who access mental health services through CAMHS.

This specialist mental health service for children and adolescents with an intellectual disability and co-morbid mental disorder is provided by community CAMHS-ID teams. The model is designed to be a guide for all CAMHS-ID teams, and to inform HSE and independent service providers in the care of children and adolescents with intellectual disability.

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 CAMHS-ID 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 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 children and adolescents 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: CAMHS-ID specialist service – focuses on specific details of a CAMHS-ID service.

Section 4: Integrated care – outlines the importance of collaborative working between the CAMHS-ID team and paediatric, disability, in-patient, educational and respite services that may provide care for service users.

Section 5: Service user's journey through a CAMHS-ID service – this section details the four main stages of care a service user and his/her family/carers can expect to experience as he or she journeys through the specialist mental health service.

Section 6: Specialist populations – outlines the specific mental health requirements of service users who may have a mild intellectual disability or an autism spectrum disorder (ASD), and where applicable, the degree of support CAMHS-ID teams can provide.

Section 7: Governance – details the governance structures for CAMHS-ID 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 a CAMHS-ID 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 CAMHS-ID teams need to operate.

1.3 The relationship between mental health and intellectual disability

Over sixty-six thousand persons (66,611) or 1.4% of the population, were described as having an intellectual disability in the Irish Census of 2016, of which 24,474 were under the age of 19 years.

It is well recognised that children with an intellectual disability have a higher incidence of mental health problems than children of normal cognitive ability. A recent NHS prevalence study in the United Kingdom estimated that around one in eight children and adolescents aged 5 to 19 years experienced a diagnosable mental health problem (NHS Digital, 2018).

Emerson and Hatton, (2007) found that children and adolescents with a mental health problem were more likely to have recognised special educational needs (SEN), including those who may have intellectual disabilities (36%) compared to their peers without mental health problems (6%). Other studies also confirm a high prevalence of education needs (Dykens EM, 2000; Tonge B and Einfeld S, 2000; Rutter M, Tizard J, and Yule W et al 1976).

Koskentausta et al (2002) found a prevalence rate of 33% for a psychiatric disorder among a cohort of children with an intellectual disability. Twenty-three per cent of this population were found to meet International Classification of Diseases 10 (ICD 10) criteria for an axis 1 mental health disorder. They reported an increased rate of additional comorbid medical and neurodevelopmental disorders including epilepsy, cerebral palsy and autism spectrum disorder among the population of children with an intellectual disability who participated in their study. This figure was confirmed by Einfield's systematic review of nine studies (Einfield 2011), which estimated the prevalence of psychiatric disorder in children with an intellectual disability to be between 30–50%.

These figures imply that one in seven, or 14%, of all children with mental health problems in the UK also have an intellectual disability and this is very likely to be replicated in the Irish population. So 30–50 % of these children are likely to have one or more mental disorders, and thus more complex mental health needs.

Children with intellectual disability (ID) more frequently present with behaviour which is challenging and complex to support and manage than children without ID. This can have an adverse impact on family functioning. In addition to having to come to terms with their child's diagnosis and behaviour of concern, parents of children with an ID also frequently have to cope with a lack of sleep, as many of these children with ID have sleep disorders. Many interventions provided by CAMHS-ID are aimed at supporting the family as well as the child with the intellectual disability.

The vulnerability of children with intellectual disability to mental disorder may be underpinned by:

- Communication difficulties, such as 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
- High rates of comorbidities in physical health, such as epilepsy, sleep disorders and cerebral palsy
- Increase in genetic conditions, including rare syndromes
- Socioeconomic deprivation and poverty
- Difficult educational experiences and insufficient supportive services
- High rates of adverse life events
- Out-of-home care (such as fostering and institutional placement) or anxious, insecure attachments
- 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 children with an intellectual disability

1.4 The presentation of mental disorders in children with an intellectual disability

The presentation of mental disorders can be influenced by a child or adolescent's level of intellectual disability and associated communication difficulties. Children and adolescents with milder intellectual disability and good communication skills may be able to describe what they are experiencing and typically present in a manner similar to children of normal cognitive ability. However, the presentation of mental disorders can be atypical in children and adolescents with moderate to severe intellectual disability.

In this population, mental disorders may present as behaviours which are problematic, for the child or their support system. They 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 biopsychosocial approach to assessing behavioural change in children with intellectual disabilities, in addition to close liaison and co-working with developmental paediatrics and neurology.

It is important for all those working with children and adolescents 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 children with an intellectual disability.

1.5 Development of mental health services for children with intellectual disability

Historically, services for children and adolescents with an intellectual disability 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 child and adolescent psychiatry services. These mental health services were mainly provided by psychiatrists, who operated a cradle to grave service and were employed through the voluntary bodies, funded by the HSE.

Children who received health and educational services from the voluntary or independent sector accessed multidisciplinary and mental health intervention from these services. Children with an intellectual disability who attended mainstream schools often had no access to multidisciplinary or mental health clinical supports.

There has been a notable commitment to child and adolescent mental health intellectual disability training in Ireland in recent years. Psychiatry of Learning Disability is one of the four specialty registers maintained by the Irish Medical Council. Specialists in child and adolescent psychiatry in Ireland receive their certificate of specialist training in child and adolescent psychiatry and are registered on the specialist register for child and adolescent psychiatry and must have completed one year oftraining in child and adolescent intellectual disability psychiatry.

The HSE disability teams have recently reconfigured services for children with intellectual disability and other disabilities nationally into Children's Disability Network Teams (CDNTs). A HSE national programme called 'Progressing Disability Services for Children and Young People' (PDS) aims to change the way that services are provided across the country to make them equitable and consistent for all children with disabilities. The aim is to provide one Children's Disability Network Team per approximately 50,000 of the population. Because of the way services have developed over the decades, each part of the country is at a different stage of reconfiguration.

When reconfiguration is fully complete, every child with complex needs in the country will have access to an interdisciplinary disability team based on the geographical location of where they live, as opposed to the service or school they attend. A complex need refers to one or more impairments contributing to a range of significant functional difficulties requiring the services and support of an interdisciplinary disability team. This process aims to end the gaps in service provision for children with intellectual disability who reside in certain geographical areas or who attend mainstream schools.

The Children's Disability Network Teams do not include psychiatry. They adopt a health and social care approach to treating the impairments associated with the child's disability and are separate and distinct from the CAMHS-D services. The CAMHS-ID services sit at a tier above the CDNTs for children and adolescents presenting with a moderate to severe mental disorders and requiring input from a specialist mental health service.

The CDNTs play an important role in mental health promotion and prevention, and are best placed to provide intervention to children presenting with mild to moderate mental health problems/mental distress, who do not require input from a specialist mental health service.

1.6 Sharing the Vison/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, *Sharing the Vision, A Mental Health Policy for Everyone* (2020), which were published as blueprints for future mental health service development.

Irish mental health policy as outlined in *A Vision for Change* (2006) emphasises the importance of specialist multidisciplinary mental health teams in delivering mental health services to the whole population, including children and adolescents with an intellectual disability.

As detailed in *A Vision for Change*, the core Child and Adolescent Mental Health of Intellectual Disability (CAMHS-ID) team is made up of psychiatry, psychology, clinical nurse specialist, social work, occupational therapy, and administrative support. Speech and Language Therapists were included as an important addition to the CAMHS-ID team in Sharing a Vision. A Vision for Change recommends 15 CAMHS-ID teams nationally, based on one per 300,000 of the population. These teams are in the early stages of development nationally, with some parts of the country having as yet no dedicated mental health service for children and adolescents with ID and mental disorder.

CAMHS-ID teams provide a specialist mental health service to children and adolescents with an intellectual disability and comorbid moderate to severe mental disorder. These teams are distinct and separate from, but closely linked to, the multidisciplinary Children's Disability Network teams, who provide a health and social care service for children with intellectual disability. It would be best practice for multidisciplinary intervention to be provided initially by the Children's Disability Network Team prior to a referral to CAMHS-ID.

A Vision for Change and *Sharing the Vision* advised that the training, skills and experience of all members of the multidisciplinary CAMHS-ID teams are crucial. The composition of each CAMHS-ID team should ensure that an appropriate mix of skills is available to provide a range of best practice therapeutic interventions tailored to the mental health needs of service users. Section 3.4 of this report outlines the mental health professionals that are recommended to comprise each core multidisciplinary CAMHS-ID 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 children with mental disorders and psychosocial disabilities to achieve their own aspirations and goals in the context of their disability, taking into consideration their parent's/guardians needs and expectations in supporting their child in reaching his or her goals.' The guiding principles of this report affirm this policy.

The process of developing the CAMHS-ID teams in Ireland has begun, with the formation of several small teams around the country. However, there is a need for ongoing investment in the development of these teams in addition to integration between primary care, children's disability network teams and child and adolescent mental health services.

Sharing the Vision highlights the importance of prioritising investment in mental health services as developed through the Mental Health Intellectual Disability 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 CAMHS ID services.

1.7 Overview of current CAMHS-ID services

Despite the over-representation of mental disorders in children and adolescents with intellectual disability as referenced in Section 1.3, access to mental healthcare in Ireland falls short of what is required to meet the needs of children and adolescents who may be at increased risk. As mentioned above, CAMHS-ID services are at 22% of the required service levels outlined in *Vision for Change*.

Families and carers of children with an intellectual disability have noted their difficulty in securing an appointment with a mental health service provider, and in understanding the referral pathway. Early detection of a potential mental disorder along with timely referral from primary care is needed.

2. Model of service overview

Model of service overview

This section 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 CAMHS-ID 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 that would enable existing and future CAMHS-ID 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 countrywide. The model also represents the HSE's commitment to improve standards and quality in the provision of mental health services to children and adolescents with intellectual disability, on par with that delivered to children of normal cognitive ability.

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

- How CAMHS-ID services can be delivered in line with best practice standards, while defining what a good CAMHS-ID service should look like.
- The roles and responsibilities of the different CAMHS-ID 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 CAMHS-ID teams.
- The support infrastructure and resources needed for a CAMHS-ID team.
- Legal and ethical considerations under which a CAMHS ID-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 not only decide how best to encompass national standards, but also howto adopt the model as necessary, based on local requirements, resources and geography.
- This model of service relates to CAMHS-ID 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 CAMHS-ID management and team members. However, based on this model's whole system and person-centred approach, it is of use to multiple users in helping them understand what a CAMHS-D service can offer.

2.3 Benefits of the model of service

The model will also help to improve the mental health service experience and outcomes for children and adolescents with an intellectual disability and their families/carers by:

- Facilitating collaboration within the existing system in a way that enables a whole-system approach, achieving better services and clinical outcomes for service users and their families.
- Facilitating collaborative working with service users, family members and carers.
- Providing better support and understanding for clinical staff members on their role in providing and contributing to the development of a specialist mental health service for children and adolescents with an intellectual disability.
- Advising staff on expected and acceptable levels of mental health 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.
- Assist in planning for CAMHS-ID service delivery, including efficient utilisation of resources and future workforce development.

When implemented, this model of service will bring mental health services for children and adolescents with an intellectual disability and a mental disorder into line with mental health services for children of normal cognitive ability, as delivered through CAMHS, allowing them 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 children with intellectual disability, both HSE and independent agencies, to deliver accessible and safe services to a high quality standard.

2.4 Guiding principles for CAMHS-ID services

This model of service is based on six guiding principles – see Figure 2 below. These guiding principles provide a pathway for the development of this model and for its subsequent recommended care.

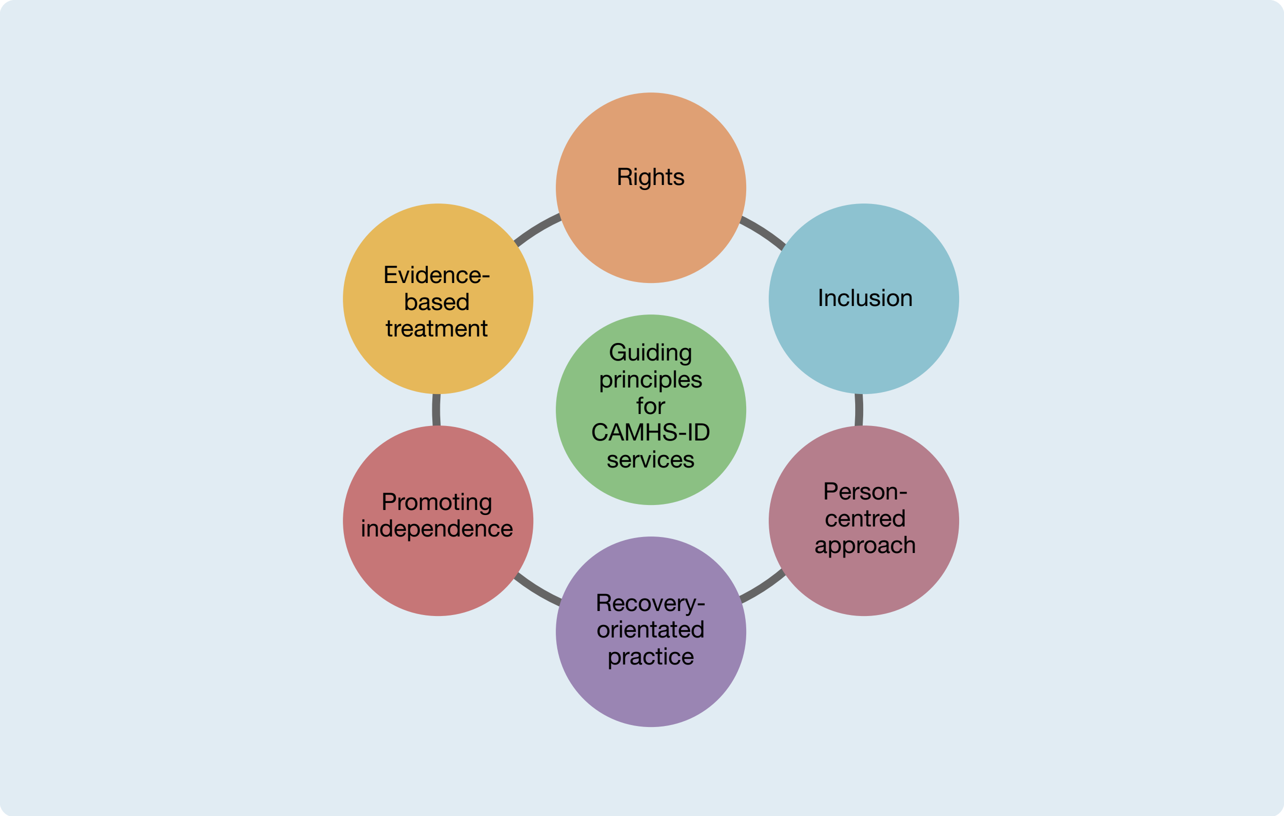

Figure 1: Guiding principles for CAMHS-ID services

Human rights

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. Article 24 of the United Nations Convention on the Rights of the Child (ratified by Ireland in 1992) specifies that the 'State shall recognise the rights of the child to the enjoyment of the highest attainable standard of health and the facilities for the treatment and rehabilitation of health. Shall strive to ensure that no child is deprived of his or her right of access to such healthcare services.'

In Ireland the *National Children's Strategy* reiterated the principle that 'children will be supported to enjoy the optimum physical, mental and emotional well-being'.

Person-centred approach

A person-centred approach to mental health maximises the involvement of the child or adolescent with an intellectual disability and their parents/carers in decision-making, rather than viewing such a person as a passive recipient of care. Involving children and adolescents and their families/carers in their care is the core of a recovery-orientated service and underpinned in Article 12 of The United Nations Convention on the Rights of a Child (UNCRC 1990). In a person/child-centred approach, the child and their parents/carers are 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/child's own perspective and that of their family, discovering what is important to them, and inviting them to participate in shared decision-making about their mental healthcare, as appropriate, taking into consideration the child's age, developmental level and capacity.

Recovery-orientated practice

Recovery-orientated care is a strategic priority for the Irish mental health service and has been set out in *Sharing the Vision* and *A Vision for Change* national mental health policies. It is also underpinned in a number of quality requirements for mental health services, including Best Practice Guidance for Mental Health 2017 and A National Framework for Recovery in Mental Health 2018–2020. Recovery means different things to different people. For the majority of people it means being able to live their best life, even with a mental disorder. Adopting a recovery-orientated approach in CAMHS-ID is about supporting children and adolescents and their carers to have hope, to feel empowered to make choices about their own mental health care, and to have control over their own goals and how to achieve them. It includes encouraging parents/carers to recognise their own needs, strengths and resources in supporting their child with an intellectual disability in recovering from a mental illness.

Promoting independence

Specialist mental healthcare for children and adolescents with an intellectual disability and mental disorder should recognise the autonomy of individuals with such a condition, while acknowledging their age, developmental level and capacity, and work in a manner that maximises their independence.

Mental health professionals should practise evidence-based medicine and continually seek to enhance their knowledge of new and existing interventions through continuous professional development. Sources of evidence can include clinical research in the areas of assessment, management and prevention of mental illness in children and adolescents with an intellectual disability.

2.5 How was this model of service developed?

This model of service was developed in collaboration with clinicians, managers, service users, family members and other mental health 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 this model of service and the previously issued ‘Interim Guidelines’, it was important to fully engage with CAMHS-ID 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, which was made up of staff directly involved in the provision of CAMHS-ID services. The model and associated document was therefore written and developed directly by staff and service user advocates.

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 and Sharing the Vision*.

It included representation from:

- Psychiatry
- Psychology
- Nursing specialists
- Social work
- HSE adult mental health operations
- Voluntary agencies
- Inclusion Ireland (who sought feedback on the MOS from families/carers of service users)

Further advice and quality assurance was sought from individual experts and professionals, including:

- A United Kingdom CAMHS-ID expert (for *external quality assurance and international benchmarking*)
- Occupational therapists, represented by Joanne Fallon, Occupational Therapy Manager

General oversight was provided by the HSE’s national CAMHS-ID 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

Service users were represented by families and carers who were invited by Inclusion Ireland to attend a focus group. A small number of families responded to the invitation to consult on CAMHS-ID services and all the feedback related to access issues and lack of specific services for CAMHS-ID due to their early stage in service development. Feedback also related to a lack of clarity in relation to accessing CAMHS services. *‘I found it hard to navigate the system even though I worked in it’*, and not understanding the difference between CAMHS-ID and the newly-reconfigured CDNTs.

There was a lack of understanding about the referral pathway and criteria for referral among service providers, as two children had been sent to CAMHS for referral but were told that they were not eligible for services. This resulted in one parent feeling her child was discriminated and ‘handled differently’ than children referred to CAMHS without a disability. There was also confusion about psychology services within primary care and CAMHS services. There needs to be clear understandable pathways for service users, their families and referrers in relation to primary care, disability and specialist CAMHS services.

2.5.3 Evidence-based services

The working group drew on evidence from previous publications and models of service development internationally; including The College of Psychiatry in Ireland (2011) position paper entitled *Mental Health Provision for Children with a Learning Disability* which outlined mental health provision at that time and made recommendations for future service developments, and The Royal College of Psychiatrists (UK) college report (2016) No. 200 *Psychiatric services for young people with intellectual disabilities.*

In addition, members of the working group benchmarked the development of the model of service against a review of international and Irish research.

2.5.6 Service models from an international perspective

Influence of Irish MHID model on CAMHS-ID model

The model of service for CAMHS-ID has been informed by the prior development of the model of specialist mental health service for adults with an intellectual disability (MHID Model of Service 2020) and the CAMHS Operational Guidelines (2019). In developing the MHID model of service, 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 children and adults with an intellectual disability and to determine worldwide trends.

In the initial developmental stages of the MHID model of service, members of the steering and working groups conducted a site visit to Tower Hamlets in London, to study the Community Learning Disability Service (CLDS) for children and adults there. The aim of that visit was to learn from the existing integrated model of service in London, to inform the development of specialist mental health services in the Irish context.

The following includes a summary of the key features identified from the site visit to Tower Hamlets as contributing to an effective MHID/CAMHS-ID service.

- **A whole systems approach** – examined all aspects of service from beginning to end and how they interacted with others.
- **Incremental gains are focused on service users** – continually addressing every aspect of the service and focusing on how best to improve a person-centred approach.
- **Good clinical leadership is needed** – need to recruit and develop good clinical leaders.
- **Good multidisciplinary teamwork is important** – working at moving towards a meaningful multidisciplinary model across psychiatry, nursing, psychology, social work, occupational therapy and speech and language therapy.
- **Integrated working between health and social services is essential** – both health and social services have developed strong working relationships and run joint clinics where clinically indicated.
- **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 active discharge planning from the beginning of inpatient stay or from outpatient treatment with a recovery plan for staying well.

It was, however, acknowledged that services for children and adolescents with an intellectual disability in the National Health Service (NHS) remain largely poorly developed, and are patchy and piecemeal across the country. It was noted that joined-up/integrated care on the whole is not evident or present.

International context

Major developments in mental health services for children and adolescents with intellectual disability have been made internationally (Canada, Serbia, UK, Africa, Mexico; please see Appendix) in the last fourteen years. However, many challenges to providing effective mental healthcare for this group remain. (Please see Appendix)

Barriers for children with learning disabilities and their families to accessing child mental health services (Jacobs et al 2016)

Structural constraints

- Parents do not know where they can get help and information about service provision (Douma, Dekker and Koot, 2006, Faust and Scior, 2008, Samuel et al., 2012, Wodehouse and McGill, 2009).
- Fragmentation of services and complexity in how services are organised contribute to difficulties in using services (Nageswaran et al., 2011, Thyen et al., 2003, Wilkins et al., 2010).
- A lack of dedicated resources is a barrier for mental health providers in meeting the needs of young people with learning disabilities and mental health problems (such as a lack of residential placements, lack of respite and meaningful and safe leisure opportunities and lack of expertise and skilled staff) (Scior and Grierson, 2004).
- Due to lack of inpatient specialist services, young persons with learning disabilities are admitted to inappropriate mainstream psychiatric services, often a long distance from the family (Faust and Scior, 2008, Scior and Grierson, 2004).

Perceptions of mental health problems

- Stigma and shame attached to mental disorder creates difficulty for some parents to seek help for their child's mental health problems (Faust and Scior, 2008).
- Due to the complexity of mental health problems both parents and professionals experience difficulty and confusion in identifying what the problem is (Faust and Scior, 2008, Scior and Grierson, 2004).
- Again, due to the complexity of the experienced mental health problem, identifying what the roles of different services are can be unclear, and families and children are not referred to the appropriate service (Betz et al., 2004, Faust and Scior, 2008, Scior and Grierson, 2004).

Perceptions of mental health services

- When parents ask for help, many feel like they are not being taken seriously, feel they are being blamed for the child's behaviour or feel labelled as being neurotic (Faust and Scior, 2008, Wodehouse and McGill, 2009).
- Parents feel that a crisis needs to be reached before appropriate services are offered to them (Faust and Scior, 2008, Wodehouse and McGill, 2009) or that they have to battle with services before help is offered (McGill, Papachristoforou and Cooper, 2006, Wodehouse and McGill.

Overcoming barriers in an Irish context

In 2017 the HSE issued the Joint Working Protocol Primary Care, Disability and Child and Adolescent Mental Health Services. Its aim was to produce an agreed operational protocol for children whose needs may cross these services. This relates particularly to referral, assessment, intervention and discharge of children and young people under the age of 18 years.

There are currently two national policies/guidelines for Disability Services/Primary Care and CAMHS. These are the National Policy on Access to Services for Children and Young People with Disability and Developmental Delay (February 2016) and the CAMHS Operational Guidelines (2019). Gaps exist in how children and young people can access support across health services when required. Wide experience shows that there are children and adolescents with complex clinical issues who do not fit neatly into one specific diagnostic criterion. Historically services have developed in differing ways, leading to inequity and inconsistency. One aspect of this inconsistency is in joint case management of complex cases between Primary Care, Disability Services and CAMHS/CAMHS-ID.

The Joint Working Protocol outlines service provision, roles and responsibilities for Primary Care, Disability Services and CAMHS. It also details the referral process, joint working, consultation, and communication. The Protocol also describes the proposed Integrated Children's Services Forum as a way to ensure a coordinated and flexible approach to the delivery of services to children and their families based on need.

3. CAMHS-ID specialist services

CAMHS-ID specialist services

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

3.1 Purpose

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

- Good quality specialist mental healthcare to children and adolescents with *moderate, severe and profound intellectual disability* and a moderate to severe mental disorder.
- Some children with mild intellectual disability and mental disorder will already be receiving mental healthcare from CAMHS-ID teams or psychiatrists in disability services due to historic arrangements. It is appropriate for these children to continue to access mental healthcare from the CAMHS-ID team for continuity of care, unless arrangements have been agreed locally with CAMHS services to take over the management of their care. Similarly, children with a moderate to severe intellectual disability may be receiving mental healthcare from a CAMHS team and should continue to access these services unless there is a clinical indication for them to transfer to a CAMHS-ID service.
- The CAMHS ID team may provide access to consultations and second opinions to CAMHS teams for children and adolescents with mild intellectual disability and more complex mental disorders, within available resources. New referrals of children and adolescents with mild intellectual disability and moderate to severe mental illness should be made to general child and adolescent mental health services.

3.2 Why are specialist CAMHS-ID services needed?

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

For CAMHS-ID 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 specialist services are best suited to:

- Children with a mental health disorder who function in the moderate, severe and profound intellectual disability range.
- Children and adolescents with limited or no verbal communication due to their intellectual disability.
- Complex medical or psychiatric needs which present challenges to diagnosis and assessment.

3.3 Scope of the service

The CAMHS-ID team is a specialist children's mental health service that aims to complement the services provided by primary care, children's disability network teams (CDNTs) and community child and adolescent mental health services (CAMHS). Children and adolescents living with a mental disorder are usually supported by the CAMHS-ID team for a limited period of time to provide specialist mental health assessment and intervention. As the person's mental health improves, the CAMHS-ID team will plan to discharge back to primary care and the Children's Disability Network Teams with a recovery plan for staying well and how to access the team again if needed.

Mental disorders are often described on a continuum of severity, ranging from mild to moderate to severe. A number of factors are taken into account when defining whether someone has a moderate to severe mental disorder and these include the diagnosis, formulation, the duration of the symptoms and the level of impact on functioning in daily living.

In practice the term moderate to severe means that the mental disorder is severe enough to cause substantial distress to the child or their family or others. The child or adolescent would have a significant impairment in functioning in two or more aspects of their life, including development, family relationships, school, peers, self-care and play or leisure activities.

3.3.1 The CAMHS-ID team provides

a. Assessment, formulation, diagnosis and treatment of mental disorders which significantly impact on everyday functioning to a degree that requires specialist CAMHS-ID input.

b. Development of co-produced individual care plans.

c. Provision of multidisciplinary team interventions for CAMHS-ID 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.

g. Liaison with children's disability network teams, education services and mental health services.

h. Working with acute children's mental health inpatient services where appropriate.

3.3.2 The CAMHS-ID team does not provide

a. An alternative clinical team to the primary care team or children's disability network team.

If a child or adolescent with an intellectual disability is attending a clinical service in a primary care or disability team, they should not be discharged from that clinical service. The CAMHS-ID team will provide specialist mental health intervention only and will not provide for all the clinical needs of the child or adolescent with an intellectual disability. The CAMHS-ID team will not duplicate the work of the clinician on the primary care or children's disability network team, but will complement their input with specialist mental health intervention to treat the mental disorder. Furthermore, CAMHS-ID team members should not provide interventions such as behaviour analysis to bridge a service gap or vacancy.

b. Access to residential services or respite for children and adolescents with an intellectual disability.

(However, if it is identified that a child or adolescent attending CAMHS-ID service requires residential services, it is appropriate for the team to advocate for such services, which are usually provided through disability services).

c. A service which assesses for the presence or absence of an intellectual disability or autism. The CAMHS-ID service will request copies of the child or adolescent's most up-to-date psychometric and social communication assessments on receipt of the referral.

3.4 What professionals work in CAMHS-ID teams and what do they do?

The CAMHS-ID team consists of multidisciplinary team members with training and expertise in supporting children and adolescents with intellectual disability and mental disorders. 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 1.7, A Vision for Change (2006) and Sharing the Vision (2020), have advised that the community CAMHS-ID team should comprise of the following:

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

Important: Not all teams will come into existence with full membership. The current national CAMHS-ID 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 train and specialise in psychiatry. The College of Psychiatrists of Ireland provides comprehensive competency-based training spanning a seven-year period 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 in community, in-patient and hospital settings.

Child and adolescent psychiatry is one of the four specialties recognised by the Irish Medical Council. Consultant psychiatrists on the specialist register for child and adolescent psychiatry working with children with an intellectual disability are deemed by the college to be competent in that speciality.

After qualifying as a medical doctor, the NCHD completes four years of basic specialist training; higher training includes three years in a child and adolescent specialty and one year completed in a CAMHS-ID service (or other relevant mental health intellectual disability training for example six months in an adult mental health intellectual disability service and six months in a CAMHS-ID service) to obtain a certificate of completion of specialist training in child and adolescent psychiatry with a special interest in intellectual disability. Consultant psychiatrists have mandatory continuous professional development (CPD).

The role of the consultant psychiatrist on the CAMHS-ID includes but is not limited to:

- Providing assessment, diagnosis and treatment of mental disorders in those with a moderate, severe or profound intellectual disability.
- The provision of information to and liaison with families and carers of children and adolescents with an intellectual disability who have developed a moderate to severe mental disorder.
- Support shared decision-making with service users and their families/carers regarding treatment for their mental disorder.
- As medical doctors, psychiatrists are responsible for prescribing medication and liaising with primary care.

- Clinical leadership of a multidisciplinary team of professionals and coordinating multidisciplinary interventions.
- Where appropriate, liaison and inter-agency, working with statutory and voluntary organisations involved in the care of children and adolescents who have an intellectual disability and have developed a mental disorder.
- Clinical supervision of trainee psychiatrists and medical student teaching.

Other roles include:

- Management of the complexity, severity and risk to the child or to others in the context of mental illness.
- Advising managers on the model of service delivery and playing a key role in the development of mental health services, adopting a recovery-orientated system of care.
- Research, audit and innovation.
- Exemplifying values, challenging stigma and discrimination.
- The implementation of relevant parts of the Mental Health Act 2001, where appropriate.

Non-consultant hospital doctor (NCHD) – as above

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

- The provision of information to and liaison with families and carers of service users and people with an intellectual disability who have developed a moderate to severe mental disorder.
- Support shared decision-making with service users and their families/carers regarding treatment for their mental disorders, 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)

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

The role of the clinical nurse specialist on the CAMHS-ID team includes, but is not limited to:

- Participating as part of a multidisciplinary team in the mental health assessment of the child or adolescent with intellectual disability, using evidence-based tools and gathering collateral information from the family, educational institutions or existing services involved in the child or adolescent's care.

- Formulating, reviewing and monitoring the progress of an individualised care plan in collaboration with the child or adolescent, their family or carers, and the multidisciplinary team.
- Discharging planning and completing a multidisciplinary report that will make recommendations for the ongoing provision of appropriate care and support (HSE, 2019).
- Working collaboratively with the child or adolescent and family, primary and secondary care and voluntary agencies in the pursuit of best health outcomes for the young person and family.
- Using evidence-based therapeutic interventions to support the young person and their family in managing a mental disorder.
- Managing a caseload of children and adolescents, triage referrals, organising home visits, school visits, and telemedicine as required.
- Liaising with, and supporing families, carers, schools, respite, day-care and other professional services and agencies in implementing specialist mental health interventions.
- Monitoring the mental health of the young person, organising reviews by consultants at outpatient clinics if required, submitting requests for additional supports, or advocating for higher levels of care if applicable.
- Contributing to service development and adapting environments for appointments and availing of appropriate tools to enhance communication with the young person.
- Collecting data (key performance indicators), liaising with other nursing professionals in CAMHS-ID for continued professional development and providing support and supervision.
- Providing teaching and training for nursing students while on placement.

Psychologist

Psychologists working on CAMHS-ID 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 CAMHS-ID team includes but is not limited to:

- Provision of psychological assessments appropriate to the mental health and developmental level of the child or adolescent with an intellectual disability and complex needs. This information can contribute to the development of a formulation and differential diagnosis.
- Formulation and development of plans for psychological interventions to treat mental disorders, including but not limited to anxiety, mood, psychotic disorders and attention deficit hyperactivity disorder.
- Development of positive behaviour support plans and tailoring psychological interventions to the needs of the child or adolescent presenting with behaviour that challenges or self-injurious behaviours.
- Working with parents to implement behavioural/psychological interventions to treat mental disorder.
- Delivering individual therapy, group therapy, and development of psychologically informed models of care to meet the mental health needs of the child or adolescent with an intellectual disability in the context of their developmental level.
- Working collaboratively with multi-disciplinary professionals in primary care, disability services, residential care settings and schools, focusing on implementing mental health interventions across settings.
- Representing and advocating for the psychological needs of children/adolescent with an ID and mental disorder.
- Research and audit.
- Service development.
- Psychologists on CAMHS-ID provide clinical supervision to junior psychology staff on specialist placements in CAMHS-ID, in line with supervision requirements.

Occupational therapist

Occupational therapists bring an occupation-focused lens when working with children, adolescents and their families as part of a CAMHS-ID team.

Children and adolescents with intellectual disability are at high risk of poor engagement in occupation due to their comorbid emotional, behavioural and psychiatric problems that may further reduce their ability to engage in activities of daily living.

- **Occupation-centred assessment** – Occupational therapists use a variety of informal and formal assessments to explore how the mental disorder of a child or adolescent with intellectual disability is impacting on their ability to successfully participate in everyday occupations. These assessments are guided by seeking to understand a child or adolescent's strengths and needs in areas such as motivation, interests, values, routines, skills and environment.
- **Occupational-focused care planning** – Following assessment, occupational therapists work collaboratively with a child or adolescent and his or her support network to develop occupation-focused goals and sensory-based interventions aimed at enhancing quality of life and supporting recovery of the child or adolescent from mental illness and reintegration back into the community or school.
- **Occupational-based intervention** – The occupational therapist on the CAMHS-ID team has a key role in providing intervention to children and adolescents where difficulties in processing sensory information from the environment impact on their mental health. The occupational therapist may work with the child or adolescent directly or indirectly, in individual or group settings and in a range of different environments, including outpatient clinics, school, home, or community-based settings.
- **Occupational therapy is tailored on an individual basis.** Examples of the types of occupational therapy interventions delivered in CAMHS-ID teams are:
  - Tailoring/adapting a child or adolescent's daily structure, routine and environment to manage the functional impairments arising from their mental disorder.
  - Psycho-sensory interventions; including enabling self-regulation and co-regulation with key caregivers.
  - Facilitating community-based engagement, and integrating or re-establishing meaningful occupations, such as returning to school or self-care tasks.

Social worker

Social workers who specialise in child and adolescent mental health services in intellectual disability work collaboratively to provide mental health interventions and supports for children, adolescents and their families as part of the multi-disciplinary team.

The role of the social worker on the CAMHS-ID team includes but is not limited to:

- **Family-focused practice** – Social work seeks to address the social and environmental factors that contribute to a child or adolescent's mental health difficulties from a holistic and 'whole-family' approach.
- **Clinical case management** – Coordinating care for a caseload of children and adolescents with an ID and comorbid mental disorder, organising home visits, supporting families and carers on mental health management strategies, and liaising with external agencies and organisations, as required.
- **Advocacy and empowerment** – Social workers work alongside the child or adolescent with intellectual disability and their family to advocate for their rights, to facilitate their empowerment and to help achieve their needs and aspirations within the context of their mental disorder. This may involve liaising and collaborating with the social worker on the CNDT and other agencies.

- **Multi-disciplinary and multi agency collaborative work** with disability services, respite and home support providers, schools and voluntary bodies; at all times with the focus of supporting the child or adolescent's mental health.
- **Mental Health Assessments** – Using a systemic lens and strengths-based, psychosocial approach in all assessments, and indeed in all interactions with service users and their families.
- **Counselling and therapeutic approaches** – Social workers carry out individual, family and group work in areas such as grief or loss, interfamily relationships, carer stress, parenting and sibling support, where they impact on the child or adolescent's mental health.

Speech and Language Therapist (SLT)

A SLT's scope of practice 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 (IASLT 2016).

For young people attending CAMHS-ID, SLT input as it pertains to their intellectual disability (ID) is provided through primary care or their children's disability network team in the first instance, with the primary focus of the CAMHS-ID SLT being the impact of communication skills on their mental health. A collaborative approach between services is encouraged.

The role of the SLT on a CAMHS-ID team covers the following key areas:

Person

The intrinsic relationship between communication difficulties related to ID and mental health can make differential diagnosis challenging. SLTs help to mitigate these risks with a focus on the speech, language and communication needs (SLCN) of the young person.

- Assessment and diagnosis of SLCN across home, school and clinic settings as required.
- Completion of dysphagia assessment and management or consultation regarding the management of dysphagia (when related to mental health and/or medications).
- Working with the young person alongside the CAMHS-ID team, to help uncover the meaning of his or her distress and to facilitate recovery, through a total communication approach, such as objects of reference, augmentative or alternative communication (AAC), pictures, written words, vocalisation, verbalisation, communication passports, accessible information, manual sign language (Lámh), picture exchange communication system (PECS), and technology.
- SLTs work in collaboration with the rest of the multi-disciplinary team to implement mental health interventions, such parent training and talk therapies and in an accessible manner.

Environment

- Identification of communication barriers within the mental health services environment and the child's environment that impact on their mental health and providing training, education, and alternative or additional means of communicating with people who access the service.
- Providing training and education, where needed, to families to help increase awareness and supports to reduce risk of parental stress and burnout.

Community

- Advocating for the additional communication supports and dysphagia needs of young people accessing CAMHS-ID in clinic, school, home, but also in the wider community.
- Advocate and educate people in the wider community of the two-directional relationship between mental health and communication difficulties.

Creative art therapist

Creative therapies such as visual art and music are recognised as an effective treatment in working in the area of mental health and intellectual disability (*Vision for Change and Sharing the Vision*.)

Creative art therapies use a non-verbal medium that allows the direct voice of the child and adolescent with intellectual disability to be heard, when he or she has difficulty using language. It allows the individual to express and act out feelings and sensations in therapy without using words.

4. Integrated person-centred care

Integrated person-centred care

Children and adolescents with intellectual disability living with a mental disorder may not only need support from a specialist mental health service, but also at various points or simultaneously, from all community services (primary care, CDNT, CAMHS-ID and inpatient services) during their illness, treatment and recovery. (Figure 2)

This model of service supports the best practice principle of joint and collaborative working of the CAMHS-ID team with primary care, community mental health services, developmental paediatrics, 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 ten-year plan* published by the Department of Health in 2019.

Children and adolescents 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. Children and adolescents with an intellectual disability are affected by mental health issues in a similar way as all members of Irish society. However, if a child has difficulties being understood or in expressing their distress or when they have coexisting physical health problems, the mental disorder can be more complex to identify. As with all mental health problems, the earlier that issues are identified and a child 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.

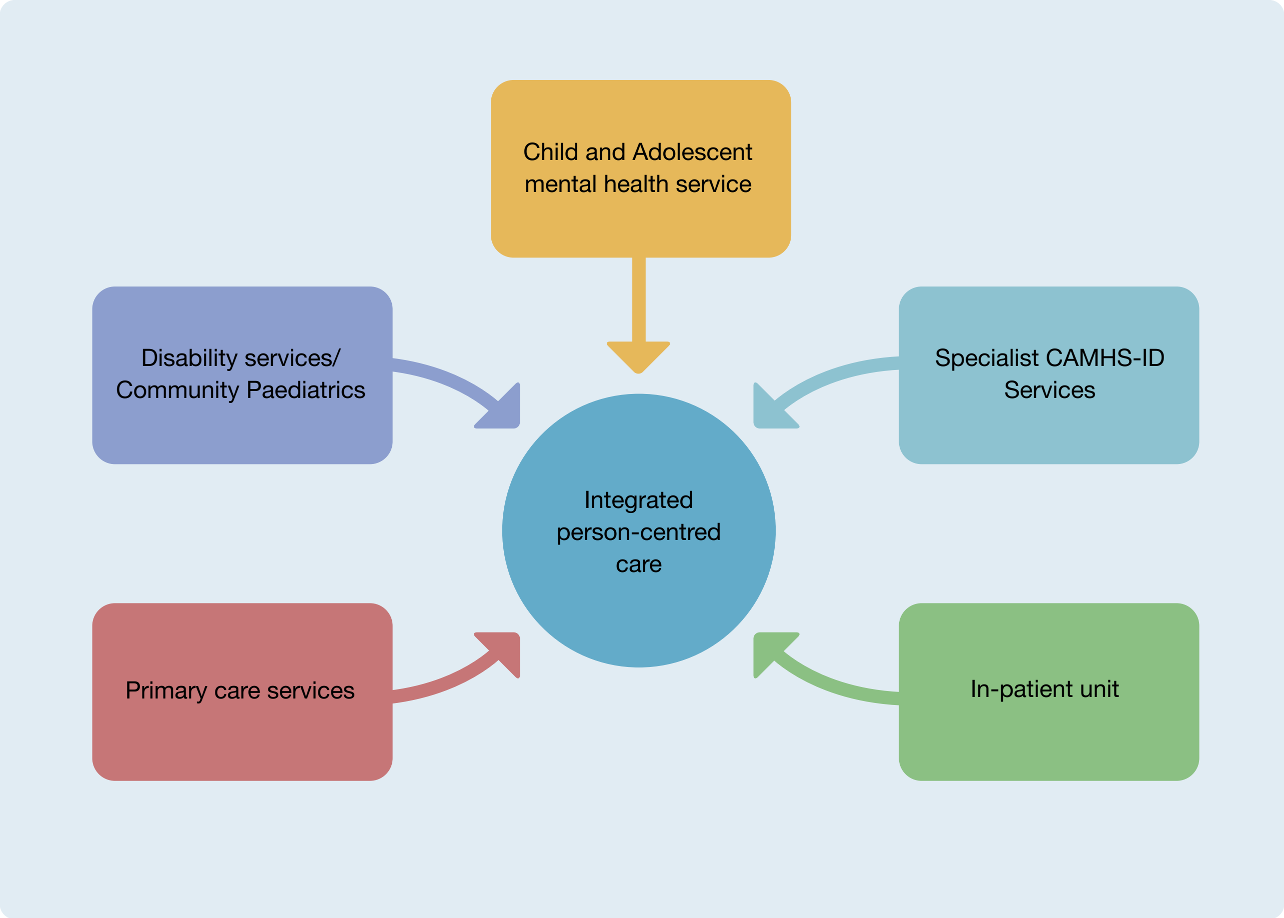

Figure 2: Integrated person-centred care for children with an intellectual disability and mental disorder.

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 children and adolescents with an intellectual disability and comorbid mental disorder 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 care 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 mild mental health problems from a range of primary care and community service providers which are available to all individuals.

The role of the general practitioner is central for the child or adolescent with intellectual disability who is experiencing a mental disorder. 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 the disorder is moderate to severe, the person is referred on to the specialist mental health services. The family context and carer needs are also often well recognised by GPs.

General practitioners also have knowledge of the child 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. A comprehensive referral from the child or adolescent’s 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.

4.2 Disability services – Children’s Disability Network Teams

Children and adolescents with intellectual disability access interdisciplinary care for their disability from their local geographical catchment area disability team – The Children’s Disability Network Team (CDNT). The CDNTs are at various stages of configuration nationally, and when fully developed there will be one interdisciplinary team per 50,000 of the population. The CDNT provide person or child-centred care that is focused on the social, vocational, educational and residential needs of the child or adolescent with intellectual disability (A Vision for Change, 2006). Through the CDNT, early detection and intervention for mild to moderate mental health problems can be provided.

In some parts of the country, the HSE have service-level agreements negotiated with independent sector organisations (Section 38 or 39) to provide disability services (CDNT) to children and adolescents.

The interdisciplinary CDNT staff may include similar disciplines to those found in CAMHS-ID teams. However, the focus within CDNT/social care organisations is on supporting the child or adolescent in relation to their disability and mild mental health problems rather than more moderate to severe mental disorders. For example, occupational therapists on the CDNT may support an individual with aids and appliances and a speech and language therapy staff member may support the individual in relation to dysphagia and communication. 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 a CAMHS-ID service structure.

4.3 Specialist community CAMHS-ID services

A Vision for Change (HSE, 2006) emphasises the importance of specialist, community, multi-disciplinary mental health teams in delivering appropriate mental health services for children and adolescents with an intellectual disability. *A Vision for Change* recommends one CAMHS- ID team per 300,000 of the population.

As detailed in *A Vision for Change* and *Sharing a Vision* the core Child and Adolescent Mental Health of Intellectual Disability Team (CAMHS-ID) is made up of psychiatry, psychology, clinical nurse specialist, social work, occupational therapy, speech and language therapy and administrative support.

CAMHS-ID teams provide a specialist mental health service for children with a moderate to severe mental disorder. It would be best practice where appropriate for intervention to be provided initially by the Children's Disability Network Team prior to referral to CAMHS-ID teams who provide assessment and intervention to children with mild to moderate mental health problems.

These specialist community CAMHS-ID services tend to be smaller in size and have a higher staff to service user ratio. Therefore, they can be more client-focused and can tailor services to adapt to the cognitive and communication capacity of service users.

Well-integrated models of care for CAMHS-ID teams have key elements which facilitate good practice, including training in intellectual disability for staff in mainstream mental health services, clear care pathways, multidisciplinary 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.

Currently most of the CAMHS-ID 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 CAMHS-ID service improvement programme is to continue to develop multi-disciplinary CAMHS-ID 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.

4.4 Inpatient treatment

The aim of inpatient psychiatric admission is to diagnose, observe and treat severe acute mental illness. As previously outlined in this document, children and adolescents with intellectual disability have a higher rate of comorbid mental disorders, 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).

CAMHS-ID teams in the community will help to play a significant role in improving integrated care within inpatient units, helping to support inpatient staff with identifying and treating acute psychiatric illness. Some admissions for children and adolescents with intellectual disability to hospital have resulted from the cumulative effects of unrecognised and unmet mental health needs.

Lack of access for families to home support or therapeutic short breaks or respite or residential services can result in inappropriate admissions to paediatric hospitals or acute mental health units.

Inappropriate admissions can have a traumatic effect on a child or adolescent with an intellectual disability and may compound their difficulties. Such situations are detrimental to the child, 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 children 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 resourcing of the multidisciplinary CDNTs within social care services to meet the needs of service users in preventing the development of a mental disorder.

There are no national specialist acute admissions units for children or adolescents with intellectual disability in Ireland and therefore those with such disabilities have to access general acute psychiatric units or paediatric hospitals for treatment of their mental disorder.

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.

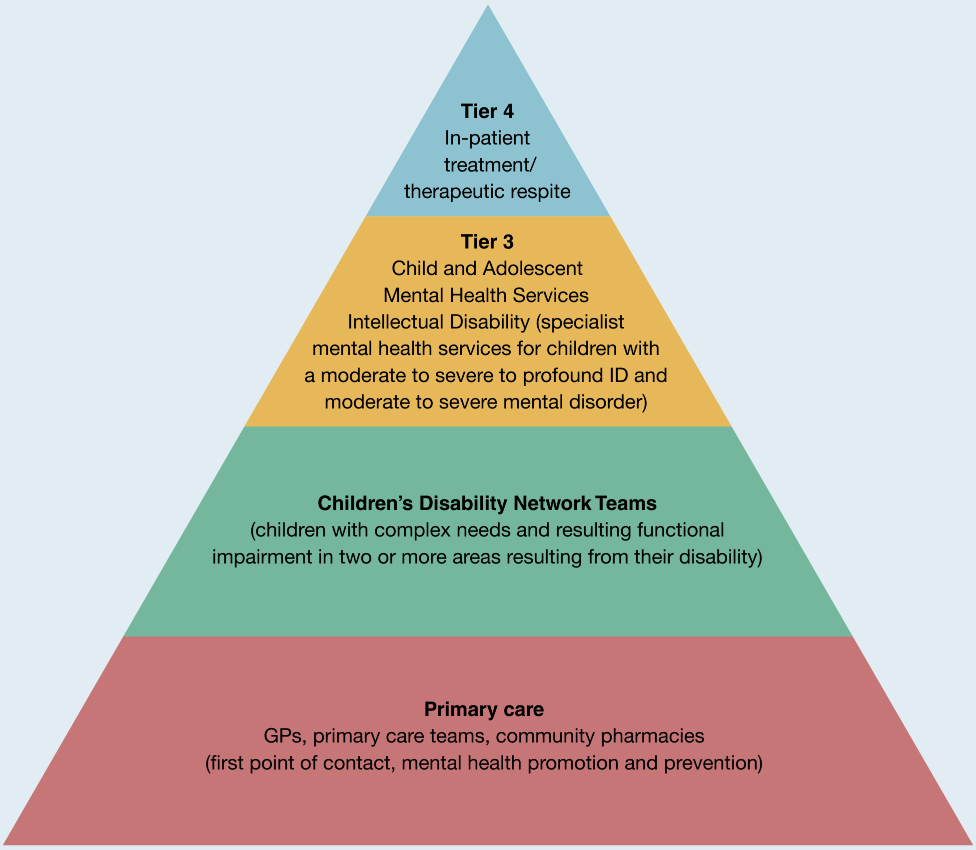

Figure 3: Stepped Care – four tiers of treatment

5. Service user journey through a CAMHS-ID team

Service user journey through a CAMHS-ID team

The following section provides details of a child or adolescent's journey through the four key stages of care within a CAMHS-ID team and their associated processes. See Figure 4 below. Additionally for each stage, key actions are highlighted, which would directly improve the care experience for the young person and their families.

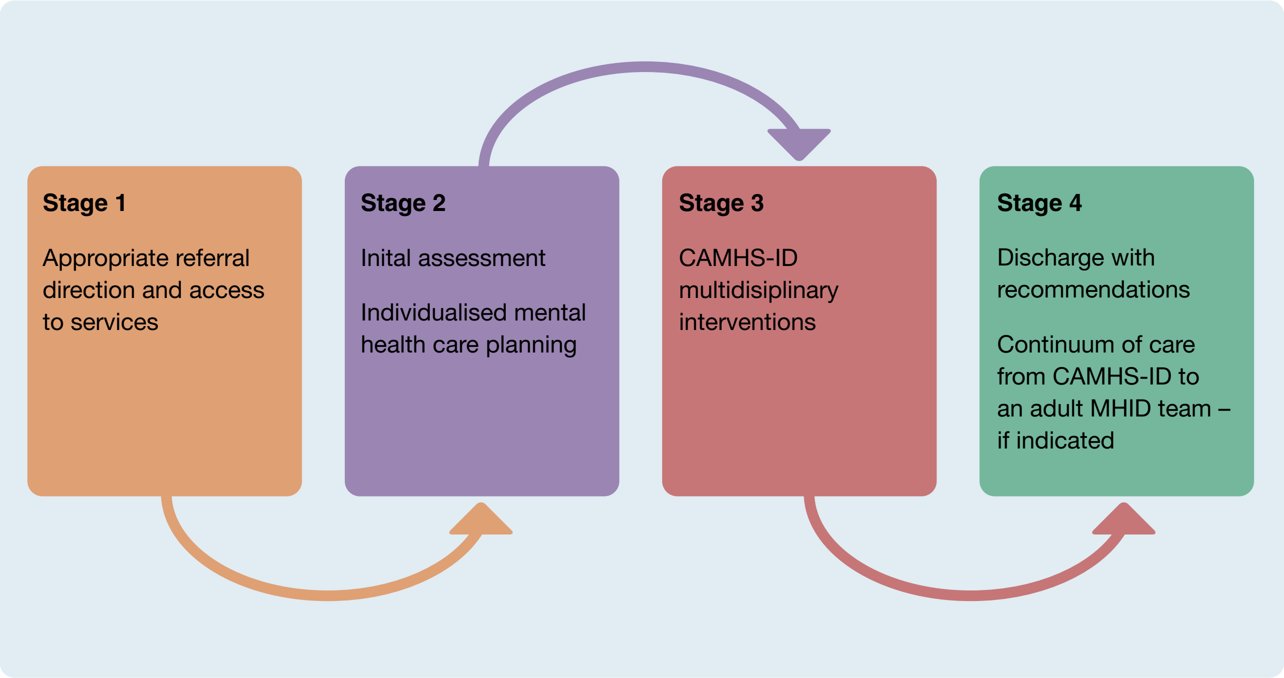

Figure 4: Key stages of a service user's journey through a CAMHS-ID service

	Overview
Stage 1: Referral and access	- Appropriate referral/direction by GP/paediatrician or psychiatrist
Stage 2: Assessment and care planning	- **Assessment:** assessment and diagnosis of the mental disorder - **Care planning:** agreeing the programme of care to treat the mental disorder with the child or adolescent and family
Stage 3: MDT Interventions	- **MDT Interventions:** Treatment of mental health disorder
Stage 4: Discharge Planning	- **Discharge:** completion of MDT interventions - Referral to adult MHID completed if indicated - **Re-referral** – if symptoms of mental disorder re-emerge, process of re-referral is explained

The Four stages of the journey for the young person and their family – Figure 5

5.1 Stage 1: Referral and access

Children and adolescents with an intellectual disability should have equal access to mental health services as children with normal cognitive ability.

In line with the Clinical Operation Guidelines (2019) for CAMHS, when deciding if a young person requires CAMHS intervention there are several factors to consider which are further discussed in the referral criteria for CAMHS-ID. It is essential to note that children with an intellectual disability in the mild range will access generic CAMHS teams for the assessment and management of a mental disorder. Children in the moderate to severe to profound range of intellectual disability, may require specialised input from a CAMHS-ID team.

5.1.1 Referral criteria

Referral inclusion criteria

The referral criteria for the CAMHS-ID team are as follows:

- The child or adolescent is aged younger than 18 years.
- Consent from parents is obtained prior to a referral being completed.
- Suspicion of a mental illness or disorder is such that the impact of this on the child or adolescent's functioning/wellbeing indicates a need for specialised mental health intervention.
- Child or adolescent has a diagnosis of intellectual disability in the moderate, severe or profound range.
- Living in the agreed catchment area of the CAMHS-ID team.
- It is recommended that all referrals are accompanied by a medical/physical health assessment. This is essential due to the complex interaction of medical and neuropsychiatric disorders.
- Comprehensive treatment within the children's disability network team has been unsuccessful or was not appropriate in the first instance.

Referral exclusion criteria

The exclusion criteria used by the CAMHS-ID team are as follows:

- The CAMHS-ID teams do not provide autism diagnostic assessments. However, referral for treatment of comorbid mental illness is appropriate in children and adolescents with moderate-severe-profound intellectual disability and autism spectrum disorders.
- Behaviours that challenge in the absence of intervention by the children's disability network team.
- Intellectual disability as a primary difficulty in the absence of moderate to severe mental health concerns.

5.1.2 Referral agents

The primary source of referral to the CAMHS-ID service is the general practitioner. In keeping with the Medical Council of Ireland ethical guidelines, the general practitioner is involved in all referrals to the CAMHS-ID team. The general practitioner is best placed to overrule an underlying medical cause for presentation and to provide details of the child's medical and family history in addition to any medication the child is prescribed. Other sources of referral include consultant psychiatrists and paediatricians. If the CDNT manager wishes to initiate a referral, this needs to be accompanied by a medical referral providing details of medical assessment, past medical and family history and treatment.

5.1.3 Further information

Further information may be requested once the referral has been received, such as results of medical investigations, psychometric reports, a positive behaviour support plan and other multidisciplinary reports.

5.1.4 Referral process

The referral process is as follows:

- A detailed letter from the child or adolescent's GP or medical doctor, outlining the symptoms of mental disorder of concern, and any underlying medical condition, family history and medications prescribed.
- Referrals will be discussed at the CAMHS-ID multidisciplinary team meeting and prioritised as appropriate. Further information may be requested, including psychometric and medical reports.
- Where a referral is accepted, the referrer and family will be advised in writing. Parents/guardians will be asked to consent to assessment.
- Where a referral is not accepted, the referrer and family will be advised in writing, giving clear justification, with appropriate recommendations, including signposting to the most appropriate services to meet the child or adolescent's needs.

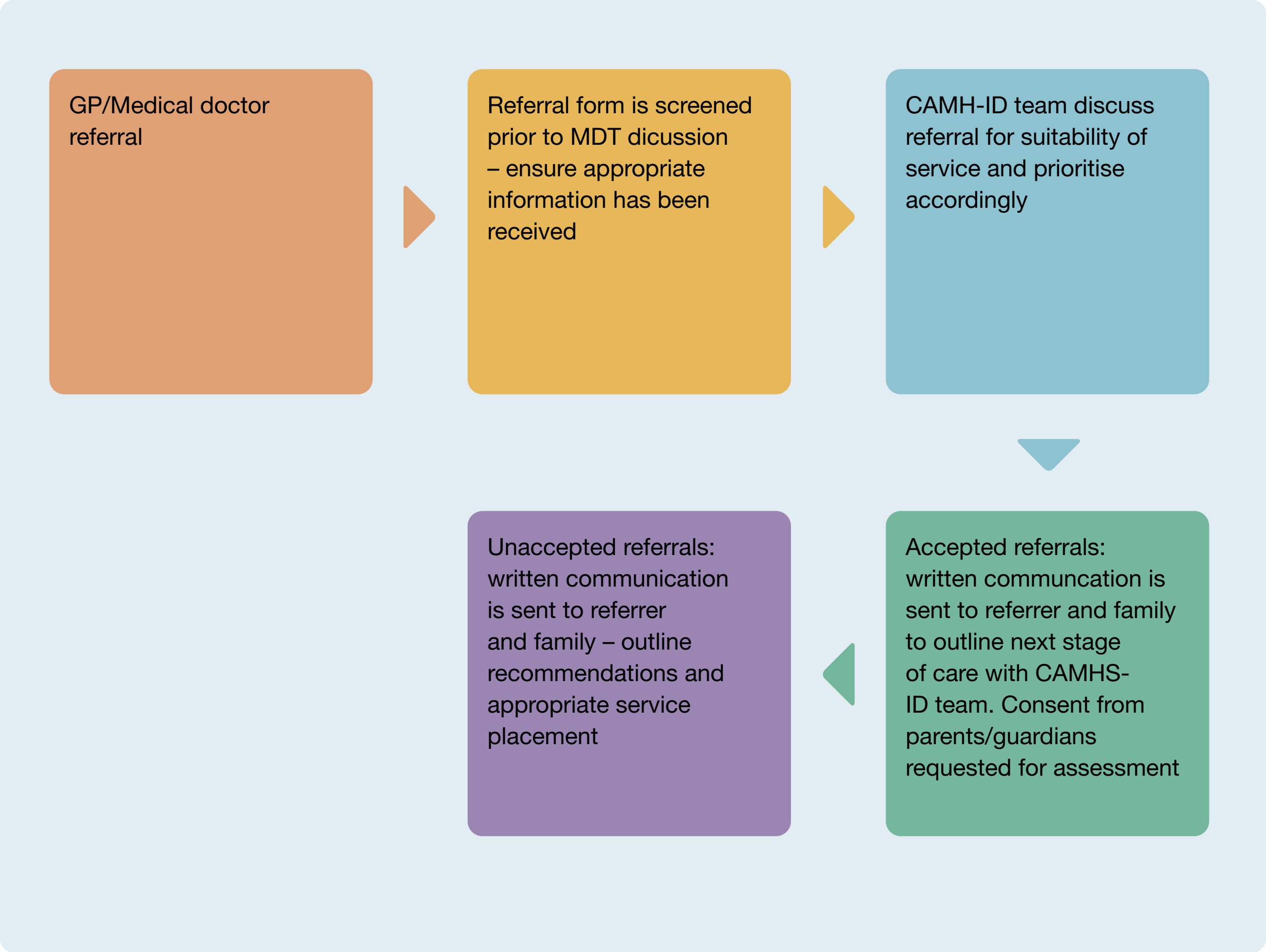

Fig:6 The referral process

5.2 Stage 2: Assessment and mental healthcare planning

The aim of the mental health assessment is to gather information about the symptoms of mental disorder and additional early development, family, past psychiatry, medical and educational history, from the child or adolescent and his or her parents or guardians in as efficient and inclusive a manner as possible. A mental state examination (MSE) of the child is also completed as part of an initial assessment.

More than one appointment is typically required, including across settings (clinic and school).

A number of factors may need to be considered in preparing the child or adolescent for assessment and providing reasonable accommodations to support their participation, including:

- Providing extra time for the consultation.
- Arranging appointments across settings to allow for assessment of the child or adolescent in a familiar environment. Typically the initial appointment is with parents in the clinic setting, followed by assessment of the child or adolescent in the school setting. Subsequent appointments typically occur in the clinic setting.
- Avoiding long waiting times in high stimulating environments such as noisy, crowded, busy, bright waiting areas, with adjustments to the environment (i.e. lighting or sound) being made if possible and appropriate.
- Identifying other physical support needs, such as those arising from physical or sensory needs and preparing for the person's communication needs, by arranging access to their preferred communication system such as lamh or PECS, occurred before, but still not explained to be available during the appointment, and where necessary, for someone to support with communication if needed.
- Following the team assessment, a key worker will be assigned from within the CAMHS-ID team (if resources allow), based on the unique needs of each service user.

5.2.3 The individualised mental healthcare plan

On completion of the mental health assessment, a member of the CAMHS-ID team will meet with the child or adolescent and his or her parents/guardian as appropriate, to develop an individualised care plan (ICP). Care planning is an on-going process throughout a service user's journey with CAMHS-ID and will need to be reviewed and updated after an agreed timeframe.

A copy of the ICP will be administered to parents and filed with the clinical notes.

Individualised care plans should include:

- Goals for attending the CAMHS-ID team.
- Treatment plan – multidisciplinary intervention +/- medication to treat the child or adolescent's mental disorder.
- Risk management and crisis plans, if required.
- A clear pathway and plan for discharge from the CAMHS-ID service.

5.3 Stage 3(a) CAMHS-ID multidisciplinary team interventions

The CAMHS-ID team provides multidisciplinary interventions to treat the child or adolescent's mental disorder and to promote recovery. Specifically this stage of care aims to:

- Promote the recovery of the child or adolescent in a way that best meets their needs by providing them with the interventions and supports agreed in their individualised care plan. (HSE A National Framework for Recovery in Mental Health Services 2018–2020).
- Provide access to multidisciplinary interventions using a biopsychosocial approach to treat the child or adolescent's mental disorder.
- Monitor the effectiveness of interventions and supports in promoting recovery.

5.3.1 Interventions process

Each child or adolescent attending the CAMHS-ID team will be provided with access to evidence-based multidisciplinary interventions, based on an assessment of their initial and on-going mental health needs and available resources.

- Evidence-based interventions will be delivered in line with best practice recommendations.
- The young person's strengths, preferences and support needs will be taken into account in the delivery of interventions with the full collaboration with the family.
- Adaptations and flexibility will be required to facilitate access to and engagement with interventions. The team will work in partnership with the child or adolescent's family and supporters to aid understanding and enable them to provide necessary supports across environments.
- Interventions will be monitored and reviewed to ensure that they are effective in meeting the young person's mental health needs and recovery goals.
- Any changes to interventions required to treat the child or adolescent's mental disorder will be discussed with the young person as appropriate and their family or carer and their care plan will be updated.

5.4 Discharge and follow-up care

The aim of the final stage of a service user's journey through CAMHS-ID is to ensure that service users are discharged from the service at the right time, and to ensure the appropriate follow-up care is in place. At the heart of the discharge stage is the focus on the service user's mental health needs and the need to work with the legal guardian/s, family and young person to ensure that they can live without the continued presence of mental health symptoms. Not all young people referred to CAMHS-ID will remain open until 18 years of age and some will require transfer to the Adult Mental Health Services for Intellectual Disabilities (AMHS-ID).

The Discharge Process

- Discharge is discussed and planned during the child or adolescent's journey with the CAMHS-ID team. This is achieved through regular care planning.
- Discharge occurs when the service user turns18 years of age or no longer requires the input of the CAMHS-ID team, due to improved mental health presentation.
- Discharge is a clinical decision by the consultant psychiatrist, which is discussed and agreed at a multidisciplinary team meeting.

- The child or adolescent is discharged to the care of their general practitioner and the children's disability network team, or adult mental health services and adult disability teams as appropriate. Figure 7 summaries the discharge options for service users from a CAMHS-ID service.
- The CAMHS-ID team adheres to good practice by ensuring all agencies or individuals who need to know the recommendations of the team for aftercare are communicated with in an appropriate and timely fashion, with the consent of the child or adolescent's legal guardian/s.
- If there is a transfer to another service, the team has a duty to ensure that 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 disorder (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 child/adolescent back to the CAMHS-ID team if this is required in the future (for those aged under 18 years). This should be explained in the closing letter.

5.5 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 simultaneous transitions, including school, disability team, social service support and respite. 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 planned transition of those adolescents requiring transfer from CAMHS-ID to adult MHID, the CAMHS-ID key worker should begin the communication between services, to ensure that the transition takes place with minimum disruption to the adolescent or their family.
- For the most complex cases a joint handover meeting or multiple meetings may be appropriate. This meeting could include clinicians from the CAMHS-ID and adult MHID teams, the adolescent and his or her parents/guardians as appropriate.
- CAMHS-ID teams could 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.

5.5.2 Improving the service user's experience

The following outlines key aspects of service delivery to support the service user experience:

- The child or adolescent has recovered from the mental disorder that led to the referral.
- The child or adolescent has a discharge plan and where applicable, access to psycho-education and other resources that will help the person and their carers or supporters to continue and sustain their recovery.
- Access to the CAMHS-ID service in the future, if required, for those under 18 years of age.

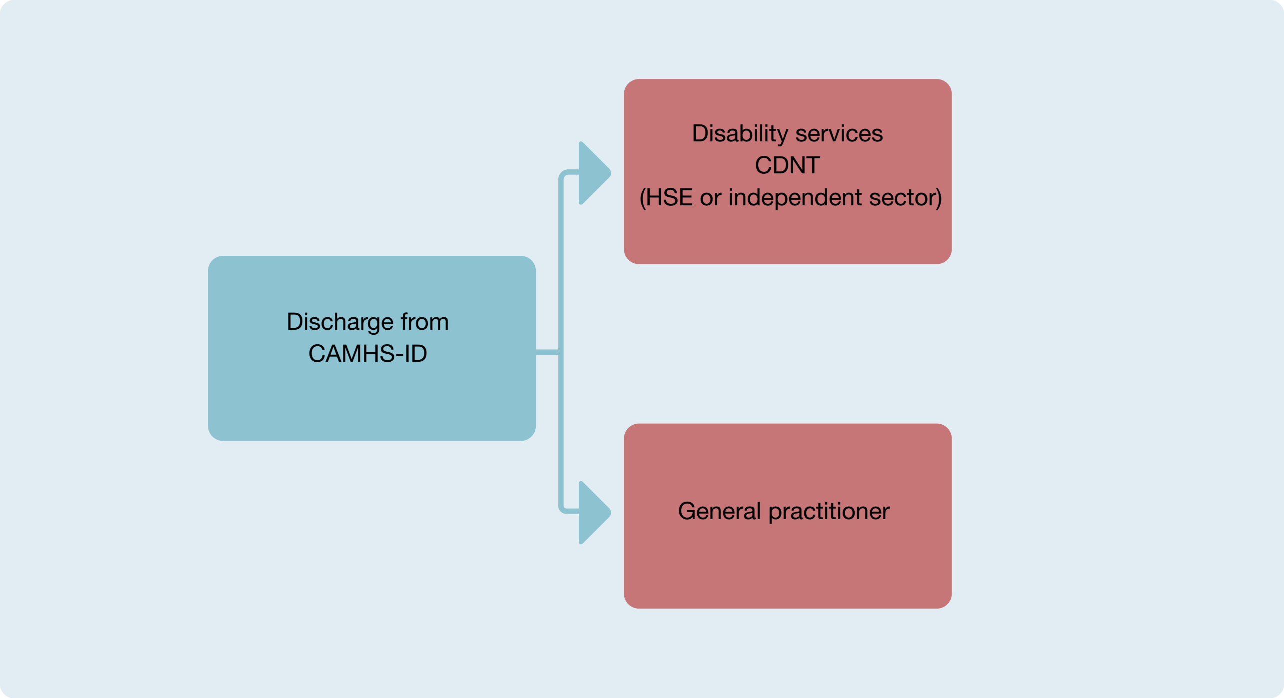

Figure 7: Follow-up options for CAMHS-ID service users post-discharge

5.5.3 Supporting Family Systems

Supporting parents, carers and siblings in caring for a child with an intellectual disability and a comorbid mental disorder is an important role for CAMHS-ID teams.

The mental health of a parent or carer of a child with an intellectual disability has been shown to be influenced by the severity of their child's mental health problem more than the degree of their intellectual disability (NICE, 2016; Staunton 2019). In addition, siblings of children with an intellectual disability may also be at increased risk of mental health difficulties.

Appropriate and early intervention for the child's intellectual disabilities and comorbid mental disorder can help mitigate the risk of carer fatigue and burnout and can support the wellbeing of the entire family.

5.6 Stage 3(b): inpatient admission

There are no dedicated inpatient beds for children and adolescents with moderate to profound intellectual disability. They do not have access to the national inpatient units in the same way as children of normal cognitive ability or mild ID. As a result, children presenting with an acute mental disorder are looked after in inappropriate settings, including acute paediatric wards, community and residential units. They have particular needs which makes inpatient unit admission more challenging for them.

Development of CAMHS-ID 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 young 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). CAMHS-ID team members should be involved in developing plans for the admission, treatment, care planning and discharge. It will be important for CAMHS-ID to establish clear understanding of the appropriate criteria for admission, admissions processes, mental health legislation and requirements.

5.6.1 Inpatient admission process

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

They should be assessed by clinicians with expertise in assessing children with ID and mental disorder

- Referral is by the consultant psychiatrist on the CAMHS-ID team and a mental disorder diagnosis which requires admission to hospital. It is important that the GP is notified.
- The process by which out of hours admissions happen should be thought through.
- 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.
- CAMHS-ID teams have an important liaison and support role with colleagues arranging admission and in the inpatient unit to assist in the diagnosis, care planning, treatment and discharge planning of a young person with intellectual disability admitted to an inpatient unit.
- Discharge back to CAMHS-ID team following discharge planning meeting.

5.6.2 Integrated inpatient care

Developing a collaborative approach between the inpatient team and the CAMHS-ID 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. Safeguarding issues need to be identified and plans put in place to address concerns.

Integrated care can be achieved by:

- A member of the CAMHS-ID team being invited to planning meetings.
- 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 CAMHS-ID team being informed of any unexpected admission and being able to see the child or adolescent on the admission ward as soon as possible.
- The staff on the CAMHS-ID team should be involved throughout admission, contributing to the assessment, formulation and treatment approaches and advising on mental health supports for the young person while in hospital, including inputs as part of a mental healthcare plan. Occupational therapy has an important role to play in 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.

6. CAMHS-ID specialist populations

CAMHS-ID specialist populations

The following section outlines the specific mental health requirements of service users who may have a mild intellectual disability, or have an autism spectrum disorder (ASD), and where applicable the circumstances and degree of service and support CAMHS-ID teams can provide for them.

6.1 Mild intellectual disability

Children with mild intellectual disability and moderate to severe mental disorder attend general Child and Adolescent Mental Health Services where they can access specialist mental health intervention and acute in-patient admission if required.

The disability services for children with all levels of intellectual and physical disability are currently being reconfigured into catchment area-based Children's Disability Network Teams. When reconfiguration has been completed all children with a disability whose needs are too complex for treatment in primary care will have access to a catchment area-based disability team, determined by their geographical location.

There is a group of children with mild intellectual disability who already receive mental health services from CAMHS-ID teams and they should continue to receive these mental health services unless it is in their best interests to transition to general Child and Adolescent Mental Health Services when the transfer of care has been agreed by the CAMHS team.

Children and adolescents 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 CAMHS teams may need the support of a CAMHS-ID team. The CAMHS-ID teams need to develop further before being in a position to work jointly with general child and adolescent psychiatry teams to deliver a fully-integrated service for people with low mild intellectual disability and complex needs. 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 CAMHS-ID teams where possible offer:

- A consultative framework to CAMHS 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.

6.2 Autism spectrum disorder

For children and adolescents 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 disorder, their condition should be assessed through the children's disability network teams. The needs of children and adolescents 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.

Children with an intellectual disability and an autism spectrum disorder should not be referred to a CAMHS-ID team unless there is concern about a comorbid moderate to severe mental illness or disorder. It has become increasingly evident that children 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 CAMHS-ID teams in the area of autism can be defined as consultation on difficult diagnoses with specialist episodic treatment of acute mental illness or disorders as required.

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 child or adolescent 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.

7. Governance

Governance

This section of the model of service outlines the different areas of governance for CAMHS-ID teams, covering accountability, communication and monitoring. The following is a summary of the key features of the governance structure:

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

7.1 Team governance

- The consultant psychiatrist is the clinical lead on the CAMHS-ID team. Each child attending a CAMHS-ID team is under the care of a nominated consultant psychiatrist. Each member of the team also has a professional and management reporting relationship through their discipline-specific line management structure, ensuring that each team member operates to the highest clinical standard.
- Each member of a CAMHS-ID team has professional responsibility to carry out clinical work with children and adolescents with an intellectual disability within their scope of practice, as defined by their professional and regulatory bodies such as the Medical Council of Ireland, the Health and Social Care Professionals Council (CORU), the Nursing and Midwifery Board of Ireland (NMBI) and the Psychological Society of Ireland (PSI).
- Each CAMHS-ID member knows their responsibility, level of authority and to whom they are accountable.
- Each team may also consider – if resources allow – the appointment of a team coordinator to facilitate the smooth running of the team as outlined in *A Vision for Change*. Permanent team coordinator roles must align with the job description set out by the mental health service team coordinator project (HSE Mental Health Service).

7.2 Clinical responsibility

In keeping with A Vision for Change, each member of the CAMHS-ID team takes responsibility for the delivery of care in a collaborative and respectful manner, always adhering to a sense of parity of esteem.

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 scope of practice.

7.3 Role of the CAMHS-ID key worker

Each service user attending the CAMHS-ID team should be allocated a CAMHS-ID key worker from within the multidisciplinary team, following the team assessment, if resources allow. It is recommended that the CAMHS-ID 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 as efficient and service user-friendly way possible, keeping the service user and his or her family 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 CAMHS-ID service.
- Coordinate all stages of the service user's journey while attending the CAMHS-ID team.
- Be the main point of contact for the service user and their family.
- Address the treatment goals and needs of the service user and their family.

7.4 Continuous professional development

All CAMHS-ID 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 their 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 CAMHS-ID 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

Within the HSE, clinical metrics about CAMHS-ID have not been collated at a national level, unlike other specialties in mental health. This meant that the work carried out by teams could not be fully evaluated. Collecting clinical metrics is in line with *Best Practice Guidance for Mental Health Services* (HSE, 2017).

To address this, from 2020, CAMHS-ID teams have been requested to record monthly 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, CAMHS-ID 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 in a CAMHS-ID 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

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 CAMHS-ID teams.

8.1 Education and training

It would be beneficial for CAMHS-ID 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 from 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 to identify gaps. Staff should have access to education and training resources such as internet, HSEI and journals.

During the development of this model of service, it was identified that to continually support CAMHS-ID 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 CAMHS-ID 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 (CAMHS and AMHS)

Integration of the CAMHS-ID team with other mental health services is beneficial for both service users and staff. 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. This ensures that staff in other mental health services fully understand CAMHS-ID services.

8.3 Facilities

A CAMHS-ID team should be accommodated in premises that provide space for the entire team. The rooms should be large enough to allow for the clinical observation of children with high activity levels, accompanied by two family members. This ideally should be in the same premises as another mental health team (CAMHS or Adult MHID).

The CAMHS-ID 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

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 CAMHS-ID 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, while legislation on deprivation of liberty is currently being advanced with ongoing public consultation on a draft heads of bill.

9.2 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).

9.3 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 these needs and a care plan approach to meeting these 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 Health and Care 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 CAMHS-ID services if there is a concern of a mental disorder.

Intellectual disability is characterised by significant limitations in intellectual (reasoning, problem-solving, planning, abstract thinking, judgement, learning from experience) and adaptive behaviour as expressed in conceptual, social, practical and 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 50–69).

- **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 35–50).
- **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 that need to be conveyed. 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).

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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 (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 only providing crisis intervention and no specific psychotherapy.

The current situation of CAMHS-ID 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.

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 from being largely in-patient services, to predominantly out-patient. 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. 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) reported 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 healthcare 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 United States 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, including the Department of Developmental Disability Neuropsychiatry (3DN) in Sydney, and was funded by the Australian Government’s Department of Health.

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 state-wide 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.

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.

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. (McCarthy, 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. 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. (McCarthy, 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. Nearly £8 billion is spent annually by the government through local authorities on care for people with intellectual disability in England, divided into 60% on social care, 30% on welfare benefits and 10% 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. Changes in public policy and the actions of parents 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 healthcare. 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 CAMHS-ID 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 – 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
- Leaders are needed 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 the 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. They 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 and 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 CAMHS-ID 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 a child with intellectual disability

As detailed above, the initial assessment of a child with an intellectual disability typically requires three appointments. More appointments may be required in more complex cases to allow for assessment across multiple settings.

The first appointment typically involves parents/carers only to obtain a detailed mental health history focusing on presenting concerns, developmental, medical family and educational history.

The second appointment typically takes place in a setting familiar to the child such as school, to facilitate a detailed mental state evaluation.

The third appointment usually for parents only allows for feedback on the assessment, defining treatment goals and development of an individual care plan.

For some complex cases where multiple agencies are involved a professionals meeting may be beneficial either before or after the initial assessment.

Before all mental health assessments involving parents and or the child

- Provide written information to parents about the child and adolescent mental health service and details about the nature and duration of the assessment, so that they can prepare themselves and their child for the appointment.
- Obtain as much information about the child's physical, mental health and educational difficulties and needs prior to the assessment, requesting necessary medical, multidisciplinary and educational reports, and read all of this information prior to meeting parents/carers and the child.
- Ask parents/school to complete baseline rating scales if appropriate.
- Address any queries or concerns that parents/carers or the child may have about the assessment process.
- Make any reasonable adjustments such as booking an extended consultation to accommodate possible complexity; avoid long waiting times in high stimulation environments; arrange 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, arrange 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

- Obtain a detailed history, assessing all potential psychopathology, and not just the symptoms and signs that the child and their family members or carers first report.
- Determine the nature, duration and severity and degree of impairment of the presenting mental health problem.
- Take into account the child and family's cultural, ethnic and religious background.
- Review developmental, psychiatric and medical history, past treatments and responses.
- 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.
- 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 child's family, social circumstances and environment, and recent life events.
- Establish or review a diagnosis using: A classification system such as DSM-5 or ICD-11.
- Assess whether a risk assessment is needed.

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

- An underlying physical health condition, including dental pain, 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 a person's mental health assessments to take into account:

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

Develop a formulation

Use the information from 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, maintaining factors and protective factors.
- The potential benefits, side effects and harms of any interventions.
- The potential difficulties and adjustments needed to deliver interventions.
- The impact of the mental health problem and associated risk factors on providing care and treatment.

Provide parents or carers and the child's GP with a summary of the assessment in report form to include diagnosis and treatment recommendations:

Offer parents/carers an opportunity to discuss the assessment report and treatment recommendations at an additional appointment if needed.

Assessment tools

During any mental health assessment, consider using tools that have been developed or adapted for children with intellectual disabilities, as this will improve the quality of the assessment. If using tools that have not been developed or adapted for children with intellectual disabilities, this needs to be taken into account when interpreting the results. Assessment tools may also be used at baseline and to monitor treatment response.

Assessment tools which may be used:

- CHAPPAS
- Connors Rating Scale. This scale for assessment of ADHD has been developed for children of typical development. It is not a reliable assessment tool for assessing ADHD in children and adolescents with an intellectual disability, as the difficulties on the scale may be symptomatic of the intellectual disability or autism spectrum disorder. This scale can be used in conjunction with a detailed clinical assessment, taking into consideration the child's developmental level.
- The Spence Children's Anxiety Scale
- The Aberrant Behavioural Checklist

Risk assessment and management plan

When conducting a risk assessment of a child in the context of a mental health assessment it is important to consider:

- 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 should include:

- Set out individual, social or environmental interventions to reduce risk.
- Be communicated to family members, carers 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 a child/adolescent who is experiencing a mental health crisis, which should include:

- an assessment of the child/adolescent'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 on a child/ adolescent 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 child/adolescent with autism spectrum disorder. Making the correct diagnosis is critical as children or adolescents 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, carer or other informant or use documentary evidence (such as school reports) of current and past behaviour and early development.
- Occur across settings, including a setting which is familiar to the child and where he or she is engaging in their usual routine.

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).
- To aid more complex diagnosis and assessment for children or adolescents with an intellectual disability, consider using a formal assessment tool, such as: the ADOS, 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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