PATTERN OF REFERRAL TO A CHILD LEARNING DISABILITY SERVICE

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Introduction

Children with learning disability have a wide range of mental health problems, the prevalence of which varies with the level of disability and the presence of additional disabilities (Einfield and Tonge, 1996; Hoare et al., 1998). A number of additional disabilities such as autism, epilepsy, cerebral palsy and sensory impairments are frequently seen in people with learning disabilities (Deb and Prasad, 1994; Deb, 2000; Forgren et al., 1990; Royal College of Psychiatry, 1998). Prevalence of autism and epilepsy increase with the level of disability (Deb and Prasad, 1994; Shepherd and Hosking, 1989). The impact of these additional disabilities on the presentation, course and prognosis of mental health problems are poorly understood. Assessment and management of mental health problems of children with moderate or severe learning disability could therefore be challenging.

Learning Disability Psychiatry provides a specialised service for adults with learning disability in most parts of the country (Bailey and Cooper, 1997), but for children with learning disabilities the provision of service is not so clear (Dossetor and Nicol, 1991). Two models of mental health service delivery available for children with learning disability are either through the Child and Adolescent Mental Health service or through the Learning Disability Psychiatry. Very often, this group of children falls between these two services leaving the community paediatricians to manage their mental health and behaviour problems (Blair et al., 2000; Royal College of Psychiatrists, 1998).
Across England and Wales 71.9% of learning Disability Services also provide a service for children with learning disability (Bailey and Cooper, 1997). While it is beneficial for children with severe and complex disabilities to be seen by a learning disability consultant with training in life span issues, this may cause difficulty in accessing resources available in the mainstream Child and Adolescent Mental Health service such as family therapy, assessment of family interaction in the day resource centres and certain group sessions. The Children’s Act 1989 emphasised the need for the greater integration of services for children (Children Act, 1989). The services for children with learning disability therefore will need to preferably be provided within the Child and Adolescent Mental Health service. While the generic Child and Adolescent Mental Health Teams can meet the mental health needs of children with mild disability, those with severe and complex disabilities would need a specialised service (Royal College of Psychiatrists, 1998).

A third option is a dedicated service for children with learning disabilities with clinicians who have training in Learning Disability, integrated into the Child and Adolescent Mental Health service. We describe here one such service available in Leicestershire, UK, and evaluate the characteristics of the patient population that has been referred to the Child Learning Disability Team over an eight month period.

Description of the service

The Learning Disability Team was established within the Child and Adolescent Mental Health Service in 1993. The team comprises a full time consultant, two full time community psychiatric nurses, a part time psychologist and a secretary. All the clinicians have had substantive training in the area of learning disability. Integration of the team into the Child and Adolescent Mental Health Service has made it possible for the team to have access to services available in the mainstream Child and Adolescent Psychiatry like family therapy service, day resource centre where child’s interactions with the family members and other children are assessed and group sessions such as self esteem group and social skills training. This eventually has helped the team to develop own resources and strategies that are necessary in the assessment and management of children with learning disabilities.

There is a single point referral system and cases are allocated at a fortnightly multidisciplinary team meeting. Children with moderate, severe or profound learning disability are referred to the team while the generic Child Mental Health Team continue to assess and treat children with mild learning disability. Cases are prioritised into three categories. Children in the first category are seen as emergency for assessment of acute mental health problems or where there is a high risk to the child or others. Those in the intermediate category who have severe behaviour problems or features suggestive of a psychiatric disorder are seen within six weeks. Children in the third category, which include all other problems, are seen usually within six months.

Assessment can be undertaken in three settings. The first appointment is usually in a neutral venue such as the outpatient clinic. This may be followed by a school visit or an assessment at home, depending on the initial assessment. The nature of the problem and intervention required
determine whether more than one clinician should undertake joint work with the child and the family. Clinicians from different departments such as the generic Child Mental Health Service or paediatricians work jointly on selected cases. There is also a joint clinic for the paediatric neurologist and the learning disability clinicians to see children who require neurological assessment in conjunction with mental health problems. Regardless of the number of staff involved in the management, one clinician takes on the role of case manager and assumes overall responsibility.

Management is eclectic utilising behavioural, cognitive, supportive and family therapy principles. For families who have difficulty in achieving improvement within the outpatient service, a tertiary service was set up in 1997. The Home Intervention Project was established to assist parents in undertaking behavioural management strategies in their own home and at times they choose. The aim of the project is to provide a high level of hands on support (10-15 hours a week) by trained staff in the initial stages of intervention and then to gradually withdraw over a period of six to nine months.

A clinician from the Learning Disability Team makes the referral to the home intervention service after the initial assessment and the outpatient work. While the home intervention team carries out the specific behavioural intervention, the case manager will continue to hold responsibility for the assessment and management of any specific mental health problems and the coordination with the multidisciplinary team and other services. The impact of the home intervention project is being evaluated at present. This however, is a descriptive study of referrals to the outpatient service over a period of eight months.

**Aims**

1. To describe the demographic details of the children referred to the child learning disability team over a period of eight months.
2. To describe the nature of the disabilities and the referral reasons of the children referred over this period.

**Method**

All the new outpatients (children) over a period of eight months were included in the study and the team member who had the case manager role completed a questionnaire designed for this study after the initial assessment interview. The questionnaire was used for the systematic gathering of information on socio demographic details, source of referral, reason for the referral, level of disability, aetiology of primary disability, presence of epilepsy, psychiatric diagnosis made after the first assessment and the management suggested.

**Results**

Sixty three children were referred during the eight months period. The mean age of the sample was 9.36 years (range = 3 to 18; SD = 4.48) and there were eight young people aged 16 or above. There were 40 boys and 23 girls. Thirteen children did not attend the first appointment. They did not differ significantly from the 50 children who attended the first appointment in terms of presenting problems.

Although more than half of the referrals were from General Practitioners (24%) and Paediatricians (32%), the service also accepted referrals from social workers
(12-19%), educational services (10-16%), and other professionals such as health visitors. Two children with mild learning disability and one with borderline intellectual functioning were also assessed by the learning disability team. Two of these children had a diagnosis of autism. The one with borderline intellectual functioning was transferred to the generic Child and Adolescent Mental Health Team following initial assessment. Forty nine children were thus accepted into the service during the eight month period. Only these children were included in further analysis.

Twenty four (49%) children had moderate learning disability and 23 (47%) had severe or profound disability. Aggressive behaviour was the main reason for referral of 29 children (59%). The other problems that resulted in referral were eating difficulties, toileting difficulties, issues related to compliance at school and home, self-injurious behaviour, repetitive obsessive behaviour and sleep problems. For 14 children a specific request for assessment of autism was made.

Twenty two (45%) children had epilepsy, which included 5 (10%) with multiple seizures. Eighteen (37%) had experienced one or more seizures in the six months before the time of first assessment, and 7 (14%) were having one or more seizures every week. While 62.5% (n = 15) of children with severe or profound disability had epilepsy, the prevalence of epilepsy among children with moderate learning disability was 30% (n = 7). Children with severe or profound disability had a higher prevalence of generalised tonic clinic epilepsy and multiple epilepsies.

Seventeen (35%) children were found to have a diagnosis of an autistic disorder after the assessment. While 9 children in this group had severe learning disability, there were 6 children with moderate learning disability and 2 children with mild learning disability. These children presented with a range of problems. While eight presented with predominantly aggressive behaviour, others had other problems like sleeping difficulties, repetitive behaviour, eating problems or toileting difficulties. A diagnosis of attention deficit hyperactivity disorder (ADHD) was made in 2 children. For the rest, further assessment was felt to be necessary before a firm diagnosis could be made.

In 8 families (16%), there were significant mental health problems among the parents. After the first assessment, a family based intervention was thought to be necessary for 22 children (45%) and individual sessions with the children were considered in 4 cases (3 of these had self harm behaviour). Medication was suggested for one child with attention deficit hyperactivity disorder. Referral to the Home Intervention Service was considered for 3 children. For the rest, further assessment in both school and home setting were necessary before a treatment strategy could be decided.

Discussion

This study gives the broad picture of the patient population attending a child learning disability service for children with moderate, severe or profound learning disability. Children with a mild learning disability continue to be seen by the generic Child Mental Health Teams. Two thirds of the children referred to child learning disability service have multiple disabilities (autism, speech and language difficulties or epilepsy). Although half of the referrals came from General
Practitioners and Paediatricians, the service also accepts referrals from other sources (Educational Psychologists, Social Workers and Specialists Health Visitors). This is in contrast with most of the adult psychiatric learning disability teams that accept referrals only from General Practitioners. In children’s services, it is necessary to accept referrals from a range of professionals who work closely with these children and their families.

Ten percent of the children were aged sixteen or above. Although in generic child mental health services children who have left full time education and are over 16 are transferred to the adult health team, children with moderate or severe learning disability in special education school frequently continue at school until the age of 19. There is a need for an effective transition service to ensure a smooth transfer of these young people with significant mental health problems to the adult learning disability service.

A significant proportion of our patients suffered from epilepsy and their epilepsy was poorly controlled in a third. The assessment of behaviour problems in this group can be particularly difficult, with complex interactions between uncontrolled epilepsy, anti epileptic medications and behaviour. A close working relationship with neurologists is therefore very important (Steffenberg et al., 1996). A joint neurology clinic provides an excellent opportunity for this. One third of the total sample had an autistic disorder. They presented with a wide range of problem behaviours. The mental health assessment in this group can be extremely challenging due to the communication difficulties and atypical presentation of the psychiatric problems. We have not explored the different management strategies used in detail, but a family based intervention was considered in half of the sample after the first assessment. An outgoing study of this cohort will clarify this further.

The sample in our study consisted of children with moderate or severe learning disability who were referred to the Learning Disability Team within the Child and Adolescent Mental Health Service. Severe disability and the presence of multiple additional disabilities make the assessment and management of this group difficult in a generic Child and Adolescent Mental Health Team.

The needs of the children with moderate or severe disability are different from that of children with mild disability. Given the nature of the problem, there is a need to have a specialised child learning disability service. The question of whether such a service should be led by a child psychiatrist or learning disability psychiatrist can be contentious but the crucial point is that the clinicians working in this area should have the necessary training in both child mental health and learning disability psychiatry. Although there are some dual training posts available, this is unlikely to solve the issue. Perhaps a better option would be to make the clinical experience in child learning disability a core component of both learning disability as well as child psychiatry specialist registrar training.

Summary

This paper describes the pattern of referral to the Child Learning Disability service available in Leicestershire, UK, over an eight month period. This service accepts children with moderate, severe or profound level of learning disability for the assessment and management of mental health problems. Sixty three
children were referred and fifty were seen in the eight month period. Although in more than half of the sample, the main reason for the referral was aggressive behaviour, the children presented with a wide variety of problems. Two thirds of the sample had additional disabilities i.e. epilepsy or autistic disorder. Severe disability and presence of multiple additional disabilities make the assessment and management of this group difficult in a generic Child and Adolescent Mental Health Team. This indicates the need for a team with specialised skills in the assessment and management of mental health problems of this group of children.

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References


