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the level of support and interest for the new service and the issue studied.

It is essential to develop old age psychiatry services in conjunction with primary care services, as 95% of mental illness is managed in the community and older adults have a high GP consultation rate (Kirby & Cooney, 1998). Although previous studies have sought GPs' views on how psychiatric services for older people should be developed (Banerjee et al, 1993; Ashaye et al, 1996; Kirby & Cooney, 1998), none of these studies specifically addressed the issue of naming a service.

Future research should include opinions of other disciplines, colleagues from other agencies, the general public and particularly family, carers and patients. Now that the community-based service is commissioned, the opinions of patients are being explored. We eagerly await their views. It would also be interesting to repeat this survey in 10 years' time and see if our title chosen has fallen out of favour. After all, our main aim was to make our service as accessible as possible to patients and their families. As J. K. Rowling rightly wrote, 'Fear of a name increases fear of the thing itself'.

### Declaration of interest

None.

### Acknowledgement

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## Children with learning disabilities and related needs placed out of borough: parents' perspective

### AIMS AND METHOD

To investigate parental experience of children with learning disability being placed out of borough. The parents of 70 children were interviewed.

### RESULTS

Parents would prefer in-borough provision but 90% were satisfied

with the current school. The main problems experienced in-borough were poor advice, delays, lack of information and family stress. After out-of-borough placement there was a reported increase in the use of speech and language therapy, occupational therapy and sensory facilities and a decrease in the use

of paediatric services, social services, and mental health services.

### CLINICAL IMPLICATIONS

Specialist services should be helpful and reduce family burden by keeping children in-borough.

Specific psychiatric service provision for children with learning disabilities varies widely. The 1994 Audit Commission publication *Seen but not Heard* stated that such children have special needs and can become marginalised. It recommended a coordinated approach involving community, child health and social services. In 1997, *Don't Forget Us* (Mental Health Foundation, 1997) described the problems of accessing services faced by parents with children with severe learning disabilities and severe challenging behaviour. It recommended expert specialist support for these children and their families. The Government White Paper, *Valuing People* (Department of Health, 2001), states:

'Children with physical or learning disabilities are more vulnerable to the full range of mental health disorders and the additional social, family and emotional stresses of everyday life'.

The prevalence of psychiatric disorder in this population is 2–3 times higher than in children without learning disabilities. In 1996, Enfield & Tonge found a prevalence of over 40% for severe emotional and behavioural disorder or psychiatric illness in 4- to 18-year-olds with learning disabilities. Less than 10% had received specialist help.

In 2002, the Assistant Director of Education in Enfield, London commissioned a review of out-of-borough placements for children with special education



needs (available on request). The two most frequently mentioned factors that were important in the decision for an out-of-borough placement were 'a specialist provision not found in Enfield' (44/67) and 'parental preference' (38/67). (A child may have more than one special need, so the total adds up to over 67.) Of the 67 children, 20 were in a residential placement.

## Method

Once ethical approval was obtained, 269 letters were sent to every parent with a child (aged 0–18 years) with a learning difficulty (as defined in the Education Act 1996 and the Revised Code of Practice for Special Educational Needs 2001) placed out of borough (total of 281 children), inviting them to participate in the study. The letters and reminders were sent out between April and October 2003. A total of 88 parents responded and 66 parents of 70 children were interviewed; 21 parents were not interviewed as their children were no longer out of borough or they declined to take part. A semi-structured questionnaire was devised. The principal researcher carried out all interviews, predominantly with the mother. Interviews lasted 45–90 min. The children were not interviewed.

## Results

Thirty-two children (46%) were placed out of borough owing to a requirement for specialist provision, 18 (26%) owing to mental health problems, 17 (24%) owing to parental preference or proximity and 3 (4%) because of a lack of vacancies in Enfield (Table 1). Most parents (90%) were satisfied with the current out-of-borough placement but 64% would still have preferred an in-borough school. The problems experienced by parents included a lack of a key professional/worker (14%), dissatisfaction with assessment/advice or not being listened to (54%), having to pay for private assessments (33%), delays in diagnosis/provision (49%), lack of information (37%), lack of communication between agencies (13%), family stress (23%), needs still unmet (16%) and lack of respite or after-school care (11%).

Parents found out-of-borough schools difficult for the following reasons:

- early rising for the child;
- longer distance to school;
- parents unable to accompany child to and from school;
- child not attending the same school as their siblings;

**Table 1. Primary reasons for out-of-borough placement of 70 children with learning difficulties**

Age (years)	Specialist provision <sup>1</sup> (n)	Behaviour/mental health (n)	Parental preference/proximity (n)	No vacancies in Enfield (n)
0–11	11	2	6	1
12–16	13	12	7	2
16–18+	8	4	4	0
Total	32	18	17	3

1. Specialist schools for speech and language, autism, epilepsy, physical disability and being deaf/blind.

**Table 2. Access to services/professionals in and out of borough**

	Services accessed before out-of- borough placement n (%)	Services accessed in borough after out-of- borough placement n	Services accessed out- of-borough after out- of-borough placement n	Overall services accessed after out-of-borough placement n (%)
Primary care	70 (100)	61	11	72 <sup>1</sup>
Physical/medical	67 (96)	15	27	42 (60)
Social services	45 (64)	18	1	19 (27)
Mental health	32 (46)	10	7	17 (24)
Specialist assessment centre (e.g. Addison House)	16 (23)	–	–	–
Educational psychologist	70 (100)	70	0	70 (100)
Voluntary organisations	36 (51)	1	0	1 (1)
SALT	37 (53)	5	40	45 (64)
Occupational therapy	18 (26)	6	16	22 (31)
Physiotherapy	10 (14)	2	6	8 (11)
Private sector	27 (39)	3	2	5 (7)
Sensory facilities	0 (0)	0	13	13 (19)

SALT, speech and language therapy.

1. Some children had two general practitioners: one at home and one at school.

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- no/very few after-school activities or opportunities to see school friends out of school;
- less contact between parents and teachers and between parents and other parents.

Children followed two distinct pathways. Of 70% first seen by health services, 81% were referred to other health professionals. Of 30% first seen by education or social services, 67% were referred to other professionals within education or social services. Mental health services were not involved until many other professionals had been involved in almost all cases.

Table 2 demonstrates marked reductions in the use of paediatric, social and mental health services, voluntary organisations and the private sector following out-of-borough placement. Conversely, there was an increase in the use of speech and language therapy, occupational therapy and sensory facilities following out-of-borough placement.

Of the parents, 59% expressed satisfaction with services but would like respite/day care (30%), social activities (14%), help with behaviour (16%), family therapy (9%) and more information (26%). The perceived satisfaction was greater in parents of younger children, with 85% satisfied with children in the 0- to 11-year-old age-group and 41% and 63% in the 12- to 16-year and 16- to 18-year age-groups respectively. Parents of the older children felt less secure about their child's future even though they were more likely to know of a plan for their child's immediate future. Among the parents of the 0- to 11-year-olds, 20% believed their child would eventually need permanent residential care. This rose to 35% of the parents of 12- to 16-year-olds and 94% of the parents of 16- to 18-year-olds. Only 26% of parents felt secure about their child's long-term future. Parents of 16- to 18-year-olds were most insecure.

## Discussion

Of the children, 71% were male and 59% were of non-UK White ethnicity. Local demographics give a figure of 43%, if unknown ethnicity data are excluded. There is evidence that young people from Black and minority ethnic communities experience unequal access to services (Beresford, 1995; Chamba et al, 1999).

The reason for the placement out of borough in 46% of cases was the need for specialist provision. Specialist schools are not available in every borough. The proportion of these children who also had mental health difficulties, which contributed to the placement, is not known; 46% had received mental health services at some point. Of the 18 children placed out of borough owing to mental health difficulties, only 61% accessed mental health services before out-of-borough placement. Mental health services were not considered early and there was poor inter-agency communication.

The 2004 Royal College of Psychiatrists' Council Report *Psychiatric Services for Children and Adolescents with Learning Disability* highlights the need for relevant

multi-agency services that address prevention, accessibility of services, diagnosis and interventions acceptable to children and families. It highlights major issues nationally in relation to service development and availability of relevant resources. Children should be able to access appropriate services to meet their specific needs. The right level of support should be made available to schools to help keep children in-borough. The marked difference in reported service provision out of borough (e.g. more occupational therapy and speech therapy), which seems to work, versus what is available in borough, which by definition has not worked, is worth noting. Factors which parents may not have noticed could easily account for much of the difference between success and failure. Poor after-school activities, problems with communication, and family stress reflect the burden of having a child with a disability whether in or out of borough. Future studies of these issues could be enormously helpful.

## Declaration of interest

None.

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