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# Mental health services for adults with mild intellectual disability

March 2020

COLLEGE REPORT

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# Executive summary

Meeting the mental health needs of people with mild intellectual disability (ID) can be a challenge to all mental health services. Not everyone with ID will be eligible to receive specialist ID services and therefore they rely on general mental health services to support them. Our purpose with this College Report is to inform readers on the complexities of providing care for this group of people, and on how general and specialist services can co-operate to meet their needs.

The report has been produced by the Faculty of Psychiatry of Intellectual Disability (ID) with assistance from the Faculty of General Adult Psychiatry of the Royal College of Psychiatrists. It revises and replaces CR175 *Enabling people with mild ID and mental health problems to access health care services* (Royal College of Psychiatrists 2012). We have aimed it at psychiatrists and clinical staff working at the frontline of psychiatric services, and general practitioners providing services for people with ID. We include a review of service provision for people with mild ID across the four countries of the UK.

We provide an oversight of the current evidenced-based thinking on what constitutes mild ID from an operational diagnostic perspective, and the role, challenges and ambiguities of cognitive testing in this population. Our systematic review of current evidence on how care for this population is delivered, and review of all relevant NICE guidance on mental health applicable to people with ID, underpin our findings.

People with ID are more likely to have mental health problems; we discuss the complexities of diagnostic overshadowing, communication and vulnerability concerns, presentation with complex psychopathology, and the difficulties in diagnosis and treatment.

We consider the barriers to access to services, at a primary and secondary care level, for either specialist ID input or mental health input, or both. Since the last report there have been significant changes and challenges influencing how mental health services for people with ID are being provided across the country, catalysed by the Winterbourne View scandal, and the resulting responses including *Transforming care: a national response to Winterbourne View* (Department of Health, 2012) and 'Winterbourne View – A time for Change' (Bubb 2014).

We describe the current practice frameworks in the different countries of the UK, identifying the key policy documents, political ambitions and direction of travel for each country for mental health issues, and how this has impacted on people with ID.

We discuss interface issues with other psychiatric subspecialties such as CAMHS and forensic services, to emphasise the need for continuing close working relationships. We recognise the challenges posed by the larger neurodevelopmental spectrum, such as autism, to those not working in non-ID services, and the potential for a vulnerable non-ID individual to fall between services.

Drawing on the evidence, we have designed a broad good-practice framework to enable psychiatrists, other practitioners, and services to self-measure and provide high quality care for people with mild ID and mental health problems. To this end we present various tools; in particular we advocate a wider use of the Green Light toolkit (2013) as this gives a voice to all key stakeholders, particularly patients and their representatives, wanting a service to meet specific local demands.

We highlight the virtues of integrated care from ID and mental health services, and end by focusing on the specifics of what constitutes good training, particularly for psychiatrists.

We present this report as an up-to-date evidence-based practical guide for all stakeholders in the care of people with ID and mental health issues: to help them navigate, deliver and measure within a complex system which can inadvertently become a 'glass ceiling' for a vulnerable population, particularly during times of major reorganisation at a national level, as is currently the case.

# 1. Background

## 1.1 Terminology used in intellectual disability (ID)

The classification systems guide our understanding of ID in clinical practice. The DSM-5 (American Psychiatric Association 2013) uses the term *intellectual developmental disorder* emphasising the importance of adaptive functioning in having skills in cognitive (language, reading, writing), social (social judgment, interpersonal communication) and practical (personal care, money management) domains. The DSM-5 emphasises the need to use both clinical assessment and standardised testing of intelligence, but maintains the recommendation of a standardised IQ assessment, with ID considered to be approximately two standard deviations or more below the population IQ mean: an IQ score of about 70 or below.

The ICD-11 (2018) lists ID as neurodevelopmental disorder highlighting the importance of adaptive functioning. The reduction in intellectual functioning on standardised IQ assessment is two or more standard deviations below the mean (World Health Organization 2015). ID is a disorder with onset in the developmental period (childhood, before the age of 18). An IQ of 69-50 achieved on a standardised test, acquired before adulthood, with impaired adaptive behaviour functioning, suggests the presence of mild ID. The global IQ score cannot be used as a concrete measure to define ID; a global IQ score is a summation of various sub-domains of verbal and performance scores, each with its own confidence intervals.

The term 'significant impairment' is defined as a person's measured abilities being two standard deviations below the average; that equates to the lowest 2% of the general population, and is commonly referred to as a standardised score of below 70 for both IQ and Adaptive Social Functioning. The measures are most accurate when, at the time of assessment, the person is not experiencing mental health, social, or other upheaval in their life that could affect their performance in tests.

## 1.2 Mental disorder in people with ID

The evidence indicates that mental health disorders are more prevalent among people with an ID than in the general population (Cooper and Collacott 1996; Deb et al. 2001). Prevalence rates vary according to patient population examined, diagnostic process, and criteria used. Recent epidemiological research suggests that the prevalence of mental illness within the adult ID population is between 20.1% - 23.4% (excluding challenging behaviour and autism) (Taylor et al. 2004; Cooper et al. 2007; Hughes-McCormack et al. 2017) compared to 16% of the adult general population (Cooper et al. 2007). Sheehan et al. (2015) identified that 21% of people with ID on GP records had a diagnosis of mental illness.

Mental health problems in people with ID are often not recognised; the complexity of multi-morbidity, communication needs, assessment, and diagnosis can lead to failure

to recognize mental disorder, and this is compounded by diagnostic overshadowing (Reiss et al. 1982), where presenting symptoms are attributed to the ID rather than a possible emerging and treatable mental or physical illness.

## 1.3 Barriers to access to services

Most mental health problems are managed in primary care with a focus on prevention and early identification (Joint Commissioning Panel for Mental Health 2012). Perera & Courtenay (2018) describe the organization and variation of mental health services for people with ID across the UK. There are some barriers to care, that people with ID share with the general population with mental health problems, in accessing specialist secondary care mental health services. These include (British Medical Association 2017):

- Inadequate funding at time of increasing demand
- Access problems and lack of integration and prevention
- Inadequate provision and quality of services
- An understaffed workforce and insufficient training

People with ID and mental health problems, due to their added vulnerability, are at higher risk than the general population of facing barriers to access to specialist care.

## 1.4 Attitudes to people with ID and mental health problems

People with ID experience discrimination in almost all areas of their lives. Ali et al (2013) reported on the barriers to care for people with physical health problems and ID that included problems with communication, problems in the relationship between health professionals and carers, and sub-standard care. While no similar research has been conducted into access to mental health services, it could be hypothesised that services often are set up in complicated teams and systems, and it can be daunting for anyone to access and navigate those at times of great distress and vulnerability.

## 1.5 Current mental health service provision for people with ID in the UK

Specialist care for people with ID in the UK is commonly provided by multi-discipline teams of health and social work professionals. Teams work in partnership with general practitioners, other specialties, social care, and private agencies. There is a particularly strong interface with social services, with health and social care integration aiming to further strengthen this link.

The assessment and treatment of mental disorder in people with ID is just one aspect of the care and support provided. Others include sub-specialist teams or pathways focusing



on issues such as challenging behaviour, offenders with ID, autism spectrum disorders, dementia assessment and management particularly in the Down population, complex physical health needs or epilepsy. Specialist ID teams provide highly specialized care delivered by health professionals who have developed the necessary communication skills and experience. The configuration of services varies across the UK.

The guidance for commissioners of mental health services for people with ID (Joint Commissioning Panel for Mental Health 2012) sets out a well-defined service organisation model to meet the mental health needs of people with ID in England (Figure 1).

### Good practice example: Transitions



An agreed protocol relating to transitions between ID and general adult psychiatric (GAP) services to remove barriers to access to services. The service receiving the referral completes the initial assessment, arranging a cognitive assessment, while holding case management responsibility. This avoids patients falling between gaps in service provision.

If an ID has been diagnosed and additional needs have been identified, depending on presentation and the wishes of the individual, family, or carers, a joint working approach might be appropriate in order to achieve a more holistic treatment and aim to achieve the best possible outcome for that individual.

### Good practice example: Joint working



Miss A has a diagnosis of PTSD for which the GP referred her to primary care mental health services. In the assessment Miss A required additional support to attend to activities of daily living provided by her family. A formal cognitive assessment was undertaken revealing that Miss A was functioning in the mild ID range, with a full scale IQ of 67.

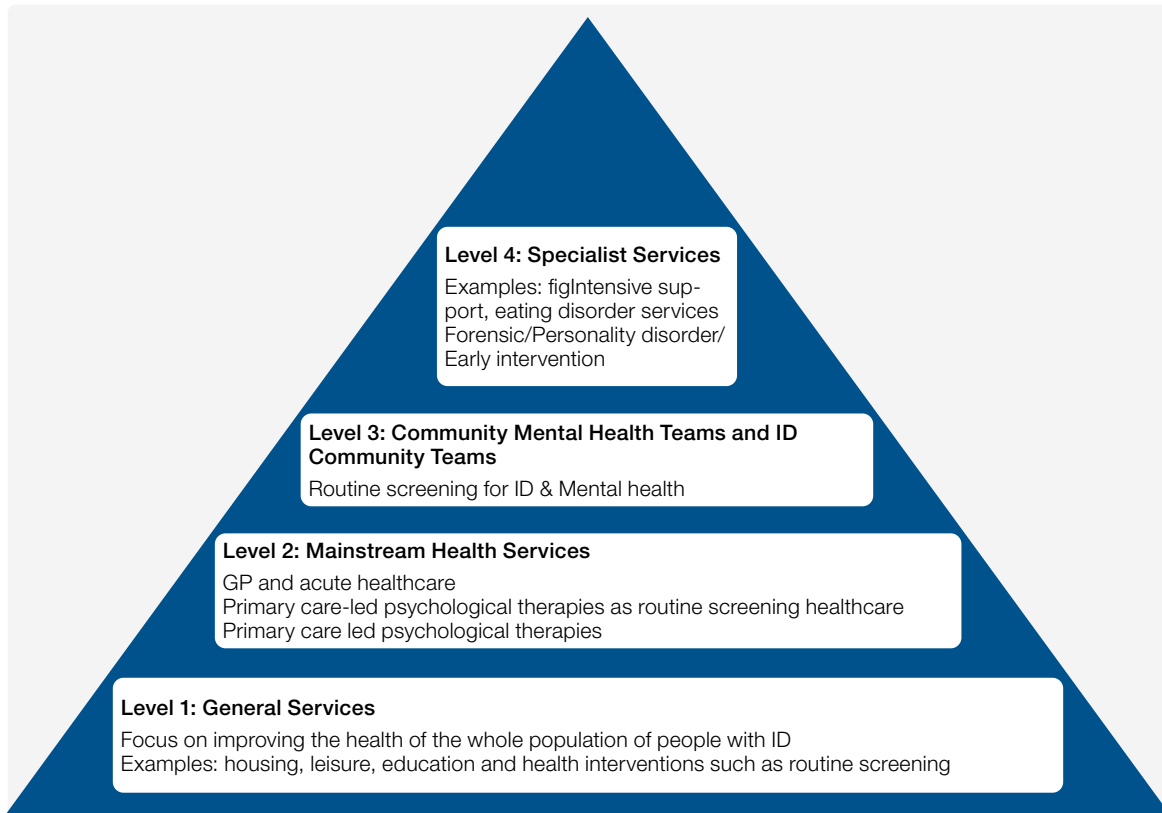
Miss A received psychological therapy from the primary care mental health services, and her additional support needs were met from the local community ID service. The Psychiatrist in ID agreed to act as her RMO if admission to in-patient services was required.

It might be appropriate for individuals treated by the ID specialist service to be shared with colleagues from general adult psychiatric services. These services are at level 4 and examples might include community-based intensive support or specialist services, such as eating disorder services. It is good practice to access the service best situated to meet an individual's needs, irrespective of intellectual functioning, and joint working can be used to support those specialist services on ID related matters such as capacity, consent or communication.

Where there is disagreement on which service is most appropriate for the person, it is good practice to consult the patient for their view. Good communication, and supportive,

reciprocal and fair working relationships between services, can make the experience for service users, their families, and carers good while providing evidence-based, outcome-focused assessments and treatments.

**Figure 1: Service organisation model to meet the mental health needs of people with intellectual disabilities in England**



# 2. Evidence for mental health services for people with mild ID

A systematic review on this topic is provided in the supplementary section of this report. The outcomes for people with ID using mental health services indicate that general psychiatric care could be improved by staff training, and in-reach from community ID teams (Chaplin 2009) that enhances outcomes in symptoms and function (Chaplin 2011). The evidence is consistent with the view that lack of skilled staff and non-integration of services are barriers to accessing MH services (Whittle et al. 2017). Enablers were a multidisciplinary approach, collaborative working and clear referral pathways.

## 2.1 Mental healthcare

Despite an increased rate of mental health problems, people with mild ID do not receive a comparative increase in care (Bouras et al. 2004). Those with borderline ID may benefit from assertive outreach (Hassiotis et al. 2001). The evidence of improvement in the person's level of functioning in specialist in-patient care is limited to Lunskey et al (2010). Chaplin (2011) highlighted the lack of evidence comparing outcomes of general and specialist ID in-patient units.

Access to specialist ID units may preclude people from using other specialised services (Slevin et al. 2008), restricting opportunities for patient therapy and education (Venville et al. 2015). People with dual diagnosis, such as ADHD or autism with mild ID, may experience difficulties or delays in gaining access to appropriate services because they do not fit specific social or health service criteria.

## 2.2 Interventions

There is limited evidence on the efficacy of group CBT in treating depressive symptoms in people with ID. The evidence is sparse and no randomised controlled trial data is available (Osugoo and Cooper, 2016). A meta-analysis of therapeutic interventions in mild ID for mental health problems found no conclusive evidence.

## 2.3 NICE guidance

In England and Wales, specific NICE guidelines exist on the management of autism and mental illness with ID. The National Service Frameworks (NSF) set quality frameworks to help achieve these. The NICE guidelines, as a group, document some broad approaches which, on the surface, would address these factors for some of the disorders. Specific guidance exists for people with mild ID and mental illness: Clinical Guidelines (CG113 and CG123)(NICE 2011a,b) suggest offering the same interventions to those with mild ID as to those without. There is paucity of data to demonstrate the current provision for those with a mild ID, and therefore it is difficult to ascertain if this approach is in fact taking place, and indeed if it is the most appropriate in terms of patient care. A review of all relevant NICE guidance for people with ID is provided in the supplementary information section of this report.

## 2.4 Conclusion

The lack of high-quality evidence on people with mental health problems and mild ID is echoed throughout the literature. There is a need for targeted and well-coordinated services to prevent people with mild ID and mental health problems from falling between service gaps (Balogh et al. 2016). Venville et al. (2015) consider that not meeting the needs of people with mental health problems and ID suggests a failure of services to fulfil human rights obligations.

There is a clear need for further evidence. There is no support for divergence from evidence-based guidelines and normal good practice for mental health problems in the general population. Increased awareness and training among all clinicians would benefit people with ID by gaining them access to appropriate services.

# 3. Policy context: caring for people with mild intellectual disabilities and mental illness

## 3.1 England

Key policies inform the treatment of those with both ID and mental illness:

- The Equality Act (Legislation.gov.uk 2010) states that public sector agencies such as the NHS must make reasonable adjustments to their practice to make them accessible and effective for people in the protected groups, which includes people with ID. This legal duty is anticipatory and means that mental health agencies are required to consider in advance what adjustments people with ID or autism will require, rather than waiting until such individuals attempt to access services.
- *No Health without Mental Health* (Department of Health Feb 2011) reaffirms the need for ‘inclusivity of mainstream mental health services for people with learning disabilities who have mental health problems’, and ‘development of appropriate skills and provision of adjustments to meet the individual needs of people with learning disabilities and autism (recognising the increased risks of a range of physical and mental health problems for this group)’.
- The National Development Team for Inclusion (NDTI) report *Reasonably Adjusted? Mental Health Services and Support for People with Autism and People with Learning Disabilities* (National Development Team for Inclusion 2012) found that whilst there were significant examples of good practice this was limited. They identified the following issues that require resolution:
  - Thorny issues about differences in eligibility thresholds
  - Access to sophisticated treatment
  - The availability of evidence regarding efficacy of particular interventions
- *Achieving Better Access* (Department of Health 2014) states that services need to become more sensitive to the needs of local populations and the diversity within them, seek to eliminate discrimination, and advance equality of access.
- *Supporting people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition* (NHS England 2015) recommends ‘simplifying the system wherever possible. This will involve reducing boundaries and stand-offs between organisations and services’.
- *Old Problems, New Solutions* (The Commission on Acute Adult Psychiatric Care 2016) identifies the need for mental health services to be fully aware of the implications following the recommendations of *Building the Right Support* highlighting

that it is 'likely to lead to more people with learning disability who may also have mental illness being treated in mainstream mental health services'.

- *Guidance for commissioners of mental health services for people with learning disabilities* (Joint Commissioning Panel for Mental Health 2012) outlines the key values and principles for effective mental health commissioning based on current policy, law and best practice.

National Institute for Health and Care Excellence (NICE) guidance has recently been developed in Mental health problems in people with learning disabilities (NICE 2016). It considers the effectiveness of psychological therapies and medical interventions. It does not recommend one specific model of service delivery to meet the needs of people with IDs and mental health problems but recommends that:

- Services should include intensive support at home and in community settings for those with severe mental health problems, those services to work closely together to facilitate joined up provision.
- Mental health ID specialists should be employed in generic in-patient mental health settings, and dedicated beds should be available to those who require admissions.
- ID services should be able to offer a broad range of psychological interventions.
- People with ID should not fall between the gaps between services, and general mental health services should be able to deliver services tailored to meet the needs of people with ID.
- There should be a leadership team that is responsible for establishing and developing care pathways for people with ID and mental health problems.

People with mild to moderate mental illness should have access to the IAPT (Improving Access to Psychological Therapies) pathway, which provides talking therapies in primary care.

The Green Light Toolkit (Department of Health 2013, rev 2017) seeks to improve mental health services for people who have ID. It is used well in some areas, but the changes to mental health services have affected how well it is used. It has gradually moved expectations away from people with mild ID being open to ID services only and needing to be treated in mainstream services, and being referred to ID services only if they have specific additional health needs needing specialist ID input.

## 3.2 Scotland

The policy context in Scotland is to provide integrated care delivery in peoples' communities, emphasizing preventative measures. The main policy drivers are:

- Health and social care integration
- The United Nations Convention on the Rights of Persons with Disabilities
- *The Keys to Life* – Scotland's learning disability strategy

### 3.2.1 Integration

Health and social care integration is a response to the demands of an ageing population with chronic health needs. The principal idea in integration is care built around the needs of the individual, not around the needs of the service.

### 3.2.2 Decision making

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (UN General Assembly 2007) was ratified by the UK in 2009. The UNCRPD has potentially major implications for how psychiatric services are delivered, including ID services. Scottish legislation relating to the care of people with ID, including the Adults with Incapacity Act (AWIA) (Scottish Government 2000), the Scottish Mental Health Act (MHA) (Scottish Government 2003) and the Adult Support and Protection legislation (Scottish Government 2007) typically encompasses substituted decision making as an appropriate way of supporting interventions for people with ID. In order to implement the wider provisions of the UNCRPD the Scottish Government have a delivery plan *A Fairer Scotland for Disabled People*, which over the period 2016–2021 aims to make equality of opportunity, access to services and independent living a reality for all disabled people in Scotland (Law Society of Scotland 2017).

### 3.2.3 The Keys to Life

*The Keys to Life* is a ten-year strategy (Scottish Government 2013b), with an emphasis on health issues acknowledging the worse outcomes for people with ID. It has four strategic outcomes related to the United Nations Convention on the Rights of Persons with Disabilities:

- *A Healthy Life*: People with learning disabilities enjoy the highest attainable standard of living health and family life.
- *Choice and Control*: People with learning disabilities are treated with dignity and respect, and are protected from neglect, exploitation and abuse.
- *Independence*: People with learning disabilities are able to live independently in the community with equal access to all aspects of society.
- *Active Citizenship*: People with learning disabilities are able to participate in all aspects of community and society.

*The Keys to Life* made 52 recommendations with an emphasis on increasing participation of people with ID in local developments, and on local delivery plans taking account of the needs of people with ID.



### 3.2.4 Mental health strategy

The 2017–2027 Scottish Government Mental Health Strategy (Scottish Government 2017) echoed previous government publications in noting the inequalities experienced by people with disabilities, and specifically the higher rates of mental illness among people with ID, advising that services be more joined up.

### 3.2.5 In-patient services

The most recent Scottish bed census showed that there were 179 ID and 82 forensic ID beds in 2017, with occupancy of 90 and 91% respectively, which is significantly higher than the King's Fund recommendation of 85%, indicating that there is an imbalance between in-patient care and community provision (Scottish Government 2013a, 2017). Across Scotland 300–400 in-patient beds are required and health boards need to provide four assessment and treatment beds for every 100,000 population.

### 3.2.6 Mental Health Care of people with ID

The issues affecting the care of people with ID in Scotland are health inequalities, a shortage of trained staff, and difficulty accessing in-patient care, appropriate high-quality community care, and meaningful day-time activities.

## 3.3 Wales

Government policy on mental health care for people with ID has evolved over the recent decade.

- *Statement on policy and practice for adults with a learning disability* (Welsh Government 2010) recommends that people with ID must have equal right of access to primary, secondary, and specialist healthcare services to that of any other citizen. It recognises that individuals with ID may have more specific healthcare needs, such as mental health.
- *Together for Mental Health* (Welsh Government 2012) is the ten-year strategy to improve mental health and well-being, stipulating that vulnerable groups should experience equitable access to and provision of services that are responsive to their diverse needs. A national e-learning training program *Treat me Fairly* has been introduced to all health boards and trusts.
- The Mental Health (Wales) Measure (Welsh Government 2010) passed by the National Assembly for Wales provides a legal framework for the support people living in Wales should receive. It places a legal duty on health boards and local authorities to improve support for people with mental ill-health and requires that mental health services focus upon people's individual needs, including the needs of people with ID.

- The Act places a duty upon mental health service providers to improve the effectiveness of secondary mental health services that includes the right of ‘relevant patients’ to have a care coordinator appointed, and the right to an individual Care and Treatment Plan in order to assist recovery.
- The Social Services and Well-being (Wales) Act 2014 (Welsh Government 2014) provides a framework for determining need, and a threshold promoting early intervention and prevention. Local authorities and health boards are required to work together to assess care and support needs, prioritizing the integration of specific services, including for people with ID.

### 3.3.1 Services for people with ID

Current practice in Wales for the provision of mental health services for individuals with a mild ID vary widely. In some localities, ID services sit within or are combined with mental health services, and in other areas they are completely separate. The interface between ID and general adult psychiatry services varies dependent upon local settings, pathways and relationships. There is a notable absence of services for offenders with ID in Wales.

The Welsh Government supports an all-Wales Integrated Autism Service to provide consistent and accessible support to those with autism and / or intellectual disabilities.

## 3.4 Northern Ireland

The Department of Health in Northern Ireland has produced policy on the care of people with ID.

- The Bamford action plan (Department of Health 2003) is the key driver for implementing the much needed positive change in services and legislation for people with ID in Northern Ireland. It recommends that trusts ensure people with ID should have equal access to the full range of primary health care services. As a result, all adults with ID will have annual physical and mental health checks. (*Delivering the Bamford Vision: The Action Plan 2012-15* (Department of Health Social Services and Public Safety 2014)).
- The *Transforming Your Care* report (TYC) (2011) proposed reshaping the integrated health and social care model, with care to be provided closer to home, shifting resources from hospital to community health and social care services (Health and Social Care Board 2011). There are variations in type of service provided between trusts and this could be partly attributed to local demands. TYC acknowledged the concerns raised by the Royal College of Psychiatrists where more work was needed in the area of access to mental health services for people with ID.
- The learning disability service framework (LDSF) in Northern Ireland sets 34 targets in relation to ID and is reviewed annually. Standard 22 of LDSF states that

people with ID who experience mental ill health should have access to appropriate support. A key performance indicator for trusts is that people with ID can access mainstream mental health services.

- The Mental Capacity Act (Northern Ireland) 2016 (Northern Ireland Assembly 2016) is an example of ‘fusion’ legislation and is widely recognised as the first in the world where mental health law and mental capacity law have been fused in one piece of legislation. The Act defines key elements such as ‘decision-making capacity’ and ‘best interest decision making’ to be used when making decisions about care and treatment of a person across health and social care.
- *Service Framework for Mental Health and Well-being* (Department of Health 2018) redesigned the framework of 2010 to focus on ‘the required service elements of access to mental health services, assessment, diagnosis, treatment, self-management and the recovery of all adults who have a mental health problem or condition’.

### 3.5 Autistic spectrum disorder

Autistic spectrum disorder (ASD) is a complex neurodevelopmental disorder, increasingly important as more autistic people are being recognised in childhood and adult life. There is considerable overlap between ID and autistic spectrum disorder, with estimated prevalence rates of 20-30% for ASD comorbidity in people with ID (Emerson and Baines 2011) and estimated prevalence rates of 40% of ID occurring in ASD populations (Autistica 2017). The majority of autistic people do not have ID, although many may have had specific learning difficulties in school years, but comorbid ID does increase health and other problems.

People with autism may present with any type of mental health disorder, but rates of anxiety disorders, ADHD, and mood disorders are especially high (Belardinelli et al. 2016). People with autism have a higher rate of suicide than the general population (7.55 times OR 6.04-9.44) and higher rates of preventable treatable illnesses and premature mortality, similar to premature mortality rates in serious mental illness, or worse if there is comorbid ID (Hirvikoski et al. 2016).

Adults with mild ID and autism usually present to adult or older people’s mental health services for any significant co-morbid mental health problems. People with autistic spectrum disorder can present with a pronounced inconsistency between functional and cognitive ability (in either direction) that may result in disputes between services on which should work with the person. The Green Light Toolkit is helpful in enabling services to resolve the question.

Services are expected to make reasonable adjustments to facilitate interventions which take the person’s level of ID and/or autistic spectrum disorder into account. There is however still a realistic possibility for individuals to ‘fall between stools’, or struggle to access appropriate services – with regard to diagnostic assessment, post diagnosis support, and treatment of comorbid mental health disorders. Diagnostic overshadowing also continues to be an issue, in that acute mental health services can attribute presentation and psychopathology to the underlying autistic spectrum disorder, rather than to a treatable mental illness. Likewise an undiagnosed ASD can be attributed to the presence of an ID.

## 3.6 Children with intellectual disabilities: transitions

Young people entering adult ID services may be referred from a variety of services which may include primary care, social care, child and adolescent mental health, paediatric, neurology, etc. There is a wide variation across the country in how services are provided for children with ID, and up to what age. It is not uncommon to find that although developmental difficulties have been identified by child and adolescent services, no definite diagnosis of ID has been made, and that in turn can delay access to the appropriate adult service. Clarity on ownership in services around transition from CAMHS to adult services is essential. College Report 200 *Psychiatric services for young people with intellectual disabilities* (Royal College of Psychiatrists 2016) discusses and details services for young people with ID and mental health problems, recommending what services should be available, with suggestions of the elements of good service provision.

## 3.7 Offenders with intellectual disabilities

There are well-recognised issues and risks in the support that offenders with ID receive. They include:

- Failure to report or prosecute behaviours, leading to the person then believing that those behaviours are acceptable
- The risk that specific needs will not be recognised or met
- Difficulty in devising effective systems for joint working
- Recognition of the need for appropriate adults to support people with ID through the criminal justice system.
- Achieving balance between diverting people with ID from prosecution and proceeding with prosecution
- Maximising the use of community disposal
- Access to dedicated community forensic ID teams
- Geographical distribution of forensic ID beds leading to people being placed a long way from home
- Lack of evidence of outcome and cost effectiveness
- Need for commissioning which promotes the least restrictive setting

In *Transforming Care* (NHSE, 2017) model service specifications describe how services for offenders with ID should be provided more in the community, with a shift away from in-patient care. Policy encourages more co-operation between community forensic ID services and generic community mental health services or specialist community adult ID services.

# 4. A model of mental health care for people with intellectual disabilities

It is an important principle of any integration that care is delivered around what is a good fit for local circumstances and need, and best suited to the local demographic. Therefore the different areas of practice across the UK should not be seen as a problem as long as the eventual goal is delivered, i.e. delivering and evidencing high quality mental health services to people with mild ID. Certain areas have developed safe and efficient structures of care delivery for this vulnerable group. There is recognition that different regions have diverse strengths and weaknesses and it is important that solutions look to build on strengths already present. Equally, when resources are limited thought needs to be given to utilising existing systems and frameworks. The challenge lies in recognising and addressing gaps. Service models of delivery will vary throughout the UK depending on geography and what services are currently in place. The report recommends identifying current expertise and pathways and modelling care along suggested standards involving ID, adult mental health services, therapy streams, and tertiary service availability.

We suggest a two-pronged approach supporting the above working model, aimed to provide a consistent and holistic framework of care at practitioner and at service levels. The model could either be directly utilised in an area with a mainstreaming approach, or help to conceptualise service coverage in areas that retain a specialised ID model for the treatment of mental illness.

## 4.1 Practitioner level

We propose criteria setting out what are essential and desirable elements for psychiatrists and their services. Service components that are essential include:

- Specialist consultant psychiatrist in intellectual disability
- An intellectual disability multi-disciplinary team
- Community mental health teams
- An intellectual disability liaison nurse

Services should have clear guidelines on the management of emergencies, with appropriate shared access to information such as a HEALTH (Helping Everyone Achieve Long Term Health) Passport. The tables below set out the skills required of a general adult psychiatrist managing people with an ID, and likewise psychiatrists in ID, with regard to mental illness.

## 4.2 General adult psychiatrists supporting people with ID

Skill set for general adult psychiatrists
<b>Essential skills</b>
Awareness of recent relevant legislation such as Mental Capacity Act 2005, Equality Act 2010, Social care Act 2012, Accessible Information Standard, or appropriate correspondent legislation in other jurisdictions
Provision of a professional development plan with identified CPD in ID
Basic knowledge of major comorbidities such as pervasive developmental disorders, physical health disorders such as epilepsy, and social issues, which can influence mental state
Knowledge of interactions between commonly prescribed psychotropic and other relevant medication more relevant to people with ID, such as epilepsy medication or anti-dementia medication
Knowledge and awareness of local pathways to refer for ID specific issues
Links with ID experts e.g. ID liaison nurse
Ability to make reasonable adjustments to meet the needs of the person with ID; adjustments may be required for effective communication by providing easy read material, in particular when planning for appointments
<b>Desirable skills</b>
Completion of a recognised training ID post as part of core training, or special interest in higher training as part of the General Adult Psychiatry CCT or equivalent
Provision of regular clinics/reviews for people with ID
Provision of a personal development plan focused appropriately on ID, and access to a peer group with specialism in ID
Existence of a job plan that clearly recognises activity in ID
Ability to use/interpret specific tools such as Mini PAS-ADD, HoNOS-LD, GDS etc.
Awareness of national developments and good practice in ID

## 4.3 Psychiatrists in ID who support people with ID and mental illness

Skill set for psychiatrists
<b>Essential skills</b>
Awareness of recent relevant legislation in general adult psychiatry
Professional Developmental Plan includes identified CPD in general adult psychiatry appropriate to the work in mental illness being undertaken
Knowledge of major psychiatric comorbidities such as depression, psychosis, anxiety, and interactions between commonly prescribed medication
Knowledge and awareness of local pathways to refer for mental illness specific issues
Links with mental health experts, e.g. psychiatric liaison nurse
Provision of regular clinics/reviews for people with ID and mental illness
Ability to use/interpret specific tools such as Mini PAS-ADD, HoNOS-LD, GDS etc.
Ability to make reasonable adjustments as required to meet the needs of a person with ID and mental illness; adjustments may be required for effective communication by providing easy read material in particular when planning for appointments
<b>Desirable skills</b>
Completion of a recognised training in general adult psychiatry in core training, or higher training special interest in general adult psychiatry as part of the CCT in Psychiatry of Learning Disability or equivalent
Provision of a clear identified personal development plan in mental illness, and access to a peer group with specialism in mental illness
Existence of a job plan that clearly recognises activity in mental illness
Facilitation of use/interpreting of specific tools such as Mini PAS-ADD, HoNOS-LD, GDS etc.
Awareness of national developments and good practice in general psychiatry

## 4.4 Service level

Identified clinical groups need to have ownership of delivering evidence-based practice, and adhere to NICE or other approved guidelines for ID and mental illness. High-quality services could be provided with the following minimum key components:

- A psychiatrist in ID with expertise in general psychiatric disorders and/or
- A general adult psychiatrist with an ID interest
- Specialist nursing support
- Appropriate psychology and therapy services
- Transition services
- Access to second opinions and tertiary services, with clear pathways and lines of responsibility.

There are various models of practice across the UK for the treatment of people with ID and mental ill health that include whether people with ID receive psychiatric care primarily from a psychiatrist in ID or a general adult psychiatrist. We recognise the importance of people having access to the service that best meets their need, and that should include access to mainstream mental health services if that is the best fit for the patient.

Appendix 2 includes example schemas for measuring service quality, which are presented as suggested frameworks that could allow commissioners and clinicians to continue to improve services in a way sensitive to local needs and practices.

## 4.5 The Green Light Toolkit

The Green Light Toolkit (Department of Health 2013, rev 2017) provides information on services that are in place and working well for people with ID and mental health issues. It can help to improve and develop local services. Using the self-assessment checklist at regular intervals allows the provider to track developments, celebrate achievements, and move towards developing better services for people with ID, benchmarked against national guidance and expectation.

With the closure of specialist in-patient beds for people with ID, more are likely to be admitted to local mental health units. Use of the Green Light Toolkit can enhance the services people receive. The current framework of care and treatment reviews could be strengthened to ensure joint participation from psychiatrists in ID in working with general adult psychiatrists to identify rapid and sustainable discharge outcomes, and to ensure specialist placements lead to targeted activities around assessment and management.

## 4.6 Benefits of integrated care

For a person with mild ID and mental health problems it is essential that there is adequate social care support and on-going assessment and evaluation of changes in social needs, especially to help sustain well-being and prevent future relapse. This requires



commissioners or providers of social care to consider the following requirements as part of their contracting arrangements.

- Ensure that staff supporting the person are trained in mental health problem awareness, with a good understanding of how mental disorder affects the person they support.
- Ensure access to relevant advocacy services, e.g. independent medical capacity advocates or independent mental health advocates in England.
- Providers of social care should ensure that support staff have good links with specialist health staff and are able to provide information about the person that helps with assessment and review of treatment.
- Ensure that staff supporting the person facilitate their attendance at clinical appointments in hospitals or GP practices, including their annual health check.
- Ensure that staff are able to follow the health action plan, and know how to respond in an emergency.
- Providers should be aware of the medication prescribed for people and support the principles of STOMP 'Stopping over-medication of people with ID and or autism' (NHS England 2016).

Social care providers can help the person by understanding how best to manage the environment the person lives in, to reduce mental illness relapse triggers, e.g. sleep disturbance, infections, alcohol etc.

## 4.7 Plans for the future: The NHS Long-Term Plan

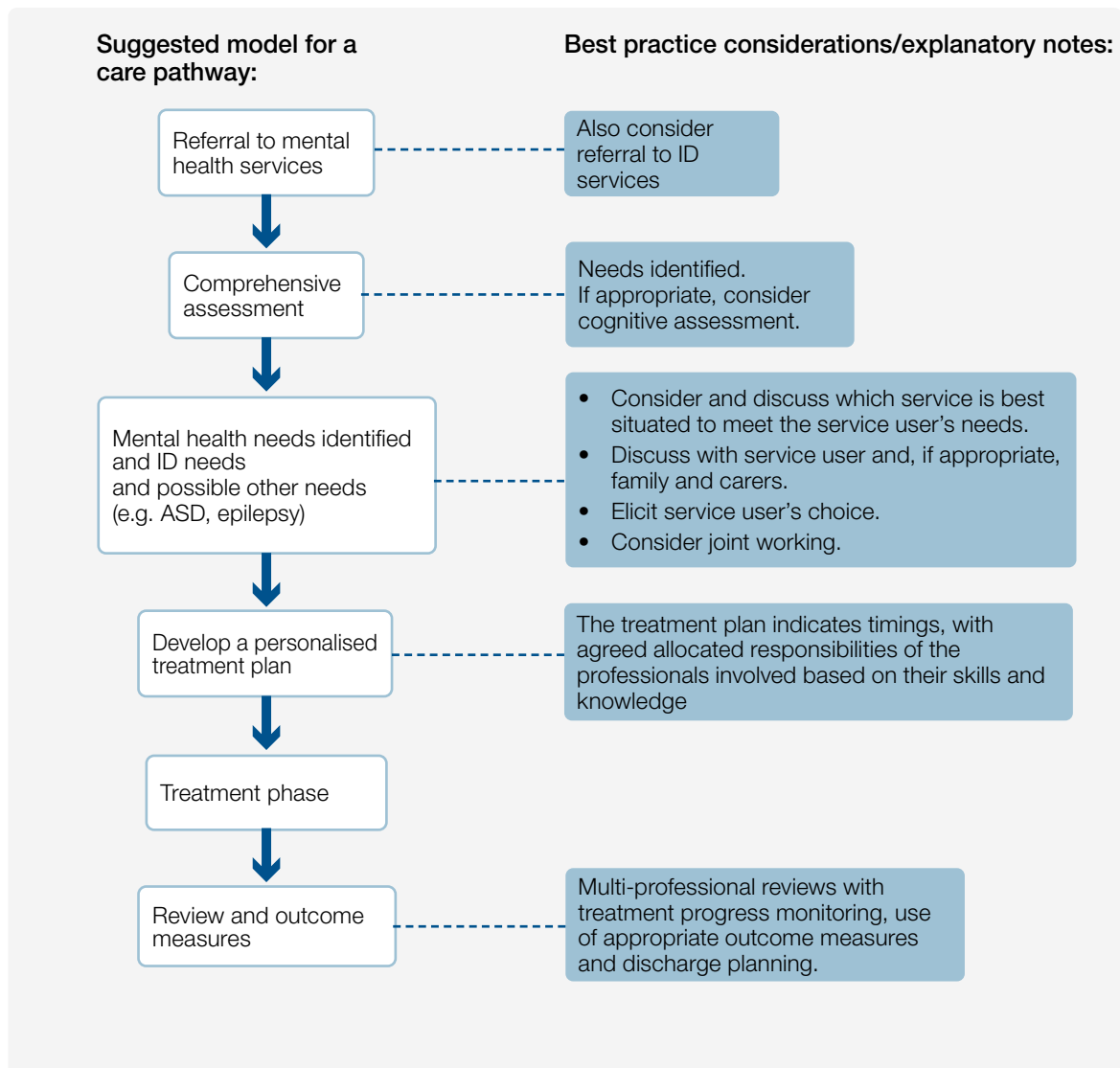
ID and autism are two clinical priorities of the NHS Long-term Plan to be implemented in local services with a focus on integrating services (2019).

## 4.8 Training issues

The *Shape of Training* review (Greenaway 2013) recommends broadening training in order to provide general care for a wide range of specialties across a range of different settings to deliver care more appropriate to the population. It calls for doctors with a broader general training, who should have the skills to meet the care needs of these individuals.

At present, core trainees in psychiatry are not required to undertake six months of a developmental psychiatric specialty in either psychiatry of ID or child and adolescent mental health, and therefore not every psychiatric trainee will have the opportunity to gain an insight into working with people with ID. In higher training, doctors can avail of dual training programmes of child and adolescent psychiatry and the psychiatry of intellectual disability. Trainees in all sub-specialties of psychiatry can undertake special interest sessions that would allow them to gain experience in working with people with ID. There is potential for these sessions to be actively promoted to general adult psychiatry (GAP) trainees in order to improve confidence and skills in this area. This is an area with great potential for future development, reflecting the needs set out by the *Shape of Training* review.

**Figure 2: Suggested model for a care pathway for people with mild intellectual disability and mental health needs**



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## Appendix 1 – The prevalence of mental illness in people with ID

Disorder	Rate
Schizophrenia	3%
Bipolar affective disorder	1.5%
Depression	4%
Generalised anxiety disorder	6%
Specific phobia	6%
Agoraphobia	1.5%
Obsessive compulsive disorder	2.5%



## Appendix 2 – Suggested desirable elements of a service for people with ID and mental health problems

Desirable Service Components
<p><b>Clinical care</b></p> <ul style="list-style-type: none"> <li>• Dedicated joint mental health and psychiatry of ID clinics*</li> <li>• Dedicated clinics for people with ID in general psychiatry, or general adult psychiatry clinic in ID setting</li> <li>• Adequate time to inquire into psychiatric issues in ID clinics</li> </ul>
<p><b>Nursing service</b></p> <ul style="list-style-type: none"> <li>• ID nurse with mental health interest*</li> <li>• Mental health nurse with ID interest*</li> </ul>
<p><b>Multidisciplinary team (MDT)</b> Consisting of psychologist, occupational therapist, physiotherapist, speech and language therapist, dietitian and social worker</p> <ul style="list-style-type: none"> <li>• Dedicated team for mental health*</li> <li>• ID-based with mental health access</li> </ul>
<p><b>Specialist services</b></p> <ul style="list-style-type: none"> <li>• On-site*</li> <li>• Link to tertiary centre</li> </ul>
<p><b>Young person to adult transition</b></p> <ul style="list-style-type: none"> <li>• Joint clinic*</li> <li>• ID or mental health clinic</li> <li>• Agreed pathway</li> </ul>
<p>*Ideal service components</p>

There needs to be recognition that delivery of services to people with major mental health issues and ID is complex, and usually cannot be made by local ID services, mental health services, and nursing in community mental health team (CMHT) services, meeting their own individual essential criteria. There has to be one or more of these services extending themselves to take the lead in ensuring all current good practice requirements are met. This would require one or more of these services/professions taking on a more skilled role. To help provide guidance a table providing different permutations and combinations between the three professions has been created, and the overall picture rated with a star rating. We would suggest that an acceptable model of care should be two stars or above.

The grid would help showcase how changes to roles in different service providers could impact on service delivery. It could help make adjustments in available resources to optimise service delivery.

The table below provides star ratings for care models combining general psychiatry, ID psychiatry and nursing. It is expected that the psychiatrist in ID will have access to a full multidisciplinary teams (MDT), including ID nurses, psychologists, occupational therapists, speech and language therapists, dietitian, physiotherapists, etc. Similarly the mental health psychiatrist is the access point to a CMHT MDT.

### Models of care

To be used in conjunction with the qualities of each service as identified:

Star rating	CMHT psychiatrist requirements	ID service psychiatrist requirements	Nurses' competence
1*	E	E	1N/2N
2*	E	E	1C/2C
2*	E	D	1N/2N
2*	D	E	1N/2N
3*	D	E	1C/2C
3*	D	D	1N/2N
4*	E	D	1C/2C
4*+	D	D	1C/2C
5*	D	D	1C and 2C

#### Key:

##### CMHT or ID service psychiatrist skill set requirement

E = Essential requirements  
D = Desirable requirements

##### ID nurses' competence in mental health

1N = None  
1C = Competent

##### Mental health nurses' competence in ID

2N = None  
2C = Competent

## Quality in ID service checklist

Service components	Reviewing	Providing	Implementing	Developing
Psychiatrist in ID with up to date skills and training in the diagnosis and treatment of mental illness OR GAP psychiatrist with essential and desirable skills in ID				
ID nurses with competence in mental health				
Psychology input to multidisciplinary team (MDT) with expertise in ID				
Well-established MDT including OT, SALT, pharmacy support				
Access to named medical link and interface protocols with GAP				
Data systems exist to support the routine monitoring and review of individual and case-load outcomes				

**Reviewing** – Clear and mature implementation, and regular audit of processes

**Providing** – Clear existence of component

**Implementing** – Some aspects of component in place, and plans working towards full achievement

**Developing** – Implementation at planning stage only