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Interventions to improve utilization of cataract surgical services by girls: Case studies from Asia and Africa

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ABSTRACT

Purpose: Gender and blindness initiatives continue to make eye care personnel aware of the service utilization inequity strongly favouring men, yet interventions to reduce that inequity, particularly for girls, are under developed.

Methods: This descriptive study gathered quantitative data on the degree of gender equity at five Child Eye Health Tertiary Facilities (CEHTFs) in Asia and Africa and conducted in-depth interviews with eye care personnel to assess their strategies and capacity to reduce gender inequity. Cataract surgery was utilized to assess the degree of inequity and success of interventions to reduce inequity in case finding, service utilization, and follow-up.

Results: CEHTF administrative data showed significant gender inequity in cataract surgical services favouring boys in all settings. CEHTFs actively seek children through community and school-based outreach, yet do not have initiatives to reduce gender inequity. Little gender inequity was found among children receiving surgical and follow-up care, although two out of three children were boys. CEHTF staff, despite being aware, offered no effective means to reduce gender inequity involving cataract surgical services. Interventions that successfully increased service utilization by girls came from individual cases, involving extraordinary effort by a single eye care programme person.

Conclusion: Community-based case finders such as Anganwadi workers in India, Female Community Health Volunteers (FCHVs) in Nepal, and Key Informants (KIs) in Africa are necessary to identify children in need of cataract services, but insufficient to increase service utilization by girls. Secondary, often extra-ordinary community-based interventions by eye care personnel are needed in all settings.



Introduction

Health-seeking behaviour for a child is known to depend on “total family income, mother’s education, number of symptoms and mother’s perceptions about severity of illness”.¹ A 2005 study found that “gender role(s) not only affects illness reporting but also affects the decision to choose a health care provider and how much to spend on the sick child”, meaning “the entire steps of a health seeking action underlying household dynamics of health care choice are different for boys and girls”.²

Congenital or developmental cataract (hereinafter cataract) has become a leading cause of preventable and curable blindness in children in developing countries.^{3,4} As a result, cataract surgery is a core component of Child Eye Health Tertiary Facilities (CEHTFs) and

finding and managing children with cataract have become key activity for their community outreach activities.⁵ Similar to adults, no biological or epidemiologic evidence reports a significant sex-specific difference in the prevalence of congenital or developmental cataract.⁶ However, sex-specific cataract surgical data show an overall boy: girl surgical ratio favouring boys of 1.3:1.⁷ While gender inequity is well established, almost no studies have reported on successful interventions to reduce this inequity.

This study sought gender-specific interventions to improve gender equity in paediatric surgical care, particularly cataract surgery, in CEHTFs in *Angkor Hospital for Children (AHC) Cambodia, Aravind Eye Care System, Pondicherry (AECS) India, Lumbini Eye Institute (LEI) Nepal, Queen Elizabeth Children’s*

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Hospital (QECH) Malawi, St. Benedictine Hospital (BEH) Uganda.

The specific objectives were to assess differences in service utilization by boys and girls to:

- determine the adequacy of current sex-specific data gathering and reporting; and
- gather efficacy evidence regarding gender-specific surgical case finding and utilization strategies.

Methods

This study gathered both quantitative data on the degree of gender equity at each institution and qualitative data through in-depth structured and unstructured interviews with clinical, administrative, leadership and outreach staff.

Two teams collected data; each comprised a local research lead who underwent supplemental training in qualitative research methods by a qualified research expert with fieldwork experience related to gender and blindness research. One project team was responsible for the CEHTFs in Malawi and Uganda, while the other team for India, Nepal, and Cambodia.

The project teams jointly created standardized data collection forms to gather annual sex-specific congenital and developmental cataract surgical rates and the proportion attending 1st, 2nd, and 3rd post-operative visits from routine hospital administrative data. They also created a case study format including a detailed observation and interview guide.

Research leads conducted initial site visits to 1) review the available and needed data with the institutional representatives, 2) tour the CEHTF to obtain an overview of the infrastructure, human resources, equipment, and basic details regarding training programmes and services offered, and 3) observe practices and conduct in-depth open-ended interviews.

The project teams also prepared a case study format including a detailed observation and interview guide. The case studies included both open-ended interviews and participant observation by research personnel. The keys steps included:

- (1) international experts meeting at project outset to develop the case study frameworks;
- (2) identifying the key programme components to include in the case study framework;
- (3) training of the interviewers;
- (4) conducting the case studies and collecting routine data; and

- (5) review of the completed case studies for accuracy by the local collaborators.

During the second site visit to each CEHTF, the project teams scheduled interviews with selected staff members and volunteers over about 5 days. These included pediatric ophthalmologists, programme coordinators, counsellors, nurses, trainers, field workers, local leaders, and volunteers trained to identify children with eye problems in their community (Table 1). None of the case studies entail interviews with children or their families.

The project teams, accompanied by translators where appropriate, used a digital recorder and interviews were transcribed if they were in the local language, translated into English and stored electronically on a password protected laptop. Research leads analyzed transcripts by thematic content. Original transcripts and a summary of the key themes were reviewed and approved by the research experts. No software was used to aid in the analysis.

Ethical approval was obtained by the Department of Surgery Research Committee from the University of Cape Town. Each CEHTF involved in the study also provided a letter of ethical approval for their facility. All institutional and community outreach participants involved in the study provided written or verbal informed consent. All study procedures adhered to the recommendations of the Declaration of Helsinki.

Results

Clinical services

The CEHTFs conducted a variable number of paediatric cataract operations in 2015, ranging from BEH (96) in Uganda to LEI (362) in Nepal (Figure 1). Significant gender inequity in cataract surgical rates were found in all settings with sex ratios strongly favouring boys in Asia (1.6:1) and Africa (1.4:1).

The proportion of children attending follow-up visits after cataract surgery, in contrast to utilization of cataract surgery, showed almost no gender bias at any CEHTF except for boys attending slightly more of the 3rd followup visit (Table 2).

Table 1. Total number of respondents by site.

Sites	Hospital staff		School staff		Community personnel	
	Male	Female	Male	Female	Male	Female
BEH	3	3	NA	NA	6	0
QECH	2	4	NA	NA	5	1
LEI	4	3	4	1	1	4
AECS	5	4	2	6	0	3
AHC	4	3	NA	NA	1	0

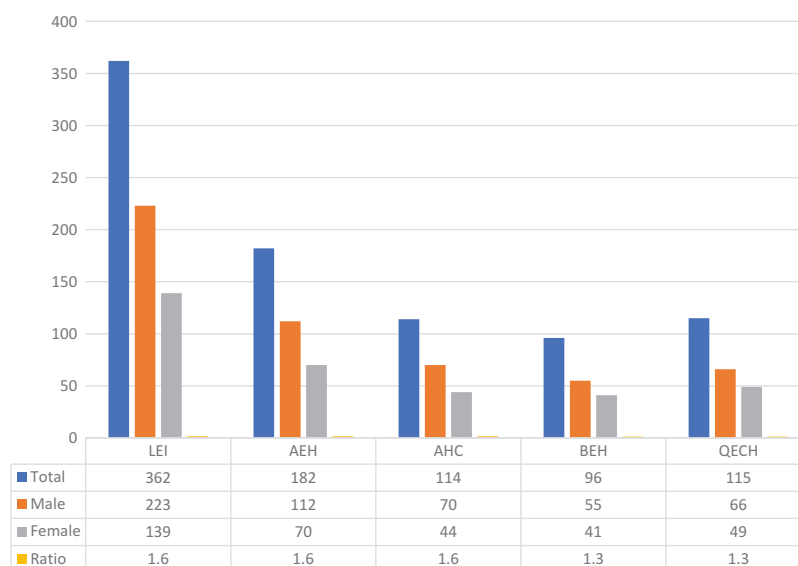


Figure 1. Children accessing cataract surgery in 2015 by site.

Table 2. Cataract surgical follow-up 2015 by site and sex.

Follow up	Sex	LEI	AEH	AHC	BEH	QECH
Attended 1st	M (%)	91	97	81	43	77
	F (%)	87	95	77	29	96
Attended 2nd	M (%)	64	95	73	16	77
	F (%)	63	89	64	14	96
Attended 3rd	M (%)	57	90	60	5	54
	F (%)	53	86	52	9	49

Hospital records also showed that, except for some discretionary items such as boys receiving more expensive (foldable) intra-ocular lenses than girls in the CEHTFs in Nepal and India, they receive equal access to high-quality care. When interviewed, very few CEHTF staff in any setting were aware of gender inequity in their paediatric services. The usual statement was that “boys and girls receive equal attention, quality of service, and follow-up care.”

Community case finding

All the CEHTFs coordinate case detection and referral systems to link paediatric patients in communities to primary and secondary health facilities and ultimately to CEHTFs for services. The eye care systems included community-based case finders such as key informants (KIs), teachers, and volunteer health workers who assess children and make appropriate referrals (Table 3).

All the CEHTFs understood the necessity of going into the community to identify children, were aware of the economic and educational challenges in rural areas, and were motivated to address such issues. Moreover, each CEHTF gathered data on the number of boys and girls who attend their facility for cataract surgery.

Despite recognizing unmet paediatric population need, the outreach activities at the CEHTFs had inadequate numbers of personnel and limited effective community-based interventions to meet that need. This lack of human resource capacity was particularly true in the African settings.

Case finding interventions in India: Anganwadi workers

Anganwadi workers are women, allotted to a population of 1000, who are chosen from the community to bridge the gap between the person and organized healthcare. This government-supported programme aims to focus on the health and educational needs of children aged 0–6 years.

A ECS trains Anganwadi workers in its service area to identify childhood eye conditions and to create awareness among the parents, teachers, and local community. A ECS conducts regular paediatric eye screening camps in each Anganwadi center.

“Anganwadi workers are the first people to interact directly with the parents regarding child’s health in the Indian villages” - **Pediatric Ophthalmologist, A ECS**

Anganwadis keep in regular communication with the hospital community coordinator and assume responsibility to ensure referred children reach the hospital. They also strongly influence the parents to take children for follow-up. A hospital staff member is assigned to take care of the children referred by the Anganwadis, which helps to engage and motivate the Anganwadis, who receive no financial incentives for their eye care work.

Table 3. Child Eye Health Tertiary Facility eye care programme summary.

	INDIA Aravind Eye Care System (AECS) Pondicherry	NEPAL Lumbini Eye Institute (LEI)	CAMBODIA Angkor Hospital for Children (AHC)	UGANDA St. Benedictine Eye Hospital (BEH)	MALAWI Queen Elizabeth Children's Hospital (QECH)
Overview of Facility	<ul style="list-style-type: none"> One of 11 eye hospitals in AECS Training for all ophthalmic personnel Research Institute 	<ul style="list-style-type: none"> Eye hospital Training for all ophthalmic personnel Research Institute 	<ul style="list-style-type: none"> Eye department in children's hospital No training No eye research 	<ul style="list-style-type: none"> Eye department in general hospital No training No eye research 	<ul style="list-style-type: none"> Eye hospital affiliated with children's hospital No training No eye research
Pediatric Department	<ul style="list-style-type: none"> 30,000 outpatients/year 4 pediatric ophthal. programme manager counsellors optometrists, opticians, orthoptist, specialized nurses 	<ul style="list-style-type: none"> 23,000 outpatients/year 3 pediatric ophthal. programme manager counsellor optometrists, opticians, orthoptist, specialized nurses 	<ul style="list-style-type: none"> 12,000 outpatients/year 1 pediatric ophthal. 1 basic eye doctor programme manager no dedicated counsellor 2 refractionists, specialized nurses 	<ul style="list-style-type: none"> 5000 outpatients/year 1 pediatric ophthal. programme manager no counsellor specialized nurses 	<ul style="list-style-type: none"> 6000 outpatients/year 2 pediatric ophthal. programme manager no counsellor optometrists, ophthalmic assistants, specialized nurses
Community outreach programmes	<ul style="list-style-type: none"> Anganwadi workers taught to identify children (under age 6) and to facilitate compliance School screening 150,000/year by using class teachers for initial vision screening 	<ul style="list-style-type: none"> Female Community Health Volunteers (FCHVs) taught to conduct house to house detection, counselling, compliance School screening 60,000/year Community outreach camps include children (20%) 	<ul style="list-style-type: none"> General outreach camps include eye personnel No community-based personnel trained in eye School screening 5000/year 	<ul style="list-style-type: none"> Key Informants (KIs) door to door visits for detection and to facilitate compliance to outreach camps no school screening 	<ul style="list-style-type: none"> Key Informants (KIs) door to door visits for detection and to facilitate compliance to outreach camps no school screening

“Anganwadi workers are highly motivated to help their community and provide high cooperation during the camps to reach all the children, boys and girls. Villagers trust/ respect them ... and they have a strong relationship with our hospital...” – **Pediatric Ophthalmologist, AECS**

This programme provides a strong community-based infrastructure that supports children reaching the hospital for care, regardless of their paying capacity, but residual gender imbalance persists:

“Even though we provide free treatment, travel, accommodation and food, parents are not willing to take the child particularly girl child to services as they lose their wages”- **Community Coordinator, AECS**

In the end, strong individual staff and community determination were necessary to persuade more resistant families to accept care.

Case finding in Nepal: female community health volunteers

The FCHV programme is a government supported-programme in Nepal. Every ward (1000 people) has at least one FCHV. In the area served by the Lumbini Eye Institute (LEI), the FCHV receives one day of basic eye

health education and educational material from the community eye care coordinator.

FCHVs know all the children in the village and go door to door to identify children in need of care and refer or bring children with obvious eye problems to outreach clinics or to LEI. FCHVs also counsel parents and family members and help with logistics, costs, and subsidies. According to LEI staff, the integration of eye care with the FCHVs programme is essential to equitable eye care service delivery and addressing gender inequities.

“FCHVs play key roles in bringing gender equality among the local community. They visit door to door to give health education and encourage parents (who give more importance to boys) to bring girls with conditions to the hospital.” – **Optometrist, LEI**

With all their competing demands, FCHVs only find about one or two younger children with serious eye conditions per month and have insufficient time to persuade parents to bring their child in for care, especially girls. They also describe the frustration and imbalance in their role “as women, trying to convince men”:

“In most cases, the grandfather or father holds the decision-making power and the health needs of women and female children are not prioritized.” - **FCHV, Nepal**

Male eye care staff have been able to overcome this double layer of gender bias by persuading the men in the family themselves, yet they seldom visit individual communities to meet with families, primarily because they have not been asked.

Recognizing the gender inequity favouring boys, LEI began increasing the intensity of its case finding beyond just training FCHVs and leaving them to facilitate utilization of eye care services on their own. As a result, LEI staff and FCHVs have experienced noteworthy success stories, where LEI staff visit specific families to accept services for their children. These stories have started to coalesce into verbally exchanged strategies to improve utilization of care by children.

Case finding in Uganda & Malawi: key informants

KIs are community members, who after a very brief training are expected to "...network widely to identify children in remote rural areas" (Hospital staff, BEH). KIs, who may be lay people or formal health sector workers, often work in a "campaign" mode to recruit children over a brief period of time following their training. After identification, a system is necessary to have the children examined by knowledgeable specialized personnel, usually paediatric ophthalmologists.

In both settings KIs identified children during a one to three-week period, typically referring about 10 children, however, often only one of whom has severe low vision or blindness. About 1/3 of the children identified were younger than school age (less than 5 years).

"KIs are very good especially when they are motivated. KIs are the best way you can mobilize the community. For example, this region has many languages; it is easier to work with KIs than to do radio promotions"
– **Hospital staff, BEH**

The interviews in both countries revealed that hospital staff are generally aware of gender bias:

Here, parents value boys more, because they think they are the heir... – **Counsellor, BEH**

We send boys to school because the boy can go to school and help the family in future- **Female KI, Malawi**

Although the CEHTFs in Malawi and Uganda both recognize gender inequity, they have inadequate capacity to address it in their outreach programmes and strategies. They explain before addressing gender inequity they must address the more fundamental need to provide counselling to families with affected children, boys and girls:

The main barrier to utilization (by boys and girls) at this institution is the lack of expertise to conduct counseling. There is a need to provide training to the required employees - **Hospital staff, QECH**

Both CEHTFs recognize that KIs are their best strategy for finding and serving more children. However, similar to Nepal, they also recognized the need for more active engagement by eye care staff. Through some initial successes the paediatric programme has intensified follow up with families of identified children:

It was through KIs that we were able to find two sibling girls whose father had been refusing surgery for them. Through the help of our Childhood Blindness Coordinator we were able to convince the father and eventually he allowed his wife to come along with girls to hospital for treatment- **Ophthalmologist, BEH**

The BEH staff in Uganda also noted the KI training package misses the important aspect of counseling, including how to properly take into account gender considerations.

I think the one area I realize that maybe during our training session that we didn't emphasize is gender. During the session I said bring all children but I needed to explain more about why we tend to see more boys than girls at the hospital...- **Hospital staff, BEH**

Case finding in Cambodia

AHC does not have eye care specific case finding. Instead, eye conditions are included in general outreach activities that include several other medical specialties. As a result, eye-specific and gender-specific case finding strategies have not developed in this setting.

Sex-specific AHC data show only moderate inequity (about 5% difference) between boys and girls for health service utilization, including eye care. However, AHC staff explain that, as one of the country's few tertiary referral paediatric institutes, AHC data are not likely representative of Cambodia.

AHC screens 10,000–15,000 children through a school screening programme every year. AHC trains teachers how to screen visual acuity, who play a major role in counselling parents and ensuring referred children reach the hospital. However, gender inequities are noted in schools:

When I visit schools for screening, I see more boys in the school than girls. There is a belief in the community that girls will do better household works than studying...- **Refractionist, AHC**

School – based case finding

School age children (6–17 years) represent over 30% of the population in developing countries. Outreach in schools concentrates on refractive error. Students with other eye problems, including cataract, are also noted and referred to the base hospital. However, in contrast to community-based case finding of preschool children, relatively little is known about gender bias for cataract cases in this older age group.

The three CEHTFs in Asia did not gather data on the referral source for children over age 5. As a result, while gender inequity exists in these older children in terms of service utilization, it is not known whether the children with cataract attend school and if they do, whether or not they are referred to hospital from their home or from school. Additional data gathering is therefore required in order to assess this older age group.

Where data gathering is adequate, glasses distribution favoured girls (1.25:1). This likely reflects several key factors, not least of which is exposure of girls to a knowledgeable and supportive context often led by female teachers.

We train teachers and create awareness among them, using mainly class teacher (home room) who work closely with the students. We are able to find the diseases in a mass. In no other approach, we can reach the children like this.- **Pediatric Ophthalmologist, AECS**

Hospital staff noted the efficiencies and benefits of using class teachers for screening, especially girls. Hospital staff also noted the opportunity for eye care professionals to examine girls in the school age population, unlike pre-school years.

Even the child from poor economic condition regardless of gender goes to school at least for food. So, it is possible for us to cover all the children in the community... – **Project Manager, AECS**

The CEHTFs recognized two knowledge gaps with regard to community-based case finding.

Improving knowledge regarding compliance

Since case finders often do not return to individual households to assess compliance, they are insufficiently aware whether the children they refer reach the hospital and receive care. The interviews revealed that case finders in almost all settings were surprised to learn of the inequity favouring boys as they claim to refer an equal, or greater, number of girls than boys. Yet once told, it made sense given the limited family resources and strong priority given to obtaining health care for boys and motivated them to increase their attention on girls.

CEHTF staff were in agreement that the “referral compliance” knowledge gap could be mitigated through more active feedback from the eye care programme. An intervention in both African sites and Nepal and India, whereby case finders provide cards to the families and keep a list of referrals, was found to be a promising way to bridge this gap. By comparing actual attendance with referral lists, programme staff can take a “non-attendance” list back to the case finder, prompting follow-up with the “non-attendance” family.

Another promising intervention is the involvement of eye care programmes with ongoing community-based women’s networks, such as microfinance groups in Africa and Anganwadi workers in India. In both cases, the community women and networks act as case finders and take on responsibility for the health of children in their area, particularly girls. As community members, they were aware of whether the children attended the eye camp and have potential strong influence, including financial, especially in the case of microfinance groups, on health seeking behaviour, particularly for girls.

Improving distribution of professional eye care knowledge

The second knowledge gap relates to the case finders themselves. Case finders in all settings explained that the real issue facing them in their role in paediatric eye care is a lack of persuasiveness due to insufficient knowledge about eye conditions, their treatment (initial and ongoing), and the likelihood of success. In order for families to accept care for their child, particularly girls, this higher level of knowledge is required at the time of case finding, as well as at the outreach camp and hospital.

The suggested innovation is to include follow-up visits by knowledgeable eye care personnel to persuade families to seek care, particularly for girls. An albeit extreme example of this successful model was provided by an Indian ophthalmologist:

I travelled by ferry, car, then 3 hours on rickshaw to visit a family with 5 children (4 girls) with cataract that had repeatedly refused to come to the hospital for care. They doubted me at first ... but eventually they were convinced, and all came for care – **Ophthalmologist, AECS**

Discussion

Primary findings, from previous work on gender and vision loss in adults, was that utilization of eye care services is strongly associated with socioeconomic and educational status of women, culture-specific decision

making in households and female literacy.⁸⁻¹² Furthermore, an example from Southern India showed that an indirect investment in female education improves all aspects of public health, through increased use of already available health services.¹³

The CEHTFs all conducted interventions aimed at increasing gender equity in service use, however, none of the CEHTFs actively tested interventions to reduce gender inequity. As a result, the case studies typically reflected individual success stories, all of which need further study to determine their broader institutional feasibility and impact.

Most of the gender inequity in this study, for both Asia and Africa, was found in case-finding. While the population-based cataract prevalence is assumed equal in boys and girls in all of the CEHTF settings, more boys than girls receive surgery than boys. None of the CEHTFs have adequate data reporting or analysis to determine 1) whether more boys than girls are found 2) whether more boys than girls who are found actually attend outreach camps and receive surgery. Interviews with community-based case finders almost all strongly stated that the key issue is not finding children, but getting the families to comply with recommended care, particularly girls.

There appears to be much less gender inequity favouring boys within clinical eye care systems. Once they are within the eye care system, boys and girls generally receive similar procedures and follow-up care. Attendance at cataract surgical follow-up by boys and girls tends to be similar in studies in Asia and Africa.^{14,15} Follow-up is clearly in the hands of parents, therefore either the families that bring a girl for surgery are not representative of the general population or good counselling at the hospital has a positive impact on follow up rates for girls.

The eye care programmes recognize that gender inequity is a result of complex socio-economic factors and often rigid cultural norms which can be difficult to challenge. Instead of attempting to alter these norms the programme managers employed strategies that accommodated these inequalities and barriers by “working around them”, thereby increasing access to and use of health information and services and improving health outcomes. The approach reflects the major findings from a systematic review of interventions to improve gender equity:

In some sociocultural contexts, these accommodating strategies may be the most appropriate, particularly as the first step in integrating gender into health programming.¹⁶

Engaging with the cultural diversity and broad socio-economic range within service communities is difficult

for individuals promoting utilization of eye care services by children. The eye health promoters, who are often minimally trained community volunteers, require substantial eye care knowledge, profound trust, and robust community and professional support to attain service utilization by children and even more difficult, gender equity for girls.

The consistent and persistent sex disparity between boys and girls, even in the four CEHTFs that have adult programmes that have reduced adult gender inequity, demonstrates the challenges faced by institutions in resource poor regions of the world. For the most part, these institutions, incorrectly assumed that the successful gender equity interventions used for women would be sufficient to result in similar success for girls. However, although they now recognize the additional eye care programme needs to provide services to girls, in most settings they do not have adequate resources (financial, technical, or personnel) to achieve equity for girls. These case finding challenges and health service resource needs are likely major factors in the sex disparity seen in most low-middle income regions of the world.⁷

Four of the CEHTFs focused on issues related to adult eye care were largely unaware of the performance of their pediatric programme, particularly in terms of case finding. The challenge in these resource-limited settings, particularly in the human resource limited settings in Africa, was how to shift attitudes among the staff of the hospitals and clinics to invest much more heavily in equitable, high quality, cost-effective, community outreach programmes to reach children.

Summary of findings

Necessary conditions to achieve gender equity in community-based case finding:

- (1) strong eye care programme leadership committed to equitable provision of eye care services, including dedicated staff time and programme funding to reach target populations;
- (2) sex-specific data gathering and reporting, at all levels;
- (3) ongoing active engagement with female community leaders and organizations;
- (4) community and household support for positive eye health-seeking behaviour;
- (5) counselling of the entire extended family involved in financial decision making;
- (6) monitoring and evaluation of sex-specific case finding and utilization strategies; and

- (7) feedback to community-based case finders regarding feasible solutions.

Additional requirements to achieve gender equity of service utilization:

- (1) community case finders must become aware of low acceptance, particularly among girls;
- (2) an eye care “utilization acceptance” programme to follow up the community-based “identification” programme;
- (3) a dynamic record-keeping system to promptly inform case-finders of referred children’s progress;
- (4) sub-programmes to connect eye programmes to children within isolated ethnic groups.

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