Overview of learning disability in children

Tom Berney

Abstract

The child/adolescent is set in a complex framework of relationships and services for the psychiatrist to work with. The medical disorders that accompany learning disability, as well as the disability itself, complicate the psychopathology so that the risk of misdiagnosis increases with the degree of disability. To be effective the psychiatrist has to work well with other disciplines and agencies, being open to their perspectives, as well as being familiar with the subculture and dynamics of disability. The work requires expertise in a variety of neurodevelopmental conditions, particularly autism and epilepsy, as well as in psychopharmacology.

Keywords adolescent; child; disability; disturbance; learning disability; mental retardation

The population

Disability can take many forms, selectively affecting various functions such as cognition, language or emotional development; its nature and degree the result of infinite permutation. It takes the child and family into its own network of relationships and care, amounting to a subculture, which the psychiatrist has to understand both to make sense of their problems as well as to enlist its help in their management. The focus is not simply about working with individuals and their families but is also about the development and use of services that will prevent as well as treat the problems that go with disability.[1]

This complex system can involve a large variety of disciplines and agencies, targeting populations that, although overlapping, are not identical. For example, while legislation pivots around the age of 18 as the time of transition to adulthood, various services stop short of this. Similarly, although learning disability is defined by an intellectual ability more than two standard deviations below the norm (i.e. an IQ of less than 70), services vary in their chosen remit with some excluding mild learning disability. All this is blurred by the needs of people, such as those with autism spectrum disorder (ASD), whose functional ability may fall far short of their intellectual potential.[2]

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History

This group was originally the remit of learning disability psychiatry at a time when it had a much wider role which included, for example, physical and genetic investigation. About 15 years ago it was proposed that all children, irrespective of ability, should be dealt with by child psychiatry; a move consistent with other policies such as Children First and Inclusion, although, lacking resources, this aspiration has remained unfulfilled. However, many learning disability psychiatrists restricted themselves to adult practice and it was left to community paediatrics to fill the gap. Recently, there has been a resurgence of interest in this group, with the establishment of specialist posts and the development of a professional network that meets regularly and encourages informal contact.

The setting

Children with learning disabilities and their families

The child and his family are at the centre of a complex of services and professionals which has the potential to become so extensive as to lose them in the gaps (learning disabilities and other developmental disorders affect males more frequently than females, therefore 'he' and 'his' are used throughout this contribution). For these children and their families, diagnosis is not just some academic exercise or even a working hypothesis but a passport to a different life, determining the way they see themselves, the solutions they select and the kind of service they get.

Diagnosis comes at different times depending on the basis of the disability. For example, while the child's physical characteristics can lead to Down syndrome being recognized at birth or the genetic history may be a prenatal pointer to Fragile-X, it may need the child's introduction to nursery or even to school to highlight the symptoms of autism. The parents then face a process of adjustment that has parallels with the process of bereavement but with the essential difference that, rather than adjusting to a single event, they find themselves in a drawn-out process. In this they develop a progressively better-defined appreciation of the nature and degree of their child's disability as he moves through his developmental stages, each point a potential crisis for them to deal with. One example is the start of education, when the child has to cope with and be compared against other children. Another is puberty, which brings with it not only the immediate issues around sexual expression but is also a reminder of the child's potential (or not) to have children of his own.[3] The process is spread over years and many families benefit from the support provided by the community learning disability teams. Services need to be flexible, adapting to the wide diversity of ethnic and cultural backgrounds in which families are rooted.

Families also require practical help as they bring up a child whose responses may make their job far from intuitive. For example, a recurrent theme is the family whose feelings (whether of empathy, pity, guilt or protectiveness) have led them to give their child whatever he wants. As he grows up and becomes physically stronger, he becomes a tyrant used to having his wishes granted (if only for the sake of parental peace), uncertain where the limits are and, not only enforcing his demands with disruptive or even violent behaviour but also continually testing to find out at what point rules will be imposed. All this in a child whose emotional needs may be no different from others at the

same developmental stage but who, less able to learn from his peer group and environment, requires more formal teaching and support.

On the other hand, for many families such difficulties are offset by a great sense of achievement in the extent to which their children overcome their disability, enjoy their childhood and grow up with good self-esteem to make their own contribution to society.

The community team for learning disability

Once disability is identified, the process of assessment and early management is the province of the paediatrician and the Child Development Team. The Community Team for Learning Disability then takes over in conjunction with education and social services. Until now, the demands of disability have overridden any considerations of age, encouraging the development of teams working across the whole lifespan. The recent emphasis on children's services (exemplified by the Children's Trust) has encouraged the development of separate teams for young people. Composed primarily of nurses, they should also include other disciplines, notably psychiatry, psychology, occupational therapy, and speech and language therapy. These teams can take a double role:

- to provide the supportive service that helps a child and his family adjust to disability as well as offsetting its accompanying difficulties; they may provide a range of additional help such as teaching communication or feeding skills, or helping the parents to prepare and implement a training programme
- to assess and treat psychiatric disturbance, the psychiatrist being an essential component.

Educational services

From the start, the child, less able to learn for himself, will need formal teaching and pre-school programmes which work intensively with both parents and child (such as Hanen, Portage and Sure Start). While these can produce substantial short-term improvements in the child's attainments and adjustment, more sustained change is likely to need further intervention (e.g. through booster programmes).

The child then moves into the educational system and its assortment of provision. The policy of inclusion encourages his needs to be met within the mainstream school but the addition of psychiatric disturbance often tips the balance towards a special school. These schools, smaller and with more structure and supervision, may be divided by age (into primary and secondary) or by ability; the labelling of the latter causing confusion. In the UK, the adoption of the term 'learning disabilities' by the Department of Health was confusingly similar to the term 'learning difficulties' used in Education – the distinction is an important one as the two systems attach different meanings to 'mild' and 'moderate'[4] (Table 1) – confusion that is compounded by the tendency to use 'disabilities' and 'difficulties' interchangeably. Schools may also specialize in particular forms of disability including autism, epilepsy, cerebral palsy and visual or auditory impairment. The more specialist the school, the more likely it is that children will be disturbed and also that they will not be local.

Depending on the nature and degree of disability, the child may need to be taught a wide variety of skills in areas as diverse as self-help, language and social and sexual relationships. Classes are smaller and the relationship between teacher and pupil is more intimate, which means that the staff can be a rich source of information both about the children and about how they relate to their families. Education is based on relationships and behavioural training so it is a natural step for staff to be closely involved in the development and implementation of treatment programmes, making the school-based psychiatric service particularly effective. However, multi-agency work can threaten confidentiality so this is subject to the family's agreement.[5]

Most children live at home but they may move into an out-of-home placement for an assortment of reasons – for example, parents who, hampered by neighbours, other children, marital disharmony or simple sleep deprivation, may be unable to contain the child, let alone provide the necessary level of consistency and supervision. Fostering and adoption have largely taken the place of the children's home but, while residential schooling was intended for children who lived too far away to attend daily, it can be a more acceptable alternative to local authority care. In some cases accommodation may extend beyond the normal term and a child may return home only for 2 to 4 weeks, usually over the Christmas holiday, or even not at all.

Transitions are a big hurdle for the child and their family, particularly as the time comes to leave school or college, and there may be specific agencies (such as Connexions in England) to help them with these difficulties.

Terms used to categorize disability

IQ*	Health	Education
	'*learning disabilities*'	'*learning difficulties*'
69–50	Mild	Moderate
49–35	Moderate	Severe
34–20	Severe	
‹ 20	Profound	

*Source: World Health Organization, 1992.[4]

Table 1

Psychiatric disturbance

How prevalent is psychiatric disturbance?

Disturbance is more common than in the general population and is more prevalent the greater the degree of disability. The actual figures depend on the definition of disturbance so that rates such as 40% tend to include 'autism' as one of the diagnoses, whether or not there are any additional problems. Even allowing for this, the rates of anxiety, conduct and neuropsychiatric disorder are much higher than in the normal population.[6,7] About 10% of the population with learning disability will have 'challenging behaviour', a statistic that tends to hide the nature and destructive intensity of the disturbance.[8]

What form does it take?

Young people with a learning disability have the full range of psychiatric disorders but this is coloured by the disability so that, where communication is impaired, it is difficult to identify a disorder if the diagnosis relies predominantly on subjective