REFERRAL PATTERNS OF CHILDREN TO A PSYCHIATRIC LEARNING DISABILITY SERVICE

Thomas Andrew Picton and Chuda Karki

Introduction

The provision of mental health services to learning disabled children has been traditionally variable throughout the National Health Service (NHS), with any one or a combination of different services involved in a particular geographical area. The recent White Paper “Valuing People” seems to recognise this when it comes to diagnosing autistic spectrum disorders, in stating “the diagnosis depends on a full and competent assessment from a child and adolescent, paediatric or learning disability service that specialises in this area” yet at the same time speaks of a future “training programme for paediatricians with a special expertise in mental health disorders” (Department of Health, 2001). This apparent shift away from learning disability services is also reflected in the recent NICE guidelines (National Institute of Clinical Excellence, 2000) for the prescription of methylphenidate which advise “diagnosis of attention-deficit hyperactivity disorder (ADHD) should be made by a child/adolescent psychiatrist or a paediatrician with expertise in ADHD”. This trend was further emphasised in a recent study of a service for children with learning disabilities within a child and adolescent mental health team (Green et al., 2001) which focused on the maxim “children should be provided for as children first and children with a particular disability second”.

How widely applicable this final statement is could be open to debate, but whether it should justify the sidelining of specialist learning disability services from having some part to play in meeting the needs of children with a learning disability is certainly contentious.

The following is a study of the service provided by the learning disability (LD) psychiatrists of Mid Essex to the local children and adolescents since 1986, when

*Dr. Thomas Andrew Picton, MBBS., MRCPsych.
Specialist Registrar in the Psychiatry of Learning Disability, Clinical Base, 14 Tye Common Road, Billericay, Essex, UK
Tel: +44(0)1277 631199 E-mail: tom@thepictons.freeserve.co.uk

Dr. Chuda Karki, BSc., MBBS., FRCPsych.
Consultant Psychiatrist in the Psychiatry of Learning Disability, Medical Department, Bridge Hospital, Hatfield Road, Witham, Essex, UK

* For Correspondence
referrals began to be made. This service is not formally commissioned by the Health Authority, but is available mainly because the consultants involved have a special interest in this area, although some funding has been available for a children’s community nurse for much of this time, released following the closure of a children’s facility in the past.

Ideally referrals were to be made of children aged 5-18, by, or at least with the approval of consultant paediatricians in the Mid Essex area, although exceptions were to be allowed. Generally the children would be attending one of the local special schools, although LD children who had been statemented and attended mainstream schools could also be referred.

Problems such as intractable challenging behaviour, functional psychiatric illness and chronic epilepsy were to be considered, in the context of a background LD, usually mild to moderate. Children would be seen at least once by the consultant psychiatrist, although occasionally by other grades such as specialist registrar, staff grade and senior house officer (SHO).

Children would generally be seen at clinics held in the local special schools, where they could be observed in this environment and access to teachers would be easier. However, hospital and community outpatient clinics were also used if this was not possible, and some children were seen at home when this was felt to be most appropriate.

As well as a diagnosis being given, further assessment, advice and support, investigations, medication, respite care and referral on to other agencies such as community nurses might also be arranged.

Discharge would come when the initial problems had been dealt with, but might be delayed at transitional stages such as that between school and further education or training, or might not come at all for some cases e.g. pervasive developmental disorder, epilepsy, who may be seen on into adulthood.

Method

Data was collected, with the approval of the two consultants involved who cover the Mid Essex region, in a non-identifiable way from the casenotes of the 74 children seen between 1986 and 2000, to include sex, age at referral, age at present, year of referral, area, type of school, source of referral, reasons for referral, number of appointments given and with which grade of psychiatrist, location of appointment, level of LD, diagnoses, management given, length of time seen and discharge status.

Results

Of the 74 patients originally referred to the service, 43 (58%) were male and 31 (42%) female. The mean age at referral was 9.3 (range 4-16).

The mean age of patients still being seen is 14.2 (range 6-20). Of patients seen at some stage who are now over 18 years of age, 4 are still being seen by the consultant, as part of a seamless service and 7 have been discharged.

The number of referrals for each year since the study began steadily rose to a peak of 12 in 1998, with the mean age at referral increasing from around 7 to a peak of 12 over the same period.

Forty seven (64%) of referrals came from the local county town of Chelmsford, the rest from small local towns such as Witham and Braintree,
apart from 3 (4%) from outside the catchment area.

Sixty nine (93%) of children went to special schools, with a mean of 8.1 appointments each. Five (7%) of children attended mainstream schools with a mean of 4.8 appointments each. Three of these referrals came from general practitioners (GPs), 4 from 1997 or later, all had mild or no LD, all had behaviour disorders, 2 had ADHD and 4 have since been discharged.

Regarding type of referrer for the sample as a whole, 27 (36%) were referred by consultant community paediatricians with 52% of cases still ongoing. Twenty four (32%) were referred by GPs with 58% of cases still ongoing. Twenty two (29%) were referred by more junior community paediatricians with 41% still ongoing. Two (3%) were referred by consultant child psychiatrists, too few cases to analyse meaningfully.

Looking at the referral letters, all made at least one clear request of the service, 47% made two or more. These were most frequently phrased in terms of advice (28%), help with management (20%), assessment (18%), to see (16%), or request respite care (15%). There were no significant associations with referrer or child characteristics. Problem behaviour was a reason for referral for 67 (91%) children, epilepsy in 10 (14%) and mental disorder in 9 (12%).

The mean number of appointments given was 7.9 (range 1-46), 79% with a consultant psychiatrist (spread over 97% of the sample) and 21% with a junior psychiatrist. There were no major differences in type of patient seen by different grades. Of the appointments offered, 15% were cancelled or patients did not attend. 44% of appointments were held at the child’s school, 25% in a community clinic, 23% in a hospital clinic and 7% at the child’s home. Males, and severely LD children made up a disproportionate number of those seen at school and home, whereas females and those with a mild or moderate disability were seen more in the community and hospital clinics.

In the sample as a whole, 19 (26%) had a mild LD, 47% of whom were referred by a GP; 20 (27%) had a moderate LD, referred evenly from GPs and paediatricians, and 21 (28%) were severely LD, 72% of whom were referred by a consultant paediatrician. The remainder included a small number of borderline, profound and not stated LD.

Twenty seven (36%) at some stage were given a diagnosis of a mental disorder, 44% of this group had a mild LD. Most common diagnoses were attention deficit hyperactivity disorder (12 children) and autism (9 children). Fifty eight (78%) were given an ICD-10 (World Health Organisation, 1998) diagnosis of behaviour disorder, 32 (43%) were diagnosed epileptic and finally 17 (23%) had a significant multisystem physical disorder such as Down’s or Rett’s syndromes. Twenty eight percent of the sample had both a mental and behaviour disorder, 14% had both with epilepsy also.

Management included further assessment, such as Aberrant Behaviour Checklist (ABC) charts (Aman et al., 1985) for behaviour assessment in 26 cases (35%) and advice and support for 34 (46%). Twenty nine (39%) had investigations ordered, e.g. an electroencephalogram (EEG) in 21 cases, usually for investigation of seizures, 16 had blood tests. Twenty four (32%) of children were prescribed new medication, most commonly carbamazepine (10 cases), thioridazine (6 cases), lamotrigine (4 cases) and methylphenidate (3 cases). Although in most cases a specific mental disorder was being treated, there were a few cases of
pure behaviour disorder treated by medication, as well as epilepsy. Twenty nine (39%) of children had respite care arranged through the service, of whom the majority had behaviour disorders (83%). Sixty nine (93%) of children were referred on to other services, such as the community nurses (86% of sample), psychology (51%), the vast majority of whom have a mild or moderate LD, the outreach team (24%) mainly moderate and severe LD, Social Services (36%), as well as a small number for occupational therapy (OT), speech therapy and one child for psychoanalysis.

Fifty percent of the original sample are still being seen by the service. Sixty three percent of those with a mild LD have been discharged, compared to 35% of those with a moderate LD and 48% of those with a severe LD. Other noteworthy figures include that only 22% of children with outreach team involvement have been discharged, and 38% only of those with epilepsy. The mean number of months seen in clinic is 41.0 (range 1-145), which does not vary significantly with sex, but jumps from 31.6 to 50.8 going from moderate to severe LD groups.

Regarding final outcome for those discharged, 10 (27%) looked to have had the problems they were referred with solved, 70% of this group have a mild LD. Fifteen (41%) could be said to have improved, 40% of whom have a severe LD. Finally, 12 (32%) were not much improved at discharge, with a majority having moderate to severe LD.

**Practical Application**

A service for children with learning disabilities, regardless of which professionals provide it needs to be aware of the increasing average age of the subjects as the service continues. Sound links with adolescent services and training in working with this group is clearly essential.

The high number of children attending special schools seems to point to the usefulness of clinics being held at such schools, for the convenience of children, teachers and parents, and the importance of a good working relationship.

The high prevalence of epilepsy indicates the need for training of those dealing with this group of children, likewise with children having autistic spectrum disorders. It is also worth noting that a significant proportion of children have a moderate or severe LD, as well as a high prevalence of behaviour disorder. Access to a behaviour therapist as well as community nurses, psychologists and other therapists with experience in working with the learning disabled is all the more important, as the high referral rate to these professionals indicates.

There are a number of cases where the use of medication needs to be considered. This will then at times necessitate the involvement of a doctor, who should be familiar with the psychotropic and antiepileptic drugs in question, as well as have experience in working with learning disabled people.

The service will need to be prepared for the most challenging cases, who will be difficult to discharge, such as those with severe LD and epileptic patients.

**Discussion**

The relatively high number of males referred to the service is of note, and can possibly be explained by the higher prevalence of disorders such as autism in this group, as well as challenging behaviour which may be less tolerable
than in females due to the size and strength of the child. This would also seem to concur with a recent study (Emerson *et al.*, 2001) of the prevalence of challenging behaviour in which approximately two-thirds of the people identified were boys/men and close to two-thirds adolescents or young adults.

The mean age of children currently being seen of around 14 against the lower mean referral age is partly understandable as many of the original referrals are still being seen several years later. However, there is also an older mean age of children referred as time progresses, as well as a steady increase in the number, possibly as the service becomes more well known. In contrast, the mean age of children seen in the Green study is 9 (Green *et al.*, 2001).

Most of the referrals came from the main town of Chelmsford, which has the highest population as well as being site of the main hospitals. Very few children living outside but attending school in Mid Essex were seen, usually because funding issues would arise and it would be difficult to utilise other local services.

The vast majority of children attended special schools, compared to a surprisingly low 58% in the Green study (Green *et al.*, 2001). Those who did attend mainstream schools and were referred relatively recently by GPs perhaps did not find the service as useful, as they tended to be seen for a shorter time and then be discharged. It may well be that links with special schools, and their familiarity with the service put special schools at an advantage there.

Although ideally the bulk of referrals were to have been sanctioned by consultant paediatricians, as in the Green study (Green *et al.*, 2001), it seems that sizeable groups were referred by more junior staff and GPs. It is noticeable that although a variety of doctors make up the group of more junior paediatricians, their cases have been seen for a much shorter time and have been discharged more frequently than those of the other groups, which could indicate that they see and refer less serious cases, especially as it is shown that 72% of the severely LD children are referred by the consultants.

In general, referral letters made it clear that help with challenging behaviour was the main concern. After being seen by the service, fewer had this label than were referred with it, as new diagnoses of mental disorder and epilepsy were made. A number of the children continued to have their epilepsy monitored by the neurologists and thus it would not be included as a reason for referral for them.

Children on average were given around 8 appointments, and were virtually always seen by the consultant at some stage, and at most appointments afterwards. An effort was made not to give too many cases to the most junior doctors such as SHOs, who would often lack experience in this specialised area, although they would often sit in with the more senior psychiatrists. The number of patients missing appointments in LD psychiatry is traditionally low, as most will be brought along by others. School clinics along with home, tended to be more suitable for those with severe LD than outside clinics. There was a fairly even mixture of mild, moderate and severe LD children seen, with perhaps more severe LD children than might have been expected.

Diagnoses were made for most children, with a higher prevalence of mental disorder in the mild LD group, although it may be easier to diagnose in these children. There were high prevalences of behaviour disorder, more than in the Green study (Green *et al.*, 2001) and of epilepsy and significant physical
disorders, as well as cases with a mixture of disorders.

It has been demonstrated that a substantial amount of further assessment, investigation (often for epilepsy related problems), respite care and referral to other agencies was also arranged. Doctors were clearly prepared to use medication sensibly when necessary.

It was perhaps fortunate to have such ready access to the children’s community nurse, and psychology and outreach team services, which were able to help with a significant number of children. Often a nursing assessment would be available even before the psychiatrist was able to see the child.

It appears to be easier to discharge patients with mild LD, but more difficult to discharge epileptic patients and those challenging cases with whom the outreach team are involved. Not surprisingly, those with severe LD tend to need to be seen for longer. However the proportion of total patients discharged (50%) was considerably higher than that in the Green study which was 17% (Green et al., 2001).

Although outcome for discharged patients is based only on subjective interpretation of comments in the clinic letters, rather than more objective measurement, it again seems those who have a mild LD have the best prognosis.

**Conclusion**

Clearly there are areas which can be studied in more detail, and subjected to more rigorous measurement and statistical analysis, but this simple study is just a start, and will perhaps encourage further work in this area, and possibly even similar services.

Hopefully the usefulness of such a service for children has begun to be shown, which there is clearly a demand for. Learning disability services can deal effectively with the children who do not quite fit into Child and Adolescent Psychiatry and Paediatric services in their present form, or at least have a very significant role to play in harmony with these services.

Since the study was carried out there are indeed now monthly meetings of agencies together which are helping to map out the future of local services.

**Summary**

This paper describes a service provided by learning disability psychiatrists for children with all degrees of learning disability, in light of recent government directives and other publications. It gives information on demographics, source of and reasons for referral, length of time seen and by whom, location of appointments, levels of LD, diagnoses, management and prognosis.

The ongoing needs of children with diagnoses of autism, epilepsy and severe behavioural problems are emphasised.

**References**


