

CR200

Psychiatric services for young people with intellectual disabilities

Revision of CR163

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Executive summary

This report is the fifth version of a document first produced in 1992 with the purpose of informing medical professionals about the development of mental health services for people under 18 years of age with significant intellectual disabilities. It replaces CR163, which was published in 2010.

Although the administrations that make up the UK differ in the detail of their policies, their overall policy is developing quickly along the same lines. There is a common will to improve services for this group and to ensure that, wherever the person lives, there is a specialist service available when necessary.

This report is intended to help people shape their evolving services. It describes policy development, the target population, common clinical problems and the challenges faced by families. It also describes the components of a model service.

A clinical service should provide:

- diagnosis and assessment
- counselling services to help the individual and their family cope with disability and the associated difficulties
- family work
- specialised individual therapies
- pharmacological treatment
- liaison and joint working with other agencies
- emergency response
- advice to the courts (expert opinion).

Academic elements of the service include:

- continuing professional development and training
- teaching for other agencies as well as the service; this should include undergraduate and postgraduate
- research and audit.

Services for young people with intellectual disabilities risk becoming isolated. To avoid this, services for this population must be an integral part of overall community services, such as Social Services and education and child health services, and supported by clear protocols. The most immediate links will be with child and adolescent mental health services (CAMHS) and intellectual disability services. The clinical team require a common base and, while this may be with CAMHS, it is essential that it is accessible by and comfortable for people with intellectual disabilities. This report describes the recommended size and composition of the service's multidisciplinary team.

The in-patient unit (which may also serve as the base for an outreach team) needs to be co-located with other hospital services to ensure the effective safeguarding of vulnerable people. The physical location is important for adequate monitoring and supervision, to ensure that the staff do not become isolated and idiosyncratic, and to provide the reassurance of additional staff in an emergency.

Introduction

Our aim is to inform the negotiations between service commissioners, clinicians and managers of mental health services for young people with intellectual disabilities and their families. This report provides an overview of the ways in which such services might be provided across the UK and the elements of a standard specification that might be adapted for local needs. As such, this report complements more academic accounts of this area of psychiatry (Bax & Gillberg, 2010; Simonoff, 2015) and a variety of service documents (see Fitzsimmons et al (2011) for a review).

Emphasis is placed on the emerging hybrid of the specialties of child and adolescent psychiatry and intellectual disability psychiatry and the contribution of the psychiatrist. However, this is only one

component of a wider, complex system that is both multidisciplinary and multi-agency.

Although there is considerable overlap between the various developmental neurodisabilities, we have confined ourselves to the needs of young people with a significant intellectual disability, a group also included in recent NICE guidance on the management of challenging behaviour and its supporting quality standards (NICE, 2015a,b). Also of immediate relevance is the substantial body of work on two neurodevelopmental disorders, autism spectrum disorder (ASD; NICE, 2011, 2013, 2014) and attention-deficit hyperactivity disorder (ADHD) (NICE, 2008; Scottish Intercollegiate Guidelines Network, 2009), as these disorders frequently coexist with intellectual disability.

Terminology

Intellectual disability

In 1991, the Department of Health adopted the term 'learning disability' (replacing 'mental handicap') for the condition termed 'mental retardation' (categorised as F70–F73) in ICD-10 (World Health Organization, 1992). The Department for Education adopted the term 'learning difficulty' in the Education Act 1993.

The ensuing confusion was made worse as the two departments used the same terminology for different levels of severity. The educational category of moderate learning difficulties largely corresponded to the health categories of mild or borderline learning disabilities. UK job descriptions, service specifications and academic publications used the terms learning disability and learning difficulty virtually synonymously, whereas in North America both terms implied specific learning disabilities.

The term 'intellectual disability' (Box 1) has now replaced all these terms and is used internationally. DSM-5 has introduced and ICD-11 will introduce 'intellectual developmental disorder' as the relevant diagnostic category, one of the group of neurodevelopmental disorders (American Psychiatric Association, 2013). The terms 'developmental disability' and 'neurodevelopmental disability' describe an overlapping but rather wider range of disability in which cognitive deficit is not necessarily present.

Box 1 Intellectual disability (intellectual developmental disorder)

This is a lifelong condition with three components:

- Ability to understand information, to reason, learn and plan is significantly below average
- Below average ability to function independently and to cope with everyday life
- Started in the developmental period (before 18 years of age)

Whether a person is best served by an intellectual disability service or by mainstream child and adolescent mental health services (CAMHS) will depend on local service agreements. Because poor functional ability is often the result of a mix of underlying neurodevelopmental disabilities, it is inappropriate to use the intellectual disability alone to determine the best service for an individual. Services should avoid arbitrary assignment by IQ, and instead take into account the nature of the young person's difficulties and the disturbance arising from them, matching them with the structure and organisation of local resources and expertise. Adult services need to mirror this flexibility if they are not to generate or re-ignite problems when a young person graduates to their care.

Young people: children and adolescents

Some services define children and adolescents by age: up to 18 years, in line with statutory thresholds, as in the United Nations Convention on the Rights of the Child. Others use school-leaving as their defining factor, an event that can occur between the ages of 16 to 19 (although there is the potential for further education). In this report, we use the term 'young person', as this is inclusive of a wide range of age and developmental stages.

Mental health service

A mental health service is delivered by a multi-disciplinary (and sometimes multi-agency) team dealing with the assessment and management of psychiatric disorders. Such disorders include a range of disturbances that can arise from mental illness, emotional problems or learned maladaptive behaviour that might be considered challenging. The boundaries of any given service are likely to depend on local agreements rather than any

national concepts. Although a service usually includes psychiatrists, they might not be involved directly with many of the young people and carers who use the service.

A mental health service is only one of many services involved in the promotion of mental health (Department of Health, 2015) and it is essential that it is well integrated with these other services. The development of multi-agency groups, such as children's trusts, and the blending of healthcare and Social Services is likely to promote such integration.

Policy

The United Nations Convention on the Rights of the Child, ratified by the UK in 1991, encouraged the development of services that ‘put children first’ and were integrated within the mainstream. These concepts were consistent with the Children Act 1989 and the Children (Northern Ireland) Order 1995, which identified young people with disabilities as ‘children in need’. The Convention’s principles were subsequently embodied in the Disability Discrimination Act 1995, amended to include education by the Education Act 1996 and the Special Education Needs and Disability Act 2001. Although these Acts have encouraged a broad and balanced education, they have also made greater demands on the young person. For example, the introduction of a national curriculum for all pupils in England, Wales and Northern Ireland, although broadly welcomed by special schools, imposed demands that potentially limit the time and resources available for individual work. It has also become clear that, compared with their peers, young people with intellectual disabilities are unfairly exposed to a variety of disadvantages (Emerson, 2015; Jacobs *et al*, 2015; Box 2).

Reconfiguration of the National Health Service (NHS), with its increasing emphasis on community provision, has accompanied a drive towards services that focus on young people rather than any overriding disability or disorder. Until 30 years ago, a major component of lifespan intellectual disability services was a mental health service for young people. A widespread shift in policy has led to the inclusion of such services within a comprehensive CAMHS. This change has coincided with the extension of the patient age range from 16 to 18 years and, in England (Department of Health, 2008a) and Wales (Welsh Government, 2014), with arrangements for those up to 25 years of age to ensure a successful transition to adult services.

The increased demand these changes have made on CAMHS, coupled with limited resources, has meant that in many geographical regions, young people with an intellectual disability (and their families) find themselves in limbo, often looking to developmental and community paediatric services to bridge the gap. Specialist intellectual disability services within CAMHS have not lost their Cinderella status, for they are still far from routinely available across the UK and even face retrenchment as a consequence of funding constraints.

Increasingly, services have become dedicated to the care of young people with intellectual disabilities in their communities, homes and schools. Although the curtailment of NHS hospital resources has encouraged the retention of young people in their community, there are approximately 165 people with intellectual disabilities who are under 18 years of age in hospital in England (Health and Social Care Information Centre, 2015). The figure has not significantly changed for 3 years and the reasons for, and locations of, their placement are unclear: it might be for appropriate assessment and treatment or it might be a reflection of inadequate community services. Although there are about 110 in-patient places dedicated to young people with intellectual disabilities, there are a further 70 places that are willing to consider the admission of young people who have mild intellectual disability in addition to their psychiatric disorder (Lovell, 2011). Provision of specialist beds is patchy – for example, there are none in Scotland and, in England, they are clustered in Northumberland and Birmingham – so that, should a young person require admission, it is likely to be at some distance from their family. Residential schools continue to flourish, some providing year-round care. Often established with minimal consultation with local agencies, they do not always have good access to appropriate healthcare. This, coupled with a lack of clarity about the division of responsibilities between, for example, the home authority and the

school, results in uncertainty, delays and fragmentation of the provision of mental health services.

The steady progress towards inclusion has reduced the number and size of specialised settings that can tolerate unusual levels of aberrant behaviour. At the same time, various factors, such as pressure on resources and concern about the legality of certain controls (e.g. the right to restrain or detain a young person) and treatments (e.g. rectal medication), have combined to make it more difficult to keep certain young people in mainstream schools. The result has been increased demand from a population that is less well supported and more diffusely scattered than in previous times, when they were grouped into special schools.

The past decade has seen specialised community mental health services for young people with intellectual disabilities become a component of a comprehensive CAMHS. However, this provision is very uneven, with there being areas in which no psychiatric services are available and other resources are wholly inadequate – a situation that can only worsen with the devolution of funding. Such inequality of service provision needs to be addressed urgently, with strategic planning, to ensure clear management responsibility and integration with other agencies.

England

The particular vulnerability of young people with intellectual disability and their need for specialist services was identified in the National Service Framework for Children, Young People and Maternity Services (Department of Health, 2004). The Children and Families Act 2014 makes specific provision for those with special educational needs and disabilities, and a government-produced good practice guide encourages regional commissioning for low-incidence, high-cost services so that people can stay as close to home as possible (Department of Health, 2008a). Education, health and care plans, which must be person-centred, specify the measures required to achieve expected outcomes and stipulate that health, education and social care collaborate in the creation of all these (Department for Education & Department of Health, 2015; 2014/2016). Formal arrangements

for specialist clinical support in residential schools are included (Department for Education, 2015).

Wales

The specialist, multidisciplinary Child and Adolescent Learning Disability Services (CALDS) supports local, secondary CAMHS and paediatric services in their work with young people whose complex mental health issues or challenging behaviour is coupled with moderate/severe intellectual disability (CAMHS National Expert Reference Group, 2013). A replacement framework is planned to support learners with special educational needs in schools, post-16 education and training. This single framework for learners up to 25 years of age provides information, advice, and early and effective interventions, and should resolve concerns and appeals (Welsh Government, 2014).

Scotland

Ten years ago, the Scottish Government, recognising the difficulties faced by young people with intellectual disabilities in accessing appropriate mental health services, established a collaboration with a multidisciplinary clinical network, to produce the *Child and Adolescent Mental Health Services (CAMHS) Framework* (Scottish Government, 2005; Fitzsimmons *et al*, 2011). An action plan was developed (Scottish Government, 2012a), a commitment was made in the Mental Health Strategy for Scotland (Scottish Government, 2012b) and Glasgow University was funded to carry out a study of the models and their outcomes.

The Education (Additional Support for Learning) (Scotland) Act 2004 made education authorities and partner agencies jointly responsible for making any necessary provisions for young people with multiple or complex needs so that they can access education. The Children and Young People (Scotland) Act 2014 contained provisions for 'Getting it right for every child' – an approach that focuses on the individual and their access to, and use of, all the services they might need (Scottish Government Social Research, 2013; Scottish Government, 2012c).

Northern Ireland

The Bamford Review of Mental Health and Learning Disability (Northern Ireland) (2006) published a report after completing a comprehensive, overarching review of CAMHS. It made specific mention of the services available to young people with intellectual disability. Noting great variation in their organisation and remit, the report proposed that these services be commissioned as part of specialist mental health services for all young people, although recognising the need for specialist skills, training and joint working with existing intellectual disability services. There has been some service development and commissioner investment since, but access to specialist, multidisciplinary and therapeutic community services for this group remains limited.

The development of this new regional, integrated CAMHS care pathway provides an important opportunity to address historical inequities and ensure services are comprehensive and

fit-for-purpose in the future. It will specifically address the mental health needs of young people with intellectual disability at a commissioning level and embrace an intellectual disability CAMHS model.

Overall

Common to all these developments is a focus on need and outcome, a concern about transition to adulthood and a community approach that integrates a range of services supporting mental health. These services include education, employment, Social Services and other agencies at the level of primary care (Foundation for People with Learning Disabilities, 2002). The Do Once and Share programme led to the development of a model care pathway (Pote & Goodban, 2007) and other publications have set out practical specifics as to how a service might operate (Bernard & Turk, 2009; Richardson *et al*, 2010) and transition might be managed (NICE, 2016).

Aims of a service

Prevention, investigation and management of intellectual disability

While the prevention and early identification of intellectual disability largely falls to other clinicians and scientists, such as public health professionals, obstetricians, paediatricians and genetic counsellors, psychiatric services can still play an important collaborative and supportive part.

The need for early intervention has been emphasised, with early diagnosis an essential preliminary (Scottish Government, 2005; Department of Health, 2008*b*). The impact of any disability is lifelong and rather than waiting until problems develop, a pre-emptive link should be made with services from the time the disability is identified, allowing the ready involvement of more specialised services as they are needed.

Early diagnosis, based in child development services, can involve a range of specialties, from developmental and community paediatrics to neurology, psychology (clinical and educational) and clinical genetics. Delayed language development is common, making speech and language therapy an important component, especially where the services and assessments are provided in a language foreign to the family or young person.

Delayed diagnosis is encountered in older children and recent immigrants. They might be identified by educational psychology and community child health services as well as by CAMHS. For those nearing the age of transition into adult services, there is a risk that action will be deferred and that they will face further delay as they work their way up a new, adult waiting list.

Management of mental health problems

The treatment of mental health problems associated with disability and the prevention of secondary disabilities are central to the psychiatrist's role in these services. The work is not just with the young person but also with their families and others involved in their care and education. Much will depend on what other services are available: supportive services such as specialised teaching and training in areas such as communication, relationships and the skills needed to lead a more independent and satisfying life. For example, social skills, emotional literacy and emotional management (e.g. relaxation training and anger management) might be more effectively taught by schools and colleges than by mental health services. Early-intervention psychoeducational programmes, such as Portage (a home-visiting educational service for pre-school children; www.portage.org.uk), EarlyBird (supporting parents when their child is first diagnosed with ASD; www.autism.org.uk/earlybird) and Hanen (teaching parents and young people effective communication skills; www.hanen.org), can help parents and young people adjust to disability.

Early assessment and diagnosis is essential and should be comprehensive, taking in the interactions and needs of the whole family, not forgetting the siblings. Many of the mental health problems of young people with intellectual disabilities are chronic, or else follow a pattern of frequent, repeated remission and relapse, particularly at times of transition, for example when changing school or service. This requires the long-term involvement of psychiatric services with the young people and their families – both directly and by liaison with the wider health, education and social service networks – to provide an integrated, multi-agency service. This might involve working with

day and residential facilities, such as schools, children's homes and different specialist units. Service networks need to be continuous (rather than episodic) and comprehensive, catering for young people of all ages with all degrees and forms of disability, as well as bridging the transition to adult services.

This report outlines the important constituents that need to be available within every local service network. The delivery of services will vary with location, depending on local resources, priorities and other service initiatives. Services need to provide a timely response and be both accessible by and acceptable to families, as the success of treatment often depends on their active participation. Some families will require high levels of personal or material support; all need to have their social and cultural backgrounds taken into

account, including race, religion, language and culture as well as the effects of discrimination. Such factors can add extra complexity, particularly with the involvement of others (e.g. interpreters, clerics, community workers and local leaders) affecting issues such as confidentiality.

The needs of these young people and their families lend a different emphasis to the service's character, in comparison with mainstream services. The more severe the intellectual disability, the more likely the work is to be behavioural and to be done through staff, family, carers and the school, with the psychiatrist an integral part of the community team. The team has to work with differences in the perceptions and acceptance of disability across the community, and one of its aims is to help people to adopt a common perception, purpose and strategy.

The population and its needs

At least 2.5% of the general UK population has an intellectual disability that means they will need specialist services at some point in their childhood (Emerson & Hatton, 2008). Nearly 40% of this group will experience significant psychiatric disorder, compared with less than 10% of those without an intellectual ability (Emerson & Hatton, 2007). This seems to be a consequence of innate factors that confer vulnerability, compounded by a range of external factors (Box 2).

Box 2 Factors contributing to mental health problems in this population

- Communication difficulties
- Limited coping strategies and social skills
- Coexistent disorders
 - neurodevelopmental disorder – notably autism spectrum disorder and attention-deficit hyperactivity disorder
 - psychiatric disorder – emotional disorder and psychosis
 - physical health problems – epilepsy, immunological difficulties, sleep disorders
- Child abuse (exposure to violence including bullying, abuse and neglect)
- Out-of-home care (e.g. fostering, institutional placement)
- Socioeconomic deprivation
- Inadequate educational provision and supportive services (e.g. a lack of local residential projects, such as respite provision and residential schooling)
- A remote, rural population
- Adverse life events

(Emerson, 2015)

Common clinical problems

Problems affecting young people

Young people with intellectual disabilities can display any of the full range of psychiatric disorders. Response to treatment is often idiosyncratic because of the underlying neurological abnormality. Other disabilities and disorders, including epilepsy, cerebral palsy and sensory impairments, co-occur frequently, as do characteristics peculiar to the underlying medical disorder (the behavioural phenotype). The problems are often long-term, especially as the underlying intellectual disability and its coexistent disorders are lifelong. Difficulties will wax and wane, with high rates of re-referral. This group needs a continuous, rather than episodic, service.

Success depends on coordination between specialised health and educational services, Social Services, voluntary agencies and local parent groups. Certain problems are common in young people with intellectual disabilities and might require a more specialised approach.

ASD

ASD is frequent in this population and often underlies referral to specialist CAMHS. Its impact on young people, their families and carers makes it essential for there to be local specialist expertise available (Scottish Intercollegiate Guidelines Network, 2007; NICE, 2011, 2013, 2014).

ADHD

ADHD is also common and a diagnosis that has to take developmental level into account. Misattribution of symptoms can leave the ADHD unrecognised and other characteristics (e.g. intellectual disability, hearing impairment, epilepsy, emotional arousal or the effects of medication) neglected or treated inappropriately (NICE, 2008; Scottish Intercollegiate Guidelines Network, 2009).

Emotional disorders

Emotional disorders are often overlooked, particularly if they present as a behavioural disorder or are the responsibility of services that do not have sufficient resources to meet such needs.

Behavioural disorders

Behaviour disorder is a frequent reason for referral that can present as aggression, either towards the self or others. Commonly a reflection of limited communication and/or ASD, it can also be associated with physical disorder, including everyday ailments (e.g. earache, indigestion and hay fever), epilepsy or the adverse effects of medication. Its management can be constrained by concerns about legitimacy of particular forms of treatment, physical intervention or seclusion (Lyon & Pimor, 2004).

Disorders of sleep, eating and elimination

Disorders of sleep, eating and elimination are particularly common among young people with intellectual disabilities and can take unusual forms (e.g. pica). They can be sufficiently severe as to precipitate family breakdown.

Child abuse

Young people with intellectual disabilities are vulnerable individuals, prone to child abuse, which can take the form of neglect, emotional abuse and sexual abuse. Both the abuse and its long-term effects often pass unrecognised (Allington-Smith *et al*, 2002; Sequeira & Hollins, 2003; Sequeira *et al*, 2003).

Offending behaviour

Offending behaviour can occur in this population, particularly in adolescence, and has become the focus of its own, specialist services.

Serious mental illnesses

Serious mental illnesses (including schizophrenia and affective disorders) can be difficult to assess. The combination of a complex presentation and limited communication skills reduces the usefulness of standard diagnostic criteria, which depend on patients being able to describe specific experiences and feelings.

Problems affecting families

Disability affects family functioning. Parents of young people with disabilities have increased rates of psychiatric disturbance (Emerson *et al*, 2010). As well as having to come to terms with their child's diagnosis and disturbed behaviour, they frequently have to cope with a lack of sleep. Insecure attachment patterns can persist from infancy and adversely affect the development of personality, making complex relationship and adjustment problems frequent. This affects siblings and makes the young person's disturbance worse (Emerson *et al*, 2010). Family problems are compounded when

services fail to take into account differences in cultural attitudes to disability.

Young people and their families can find themselves excluded from mainstream services for a variety of reasons (Box 3).

Box 3 Barriers to mental health services

- Exclusion from CAMHS and intellectual disability services
- Exclusion from other tier 2 services (e.g. school counselling services)
- Difficulties accessing traditional, clinic-based CAMHS as a result of physical disability and/or severe challenging behaviour
- A lack of awareness across health, education and social care of neurodevelopmental disorders and their effects and associated health problems
- 'Diagnostic overshadowing', in which symptoms are misattributed to the intellectual disability (leaving them untreated)
- A conflict between agencies – in criteria, terminology or provision (whether at a professional or agency level) – that results in families being left stranded between services

What should a service provide?

As well as providing the full range of conventional psychiatric intervention strategies, the service must take into account the particular needs arising from disability, and place an emphasis on prevention as well as treatment (Foundation for People with Learning Disabilities, 2002). However, there is very limited research to meet the demand for evidence-based treatments for these disorders in this population. Presentation and response are often atypical in young people with intellectual disabilities, and instruments developed for young people of normal ability are often unsuitable. More appropriate outcome measures are being piloted by the CAMHS Outcome Research Consortium.

Demands that are specific to services for young people with intellectual disabilities are described for the following areas:

- diagnosis and assessment
- counselling services
- family work
- specialised individual therapies
- pharmacological treatment
- liaison and joint working with other agencies
- emergency response
- advice to the courts (expert opinion).

Diagnosis and assessment

Diagnosis is only one element of a wider assessment that includes the young person's general level of functioning within their social context, both at home and at school. In addition to psychiatric and psychological assessment, specific assessments of areas such as communication, motor and sensory anomalies require access to the additional expertise of speech and language therapy, physiotherapy and occupational therapy, respectively.

Counselling services

Both the young person and their family will require counselling. The young person will be vulnerable to adjustment problems as they come to recognise their limitations in comparison with their peers and siblings. The family have to deal with the implications of the diagnosis and the outlook, a long-term issue that will recur, particularly at times of transition (Bicknell, 1983). Genetic diagnoses give rise to emotional issues in families that can go beyond the competence of genetic counselling services.

Family work

Family work involves helping families understand their child's behaviour, facilitating the development of parenting skills, enhancing family coping mechanisms and promoting appropriate play, occupation and communication. This work will be performed by different members of the clinical team, and will include liaison as well as direct clinical work. Therefore, in addition to good teamwork, it requires strong multi-agency relationships to ensure that the clinical input is coordinated effectively with other ongoing work, notably that done by social and educational services but not forgetting independent organisations.

Specialised individual therapies

Certain forms of psychological therapy are of established use for young people with intellectual disabilities, including a variety of behavioural and psychodynamic approaches and other focused forms of treatment. Therapeutic approaches available in mainstream CAMHS and in other areas of intellectual disability, such as cognitive-behavioural

therapy, functional analysis and positive behavioural support, should be equally open to this population. Such work can be done by a generic team, shared with, or referred to, a separate outreach team whose members have the necessary expertise, experience and time

However, the evidence base for such work within this population is limited. It is often assumed that the evidence base derived from young people of normal ability is applicable, but this is questionable, particularly when adaptations are necessary (e.g. to cope with communication and conceptual difficulties).

Pharmacological treatment

Drug treatments are of value in many conditions and situations (e.g. psychotic illness, affective disorders, ADHD and the psychiatric sequelae of epilepsy). Overuse of medication is a concern, particularly as adverse and idiosyncratic effects seem more likely, and often pass unrecognised, in this population. Consequently, the prescription and monitoring of psychotropic medication for this patient group requires specialist psychiatric advice and this, in turn, needs the support of peer-group supervision (Bernard & Turk 2009; Turk 2014).

Guidelines take a cautious approach to the use of psychotropic medication, which should only be used as an adjunct to other measures and with an increased level of baseline investigation (NICE, 2015a,b). Despite the promotion of shared-care contracts, their acceptance by general practitioners has been limited, in part reflecting the extent to which prescribing for this population is off-label.

Liaison and joint working with other agencies

Psychiatric work is delivered as part of a multi-disciplinary, multi-agency team. Inter-agency partnership is central to all CAMHS work, not only in commissioning and service development but also at clinical levels. The multi-professional network should give the patient and their family a

virtual 'front door' into a comprehensive CAMHS, rather than leaving them to negotiate a maze of services (Department of Health, 2008a).

The network can be a complex arrangement in which the team has other roles; for example, the provision of support at a primary level. Although there has been an expansion of services specific to young people, many intellectual disability teams provide a lifespan service that includes adults. Regardless of how it is provided, the psychiatric service must be closely coordinated with all the following services.

- Other young people's health services, including generic child psychiatry, paediatrics, and community child health (e.g. community paediatricians, school doctors, school nurses and dentists).
- Intellectual disability services, particularly health and local authority teams for young people with intellectual disabilities. Although occupational therapy and speech and language therapy might be part of one of these teams, they might also be fragmented across a variety of agencies and generic services.
- Educational services, including the school psychological service and school staff.
- Social Services: social workers and care workers, as well as the variety of people who organise special aspects of care, such as out-of-home placement (which might be in the independent sector).
- Employment support agencies (e.g. Connexions).
- Services involved with offenders (e.g. youth offending teams and youth justice teams).
- Voluntary agencies, including (where relevant) interpreters, clerics and community workers as well as the various parental groups.

Liaison is complex, the more so as many of the personnel are part of wider services that are not specific to intellectual disability or young people. It is essential that resources are available to allow consultation with others, with the aim of making the generic services accessible and useful to all religious, cultural, social and ethnic groups.

The boundaries of clinical confidentiality is an issue whenever the patient has limited capacity

for consent and the extent of the team is unclear. A non-healthcare agency, such as a specialist school, can have an intimate knowledge of the young person and their family. That they fall outside the health service is of less significance than the fact that confidentiality limits are determined largely by the expectations and explicit agreement of those involved (Royal College of Psychiatrists, 2010).

The transition to adult services

Transition from child to adult services is a normal development but is particularly stressful for this vulnerable group, who face multiple, concurrent transitions with changes of school, social service support, community team and psychiatrist. It brings the loss of key support figures, such as the community paediatrician, the school nurse and the teacher. Last-minute arrangements and feelings of uncertainty and helplessness all increase stress and can reverse the progress that has been made. Various strategies are being developed to manage the process better, a notable example being the Education Health Care plan (Department of Health, 2015).

Further difficulties arise where the receiving services have a different perception of their remit; for example, adult mental health services might not accept people with a mild intellectual disability or accept the management of neurodevelopmental disorders as within their remit. Transition for young adults in secure care to adult low or medium secure facilities is especially problematic. Local transition pathways that include the support and infrastructure to ensure they work need to be developed (NICE, 2016).

A comprehensive service might draw on child psychiatrists and intellectual disability psychiatrists as well as other mental health professionals; clearly defined care pathways are therefore essential. It is also essential that there is no gap in provision, particularly where services are not coterminous, and that all referring agencies are aware of the

nature of provision and the referral procedures, including those for emergencies. People of differing age and disabilities have very different needs, which are best addressed from a developmental perspective. They should have access to the services best able to meet their needs, rather than being arbitrarily allocated to them based on IQ score or date of birth.

Emergency responses

The nature of this population's clinical problems, their circumstances and the available resources mean that emergencies and their management differ from those seen in mainstream CAMHS. A specialist out-of-hours service for young people with intellectual disabilities is the ideal. However, this is not feasible for much of the UK, so responsibility is likely to fall to the local CAMHS or even more generic services. Here, the difficulties of involving others can be reduced by:

- developing and/or following suitable guidelines, protocols and clear individual care plans that identify likely emergencies and suggestions for their management
- ensuring that the response is a multidisciplinary one, rather than falling to a single individual.

Advice to the courts (expert opinion)

The courts, both civil and criminal, require assistance in understanding and dealing with young people with intellectual disabilities. There is a shortage of expertise in what has become an increasingly specialised area of work that few psychiatrists are willing or equipped to undertake. Given that it will be required to respond to judicial decisions, a service needs to be clear regarding the extent to which it will provide input (Royal College of Psychiatrists, 2008).

Academic work

Continuing professional development

Services for young people with intellectual disabilities require psychiatrists whose competencies bridge both child psychiatry and intellectual disability psychiatry. Most psychiatrists, coming from only one of these backgrounds, only acquire the necessary additional skills once in post. From the start, these specialist posts must ensure that their appointee acquires the additional skills, knowledge and experience essential to clinical effectiveness. All involved in this unusual specialist area require access to appropriate education programmes if they are not to become isolated and idiosyncratic.

Teaching

Because joint working with other disciplines and agencies is an integral element of their work, specialist services for young people with intellectual disabilities can provide support, training and clinical

experience to others, if given the resources. They can be particularly valuable in enhancing mutual understanding (necessary for easy cross-referral), as well as contributing to the direction of future research.

The effects of brain dysfunction, environmental factors and their interaction is at its most obvious in this area of psychiatry, making it an ideal teaching ground for both medical students and postgraduate trainees (Hollins & Bradley, 1987).

Research and audit

The causes, nature and outcomes of psychiatric problems in young people with intellectual disabilities are often poorly understood. The lack of evidence for the effectiveness of various treatments is mirrored in the lack of guidance about their use. This is something that can only be remedied by research and audit, which require an academic infrastructure to sustain them (which might come from a regional centre).

Service development and planning

Although the growth of comprehensive CAMHS has led to an increase in services for young people with intellectual disabilities, most are still at an early stage of development, inadequately resourced or even stuck in a planning process. To many, this reveals a service gap, as the assistance previously provided by lifespan intellectual disability services is reduced. It is difficult to quantify across the country, but the number of out-of-area placements (whether educational or health) gives some indication of the success of the local service.

The reconfiguration and integration of health, social and educational services encourages evolution. Success requires that those delivering the service are closely involved in its development, but this can only occur if they have sufficient time and resources.

What does a good service look like?

The constituents of a service for young people with intellectual disabilities will be determined by local needs and resources. However, there are elements that are common to all.

Service structure

Although this service, a hybrid of two psychiatric specialties, is an integral part of a comprehensive CAMHS, it also needs to be linked to other parts that provide specialist assistance to young people with intellectual disabilities. Special schools often act as this link, as well as arrangements such as split posts, which bring together two agencies or specialties. Shared issues mean that intellectual disability services are frequently a major source of support and training for staff, and local circumstances will determine how this is managed. In addition, there has to be an overlap with adult mental health services to ensure that an eventual transition to adult services is comfortable. These relationships should be underpinned by clear protocols that ensure that a patient is not forgotten in, or delayed by, the mismatched set of boundaries that are set for age, ability and location.

Location

Both local and larger regional services can contribute services for this population, following a model in which the lower tiers are provided locally (as an integral part of the district's overall community services) and supra-district tier 4 services are accessible as needed (Williams & Richardson, 1995).

Effective teams require a common base, particularly as most of the work takes place in settings outside the clinic, such as the young person's home or school. Often this work will be performed in conjunction with CAMHS as part of a comprehensive service. However, the service's base must

be accessible to patients and their families, and the environment and staffing of an out-patient facility should be calm, robust and able to cope with challenging behaviour with minimal risk.

Access to in-patient beds is essential. These beds should be distributed across the UK, so that patients can maintain contact with their families, communities and local services.

Multidisciplinary team

The service is characterised by its multidisciplinary team. Although its members' roles are partly determined by their core skills, much will depend on their other skills, experience and availability. The team's efficacy and flexibility will depend on having close relationships and role diffusion.

Team membership

Psychiatrists

Whether drawn from child or intellectual disability psychiatry, the team's psychiatrists should have competencies in working with young people with intellectual disabilities as well as familiarity with the nature and presentation of the disorders associated with this group. Given that the demand for such psychiatrists exceeds supply, it is likely that they will need further training, experience, peer support and supervision after appointment. The post should accommodate this, including allocating time for it. In addition, psychiatrists should be encouraged to link with wider groups (such as the Child and Adolescent Intellectual Disability Psychiatry Network; caidpnetwork@gmail.com).

Clinical psychologists

With particular expertise in behavioural analysis and interventions, as well as psychometrics, clinical

psychologists have essential skills for working with this group and can provide guidance and support to other professionals. They will often take the lead in individual therapy with young people and in some family work. Other key roles that clinical psychologists can perform are in teaching, supervision of others and research.

Community nurses

Coming from various backgrounds, including mental health, intellectual disability and child health, community nurses form the backbone of most services. Essential elements of their success include a willingness to work with young people and their families, a flexible approach and an appreciation of the importance of factors such as education, social support and housing. They are often the ones available to respond to crises, to support the young person and their family in accessing acute health services and, by liaison with adult intellectual disability services, ensure a smooth transition. Nurses are often involved in parent education groups, school liaison, consultation, training and early intervention.

Speech and language therapists

Communication is a fundamental issue for most young people with intellectual disabilities, and therapeutic work is dependent on a good understanding of their difficulties. The speech and language therapist can not only identify subtle difficulties and establish the best strategies to manage these, but also provide the young person, family and care workers with the resources and training they need. In addition, liaison with school-based colleagues makes for a further link between the team and the young person's community.

Occupational therapists

The occupational therapist's expertise extends across areas such as functional adaptation, the development of self-care skills, accessing meaningful activities in the community, fine and gross motor skills, and sensory evaluation and interventions.

Team size

The community team should have 5–6 whole-time equivalent (WTE) members for a general population of 100 000; this is the recommendation of the Children's Taskforce involved in the development of the National Service Framework (Department of Health, 2004). The breakdown will depend on local preference, but the core team must include the disciplines listed above, while also drawing on the wider CAMHS team for other specialist therapists (e.g. family, music, art or play therapists).

A typical team, working with all young people with a significant intellectual disability (approximating to an IQ < 70) across a general population of 250 000, might comprise:

- 1 WTE child and adolescent intellectual disability psychiatrist
- 2 WTE clinical psychologists
- 5 WTE community intellectual disability nurses
- 2 WTE support workers
- 1 WTE speech and language therapist
- 1 WTE occupational therapist (with additional training in sensory therapies)
- 1 WTE secretary.

Adequate secretarial support is essential for the team's effectiveness, as are other managerial and back-up staff. Where there is a high density of a particular ethnic group, the team might include bilingual workers or link workers, or have creative links with local voluntary agencies.

For psychiatry

Community service

A community service for young people with severe intellectual disabilities requires a minimum of two sessions of consultant clinical time per 100 000 total population. If the service also covers mild intellectual disabilities, this will require a further three clinical sessions. These sessions do not include time for administration and continuing professional development.

These session numbers reflect the demands that come with the high prevalence of disorder that accompanies organic pathology, the community orientation of the work and the substantial amount of time spent in multidisciplinary and multi-agency liaison. The level of demand also depends on other local factors, such as social demographics, geography, the size and expertise of the community team and the extent to which general practices are prepared to take on responsibility for continuing care and prescribing.

In-patient units

An in-patient unit requires approximately one WTE consultant for every 12 beds, taking into account the significant need for work in the community before admission and (more extensively) at discharge, often at some geographical distance. Although a secure unit might have a lower turnover than an open unit, this is offset by the greater demands of the legal framework. The in-patient unit might be the base of an outreach team.

Material resources

Much of a service's work is done in the community, which requires that it has the means to maintain service contact, in addition to the same resources as the rest of CAMHS. These include, for example, remote-access computers, electronic diaries, mobile telephones with good coverage, and arrangements for digital dictation and transcription.

Community and outreach services

Repeated appointments in standard working hours at a clinic are often beyond the means of a working family, who are often already struggling to cope with the many commitments that come with caring for a young person with a disability. Community services imply substantial flexibility to allow out-patient and community activities (carried out in conjunction with the other staff and agencies) to be accessible. This means they happen at an appropriate time and place, whether in the school or the home, and staff need both the means and time to travel.

Young people who cannot be cared for safely or adequately at home might find themselves in a variety of out-of-home placements. A substantial amount of the community psychiatrist's work will be in collaboration with foster homes, children's homes and residential schools (Berney, 2009) as well as with generic child and adolescent in-patient services. The complexity and size of their workload depends on their familiarity with and expertise in these disabilities.

A specialist outreach team can provide intensive assessment and management of mental health problems and challenging behaviours in the home, avoiding the need for in-patient admission in the majority of cases. With the help of this team, local services such as schools and short-break and voluntary services can develop the skills to be able to work safely and effectively. However, although this approach can give the family the confidence to cope, it will not be appropriate for every case, as circumstances such as the needs of other siblings or the mental health of a parent might require an out-of-home placement.

Whatever form they take, services should take into account the different patterns of family life and reflect the cultural, ethnic and religious diversity of the population they serve.

In-patient facilities

There will remain some young people whose behaviour and circumstances are such that they cannot be safely or adequately treated other than in specialist in-patient facilities (O'Herlihy *et al*, 2001). Such facilities allow the assessment, diagnosis and treatment (both short and medium term) of complex, difficult cases in a setting that provides developmentally appropriate care. Young people with violent behaviour require higher staffing ratios than those in most other psychiatric units, as well as a robust and well-structured physical environment that meets their particular needs. The priority must be the safeguarding of this vulnerable group and therefore the unit must not be out of the way – it should be co-located with other in-patient units. This is important for effective staff support and supervision, to ensure that the staff do not become isolated and idiosyncratic, and to provide the reassurance of additional staff in an emergency.

Commissioners should keep several important things in mind:

- There must be provision for the full range of young people and their needs. They should provide for both mild and more severe degrees of disability, for young people, for emergency as well as planned admissions, for formal detention under the Mental Health Act 1983 and for offenders.
- The beds they commission must meet their needs, with clear operating policies. These should include well-defined protocols and criteria for admission, with provision for a thorough, pre-admission, community assessment. In-patient resources complement (rather than replace) the community approach for young people, and close liaison between the in-patient service and the local team is necessary to minimise the disruption and duration of admission. This need for out-patient and outreach work must be recognised and budgeted for in any admission.
- Young people need to maintain contact with their families and community services. In-patient units should have good links with community services and have a clear, integrated pathway of care that includes a plan for discharge. The greater the geographical distance from the patient's home, the harder it is to achieve either of these things, so each region should have access to appropriate local beds.

Beds

The number of beds that need to be accessible by a service will depend on the other resources available in the community, which includes not just the community team but also local education services, Social Services and other health facilities (e.g. short-break services for young people with challenging behaviour) (Smith & Berney 2006). A local population of 1 million requires about:

- 3–4 beds for young people with severe intellectual disabilities
- 2–3 beds for young people with mild intellectual disabilities

- 1 bed for young people who require low-secure provision (this is for those who require security because of the intensity of their disturbance or because of the risk they present to others). Although it might be at a supra-regional level, it is distinct from the national need for medium-secure beds.

Evaluation

Specialised services risk isolation and idiosyncrasy. The very different nature of their clinical work can separate health professionals from their peers and cause teams to develop an introverted culture that doesn't keep up with changing practice. Such personal and professional isolation can encourage the development of unusual, sometimes dangerous, practices and difficult relationships with others.

It is essential that a service builds in mechanisms to support self-scrutiny, comparison with others, and professional and social networking. It should aim to encourage professional development and to develop or discourage innovative clinical practice depending on its merits. Two systems have been developed, both using self-review and peer review to develop and uphold standards.

- For community work, there is the Quality Improvement Network for Multi-Agency CAMHS. Developed for mainstream CAMHS, it has a specific subsection for intellectual disability services.
- For in-patient services, there is the Quality Network for Inpatient CAMHS.

A service must be acceptable to young people and their families and be committed to seeking and acting on user and carer feedback (Department of Health 2007). Less-formal feedback can be obtained through clinical work, from parent support groups and from other professionals.

All these strategies complement the work of the statutory bodies that have been established to monitor healthcare activity, such as the Care Quality Commission in England, Healthcare Improvement Scotland, the Healthcare Inspectorate Wales, and the Regulation and Quality Improvement Authority in Northern Ireland.

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