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 the eyeglasses, visual aids, or 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 through support to nongovernmental organizations (NGOs) that deliver services to populations in need. The goals and priorities of the program are to:

- Expand delivery of high-impact direct services, including screening, treatment, and education and rehabilitation.
- Scale-up innovative approaches to service provision and program implementation.
- Contribute 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 41 grants to 24 local and international organizations to support work in 29 countries across Latin America, Asia, and sub-Saharan Africa. The majority of grant awards support service delivery efforts that provide comprehensive services for children, from case detection and treatment, to follow-up care. The following case study provides an in-depth look at Child Sight Foundation (CSF), a child blindness grantee providing education and rehabilitation services for children in Bangladesh.

Beyond Clinical Services: Providing Education and Rehabilitation Services for Blind and Visually Impaired Children

Child blindness remains a significant global health problem. The physical, social, educational, and economic consequences of child blindness impact the entire family. In developing countries, where 75% of blind children live, families often do not have access to the specialized resources they need to improve the quality of life of their children. In addition, lack of human resources and political commitment further impede children from accessing these services, resulting in social isolation, low self-esteem, and lack of independence.

From November 2007 to October 2009, CSF helped to bring specialized services closer to the children who need them. Using a process of identification, training, counseling, rehabilitation, education, advocacy, and vocational training, CSF helps blind and visually impaired children in Bangladesh move from a life of dependence and isolation, to a life of confidence and self-reliance.

Child Sight Foundation/Bangladesh: Bringing Services Closer to Children Who Need Them

Bangladesh is one of the poorest and most densely populated countries in the world, with 36 percent of the population living on less than US$1.00/day. Childhood visual impairment and blindness is a major public health problem in Bangladesh, and recent research led by the Child Sight Foundation (CSF) shows that an estimated 40,000 children in Bangladesh are blind, and an additional 1.2 million children suffer from visual impairment.

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The majority of the eye care facilities and rehabilitation services in Bangladesh are located in the urban areas of Dhaka and Chittagong, despite the fact that 80 percent of the country’s 150 million people live in rural areas. This presents a significant problem for children who are financially or physically unable to travel from their rural villages to the country’s urban centers to receive the services they need.

Using a comprehensive approach to service delivery, CSF brings education and rehabilitation services into the homes and communities of blind and disabled children in the districts of Sirajganj and Shahjadpur, eliminating the need for them to travel to distant urban areas.

**Identifying Children**

Identifying blind children who are not currently enrolled in a special education school or an existing rehabilitation program is challenging. The stigma and prejudice surrounding blind and disabled children in Bangladesh often compels parents to keep their children at home, hidden from the public eye. CSF uses the “Key Informant Method” (KIM) to identify these children.

**Table 1: A timeline of activities for the key informant method**

<table>
<thead>
<tr>
<th>Activities</th>
<th>Weeks</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mapping social networks</td>
<td>1</td>
</tr>
<tr>
<td>Networking and sensitisation</td>
<td>2</td>
</tr>
<tr>
<td>Organising a local group of key informants</td>
<td>3</td>
</tr>
<tr>
<td>Key informant training</td>
<td>4</td>
</tr>
<tr>
<td>Health communication and case finding</td>
<td>5</td>
</tr>
<tr>
<td>Supporting key informant activities</td>
<td>6</td>
</tr>
<tr>
<td>Planning and organizing the eye examination day</td>
<td></td>
</tr>
<tr>
<td>Eye examination day</td>
<td></td>
</tr>
<tr>
<td>Documentation and monitoring</td>
<td></td>
</tr>
<tr>
<td>Referral and follow-up</td>
<td></td>
</tr>
</tbody>
</table>


**Training Key Informants**

CSF partners with local community volunteers, and trains them to become “key informants” (KIs). Individuals that are well-known within the community, including teachers, social workers, community leaders, religious leaders (Imams), traditional healers, local journalists, and college students, are recruited to become KIs. CSF organizes KI trainings during which volunteers learn methods for identifying children suspected of having a visual impairment, and receive manuals, flipcharts, posters, and child blindness leaflets for distribution in their communities.

When training is completed, key informants spend six weeks working in their sub-districts, networking as widely as possible so that children in difficult-to-reach, remote corners of the district are identified and referred for treatment. From 2007 to 2009, CSF trained approximately 800 key informants, bringing the total number of trained KIs in Bangladesh to 20,000. Since 2001, over 15,000 children have been identified using this method.

**Examining Referred Children**

Identified children are either referred for screening, examination, and treatment by an ophthalmologist at a local participating clinic or hospital, or they are asked to come to a local “eye examination camp.” Examination camps are large-scale, community-based eye examination days during which groups of trained ophthalmologists examine all individuals in the community who are in need of eye-care. Key informants distribute information about upcoming eye examination camps during their community rounds, and encourage parents to bring children to the camp for examination. Blind and visually impaired children who are examined and will not benefit from refraction or medical treatment are enrolled in CSF’s home-based rehabilitation and inclusive education program.

**Parent Advocacy**

CSF works closely with parents whose children are referred for home-based rehabilitation, as parental commitment is crucial to the success of a child’s rehabilitative program. Due to a lack of information, training, and resources, however, parents are sometimes hesitant to commit the time and energy necessary to rehabilitate their child. Families are often unaware of the capabilities of their visually impaired or disabled children, and may feel that their child is unable to learn, contribute to the regular operations of the household, or participate in normal activities. Many parents are afraid that their child will be ostracized or stigmatized in the community, and therefore prefer to keep them at home rather than send them to school. Furthermore, most parents do not know that national policies in Bangladesh require schools to admit all children into their classrooms, regardless of the child’s ability.

“When parents in these districts have a blind child, they do not know how to teach that child, support them, or if the child is able to work around the house, or go to school. As a result the child often stays in the home with nothing to do, and does not know how to bathe themselves, use the toilet, or any of these basic skills. Blind children are able to do these things, but they do not know how unless someone teaches them using the correct methods,” said Ali Ahad, CSF Project Coordinator.
Community-based Rehabilitation

Community-based rehabilitation is currently the preferred model of service delivery for persons with disabilities, including visual impairment, in developing countries like Bangladesh. Rehabilitation in professional centers, usually located in urban areas, is not a practical solution for children residing in resource-poor and geographically isolated rural community settings. Home-based rehabilitation is often the only solution for children who do not live in urban areas.

When a child is referred for home-based rehabilitation, a CSF-trained rehabilitation officer visits the child’s home to perform an analysis and design the program. Each rehabilitation program is tailored to the specific needs of the individual child based on their mental and physical capabilities. The child receives one-on-one training in basic life skills, fine and gross motor skills development, language, mobility, cognition, and social communication and interaction. Children who are completely blind receive Braille training and any other assistive devices they need. The rehabilitation officer also acts as the child’s advocate within the family, community, and eventually, the school system. Counseling is provided and parent and family involvement is encouraged throughout the process, enhancing the family’s ability to support their child.

Inclusive Children’s Clubs (ICC)

Forming close relationships and being accepted by other children in the community is vital to a blind and visually impaired child’s self-esteem, motivation, and educational progress and success.

“If a child does not gain experience socializing and communicating with adults and peers before entering the school system, the probability for their educational success is lowered,” said Afrozia Parvin, CSF Research Officer.

To foster a smooth transition between home-based rehabilitative care and enrollment in the school system, CSF designed the Inclusive Children’s Club (ICC) — a social and educational outlet that allows for visually impaired and blind children to interact with their sighted peers in a positive and supportive environment. The ICC cultivates a sense of belonging, reduces stigma and fear, and helps to mainstream the child back into the community of children. ICCs are hosted at the CSF office or by the blind child’s family at the child’s home, with financial, operational, and logistical support from CSF. CSF provides games, books, musical instruments, sports equipment (such as cricket equipment with a musical ball that is suitable for visually impaired children), and educational materials that are often otherwise unavailable in the community. All children living in close proximity of the club are invited to join.

Community children that attend the club learn about blindness and visual impairment as well as other subjects such as history, art, and music. The goal of the ICC is for both blind and sighted children to learn that they are able to socialize, play and interact together easily. This non-formal peer-to-peer approach enhances the blind and visually impaired child’s self-esteem and communication skills, and is a vital next step in socialization training before enrollment in the school system.

“Peer-to-peer assistance happens as children with normal vision naturally begin to help their visually impaired-friends, helping them get to and from school and feel wel-

CSF works diligently with parents to increase their knowledge, reassure them of their child’s capabilities, and reinforce the message that blind children are fully able to participate in everyday life in the home, school, and surrounding community. The organization counsels parents and involves them in local self-help groups, which promote group problem solving and teach parents how to advocate for the rights of their children at the community and district levels. Participating parents set the agenda, and all sessions are participant-led and facilitated by CSF staff.

come and accepted in their peer circle,” said Johurul Jewel, CSF Program Manager.

Inclusive Education

Research has shown that schools that have an inclusive orientation towards blind and disabled children contribute to the effective prevention of discriminatory attitudes in communities and societies. Inclusive education teaches children at a young age that disabled individuals have the same rights as able-bodied individuals, and that they, too, can learn, work, and accomplish great things.

CSF works with elected officials at the district and community levels to promote this way of thinking, and to garner support for inclusive education for blind and visually impaired children in the community. If district officials authorize the implementation of an inclusive education program, CSF begins advocating with school staff on the importance of inclusive education, and training teachers and principals in methodologies for teaching blind children in the classroom. CSF provides the child’s history to the school, and explains that the child has gone through an intensive rehabilitation program and has received lessons in classroom etiquette.

Once the school is prepared and teacher training is completed, visually impaired and blind children, their parents, and CSF staff visit the school for orientation. Classmates who live near the blind or visually impaired child (and who have often attended the ICC) are asked to volunteer to assist the child at school, and to ensure the child gets to and from school safely. Teachers are provided with the educational and assistive materials necessary for the visually impaired child to be successful in the classroom.

Ali Ahad, Coordinator for CSF said, “The children become very close at the ICC. Sighted children become friends with the disabled child, and help him [or her] at school and on the way home.”

Sensitization, Advocacy, and Media Campaigns

Disabled, blind, and visually impaired children in Bangladesh are further challenged by a pervasive public perception that education for blind and disabled children is either unnecessary or unsuccessful. CSF attests that a lack of knowledge and awareness about the causes of visual impairment and the potential capabilities of children facing these challenges often results in stigmas, negative attitudes and community apathy toward the visually impaired children.

CSF works at the household, community, district, and national level to distribute key messages to reduce the stigma and prejudice surrounding child blindness and visual impairment, change public opinion, publicize the rights of the child, and draw attention to existing national policies on inclusive education for blind and disabled children.

“There is a national policy in Bangladesh stating that disabled children — including blind and visually impaired children — have a fundamental right to education and must be granted access to schools. But this policy has not been publicized in any way, and parents, teachers, and school administrators in remote areas of the country do not know that disabled children are not only physically and mentally able to go to school, but required by law to be allowed access to school,” noted Johurul Jewel.

CSF distributes advocacy information and messages through key informants, community examination camps, and designated Child Sight Journalists (CSJ) — national television and print media professionals reporting on issues related to health, human rights, development, and women and children’s issues in Bangladesh.

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Coordination and Partnerships
CSF works with district-government-level officers (from the Departments of Health, Education and Social Welfare) of Sirajganj and Shiradhpur to gain support for the implementation of home-based rehabilitation and inclusive education programs in these school districts. Partnering with local community leaders—who are often more influential and autonomous than district-level officers—has been crucial to the community endorsement of CSF programs, and to creating partnerships with school headmasters, principals, and teachers.

CSF founded the Upazilla Child Sight Society, an advocacy group that brings together elected officials, influential community members, school staff, and parents at the sub-district level to discuss the importance of inclusive education for all children within their communities. This forum has fostered an open dialogue between stakeholders, allowing them to work together to create solutions to the challenges facing their education system.

At the national level, CSF is the secretariat for the Child Sight Network, a nationwide network of 70 development organizations working to create a more inclusive environment for blind and visually impaired children in Bangladesh. The network is an advocacy, policy development, and technical resource for organizations combating childhood blindness, visual impairment and disabilities in the country.

Barriers to Implementation
CSF cited parents’ and teachers’ negative attitudes and lack of information as challenges to program implementation. In addition, lack of public awareness about blind and disabled children and a failure to implement national-level education policies are also persistent barriers.

Parents
Parents’ and families’ attitudes about the capabilities of their blind children are often barriers to the uptake of rehabilitative services. CSF works to change this perception in the home by training parents and caregivers, and including them in the rehabilitative process. Fostering a hands-on approach and discussing the parents’ dreams for their child is another way CSF overcomes this barrier.

“All parents want education and a good life for their children. Convincing the parents that the child can still have a healthy and fulfilling future as a teacher or an Imam, or that the child can receive vocational training so he or she can have their own job, is key to changing a parent’s attitude about the need for their blind child to receive the initial rehabilitation and attend school,” said Johurul Jewel.

CSF reaches further into the social network of the family and community, contacting neighbors and relatives and inviting them to partake in the rehabilitative process as well. This creates a support circle around the child, increasing the probability that the child’s rehabilitative program will be successful.

Education System
Many teachers believe that blind children are incapable of learning in a classroom alongside their sighted peers. CSF often has to provide several rounds of counseling and trainings to teachers before schools are willing to admit blind and visually impaired children into their classrooms. Teachers in Bangladesh (who receive minimum-wage salaries) are often not motivated to take the time to attend teacher trainings for children with disabilities, or spend extra time during and after school hours working with blind children who may move slower through their lessons than their sighted peers.

Jasmine, 7, Sirajganj, Bangladesh
Jasmine was born in a remote village of Bangladesh. The only daughter of a rickshaw driver, Jasmine was born blind. Jasmine’s parents confided in CSF that while they loved their daughter, they didn’t understand why Allah had chosen to give their daughter a disability. They feared their daughter had been cursed, that her illness was related to a sin.

CSF worked with Jasmine’s parents and encouraged them to enroll their daughter in a home-based rehabilitation program. When rehabilitation first began, Jasmine was extremely introverted, could not communicate, and was very unhappy. She had little independent mobility and constantly held onto her mother’s dress for support.

CSF worked with Jasmine to improve her communication, socialization, cognition and self-care skills. She was soon admitted into Class 1, where she learned to sing, speak, and recite poetry.

Jasmine and her family cited that Jasmine had often been the target of verbal abuse in her community. Through CSF-led community advocacy meetings and self-help groups, Jasmine has been able to form a support network within her community to combat the prejudice against her.

Jasmine now regularly goes to school and dreams of becoming a teacher when she grows up.
CSF works with teachers and school principals to change their attitudes and opinions about inclusive education by coordinating introductions to visually impaired students, teacher trainings, and information about national policies in Bangladesh on the rights of the child.

**Policy-level**

Despite the fact that there is a national inclusive education policy in Bangladesh stating that the education system should admit all children regardless of ability, it is rarely enforced or communicated within the education system. Parents, district officials, and school administrators are often unaware that this policy exists.

CSF works with the national and district governments and their education, health, and social welfare departments to implement the National Disability Act within the education system. CSF emphasizes inclusive education as a basic right for all children, regardless of their ability, and actively lobbies the Department of Education to adopt this philosophy, shifting from a welfare-based, charity education approach to a more human rights-based approach.

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**Results**

From 2007-2009 in two districts of Bangladesh (Sirajganj and Shiradhpur), CSF:

- Screened, examined and referred over 230 children for medical, optical, surgical and rehabilitative interventions.
- Enrolled 200 children in home-based rehabilitative services.
- Trained an additional 13 ophthalmologists working at the district and community levels.
- Trained 205 community volunteers (children, families, caregivers) to be “buddies” to blind and visually impaired children in their communities.
- Involved 80 percent of parents of blind or visually impaired children in advocacy, self-help, and awareness-raising efforts.
- Enrolled 160 children into inclusive education programs at local schools in the community.
- Identified and prepared 33 additional schools for attendance by children with blindness, visual impairment, and additional disabilities.
- Trained 46 school teachers and staff in inclusive education, methodologies for teaching blind children, and the Braille system.
- Established six additional successful and ongoing parent self-help groups.
- Trained 800 key informants.

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### Table 2: Distribution by gender, age, and division within the different methods of case ascertainment

<table>
<thead>
<tr>
<th>Gender</th>
<th>Special education</th>
<th>CBR</th>
<th>Key informants</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Boys</td>
<td>280 (71.1)</td>
<td>180 (60.8)</td>
<td>760 (61.0)</td>
<td>1200 (63.0)</td>
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<tr>
<td>Girls</td>
<td>114 (28.9)</td>
<td>116 (39.2)</td>
<td>485 (39.0)</td>
<td>715 (37.0)</td>
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<tr>
<td>Age years</td>
<td>p=0.001*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-5</td>
<td>8 (2.0)</td>
<td>8 (2.7)</td>
<td>27 (1.9)</td>
<td>43 (2.3)</td>
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<tr>
<td>6-10</td>
<td>121 (30.7)</td>
<td>86 (29.0)</td>
<td>168 (13.2)</td>
<td>361 (31.6)</td>
</tr>
<tr>
<td>11-15</td>
<td>265 (67.3)</td>
<td>168 (56.8)</td>
<td>594 (47.7)</td>
<td>1027 (53.1)</td>
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<tr>
<td>Visual acuity</td>
<td>p=0.008</td>
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<td></td>
<td></td>
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<tr>
<td>SVI</td>
<td>19 (4.8)</td>
<td>23 (7.8)</td>
<td>122 (9.8)</td>
<td>164 (8.5)</td>
</tr>
<tr>
<td>Blind</td>
<td>375 (95.2)</td>
<td>273 (92.2)</td>
<td>1123 (90.2)</td>
<td>1771 (91.5)</td>
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<tr>
<td>Dwelling</td>
<td>p&lt;0.001*</td>
<td></td>
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<td></td>
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<tr>
<td>Rural</td>
<td>344 (87.3)</td>
<td>287 (97.0)</td>
<td>1361 (97.7)</td>
<td>1847 (95.5)</td>
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<tr>
<td>Urban</td>
<td>50 (12.7)</td>
<td>9 (3.0)</td>
<td>29 (2.3)</td>
<td>88 (4.5)</td>
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<td>Family history</td>
<td>p=0.164</td>
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<td></td>
<td></td>
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<tr>
<td>Yes</td>
<td>91 (23.1)</td>
<td>76 (25.8)</td>
<td>259 (20.9)</td>
<td>426 (22.1)</td>
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<tr>
<td>No</td>
<td>303 (76.9)</td>
<td>219 (74.2)</td>
<td>982 (79.1)</td>
<td>1504 (77.9)</td>
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<tr>
<td>History of consanguinity</td>
<td>p=0.77*</td>
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<td></td>
<td></td>
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<tr>
<td>Yes</td>
<td>62 (17.0)</td>
<td>55 (19.2)</td>
<td>228 (18.0)</td>
<td>348 (18.0)</td>
</tr>
<tr>
<td>No</td>
<td>302 (83.0)</td>
<td>235 (80.8)</td>
<td>1010 (82.0)</td>
<td>1547 (82.0)</td>
</tr>
<tr>
<td>Age of onset</td>
<td>p&lt;0.001*</td>
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<td>Congenital</td>
<td>139 (35.3)</td>
<td>112 (37.8)</td>
<td>361 (29.0)</td>
<td>612 (31.6)</td>
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<td>Infants</td>
<td>46 (11.7)</td>
<td>56 (18.9)</td>
<td>314 (25.2)</td>
<td>412 (21.4)</td>
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<td>1-5 yrs</td>
<td>235 (68.3)</td>
<td>34 (32.0)</td>
<td>303 (22.9)</td>
<td>737 (39.2)</td>
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<td>5 to &lt;16 yrs</td>
<td>74 (18.8)</td>
<td>34 (11.5)</td>
<td>209 (16.8)</td>
<td>317 (16.4)</td>
</tr>
<tr>
<td>Disability</td>
<td>p=0.005*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>7 (1.8)</td>
<td>17 (5.7)</td>
<td>72 (5.8)</td>
<td>96 (5.0)</td>
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<tr>
<td>No</td>
<td>387 (98.2)</td>
<td>279 (94.3)</td>
<td>1173 (94.2)</td>
<td>1839 (95.0)</td>
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<tr>
<td>Total</td>
<td>394 (100)</td>
<td>296 (100)</td>
<td>1245 (100)</td>
<td>1935 (100)</td>
</tr>
</tbody>
</table>

Aftab, 9, Shirajganj, Bangladesh

Aftab Ali Sheck was born blind. His father, a rural farmer in Sirajganj district of Bangladesh, did not have the means to provide specialized schooling or therapy for his son. As a result, Aftab was unable to go to school with the other children in his village, or perform any basic self-care activities. He did not know how to brush his own teeth, use the bathroom by himself, comb his own hair, or bathe.

In 2009, a key informant identified Aftab and referred him to the Child Sight Foundation in Sirajganj. CSF performed an assessment, and enrolled him in its home-based rehabilitation program. CSF volunteers came to Aftab’s home daily, and worked with him through an intensive rehabilitation program.

CSF volunteers worked with Aftab’s parents to create and host an Inclusive Children’s Club (ICC) at their house. The village children were excited to join the new children’s club at Aftab’s house, and quickly formed friendships with him. Through the ICC, Aftab excelled in music, gained confidence, and loved socializing with the other children from his village. Soon Aftab was ready to go to school. His new friends from the children’s club walked him to and from school, and helped him in the classroom throughout the school day. Aftab can now be seen participating in class, playing with friends, and learning to navigate his new environment.

“Before I did not play or sing. Now I have friends. I go to school. I play music with my friends,” he said.

CSF’s experience has shown that the key informant method is a very effective approach for identifying blind and disabled children in Bangladesh (including compiling names from special education school rosters or other community-based rehabilitation programs). Children identified by KIs are likely to be young in age (0–5 years), from rural areas, and severely visually impaired (rather than completely blind). These findings show that there is an opportunity for child eye programs to utilize KIs to identify children with visual impairments early on, while the prognosis for sight-restoring surgery is still good.8

Recommendations and Way Forward

During the two-year grant cycle, CSF implemented a comprehensive service delivery program — from child identification, to rehabilitation, to enrollment in education programs — many aspects of which are still ongoing and community-owned (such as parent self-help groups and the Inclusive Children’s Club). The success and sustainability of these programs illustrates the potential ability for scale-up in other districts of the country.

Funding constraints impact other program areas, including the provision of the Braille system and other necessary assistive devices to newly identified blind children in the community.

Additionally, a blind or severely visually impaired child requires approximately five years for rehabilitation, while grants cycles are often short term, ranging from one to two years in length. Going forward, donors offering longer-term funding would enable CSF and other NGOs that address the needs of low vision and blind children to fully and successfully integrate these children into society.

Further collaboration with the Ministry of Education, NGOs, and school administrators is necessary to publicize and promote the national inclusive education policy of Bangladesh. Raising awareness of this policy will enable CSF and other implementing organizations to more quickly and easily enroll children into community schools.