



## Expanding and Improving Surgical Services for Children

### Summary of Grantee Accomplishments:

- Screened 95,576 children for visual acuity and basic eye conditions
- Performed 479 sight-restoring surgeries for children
- Provided eyeglasses to 973 children
- Averted 23,950 years of life with blindness



Photos: Pediatric ophthalmic theatre at the tertiary unit, Uganda. Sightsavers International.

### A2Z Child Blindness Program: Tackling Avoidable Blindness through Partnerships

Approximately 1.4 million children worldwide are blind. In addition, nearly 17 million children with low vision or impaired sight lack eyeglasses, visual aids, or the services they need to help them function. As a component of A2Z: The USAID Micronutrient and Child Blindness Project, the A2Z Child Blindness Program uses competitive grants to reduce child blindness and improve eye health. Grants provide support to NGOs that deliver services to populations in need. Program goals and priorities include:

- Expanding delivery of high-impact direct services, including screening, treatment, education, and rehabilitation.
- Scaling-up innovative approaches to service provision and program implementation.
- Contributing to the global knowledge base on effective approaches to large-scale child eye health programs.

Managed by AED since 2005, the A2Z Child Blindness Program has awarded 32 grants to 23 organizations to support work in 25 countries. The majority of grant awards support service delivery initiatives which aim to provide comprehensive services for children from case detection to treatment and follow-up care. This case study provides an in-depth look at USAID/A2Z grantee experiences in delivering medical and surgical services to children in India (Sadguru Netra Chikitsalaya), Nigeria (Helen Keller International), Niger (Helen Keller International), Tanzania (Kilimanjaro Centre for Community Ophthalmology), and Uganda (SightSavers International).

## Childhood Blindness in the 21<sup>st</sup> Century

Today in Africa and Asia, blindness resulting from vitamin A deficiency and measles is rare. While micronutrient-related blindness has decreased, blindness and visual impairment in these two regions has not been adequately addressed.

To eliminate avoidable child blindness in the 21<sup>st</sup> century, other leading causes of childhood blindness, such as congenital and developmental cataracts, need more attention. These conditions—which often require surgical or other specialized interventions—have led to a growing programmatic investment in tertiary level interventions. The establishment of Child Eye Health Tertiary Facilities (CEHTF) across Africa and Asia has created the capacity to provide this specialized care for children. However, the impact of CEHTF in Africa and Asia has been limited, as grantees have found few successful public health approaches for identifying children in need, referring children to CEHTF, and providing quality services and follow-up care to children and their families.

USAID/A2Z grant recipients sought to address these barriers by developing strategies for identifying, referring, and transporting children to hospitals and CEHTF, improving the quality of services provided at these facilities, and enhancing the quality of follow-up care and counseling provided to children and families.

### Overview of Experiences: *Overcoming Barriers to Identification and Referral of Children*

HKI, KCCO, SNC, and SSI implemented programs in five countries: Niger, Nigeria, Tanzania, India, and Uganda. At all implementation sites grantees recognized that children were not receiving the medical and

surgical services they need. Grantee research indicates that barriers to increasing coverage exist at both the community and healthcare provider levels.

At the community level families often have misperceptions related to eye conditions, including the belief that the condition can “fix” itself, or that it is the result of witchcraft. In some communities the stigma associated with visual impairment causes parents to hide their children. Parents of young children often think they should delay treatment until their child is older.

Strategic outreach activities were needed to address these misperceptions so that children suffering from blindness or visual impairment could receive the treatment they need. All projects prioritized strong community outreach for identifying children in need, whether through key informants (KCCO/Tanzania) or at the community level through DRS—a non-surgical outreach initiative which includes hospital transportation for children who need surgery (HKI/Nigeria). Organizations also identified children through market-day screening and health centers (HKI/Niger), or through school teachers (SSI/Uganda). In India, SNC employed a multi-pronged approach using existing government health staff, community health educators, school teachers, and vision centers. In Tanzania, KCCO’s training of health centre staff revealed the importance of working directly with communities. For every key informant KCCO trained in the community, three children were identified (see table 1 on page 3).

Overall, these community outreach programs resulted in the screening of 41,788 children in four African countries, and 53,788 children in India (see

**Mariama Ado** is a 13 year old girl who lives with her mother in the village of Dan Tchiao, in the medical district of Magaria, Niger. She had been suffering from a bilateral congenital cataract since birth and knew the darkness of blindness. Her mother and neighbours believed that her blindness was the result of demons. After their village was visited by an advocacy team from HKI her mother decided to bring Mariama to the Zinder National Hospital where she had cataracts removed from both eyes. Mariama returned to the hospital 45 days after her operation for a follow-up visit. Her mother informed the project that Mariama had previously been visited by five suitors, but all had abandoned her because of her blindness. Now that Mariama can see she will be able to choose her husband.





**Alexander Mallya** is a 7 year old boy from the rural Moshi District in the Kilimanjaro region. Alexander was not born with an eye disease, however he developed a white spot on his pupil when he was 3 years old. His mother thought it was normal, until she realized that Alexander was quickly losing his sight. Initially, his parents tried to use traditional herbs to treat him, which only worsened the problem. Alexander's aunt advised his parents to take him to KCMC for further management. By this time, he was 4 years old. The KCMC surgical team operated on both of his eyes, and provided him with spectacles. Alexander was hospitalized and received follow-up care to ensure that his condition was stable. He is now more active and can play with other children. His family is happy that their child will be able to attend school now that his sight is restored.

Table 1: Children identified by key informants and health workers in Tanzania

	Key Informants	Health Workers	Total
Number trained	197	63	260
Number of children identified with serious eye problems	549	22	571
Productivity (children/trained)	2.78	0.35	

figure 1). India is an outlier and is not included on the chart due to population density, large catchment area, and the developed network of eye care services at the Indian project implementation site.

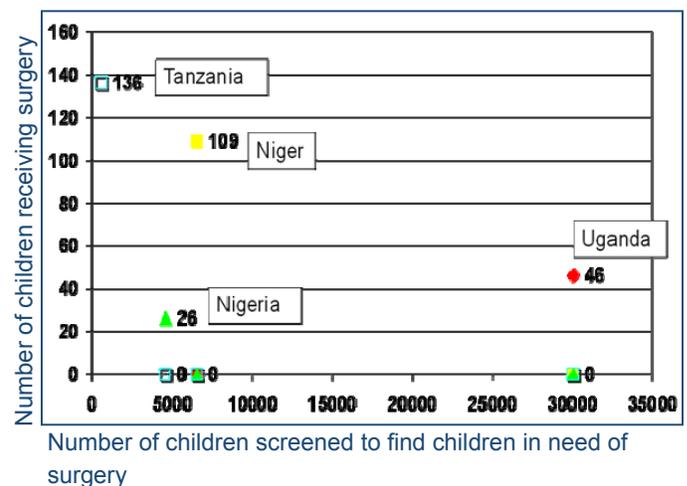
At the health-care provider level, implementing organizations found that there is little understanding of the need for urgent referral of children with blindness or visual impairment. Infants are not routinely screened for visual impairments at birth or time of immunization. A unique and potentially useful approach that SSI incorporated into their vision screening and outreach strategy was the inclusion of eye screening for children during Child Health Days in Uganda. Integrating eye screening into standard practices associated with immunization and other child health activities will ensure that eye care is part of a routine child health approach.

Furthermore, grantees found that there were no strategies in place to ensure that identified children successfully reach a CEHTF or hospital to receive the eye services they need. Identifying children and transporting

them to hospitals therefore became key components of many grantee interventions. HKI/Nigeria incorporated transportation costs for patients and their families into their program. The SSI/Uganda project took the approach that every child should be brought by a local ophthalmic clinical officer to Kampala for surgery and follow up. When necessary, KCCO/Tanzania covered the cost of transport for the parents to bring their child to hospital for surgery as well as follow-up care. SNC/India recognized that many children who were referred did not come for surgery, and adapted their approach to put additional effort into tracking children who received referrals. Teachers and community health volunteers reached out to families to encourage them to bring the children to the base hospital for assessment.

While the provision of transportation has considerable cost implications for the implementing organization, grantees measure this cost against the cost of a life-long burden of blindness or vision loss.

Figure 1: Number of children who were screened and received surgery



## ***Ensuring Quality Visual Outcomes and Follow-up Care***

Implementing organizations used different approaches to improve the quality of services at CEHTF and hospitals. HKI/Niger focused on advanced training of ophthalmologists in pediatric surgery and surgical care for children, including cataract surgery. These trainings contributed to an improvement in the method of anesthesia used for children and a mastery of the technique of pediatric ocular and cataract surgery.

Lack of post-operative follow-up care limits the effectiveness of cataract surgery, and ultimately the educational and economic opportunities of the child. Therefore, follow-up care is a programmatic focus of all A2Z grantees. HKI/Nigeria, for example, improved the quality of their follow-up care by ensuring that all patients recovering from cataract and glaucoma surgeries had their first post-operative visit within twenty-four hours of the operation. As a result the surgical team was able to immediately address possible complications, such as ocular infection. HKI's initial follow-up visit was undertaken by the surgeon and mobile team, with subsequent follow-ups occurring four weeks after surgery. Screening for visual acuity by an optometrist during follow-up visits established the level of improvement resulting from the surgical intervention.

Counseling of parents was also viewed as an integral component of high-quality pre- and post-operative care, and was adopted by SNC/India, KCCO/Tanzania, and HKI/Nigeria. Additionally, HKI/Nigeria used the DRS outreach service as a means to counsel parents and others regarding eye care for children. Overcoming barriers to post-operative follow-up was challenging for all projects, since it involved activities both at the community and hospital levels.

All grantees recognized that a comprehensive pediatric eye care team is necessary to deliver high quality eye services to children. This team should consist of a pediatric ophthalmologist, pediatric anesthetist, childhood blindness and low vision coordinator, and a well-trained optometrist.

## **Results**

USAID-funded initiatives in both Asia and Africa have led to significant reductions in years spent in blindness. This was accomplished while researching and applying best approaches to identifying children in need of services, and ensuring that these children receive high quality surgical services and visual rehabilitation. While much remains to be done globally, the lessons learned from these projects can help guide future strategies, benefitting not only children and their families, but society as a whole.

From June 2006—June 2008, implementing organizations screened 95,576 children for visual acuity and basic eye conditions. All projects worked to find ways to ensure that every child identified received quality eye care services by creating comprehensive eye care teams and providing counseling and follow-up care. Although different approaches were used, the projects led to 479 children in five countries receiving sight-restoring surgery, while 973 other children received spectacles for refractive error. Overall, the investment in the five projects has resulted in nearly 24,000 years of blindness averted, as children who received surgery have an estimated life expectancy of 50 years.

Most children have good vision, healthy eyes, and low rates of refractive error and surgical needs,

**Venila Rhodes** is a 12 year old girl from Hai District in the Kilimanjaro region. Currently, she attends a special school for children with visual impairments. Venila was first taken to the hospital for her vision problems when she was 3 years old. The hospital referred her to KCMC where she received cataract surgery. During her post operative follow-up care, it was determined that Venila needed cataract surgery in her other eye. She received this surgery, but was unable to receive follow-up care due to the financial constraints of her family. Venila continued experiencing vision problems until her school was visited by KCMC, and determined that Venila needed a secondary IOL operation. She received the surgery at no charge. KCMC also provided Venila with spectacles. Venila was afraid to undergo another surgery, and believed her eyes would be damaged. After surgery however, she was extremely happy with her visual improvement, and her glasses allowed her to be more productive and happy in the classroom.





Photos show condition pre- and post-cataract surgery.

suggesting that targeted approaches to identifying children with refractive, medical, or surgical needs are required. Although 30,060 children were screened in Uganda, only 46 children (or one for every 493 children) required surgery, and 15 received glasses. This compares with screening 12 children in Niger, 16 children in Nigeria, and four children in Tanzania to find one child in need of an intervention. Screening in India led to more children receiving surgical, medical, or optical services. Screenings at vision centers and the base hospital proved to be the most productive channels for reaching children in India.

### Lessons Learned: Improvements Needed in Training and Policy

Lessons learned from the five highlighted USAID-funded projects could inform revisions of existing training programs and contribute to policy improvements. The three most important lessons learned from these medical and surgical interventions are:

- Engaging directly with the community is important.
- Utilizing several targeted approaches to find children is more effective than a “shot-gun” approach.
- Building strong systems to ensure that children identified reach the surgical facility, obtain surgery, and receive post-operative optometric and low vision services.

### Expanded Training for Primary Health Workers

Healthcare workers who are chosen to receive pediatric eye care training will vary from country to country.

Few primary health workers in Africa and Asia, including those immunizing children, have received training in pediatric eye care needs. The possibility of incorporating pediatric eye care training messages into child immunization training curriculums for healthworkers should be explored. Health education messages which are relevant to pediatric eye care should be promoted. Standardized health education cards, which can be adapted for each country, might also be helpful. Health training programs currently in place in a number of countries, including Tanzania and India, could be utilized better.

The grantee experience also highlights the need to train a comprehensive pediatric eye care team. While all projects trained or had a pediatric ophthalmologist, they often did not have access to a complete, comprehensive team consisting of a childhood blindness and low vision coordinator, pediatric anesthetists, optometrists and low vision specialists. This caused many projects to struggle with follow-up and post-operative services.

### Policy Development

At the national level, CEHTF catchment areas must be better defined. WHO recommends one CEHTF per 10 million people, and these guidelines should be followed. Tanzania, a country with a population of 38 million, requires four CEHTF. The country, however, is currently operating with two: one in Moshi and another in Dar es Salaam. New CEHTF should be added only in areas which are not currently covered, as duplication of surgical services is

extremely expensive, causes frustration, and leads to confusion of health staff regarding appropriate referrals and follow up.

Coordinating service delivery requires the involvement of all partners. Organizing a small Childhood Blindness Working Group under the auspices of the National Prevention of Blindness Committee in every country with a CEHTF would be helpful. This committee should be tasked with ensuring efficient coordination, reviewing and adopting evidence-based strategies, and working with training institutions to integrate eye screening into routine child health services.

### Way Forward

Further support for child eye health activities should be linked to the provision of a basic package of eye care services (including post-operative refractive correction, low vision services, and appropriate educational placement). Although there are a number of documents identifying the components necessary for this “package” of services, it might be useful to compile these into a set a guidelines for the purpose of funding.

Implementing organizations agree that it is not necessary or desirable that all services be provided free-of-charge. Hospitals should be fully aware of the total cost of providing high-quality eye care services for children before implementing a pediatric surgical eye care project. Facilities unwilling to invest in comprehensive services for children should be discouraged from developing a surgical program.

Better systems must be put in place to ensure sustainability in identifying visually impaired children, and maintaining access to the surgical, medical, post-operative and follow-up care that they need. Targeting school children appears to be an ineffective method for identifying and referring children, as the most effective surgical interventions for congenital and developmental cataracts occur within the first few years of life. None of the featured organizations anticipate that ser-

vices for identifying, referring, and providing surgery to children can be maintained through government support or patient fees alone. KCCO calculated the cost of surgery for congenital or developmental cataract, and initial findings suggest costs in the range of \$500 per eye.

While governments can cover some costs—such as

Table 2. Sustainability of tertiary eye care services in Children: What it really costs to perform congenital cataract surgery on a child (calculations from Tanzania).

Type of cost	Amount (US\$)
Hospital: ward expenses	\$134.20
Hospital: Surgical expenses	\$300.14
Hospital: Follow up expenses	\$47.00
Patient expenses: direct costs	\$58.98
Patient expenses: indirect costs	\$17.48
Total	\$557.80

Type of Cost	Percentage
Salaries	54
Transport, food, etc.	24
Consumables	22

salaries—most costs will require continued external support. The above estimate includes transport costs to the hospital and lost opportunity costs for parents, but does not include the cost of key informant trainings. Thus, in all project settings, it is likely that organizational sustainability can be developed, but that financial sustainability will require continued external funding.

