

Using Key Informants to Identify and Refer Children who need Eye Care Services

A manual for Africa



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Preface

Vision 2020: The Right to Sight, a global initiative sponsored by the World Health Organization and International Agency for the Prevention of Blindness, aims to eliminate avoidable blindness by the year 2020. The initiative targets childhood blindness as one of five major areas of avoidable loss of vision. WHO estimates one new occurrence of childhood blindness worldwide each minute and 500,000 new cases of child blindness per year. 75% of these children live in developing countries, particularly Africa and Asia, where proportions of populations under 16 years is high, services are limited, and weak connections between communities and eye care services often prevent effective treatment. In spite of these problems, efforts to abolish avoidable blindness have brought about significant changes in Africa in the last 20 years: vitamin A supplementation and measles immunization have greatly decreased corneal blindness in children; facilities where children can receive good quality surgical services continue to increase in number; and follow up services (refraction, low vision care, rehabilitation) have become more commonplace. Still, much remains to be done.

This manual represents the efforts of two African organizations (Blantyre Institute for Community Ophthalmology and Kilimanjaro Centre for Community Ophthalmology) to synthesize experiences using key informants for the recognition and referral of children with severe vision loss or blindness. While by no means exhaustive, we release this manual with the hope that techniques described here will prove useful to other pediatric eye care providers.



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Rationale for the Manual

Addressing childhood blindness, similar to addressing the other components of VISION 2020, requires a systematic approach: multiple activities that need to be combined to address the problem successfully. The systematic approach must involve several steps, including estimating the need for child eye care services, setting targets, and instituting systems for monitoring and reporting progress. Thus, this manual will include information both systematic and supportive to provide a solid foundation for utilizing the key informant approach.

There is a growing body of literature on the use of key informants to assist with the identification of children with severe visual impairment or blindness and other health conditions. Readers are encouraged to review supplementary literature (see suggested readings in the appendix).

There are distinct social and cultural differences between Asia and Africa and it may not be possible to completely copy approaches used in Asia into the African context. This manual, based on projects and research conducted in various districts of Tanzania (Lushoto, Babati, Keratu, Singida and Musoma) and Malawi (Mulanje, Zomba and Mangochi), is specifically concerned with Africa and geared toward eye care providers, managers, coordinators, and those who work in the field of child eye health.



Determining the Magnitude of Need

At the National Level:

Before implementing strategies to provide services to children with any visual impairment, the magnitude of the need for services must be considered. Although information on childhood blindness in most countries is limited, it is important to gather any available national data.

This information should include:

- Information on vitamin A supplementation and measles immunization coverage
- Information from ophthalmologists regarding the frequency with which they see vitamin A-related corneal conditions
- Information from schools for the blind (primarily information on causes of blindness in children who recently experienced loss of sight rather than those who became blind a decade ago)
- Data from Child Eye Health Tertiary Facilities (CEHTF) regarding the number of congenital/developmental cataract surgeries in the past year and where the children are from, as well as statistics on other eye surgeries performed, such as glaucoma and strabismus.

This data, when combined with information from some recent surveys in Africa conducted by several governmental and non-governmental organizations and academic centres on childhood blindness and cataract, will enable reasonable estimates of childhood blindness at the national level. These estimates are rough calculations and likely to obscure considerable variations in terms of service delivery throughout the country: nonetheless, these numbers (likely to range from 0.2 to 1 per 1,000 children under 16 years of age) provide a reasonable basis for assessing need.

At the VISION 2020 “District” Level

A VISION 2020 “district” of approximately one million people is distinct from an administrative district, which often has a much smaller population. Determining district needs, while important for the purpose of planning, can be difficult. There is a generic model for VISION 2020 district planning: first, situational analysis of the needs and resources; second, setting aims, objectives and priorities; third, planning and setting a timeframe and budget; and fourth, deciding on monitoring and evaluation procedures. The same basic guidelines apply to planning for childhood blindness. In addition, proximity to a CEHTF, socioeconomic status and access to health care (quality of nutrition, Vitamin A and measles coverage) will likely significantly impact current levels of childhood vision impairment.

Population-based Estimates

Many districts throughout Africa have not benefited from specific community-based programmes or efforts to identify or refer adults or children with severe visual impairment or blindness. The absence of such programmes in these districts often explains the lack of statistical information on childhood cataract. However, it is possible to make some estimate of the prevalence of childhood cataract using census data. Such an estimate should be made for each VISION 2020 district in the country in order to determine the estimated incidence of childhood cataract and level of need.

According to WHO estimates, in each district of one million where there have been no community programmes there are likely to be approximately 100 children with congenital and developmental cataract. For example, a district of 2.4 million people without any community efforts to address loss of vision or a CEHTF presence most likely has approximately 240 children who suffer loss of vision due to congenital and developmental cataract. Estimates will be lower in districts that have programs to identify and refer people in need to eye care services.

Example:

District of Nsua = 2,400,000 people (2.4 million)
Children with cataract = $2.4 * 100$ children = 240 children

This figure represents the backlog of cataract cases and is liable to change with the development of community programmes that improve access to treatment and surgery for children.

Incident congenital cataract has been estimated at approximately 20 children per one million total population per year.

Example:

District of Nsua = 2,400,000 people (2.4 million)
Children with cataract = $2.4 * 20$ children/year = 48 children/year

Setting Targets

Calculations in the previous section facilitate planning and provide members of VISION 2020 implementation teams and CEHTFs with target numbers of children to find and refer for treatment (or, in the case of CEHTF, provide with surgery). Based on these numbers, district teams can set annual targets in three areas:

1. Identification and referral of children with severe vision loss or blindness
2. Identification and treatment (surgery) of children with cataract
3. Proportion of children who return for follow-up treatment (spectacles and low-vision devices).

Targets for rehabilitation, although beyond the scope of this manual, are also important to keep in mind.



Strategies to Identify and Refer Children with severe vision loss or blindness

Detection and Referral

Achieving the best result of pediatric cataract surgery is very much dependent on early identification and prompt referral. In Africa many babies and young children have contact with health workers at different points during infancy and childhood, all of which could provide opportunities for identification of infant cataract. The evidence, however, shows that these opportunities are either ignored or inappropriately managed, not resulting in proper referral for surgery.

Primary health workers and other health care representatives, if trained, can have the necessary skills to differentiate a “white pupil” (opaque lens) from a normal one. Upon recognition of “white pupil” a health worker should immediately refer the child. The health worker must also be able to counsel parents as to the gravity of the problem (e.g. risks of retinoblastoma) and the importance of timely appearance at a hospital.

Clearing the backlog of existing cataract-blind children

In most African countries there is a large backlog of congenital or developmental cataract in the community. The availability of accessible surgical facilities for children with visual impairment or blindness provides an opportunity to clear this backlog. Addressing the needs of these patients will clear the backlog, identifying many older children who have vision loss that cannot be fully corrected, but whose vision nonetheless improves with surgery. In most such cases, despite less than ideal timing of surgery, proper refraction and low vision services can produce a relatively good outcome.

Clearing the backlog will serve a number of other purposes. First, it will generate awareness of childhood blindness and cataract among professional and non-professional groups concerned with childhood eye care. Second, it will set the stage for implementing plans for addressing incident cases. Third, it will serve as a learning tool for an eye care team to better understand and address barriers to the acceptance of surgery. Fourth, it engages communities in addressing eye health.

All potential strategies to clear the backlog have not been rigorously tested but evidence suggests a number of different effective approaches. The key informant strategy is one such approach, and can be used alone or in combination with other activities.



Using Key Informants to Identify Children in the Community

Key informants are village members, selected and nominated by village leaders, who identify and create lists of children who are believed to have problems seeing and then refer them for clinical examination. They accomplish this through interaction with community and religious leaders, public meetings, and visits to schools or individual homes. Evidence from a number of countries shows that key informants can be effective in identifying many children with severe visual impairment or blindness at the community level. One key informant can usually cover a total population of 1,000 to 5,000, depending upon population density and strength of community organizations. Most key informants will identify only one to three children; some will find none in their assigned areas. Once children have been identified, the KI ensures that they attend eye screening, held at a mobile eye clinic or other health care facility, to determine if treatment is needed.

Most key informants volunteer for a specific (very short) length of time, but some can be engaged long-term. Training is very basic and does not aim to enable KIs to test vision, which is complicated and unnecessary in their role. KIs need to know how to identify children who are believed to be blind or who have severe visual impairment, collect their names, and refer them for screening. Monitoring the activities of key informants can enhance their output. Thus, a coordinator should monitor the KI programme.

There are many advantages associated with the use of key informants. These include direct and inexpensive implementation, efficiency in eliminating false positives, and referral of large numbers of children who have significant eye problems requiring treatment. The main disadvantage associated with the use of key informants is their high drop out rate after training.



Planning

Situational Analysis

It is important to have thorough knowledge of the program area and the current health-related activities or programs there. This knowledge should include reviews of maps, reports, and any other pertinent literature. When designating program areas, pay particular attention to areas in which other organizations may have instituted community-based eye care programs and discuss plans with them early.

Mapping

It is important to have a meeting with all the stakeholders in the health sector (especially stakeholders involved in eye health) and coordinators (who are explained in the next section) to plan out areas of work. Participants in this meeting should use a map of the project area and the latest census of each village to determine practical steps in outlining the work.



Role of a Coordinator

To ensure that blind or severely visually impaired children receive proper medical care at a CEHTF, a coordinator should be attached to each facility. The coordinator will be responsible for managing and overseeing KI projects. Specifically, a coordinator trains field assistants (who then go on to train key informants), arranges logistics for outreach, and contacts field workers to liaise with village leaders. Additionally, a coordinator can do all project reporting to sponsors, analyze data, organize meetings and planning activities, and ensure that all children are followed up.

Selection of Key Informants



Village leaders will be responsible for selecting key informants. They will be free to adopt their own techniques, which may involve calling a village meeting to ascertain interest, interviewing prospective KIs or contacting capable individuals directly. Leaders must take care to select the most competent person and not simply give privilege to relatives who may not be capable of performing the duties of a KI.

Leaders will need formal letters informing them of the project and soliciting their cooperation. The letter should include a list of critical attributes of a key informant to aid leaders in the selection process and clarify that KIs are volunteers, not employees. Finally, the letter to the village leader must describe the need for the leader to provide a letter of introduction for each selected KI to bring to training. This letter of introduction will prevent the appearance of unsolicited potential key informants at training.

In most settings key informants are volunteers and do not receive a salary. They must understand this arrangement prior to beginning training. However, it is usually necessary to offer some form of incentive for motivation. The organization running the training usually absorbs the costs of transportation to and from training, lunch, and refreshments during the day. In addition, small items that can also advance publicity (such as t-shirts and KI identity cards) may prove useful. Participants should each receive a certificate upon completion of training.

All key informants should have certain skills and attributes. These include literacy, some free time (four days over the following month for training), status within his/her community, confidence in public speaking, geographic knowledge of community and surrounding area, and physical mobility in the community.

Training

Field Assistants

Field assistants or surveillance assistants are personnel responsible for training and managing key informants. They serve as a link between the CEHTF coordinator and the KIs. Ideally, field assistants should live in the district where key informants are to be trained.

Responsibilities of the field assistants include:

- To inform all the community leaders on the project activities in the villages (this includes delivering formal letters to the village leaders)
- To liaise between the coordinator and the key informants from his/her district
- To work with the key informants to determine a date and place for screening and inform the coordinator of logistic arrangements.
- To prepare monthly reports of training and screening activities and submit them to the coordinator who will then prepare quarterly reports for the donor organization.

In instances where there are no field assistants (due to funding constraints or lack of personnel) the coordinator takes responsibility for all the above activities. If necessary, field assistants or coordinators can seek help with training and screening from other health care workers in their district.

It is important to thoroughly train field assistants, as they will be in charge of training key informants. Training programs should include:

- How to engage community leaders and assist in selection of key informants
- How to train key informants
- How to plan and supervise mobile eye clinics for screening
- How to plan and supervise transport of children to the CEHTF
- How to facilitate follow-up of children after surgery (considering the possible provision of rehabilitation services)
- How to maintain communication with all key informants
- How to remain in close contact with all children who have received surgery
- How to keep thorough, accurate records and report pertinent data



Community Engagement

After training the field assistants and before the first training of selected key informants it is useful to start raising awareness of the project and childhood blindness and visual impairment in the communities. This can be done through radio, posters or information sheets to village leaders.

- Print materials: Posters and leaflets (preferably colored) with large photographs of a child with cataract can be displayed at schools, nurseries, health centers, shops, places of worship, bus stops and tea shops.
- Radio: Messages and announcements about the serious nature of vision loss in children and possibilities for treatment and surgery can be broadcast through communities via radio.
- Local TV: Stations can broadcast promotional messages and jingles furthering knowledge of child eye health and awareness of treatment.

All health education materials must include contact information for the nearest hospital: telephone numbers (landline and/or mobile) and a detailed street address with P.O. Box number for accessibility to patients.

The health communication messages should highlight the following:

- Blindness or severe vision loss in children is rare.
- Infants with blindness or severe visual impairment need to be seen by an eye health professional as soon as possible.
- Children can safely undergo surgery as young as one month old.
- Appearance of a “white pupil” should be treated as an emergency and the child should be immediately referred to an eye doctor.
- Most children with vision problems can be enrolled in normal schools; they may need extra assistance with reading.

These messages must be clear and concise. They can accompany photographs of a rehabilitated child on posters or interviews and testimony in radio and television promotions.

Key Informant training

The training can be done in half a day and should focus on how to identify children with severe visual impairment or blindness, basic information about pediatric cataract, strategies to raise awareness, steps to be followed to make sure the identified children get proper treatment in time and any possible rehabilitation procedure. See appendix A for a suggested training format.

Venue



Ideally training should be at an easily accessible central location, in a venue with all required facilities for training. Large towns may not be practical due to their distances from villages and the high cost of transportation. When selecting a venue, consider population density, transport systems, and distances to be traveled. Conducting training close to the key informants' own villages will avoid problems of late arrival and cut down on travel costs.

Outreach & Follow Up

Child Eye Health Outreach Screening

At the end of the training there should be a discussion about stations or (preferably) health facilities close to the key informants where screening can conveniently take place. Evidence suggests that having an established date, time, and location for examination greatly improves the numbers of children who appear.

One station can service a number of villages, depending on the number and locations of KIs in a given area. A screening clinic is carried out by an eye specialist or an ophthalmic clinical officer (assisted by a field assistant or local health staff) and should take place three weeks after the training. The examiner should use a standard examination form. It is the responsibility of a KI to make sure that all the children they identify attend the screening clinic.

KIs should clearly explain to the parents/guardians that they suspect the child to have a problem and only medical personnel can confirm the diagnosis and prognosis on the examination day. It is best if KIs can personally escort any identified children to the screening station.

All children found with operable conditions should be immediately referred to the CEHTF for surgery. Medical care should be provided on the spot; children requiring optical or low vision care must be referred to the relevant care provider with a referral letter. Some children without visual impairment but with other health problems will be brought for screening and will need assistance in receiving proper care. Furthermore, children who require additional rehabilitation services such as low vision devices should be assisted in obtaining such services.



KI Assistance with Follow Up

Although evidence has yet to be generated systematically, there should be a potential for KIs to assist with follow up of children who have received surgery or low vision services. Follow-up is a crucial step in the rehabilitation process of children who have received cataract surgery. Childhood blindness and low vision coordinators at the CEHTF are responsible for active tracking of children to encourage follow-up after surgery. Children should also be carefully observed after surgery to monitor results and provide low vision devices to those in need.

Monitoring and Evaluation

Ideally, the project coordinator should monitor continuously and prepare a quarterly report on the project activities. This helps the responsible organization to keep accurate records of numbers of people trained as KIs and of children found and referred through the program, enabling evaluations of the program's efficiency. Forms used to monitor and evaluate KI programs will depend on the sponsoring organization, and therefore will be site-specific.

Different variables can be measured depending on specific quantitative targets and objectives of the project. Variables to monitor include gender, age, numbers of children identified by KIs and screened (and percentage found with cataract), number of surgeries performed, outcomes of those surgeries, number of children who needed low vision devices, number of children who obtained said devices, and number of children who returned for follow-up. Indicators selected should be specific, measurable, appropriate, reliable and time-sensitive.



**APPENDIX A:
Training Curriculum for the Key Informants**

Task	Skills needed	How to teach specific skills	KIs should know:	How to teach
1. Identification of children with blindness or severe visual impairment	Key informants must be able to determine whether or not a child has severe visual impairment or blindness.	Show pictures of children with cataract and other blinding eye diseases. In some pictures the eye should look normal and the KI should make a decision based on what the child's parents say.	<ul style="list-style-type: none"> — their role in the program and in the community — that blindness (especially due to cataract) can also occur in children and not only in elderly — a white pupil in children should be treated as an emergency case — some blindness is not visible 	Use short lectures on perceptions of vision loss and blindness and consequences if children are left untreated
2. Proper recording of identified children with severe visual impairment and blindness	Key informants must be able to record background information of the children they find. This information includes name, age, sex, child's village, village leader, contact details.	Give an illustration on how to fill in the report forms.	— such information will be used to relocate and keep track of the children identified	Mention the use of each variable in the form and let them practice filling in a sample form on their own.

3a. Transport arrangement for the child and caretaker from the village to the screening site	KIs are responsible for referring a child identified for examination at a screening site, and for making sure the child gets there.	Instruct KIs to work closely with field assistants, health staff, or others to organize a screening site and ensure maximum attendance.	— different basic strategies to counsel parents regarding the importance of surgery	Cover this information during the opening lecture about blindness.
3b. Transport of those with surgically manageable conditions (e.g. congenital or developmental cataract) to tertiary facility	KIs must be able to organize transport between their villages and nearest tertiary facility.	Emphasize to KIs the importance of providing social support.	— importance of providing social support to children and families	To be covered in the lecture
4. Referral of children who would benefit from low vision services	KIs must be able to identify children who need low vision services.	Discuss system of referral and methods to ensure child gets low vision devices.	— difference between blind children and low vision children	To be covered in the lecture
5. Promotion to parents and the community	Key informants should be able to interact with community groups and leaders to transmit important information.	Ask KIs to target specific areas for promotion. Set a task to assess their interaction skills.	— importance of spreading knowledge about pediatric eye disease	To be covered in the lecture
6. Convey proper information to parents whose child has visual impairment	KIs should be able to give important information about childhood cataract and the process after recognition to parents whose children are affected.	Give the KIs important information about childhood cataract and the process of education and counseling.	— basic information about pediatric cataract and possible treatment	To be covered during the lecture

**APPENDIX B:
Child Reporting Form**

#	Item	Response
1	Today's Date	
2	Child's Name	
3	Age	
4	Sex	<input type="checkbox"/> Male (1) <input type="checkbox"/> Female (2)
5	Father's Name	
6	Mother's Name	
7	Contact information (cell phone)	
8	Village	
9	Village Leader	
10	Explain how you found this child:	

APPENDIX C:
Supplementary Literature

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