

## 7

## Young People with Learning Disabilities

David Dossetor

### Introduction

Learning disability is the accepted term in the UK for intellectual disability (ID) and is defined by the *International Classification of Mental and Behavioural Disorders*, 10th revision (ICD-10) as significant limitations in intellectual functioning and adaptive behaviour for everyday skills that onset before 18 years of age.

Around 2–3% of the population have ID (IQ < 70), of whom 1% have moderate, severe or profound ID. Generally, the rates are higher in boys than in girls and it is more likely to be identified at school age. Psychiatric disorder is found in 30–50% of children with ID. This constitutes 14% of all childhood psychiatric disorders, rising to 25% if autism spectrum disorders (ASDs) are included. Most young people with mild ID are seen in mainstream psychiatry services. This chapter focuses on the mental health challenges of those with moderate, severe and profound ID [1].

While caring for a child with ID is usually a greater challenge than caring for a neurotypical child [1], the presence of emotional or behavioural problems has a greater effect on the family than does the ID. Families who break down as a result of the challenge of caring for a child with ID generally fail to resolve four main adaptive tasks [2]:

- the need to adjust to a child with developmental differences;
- managing the burden of increased care persisting into adolescence and adulthood;
- understanding the child's emotional and behavioural disturbance and seeking appropriate help;
- dealing with the cumulative effects of the preceding factors on family wellbeing and relationships.

Comprehensive child and family services are needed to resolve all of these challenges [3] and can do much to mitigate the additional cost to families and communities of the associated emotional and behavioural disturbance.

### The Changing Context

#### Human Rights, Equity of Access to Services and Social Inclusion

There is increasing awareness of the human rights of people with an ID to have equity of access to mainstream and specialist mental health service provision, and to be socially

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included in their communities. The long-term use of inappropriate inpatient care for those with mental health difficulties and/or challenging behaviours must be replaced with appropriate mental health care in the community [4,5].

The needs of young people with ID for specialist mental health provision are high due to the frequency and severity of their emotional and behavioural disturbance combined with their intellectual impairment. Mental health clinicians working with this population face a range of problems of greater complexity and differing in type from those generally presenting in child and adolescent mental health services, e.g. extreme repetitive self-injurious behaviour, extraordinary levels of anxiety and hyperactivity and insightless rage and violence sometimes driven by stereotypic preoccupation. Mainstream therapeutic interventions for such problems are less likely to be effective [6]. There is a paucity of research into these severe disturbances which, particularly in the context of behavioural phenotypes, could generate new understanding on the biodevelopmental–psycho-social–cultural mechanisms underlying these problems, and on alternative approaches to intervention.

This emotional and behavioural profile indicates a need for considerably greater access to services than that required by a neurotypical population. In fact, a lack of professional training, failure to understand the needs of those with disabilities, or just plain fear of not being able to provide appropriate help means that those with disabilities get *less* rather than equal access to appropriate expertise. Yet, the evidence shows that the provision of better mental health services enables families not just to adapt, but also to find advantages to having a family member with an ID [1]. Evidence suggests that with better services over time, more families with a child with ID experience an improved quality of life.

The quality of services for this population also affects both mortality rates and parameters of social inclusion, such as employment and sustained family care [1,4,5]. Yet the evidence shows that while the survival rates of people with an ID have increased, they still have a life expectancy of 15–20 years less than the mainstream population. In terms of social equity, while communities have become more affluent, the gap between the social inclusion and achievement of people with an ID and the mainstream population is seen to be widening [7]. Thus the mental health of this minority group has to be considered in a health, social and political context.

## Assessment and Intervention

### Quality of Life, Developmental and Mental Health Factors

The quality of life (QoL) of young people with long-term physical and mental health difficulties is now recognized as an important outcome criterion [8]. While satisfactory standardized QoL measures have yet to be developed for this population [8], understanding what contributes to the QoL of young people with ID and their families is a prerequisite for working in this area (see Box 7.1) [1,9,10]. The aim of appropriate intervention is to enable any child with an ID to have a ‘good enough’ quality of life. Clinical assessment of this outcome will need to take into account both the family and young person’s perspective, wherever possible.

Assessment of children and adolescents with disabilities requires a developmental perspective that considers the sequential acquisition of skills in the physical, intellectual, social and emotional domains of development (Box 7.2). Such a multidimensional

**Box 7.1 Quality of life assessments**

Quality of life assessments ask young people and their families, 'How satisfied are you with your life as a whole?' Assessment focuses on the primary domains underlying the concepts of inclusion and participation, i.e.:

- An adequate standard of living
- Feeling safe
- Reasonable health
- Connected to valued relationships
- Linked to a community
- Contributing a worthwhile role
- A sense of purpose, productivity and hope for the future

**Box 7.2 The main domains of development**

- **Motor and sensory development and integration** – e.g. coordination, sitting still, a capacity for calmness and concentration
- **Independence skills** such as dressing, eating, hygiene and toileting skills. These provide a reasonable indication of general intelligence in the early years prior to school entry
- **Communication and language** – receptive and expressive verbal skills; non-verbal (including object and picture communication) skills
- **Emotional, social and play skills** – these are among the most complex developmental skills (fuller discussion of this area of development can be found in Chapter 10)
- **Quality of imagination** – stereotypic rigidity or imaginary preoccupation at the expense of social interaction versus the ability to build reciprocal ideas
- **Educational and adolescent community integration skills** – keeping safe, accessing services, managing money (schools are the primary setting in which these skills are developed and tested)

developmental approach provides a normative framework against which to consider disturbed behaviour, particularly in the context of extreme or challenging behaviours [10].

It is also important to assess the developmental mental competencies that are essential for initiating and sustaining satisfactory social interactions with others (see Box 7.3).

The assessment of psychiatric disorders in young people with ID is complicated by their behavioural presentation and their difficulties in reporting on, and evaluating, their mental states (see Box 7.4). It can also be difficult to differentiate between features of ID phenotypes and those of some psychiatric conditions, e.g. the difficulties in social anxiety that form part of the autism spectrum phenotype [11]. Diagnostic difficulties are exacerbated by the overlap between 'challenging behaviour' and 'psychiatric disorder' [12]. Thus, mental health assessments need to be undertaken by professionals with training in ID. Research in mild ID shows there is diagnostic reliability but differences in validity [13]. For example, while attention deficit hyperactivity disorder (ADHD) has diagnostic reliability, it differs from ADHD in a mainstream population. It has a

**Box 7.3 Development of the mind and mental competencies**

- Identification of self and non-self
- Motor regulation and coordination, sensory modulation
- Selective attention and attention switching
- Communication skills and theory of mind
- Emotion recognition, regulation and empathy
- Self-concept and self-esteem
- Reciprocal social interaction and relationship-building
- Reality-testing, perspective-taking and other executive function skills

These are best evidenced by the capacity to make new good quality peer attachments. The most important skills are:

- Development of attention and concentration, a prerequisite for learning
- Development of theory of mind to comprehend relationships

**Box 7.4 Difficulties in mental state assessment**

- Subjective mental phenomena cannot be reliably elicited < 7 years or IQ < 45 – cannot rely on for diagnosis of depression or psychosis.
- Difficulty articulating abstract or global concepts, e.g. describing mood
- Answers given to please the interviewer.
- Intellectual distortion: not understanding the implication of 'do you hear voices?'
- Diagnostic overshadowing – attributing psychiatric symptoms to the underlying intellectual disability.
- Baseline exaggeration or intensification, e.g. increase in self-injurious behaviour at a time of stress – an extreme response may be due to an anniversary of a loss or a change of a teacher/staff/classroom/accommodation/family visits that carers may not identify.
- Stress on coping with a lack of cognitive reserve leads to disintegration, disorganization or psychotic behaviour – distinguishing behaviour disorder from adjustment disorders and psychosis.
- Delusions and hallucinations are frequently difficult to distinguish from a range of normal developmental phenomena, e.g. concrete thinking, pretend friends, stereotypic thinking and imagination, especially in autism spectrum disorder.
- Irritability and explosive anger may be common problem of challenging behaviour but is associated with depression and mania.

prevalence of 30%, is as common in girls, and has stronger associations with family functioning, depression and social impairment. Standard treatment with stimulants is not as effective and is associated with more side-effects.

Problems of ASD, ADHD, anxiety disorders including, post-traumatic stress disorder and obsessive compulsive disorder, repetitive self-injury and disruptive behaviour disorder are more frequent in young people with ID than in the general population [10,11,14]. Substance abuse and conduct disorder are less frequent. Combinations of disorders are

the norm [14]. There is almost no research on the reliability and validity of psychiatric diagnosis in young people with severe ID. The separation of disability services and behaviour support skills from mental health services leads to a lack of collaboration between disciplines on helping young people with ID. The contribution of developmental psychiatry has been held back by the lack of diagnostic research [14]. However, the specialist in ID psychiatry has to consider the explanatory value of different approaches, e.g. that of psychiatric diagnosis versus that of challenging behaviour with its inherent behavioural approach, and look at the implications for intervention and improvement. However, the best questionnaires on emotional and behavioural disturbance, such as the Developmental Behaviour Checklist, provide a useful checklist of symptoms but do not convert to psychiatric diagnosis [15].

### Child and Family Factors

Interactions between a range of child and family factors influence child outcomes (Box 7.5). Child genetic differences elicit differences in parenting responses, and some children are more genetically sensitive to certain environmental factors, such as abuse/neglect [1]. Longitudinal studies show that biological qualities have a greater part to play in the persistence of child emotional and behavioural disturbance, with family factors making a smaller contribution (8%) to variances in outcome [15]. In general, therefore, young people with ID are more likely to contribute to problems of family functioning than the other way around, particularly those with challenging disorders such as ASD. Nonetheless, the ability of families to adapt to the demands of parenting a child with ID is important, and family relationships can be significant contributors to complex mental health presentations in young people. For example, parental mental health difficulties can impact upon parenting skills. The prevalence of chronic burn-out, stress, anxiety and depression in parents of young people with ID is high (approximately 25% in clinic studies) [16]. Accordingly, careful family assessment, on a number of family relationship dimensions is needed. These include, for example, problem-solving, communication, roles, affective responses, affective involvement and behaviour control [17].

### Educational and Service Influences

In young people with mild to borderline ID, community and family factors are primary causal influences on child outcome [7], with school (and preschool) also exerting a major influence. Partnership between parents and teachers is important in meeting special developmental and well-being needs. In children with ID, engagement with, and

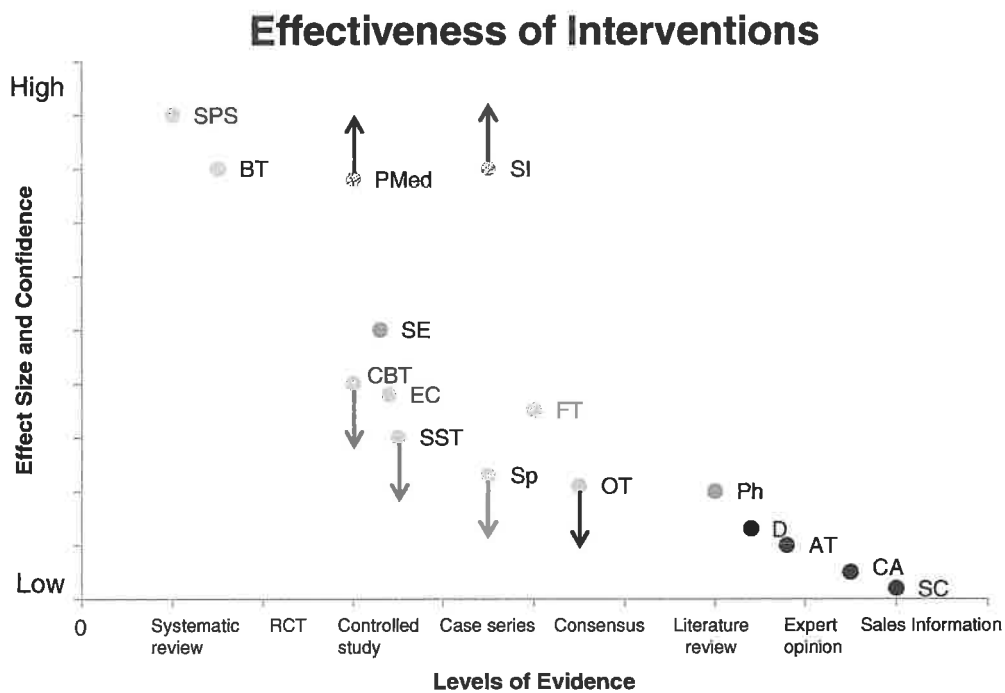
#### Box 7.5 Contributors to the ease or difficulty of child-rearing

- Health problems, especially neurological, including sensory deficits
- Intellectual ability, including learning problems and neuropsychiatric deficits
- Temperament, with genetic and environmental contributors
- Environmental milieu – emotional warmth, stimulation, predictability and consistency
- Earlier experiences, positive or traumatic
- Attachment style and strength

the quality of management of other child services make important contributions. These include respite care services, and the other paediatric and health professionals who work with this population. These partners' professionalism, communication, and collaboration are often key determinants of outcome. Complex cases necessarily involve many carers and professionals.

### Types of Intervention

Interventions for young people with ID and emotional and behavioural problems range from training in parenting skills to the use of fringe interventions such as chelating agents and oxygen therapy (see Figure 7.1). As can be seen, there is good evidence that



**Figure 7.1** Effectiveness of modalities of intervention for emotional and behaviour disturbance. The x-axis is the confidence or effect size of a type of intervention, and the colour designates speed of intervention effect, which influences intervention in the context of acute presentation and family crisis. Green dots, rapid effect – days to weeks; yellow dots, intermediate effect – weeks to months; blue dots, slow long-term effects – months to years. The arrow designates the change in importance in more severe disturbance. The graph also highlights the place of fringe and alternative approaches that naive, desperate families are often drawn to in the 'free market of economy of health'. Abbreviations are as follows: SPS, specialized parenting skills [21]; BT, behaviour therapy, including carer/staff training [19]; PM, psychotropic medication; SI, safety intervention, including self-protective skills, room modification; CBT, cognitive behaviour therapy; SE, special education: skills to match needs; EC, emotion-based social skills training/emotional coaching; Sp, speech therapy and augmentative and alternative communication; SST, social skills training; FT, family and systems therapy; OT, occupational therapy/sensory integration; Ph, physiotherapy; D\*, diet; AT\*, alternative therapy; CA\*, chelating agents, oxygen therapy; SC\*, stem cell therapy; \*, not approved by author.

parent training, behavioural intervention (including applied behavioural analysis) and psychotropic medication are effective, although there is less information on the persistence over time of intervention effects [18,19]. Evidence for effectiveness is based upon a combination of cohort studies and clinical consensus, as funding for randomized control trials has been limited.

## The Development of Services

There is a lack of international consensus on models of service provision, and limited evidence on service outcomes [4,20]. The components of various service models are outlined in Box 7.6. As an illustration, our own tertiary ID team consults to young people and their families, to mental health, disability and special educational services, and to non-government agencies. A wider range of disciplines and skills is required than is generally provided in mainstream child mental health services (see Box 7.7).

While consumers are clear that the failure to meet their disability mental health needs will continue without specialized mental health expertise [23], the support for professional specialization and funding of community-based services has been slow since the deinstitutionalization of the 1980s, and varies between countries. For example, in the UK, the 2004 National Service Framework [5] recommends a community-based ID service that includes input from psychiatrists and psychologists alongside other health professionals, such as speech therapists and occupational therapists. In contrast, across

### Box 7.6 Proposed service models

- Assessment, including observation, clinical, behavioural and environmental assessment, and diagnosis
- Specialized individual therapies
- Pharmacological therapy
- Parent skill building, including stress management, problem-solving, coping strategies and building social support [1,21]
- Family and systems assessment and therapy
- An interdisciplinary team approach
- Individualized and structured group approaches
- Acute and 24-hour emergency services
- Consultation in-reach and community outreach programmes
- Short-term intensive in-patient/residential programmes
- Partnerships within/across clinical teams and community-based services, including education, respite, welfare, non-government disability organizations and employment services
- Wraparound approaches with relevant community-based services
- Highly specialized services for gaps in service provision such as forensic and youth offending
- Capacity-building of specialist skills across a range of disciplines
- Transfer of knowledge and relationship-building between developing specialist programmes and generic services

**Box 7.7 Range of skills within a tertiary young person's learning disabilities partnership clinic**

- Paediatrician and child psychiatrist for assessment of health, mental health, multidimensional formulation and medication
- Multidisciplinary allied health skills, including:
  - clinical psychology, occupational therapy, speech therapy, special education, pharmacy, case management
  - skill-building approaches: support specialist skills of treating teams [10]
  - specialized therapies, e.g. emotional/social learning, modified and trauma-focused cognitive behavioural therapy, play therapy.
- Family and system skills and cultural expertise
  - including specialized parent training, e.g. Stepping Stones Parent Training [21], parent-child interaction therapy [22]
  - the system issues (also separate special systems evaluation service)
  - the need to match environment to developmental/psychiatric need.
- Legal assessment of child protection, abuse and neglect
  - interface with welfare and intensive support services, e.g. for young people in out-of-home care
  - legal: human rights/child protection, e.g. when service systems are failing.
- High level of interagency collaboration and service agreement
  - to influence each other's service systems for the needs of the child and family
  - match service provision with clinical need versus business funding formulas.

Australia there is a dawning of recognition of the need for specialized ID services to be embedded in mental health service frameworks. Service provision is at different stages of development in individual states (see, e.g., NSW Ministry of Health [24]). Service requirements include a focus on reasonable adjustments, support, inclusion and participation. They also require early intervention for mental health needs facilitated by access to, and partnership between, paediatrics and general and specialist mental health services [25].

## Conclusion

Between 30% and 50% of children with ID will evidence a psychiatric disorder. Their complex presentation results in a high need for mental health services. Assessment and intervention need to address both child and family factors. The separation of disability services from mental health services is unhelpful. Over the last 25 years, the need for sub-specialist multidisciplinary learning disability mental health services has come to be appreciated, but the development of such services and sub-speciality skills has been slow. The rights of young people with learning disability of access to community-based mental health services, alongside the growth of neuroscience and psychiatric intervention research, make this an exciting and growing area of multidisciplinary multiagency clinical endeavour and collaboration.



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## Internet Resources

Chi-Mat: <http://www.chimat.org.uk/ldcamhs> – *some key resources on a range of topics relating to learning disabilities and child and adolescent mental health services*

Fletcher R, Loschen E, Stavrakaki C, First M (eds) (2007) *DM-ID: A Textbook of Diagnosis of Mental Disorders in Persons with Intellectual Disability*. National Association for the Dually Diagnosed (NADD), United States. [www.dmid.org/](http://www.dmid.org/)

*Journal of Mental Health for Children and Adolescents with Intellectual and Developmental Disabilities: www.schoollink.chw.edu.au – an Educational Resource & CHW School-link Newsletter; a free electronic interdisciplinary journal with review articles and reports on innovative treatment approaches*

Learning Disabilities: <http://www.rcpsych.ac.uk/healthadvice/problemsdisorders/learningdisabilities.aspx> – *the Royal College of Psychiatrists' page of readable and well-researched information for the public*

The Royal College of Psychiatrists Psychiatry of Learning Disability Reading List: <http://www.rcpsych.ac.uk/pdf/23%2009%202011%20LD%20PSYCH%20READING%20LIST.pdf>

Young Minds: [http://www.youngminds.org.uk/training\\_services/training\\_and\\_consultancy/resources/schools/1775\\_children\\_young\\_people\\_with\\_learning\\_disabilities](http://www.youngminds.org.uk/training_services/training_and_consultancy/resources/schools/1775_children_young_people_with_learning_disabilities) – *an information pack including a chapter on mental health difficulties in children with learning disabilities*



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