# Identifying children with mental handicap in new referrals to a community child and family service

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Clinical experience suggested that between one tenth and one fifth of new referrals to a county-wide child and family service were referrals of children who had mental handicap. The purpose of this project was to establish the proportion prospectively with the clinical assessment used routinely by the service.

The national prevalence of mental handicap "of a degree likely to need special services at some point in their childhood" has been estimated at 100 children per 100,000 general population (Royal College of Psychiatrists, 1992). Epidemiological research has reported that both organic pathology and 'social pathology' influence the extensive use of health, education and social services by these children (Fryers, 1987). For example, organic pathology is particularly common in children with severe mental handicap and the level of psychiatric morbidity among this population is high, at least 60% (Gillberg et al, 1986).

The College has noted these figures and produced a set of guidelines (or 'key characteristics') for coordinating local child and family and mental handicap services (Royal College of Psychiatrists, 1992). The report also indicates the likely importance in the future of contracting the available specialist expertise to deliver this service.

The aim of this initial project was to ascertain the proportion of children with a mental handicap, rather than the level of demand on the Brynffynnon service for a particularly detailed assessment.

#### The study

The number of new referrals in which the index child had mental handicap was identified prospectively for all new referrals from 1 to 31 October 1992 (the 'October cohort'). A new refer-

ral was defined as a request to the Brynffynnon Child and Family service for assessment of a child not currently under review, and aged 18 years or less at the time of the referral.

Ascertainment was undertaken of all new referrals using the referral registers of teams covering the four geographical areas of Mid Glamorgan. Each area team is composed of clinical staff with either medical or social work qualifications, and secretarial support staff, and is led by a consultant in child and adolescent psychiatry. The teams are based at peripheral community clinics throughout Mid Glamorgan, and coordinated from the Brynffynnon centre in Pontypridd.

Each child in the October cohort identified as a new referral was assessed routinely by a team member or members using a multidisciplinary approach. Those children subsequently identified by the assessing team member(s) as having a degree of mental handicap were assessed further by systematic case note review using a short proforma.

No direct contact with patients or their families was required for the purposes of the project alone, although informed consent was specifically sought from Brynffynnon team members concerning the nature and purpose of the survey.

A diagnosis of mental handicap was made from the case-notes in accordance with the diagnostic criteria of the International Classification of Mental and Behavioural Disorders, tenth revision (World Health Organisation, 1992). The diagnosis was made by reviewing clinical assessment(s) using interview, school report and medical or educational reports, psychometric assessment(s) or a combination of these methods.

The term mental handicap has been used in accordance with local practice rather than the term mental retardation. Mild mental handicap

was therefore defined as IQ (intelligence quotient) 50–69, moderate mental handicap IQ 35–49, severe mental handicap IQ 20–34 and profound mental handicap IQ <20.

### **Findings**

The service received 192 new referrals in October 1992. Of these, 40 (21%) failed to attend for assessment, and one child referred was unaccounted for. Of the 151 children who did attend, 12 (6% of the total) were identified as having a degree of mental handicap.

Eight of the identified children were male, four female. The average age was nine years (range four to 15 years). The degree of handicap was reported as mild in nine children, moderate in two and could not be established in one.

Additional psychiatric diagnoses of conduct disorder were present in seven children and emotional disorder in three, with a neurological or metabolic diagnosis in three children. In only one case were the results of any psychometric assessment identified from the case notes prior to referral.

#### Comment

The Brynffynnon service uses a series of centrally based registers to record each new referral and basic demographic data, and allocates a code number to each child.

Using the referral registers, each new referral was identified allowing children an equal opportunity of being included in the project. In this way, all but one of the new referrals in one month were accounted for during the project.

In 1991, the population of the county of Mid Glamorgan was 534,101 (Mid Glamorgan County Council, 1991). Using the figure of 100 children per 100,000 general population (see introduction), there would be a county population of at least 540 children with mental handicap "of a degree likely to need special services at some point". Indeed, it may be that the College document refers to children with learning difficulty of a significant degree, and the actual prevalence figures for the population identified by the clinical method described here is even higher.

Some of these children will be under long-term review by primary care teams, others by the child and family team or by specialist mental handicap services (for the latter, particularly those with severe and profound handicap). This study shows that a significant number are, however, newly referred for assessment to the child and family service. The rate appears to be around 12 per month or, by extrapolation, around 140 per year.

The value of this finding rests on the clinical method of identifying children with mental handicap. The World Heath Organisation have

published diagnostic guidelines for the classification of mental handicap (or mental retardation). However, a strong emphasis is placed on the assessment of IQ or intelligence quotient, which demands an objective psychometric assessment. During this project it was noted that only one child had received such an assessment at the time of referral.

Reliance on psychometric assessment alone to identify the proportion of new referrals of children with mental handicap would have underestimated the size of the actual population.

'Intelligence' is a complex concept and any diagnostic guidelines referring to intelligence or ability will be an oversimplification. In practice, the team members who had conducted the routine assessments were readily able to identify the children whom they had assessed as having a degree of handicap.

The ICD-10 (World Health Organisation, 1992) includes a series of prototypical descriptions which incorporate descriptions of a child's capacity to learn from experience and also the ability to adapt to its environment. These descriptions are readily recognised in the children seen in practice, and this more pragmatic approach was therefore used in the study.

Using this method, 6%, or three in every 50 new referrals, were identified as having mild or moderate mental handicap, refuting the original clinical impression, but demonstrating the clear advantage of the clinical assessment over reliance on psychometric testing alone.

The implications for service delivery to this population are clear. The results of this project show that a significant number of children with mental handicap (around 140) are newly referred to the child and family service in Mid Glamorgan each year.

Gillberg et al (1986) indicated that some of these children need "intense and continuous psychiatric care". For the population served by Byrnffynnon the full extent of this need remains unidentified, but the establishment of this cohort should provide a valuable resource for further observational and outcome studies.

Further study is required to determine the relative proportions of children with mental handicap served by primary care teams, mental handicap specialists as well as child and family services, to provide the care for all these children – the 'key characteristics' described by the College blueprint for such endeavours.

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## Grief counselling for bereaved families with children

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The effects of losing a loved one through death on the physical and mental health of both adults and children are well documented in the literature. Children are likely to be referred to mental health professionals for various behaviour and emotional problems which may have a causative link with a bereavement within the family. In this paper I discuss the need for preventive work and, propose a role for child psychiatric services in preventive work for bereaved families with surviving children and adolescents. A ten-point plan is suggested as a guideline.

Most studies on the effects of bereavement on children have been of children who have lost a parent through death. In a 13-month follow-up study of 105 two to 17-year-old children bereaved of one parent, there was an increase in dysphoria, bed-wetting, temper tantrums, falling school performance, and loss of interest in activities, although this did not lead to an increase in psychiatric or general medical consultations (Van Eerdewegh et al, 1982). The same study found that the mental health of the surviving parent was a contributory factor to the mental state of the child. In a later paper, Van Eerdewegh et al (1985) pointed out the potential importance of availability of a support system and the quality of the relationships between the family members before and after the death. In a follow-up study of 20 families who lost a child from leukaemia, Binger et al (1969) found that in half the families one or more previously well siblings showed behaviours suggesting difficulty in coping. These included enuresis, headaches, poor school performance, school phobia and severe separation anxiety.

In my own practice in a National Health Service child and family service, a significant number of children and adolescents are seen who are referred for various emotional and behavioural difficulties, but on assessment it becomes clear that the presenting symptoms have a causative link with a bereavement within the family. Some of the common presenting symptoms are enuresis, encopresis, conduct problems, selfpoisoning, somatic symptoms, uncontrolled psychosomatic illnesses, relationship difficulties and poor school performance. The children and the families who are referred are usually in one of three stages in relation to the bereavement, namely those facing an imminent loss, those experiencing acute grief, and those with unresolved grief up to several years following the loss. Most children respond well to help with grief work and, in the majority of families, helping the parents to work through their own grief leads to resolution of grief in the children as well (Ubeysekara, 1985).

#### Prevention

By the time these children are referred with behavioural and emotional problems, they are likely to have suffered significant social, emotional, educational, behavioural, and relationship difficulties following a bereavement

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