

Factors influencing general practitioner referrals to a tertiary paediatric neurodisability service

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SUMMARY

This study investigated factors influencing general practitioner (GP) referrals to a tertiary paediatric neurodisability service, including the reasons for referral, the children's characteristics, and the involvement of secondary specialist services in the referral. Fifty general practitioners (GPs) referring consecutively to the Neurodisability Service, Great Ormond Street Hospital for Children, London, were interviewed in a cross-sectional study using a postal questionnaire. The main findings were that two-thirds of the GPs did not contact secondary specialist providers prior to referring. The majority (78%) of GPs were responding to parental concerns in the context of a lack of medical diagnosis in 74% of the children. The main (90%) reason given for referral was for parents seeking a second opinion outside their district network. The findings highlighted the influence of parents over GPs' referrals to tertiary neurodisability, and, in light of this, raised issues for consideration for effective organisation of child disability health services.

Keywords: *child health; paediatrics; neurodisability; tertiary referral.*

Introduction

ACCORDING to the tiered model of child disability health services,¹⁻³ child referrals should flow from primary to secondary level. Health districts have developed child development/disability teams to provide specialist diagnostic assessment and local management of care,⁴ and referrals to tertiary regional and supra-regional specialist services are only required for more complex or rare problems and would not be expected generally from primary level. Contrary to expectation, general practitioner (GP) referrals have continued to flow steadily to the tertiary Neurodisability Service (NDS) of Great Ormond Street Hospital for Children. This has raised questions of the appropriateness of these referrals and prompted this investigation of GPs' referrals to tertiary level. The aims of the study were to establish:

- whether GP referrals to tertiary neurodisability were 'by-passing' secondary services (i.e. the child had not been seen by appropriate secondary services or the local paediatrician had not been consulted about the referral),
- the factors influencing GPs' decision to refer, and
- the child's characteristics.

Method

A consecutive review of GPs referring to the NDS from April 1996 to April 1997 was completed. GPs were included if their referral letter indicated a broad neurodevelopmental question, such as differential diagnosis. Fifty GPs fitted this criterion and were included. Thirteen GPs were excluded because of specific requests for specialist clinics, such as the osteogenesis imperfecta clinic, which serve a supra-regional or national population. A standard questionnaire with forced choice and open-ended components was sent to the GPs on receipt of their referral letter (100% response rate). Data were collected mainly through postal interview; telephone liaison by the tertiary team provided information on secondary service involvement.

Results

The main results are summarised in Table 1. The referrals came from 25 health authorities in south east England with no evidence of clustering. The majority of children had been seen previously by an appropriate district/secondary level service, but the local paediatrician had not been consulted about the majority of referrals. Nearly one-quarter of the GPs lacked knowledge of district paediatric services. The ages of children varied widely and three-quarters lacked a definite medical diagnosis. Conditions raising concern were, in particular: dyspraxia, autism, attention deficit hyperactivity disorder, and global developmental delay/learning difficulties. The majority of GPs stated that the first person to ask for the referral was the parent. GPs often gave multiple reasons for referring: the most frequently stated was of parents seeking a second or independent opinion. Other reasons included prior knowledge of the Neurodisability Service and having previously referred to the Service. A sizeable proportion of the reasons given concerned local differences of opinion, particularly between the parent and local service providers.

Discussion

Unlike the referral flow envisaged in the tiered model, GPs were tending to 'by-pass' consultation with secondary service providers when referring children to a tertiary neurodisability service and they were responding generally to parental concern. Parents were seeking an opinion (often a second opinion) when a definite medical diagnosis was lacking for their child's disabling condition or when experiencing a difference of opinion with local service providers. These findings must be interpreted cautiously as the study was small-scale and not necessarily representative of other tertiary paediatric neurodisability services or the wider GP population (whose outpatient referral rates vary).⁵ The study was restricted to GPs' viewpoints and lacked cross-validation with parents or secondary level professionals. For instance, it was unable to clarify whether it was the parents, GPs, or someone else who first suggested the NDS and whether GPs felt under pressure to comply.

Nevertheless, issues are suggested that warrant further discussion and investigation. Within the context of some parents' desires for a second opinion (more frequent in the area of child

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Table 1. Characteristics of GP referrals to tertiary paediatric neurodisability service.

Characteristic	Percentage (n = 50)
Relationship with district services	
Local paediatrician not informed of referral	66 ^a
GP lacks knowledge of district services	22
Child been seen by appropriate district service	65
Child characteristics	
Mean age	6 years 7 months (SD = 4 years 3 months)
Lacks definite medical diagnosis	74
Geographical location	Diverse (25 health authorities)
Who initiated the referral?	
Parent	78
Other professionals	12
GP	8
Not known	2
Reasons given for referral	
Parents seeking an opinion (first or second)	90 (62% [n = 50]: second opinion stated)
GP had prior knowledge of NDS	48
Local difference of opinion	36 (72% [n = 18]: parent versus provider)
Lack of comparable diagnostic service locally	36
Previously referred to NDS	24
Other (e.g. family new to area)	12
Intervention sought	
Comprehensive assessment to reach diagnosis	62
Advice on child's needs and management	48
Opinion on child's condition and prognosis	12
Other (e.g. parental counselling)	10

^aThree GPs were intending to inform the paediatrician of the referral.

disability than in other areas of paediatric practice⁶), primary, secondary, and tertiary providers, and purchasers will need to clarify priorities and develop guidelines for involvement of specialist and tertiary paediatric neurodisability services. This would facilitate ongoing audit of satisfaction of parents and local providers with the involvement of tertiary services. Some GPs may require up-to-date information concerning local specialists including disability services and a focus on communication with secondary providers. Finally, research is needed into the extent to which disability services are meeting parental needs. Tertiary intervention has a potentially important function for parents of providing a second or independent opinion outside the district network. Nevertheless, improved management of care at district level, such as post-diagnostic support, might decrease the demand on GPs to refer.

References

1. Department of Health and Social Security. *Report of the Committee on Child Health Services. Fit for the future. Vol. 1.* [Cmnd 6684.] London: HMSO, 1976.
2. Department of Health and Social Security. *Health services development: Court report on child health services* [HC (78) 5/LAC (78) 2.] London: HMSO, 1978.
3. Bax MCO. *District handicap teams: structure, function and relationships.* London: DHSS, 1985.
4. Bax MCO, Whitmore, K. District handicap teams in England: 1983-8. *Arch Dis Child* 1991; **66**: 656-664.
5. Roland M, Coulter A (eds). *Hospital referrals.* Oxford: Oxford University Press, 1992.
6. Robards MF. *Running a team for disabled children and their families. Clinics in developmental medicine.* [No. 130.] London: MacKeith Press, 1994.

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