

## Executive Summary

Since 2008, the International Centre for Eye Health at the London School of Hygiene and Tropical Medicine, in partnership with the Child Sight Foundation in Dhaka, has been engaged in the development, testing, validation and evaluation of the Key Informant Method to identify children with disability living in the community in Bangladesh. This report results from a qualitative study that aimed to a) identify and assess the barriers preventing uptake of referrals, and b) recommend ways in which the rate of referral uptake could be increased in a developing South Asian context.

Using the methodologies of critical and applied medical anthropology, fifty-one case studies were completed in the districts of Sirajganj and Natore over a three-week period in November-December 2010. The cases were purposively selected and focused on children presenting with epilepsy, physical impairments (cerebral palsy, clubfoot, cleft lip and palate), hearing impairments and visual impairments. Interviews were conducted with the parent(s) of the referred child and were determined by issues they self-identified as priorities.

The research explored local causative frameworks and the treatment-seeking behaviour of parents prior to attendance at a screening camp. We investigated the experience of attending a camp and the referral procedure, in detail. Factors influencing referral uptake were complex and interrelated, and were found to include: the severity of the impairment; the surrounding community; the cost of treatment and transport; the location of treatment; and disappointment following camp attendance. Referrals made at a screening camp fell into five categories: assistive devices; epilepsy medicine; surgery; therapy; and further investigation. Key factors influencing the uptake of each were examined. In addition, we analysed the main concerns that parents experienced in caring for a child with an impairment, and questioned the reasons why some actively chose to ignore referral. The social presentation of disability was also explored, particularly in relation to a daughter's marriage prospects and the ability to live as an independent adult.

Recommendations focus on ways in which both the KIM and screening camps can better facilitate referral uptake. It is suggested that:

- Expectations should be contained and matched.
- Simple, concise and accurate explanations (of the impairment, referral process and potential treatment) must be offered.
- Healthcare professionals should be provided with camp specific training.
- Counselling at the camps must be improved.
- The organisation of referrals needs to be standardised.
- Sustained follow-up should be implemented.
- The KIM network should be maximised.
- The surrounding community could be better harnessed.
- A parallel system of healthcare provision should be avoided.
- Local healthcare practitioners should be better educated about the camp and further involved in the referral process.