

To the Editors:

Pathways taken by parents of disabled children

Facilities and help for children with developmental delay are often inadequate and delayed in Sri Lanka. Community surveys and case-load analyses in outpatient departments (OPD) have shown that only a fraction of developmentally disabled children receive help (1,2). If facilities and professional help are to be made more freely available, the current process of obtaining health care merits investigation.

At present the mechanism for early recognition of developmental delay in the community is the screening of infants in child welfare clinics (CWC), with the use of the child health development record (CHDR).

We investigated the efficacy of this method of screening. The timing and process of recognising developmental delay, and the sequence of contact with health professionals was investigated in 200 new or follow up patients attending the University Child Development Clinic at the Lady Ridgeway Hospital for Children, Colombo, over a period of 8 months. This clinic accepts medical and non-medical referrals, and provides an outpatient service for children with varied developmental disabilities ie. mental retardation, cerebral palsy, speech disorders etc.

A semi-structured questionnaire administered by one of us, invited comments of parents on the date (as accurately as possible), the description of events and the person by whom the initial recognition of the problem was made. Patient characteristics, parental income and parental educational level were noted, and parents were asked to record their views on the help received from the different professionals in their own words. The CHDRs were evaluated regarding entries of developmental milestones.

The study sample had a mean age of 5 years 9 months (range 5 months to 12 years) and 67.5% were boys. 52% had cerebral palsy, 62% were mentally retarded and 86% had speech disorders. The mean age of detection of physical disabilities was 6 months (SD \pm 1.4), mental retardation without motor problems 18 months (SD \pm 3.6) hearing impairment 18 months (SD \pm 9.2) and visual impairment 4 months (SD \pm 0.8).

In 74% of patients the problems had been detected by the parents or relatives. General practitioners and doctors in OPDs had detected developmental problems in 18% and 8% respectively. None of the parents had been alerted to the problem in the CWC or by the Family Health Worker. A delay in developmental milestones was reflected in only 6% of CHDRs. In 89.5% the relevant cage (cage F) was incompletely filled and did not indicate any abnormality. 4.5% of CHDRs did not have a single entry in cage F.

Following the detection of developmental delay the parents took a variety of different pathways in search of help (Figure). The hospital OPD was the first point of contact for the majority and was the preferred pathway for

63.6% of severely disabled and 74.8% of children with multiple handicap. However, parents rated general practitioners as better information givers than paediatricians and OPD doctors.

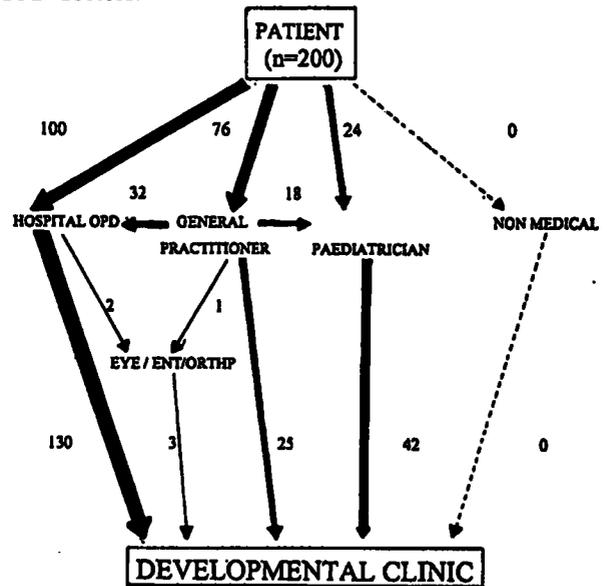


Figure 1. Pathways taken by parents of disabled children (Numbers indicate number of patients)

This study provides information only on those children presenting to the development clinic and does not include children in other settings, or those who did not reach any type of help. However, this data provides pointers to further research and to the following conclusions: paediatric disability services are not readily available; the CHDR is under-utilised as a developmental screening tool.

Recent surveys have shown that 99.5% of infants in rural areas in Sri Lanka have a CHDR (3). We recommend that more staff time and motivation be given to the aspect of developmental screening for more effective use of the CHDR. Since OPDs of state hospitals were the main pathway taken by the severely disabled, we recommend that the OPDs of the larger hospitals be staffed and equipped to cater to the needs of developmentally disabled children.

References

1. Guruge K. Lamasarana - establishment of a community based rehabilitation centre. *Ceylon Journal of Child Health*, 199; 25: 37-8.
2. Weerasinghe I. The problems of ambulatory paediatrics at Lady Ridgeway Hospital. Proceedings of the 31st Annual Congress of Sri Lanka Paediatric Association, 1996: 31.
3. The Matala Survey. Weekly Epidemiological Report. Colombo: Ministry of Health August 1997; 25:(35) 4.

(The editors apologise for the inadvertent delay in publishing this article)

Manouri P Senanayake, Senior Lecturer, and D J M N R Jayamaha, TUN de Silva and S Bahirathan, Demonstrators, Department of Paediatrics, Faculty of Medicine, University of Colombo.