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Article 53 of the 1994 Salamanca Framework for Action addresses the need for early childhood education for children with disabilities:

*The success of the inclusive school depends considerably on early intervention, assessment, and stimulation of the very young child with special educational needs. Early childhood care and education programs for children aged up to six years ought to be developed and/or reoriented to promote physical, intellectual and social development and school readiness. Programs at this level should recognize the principle of inclusion and be developed in a comprehensive way by combining preschool activities and early childhood health care.*

A comprehensive approach that links education and healthcare in Bangladesh is critically important given the serious nutrition issues related to poverty that impact directly on a child's cognitive development. Failure to respond to the nutritional or health needs of the young child may cause irreparable neurological damage and cognitive damage. Parents and family members need to be empowered with knowledge and skills to understand and serve the development needs of children.

The decade 1993-2002 was proclaimed by the United Nations Economic and Social Commission for Asia and the Pacific (ESCAP) as the Asian and Pacific Decade of Disabled Persons. In May 2003 the ESCAP adopted a resolution on promoting an inclusive, barrier-free and rights-based society for persons with disabilities in Asia and the Pacific. It supplements the UN Millennium Development Goals and proclaims an extension of the Asian and Pacific Decade of Disabled Persons for another decade, 2003-2012. Guidelines for government actions to be undertaken during the decade, known as the Biwako Millennium Framework, were developed to conclude the first decade and set priorities. The framework identifies seven priority areas for action, including areas of particular relevance to children, "early detection, early intervention and education" and "access to information and communications, including the information, communication and assistive technologies."<sup>29</sup>

The United Nations Standard Rules on the Equalizing of Opportunities for Persons with Disabilities (referred to as the "Standard Rules") was adopted by the United Nations in 1993. It is one of the international conventions that supports the rights of persons with disabilities and provides guidance to governments on making social, political, and legal changes to ensure that persons with disabilities become "full and equal citizens of their countries." The Government of Bangladesh adopted the Standard Rules in the same year.

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<sup>29</sup> (Short form) Bryskov et al., *Disability in Bangladesh*, 19-20.

The Convention on the Rights of the Child (CRC), to which Bangladesh is a signatory, establishes minimum standards for every aspect of children's lives, including education. The core minimum targets for education include free, compulsory primary education for all (Article 28) and the right of disabled children to special care and training designed to help achieve self-reliance and a full and decent life in society (Article 23).

## National Context

In Bangladesh, the national framework for disabilities is the Bangladesh Constitution which states "no citizen shall, on grounds only of religion, race, caste, sex, or place of birth be subjected to any disability, liability, restriction or condition with regard to access to any place of public entertainment, or resort, or admission to any educational institution." In 1995 the first National Policy for the Disabled was approved by the Government, which "mainstreamed disability into the country's development agenda."<sup>30</sup> An Action Plan to operationalize this policy was approved in 1996.

The Bangladesh Parliament adopted its first comprehensive disability legislation, the Bangladesh Persons with Disability Welfare Act 2001, in April of that year. The legislation includes definitions of persons with disability that identifies those with physical disabilities, visual impairment, hearing impairment, speech impairment, mental disability (cognitive disability or mental retardation), and mental illness, characterized as "...loss or damage, partially or wholly, of mental balance."

Persons with multiple disabilities (more than one type of impairment) are also covered under the Act, whether the cause of the disability is congenital or a result of accident or disease, maltreatment, or other reasons. If a person is incapacitated and unable to lead a normal life, either partially or fully, as a result of the disability or mental impairment, the Act identifies that person as one with a disability.

On May 7, 2002, The National Action Plan for People with Disability (PWD) was promulgated as a directive from the office of the Prime Minister. The Action Plan stipulates what needs to be done to realize the goals of the Disability Welfare Act in five areas: education, health, employment, accessibility, and transportation.<sup>31</sup> As examples, the plan recommends creating mass awareness about disability as a method of prevention; conducting surveys and registration at birth for the identification of disabilities; providing special schooling and logistical support, including disability in the curriculum; teaching children "alongside general students;" setting up programs of inclusion of severe and multiply handicapped students for education; and developing public accessibility so that disabled persons will have communication and mobility. A major constraint to implementation of the Action Plan is funding, discussed elsewhere in this report. This action plan has not yet been implemented.

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<sup>30</sup> Ibid., 21.

<sup>31</sup> Meenu Bhambani and Maj-Lis Voss, *The World Bank and Disability in South Asia A Portfolio Review*, (Washington, DC: World Bank, October 2003).



households where most illiterate persons lived. Conversely, when the rate of literacy increases there is a concomitant decrease in incidence of disability. Only two percent of persons with disability were found in households where all family members were literate. A UNICEF study in 2000 found that literacy rates in Bangladesh for females were 29 percent, 52 percent for males.

Parents in poverty, most of whom are illiterate, are not aware of their fundamental and constitutional right as parents to demand an education for their child. This is especially applicable to parents of children with a disability. Children with disabilities tend to be neglected and ignored, tend not to be taken outside the home because of embarrassment and potential teasing and ridicule from others. They are often abused by family members and others in the community who are caught up in this negative stigma. The children lead isolated lives, excluded from their peer groups. This aloneness has a very negative effect on the self-concept and self-esteem of disabled children, a contributing factor to poor school performance.

The media has neither included children with disabilities in their programming nor do children with disabilities have access to print and non-print materials. With respect to the media, children with disabilities are “invisible;” they don’t exist.

Access to school and retention in school are negatively influenced by the fact that school management committees (SMCs), community leaders, and village leaders (Imams) do not accept children with disabilities, with few exceptions. School managers (principals and head masters or mistresses) do not welcome them either, reflecting community attitudes that children with disabilities will harm other children or they are “hopeless” to teach. Likewise, typically developing children absorb negative community and societal attitudes and will not or do not know how to interact with children with disabilities.

School environments are not supportive of special needs education. They do not include adequate hygiene (toilets) for children with disabilities, appropriate furniture, assistive devices (e.g., Braille and hearing aids), and appropriate educational materials. Special teaching equipment is not available in the country’s schools. The government, although it has stipulated a policy of inclusive education, has not provided the resources or the will to ensure that children with disabilities do, in fact, attend mainstream schools.

Trained and motivated teachers are critical to provision of a quality education for all students, and especially for those with disabilities. In Bangladesh, there is a scarcity of such skilled teachers. Curriculum adaptations are often necessary, but they do not exist.

Awareness programs are needed to create greater awareness of parents and family, teachers, community members, SMCs, and the disabled children’s peers. These programs can be offered through NGOs, self-help organizations, Government efforts, and other means.

Expectations influence educational achievement. Parent expectations, as well as teachers’ expectations, are limited by their feeling that these children can’t learn. Inability to learn is often confused with stubbornness when in fact the child could learn and perform if appropriate training, support, and materials were available.



















More recently, BRAC initiated services for children at the preprimary level. These programs target children with mild to moderate disabilities ages 5 to 6 (with the option to age 7, if indicated). These programs have served a total of 683 students in these areas: physical impairments (307); intellectual (88); visual (73); hearing (40); and speech (175). Children with physical impairments and speech difficulties represent 71 percent (n = 482) of the total number served in BRAC's preprimary program.<sup>54</sup>

## SUCCEED

SUCCEED is a four and a half year project in early childhood education developed by Save the Children Federation, Inc. (SC) to support achievement of USAID/Bangladesh's Strategic Objective 10: Improved Performance at Early Childhood and Primary Education Levels through Innovative Learning Models. Its funding is \$12 million. The project was signed into effect in August 2004 and was to be officially launched January 30, 2005. However, due to political unrest and a hartal (general strike), formal launching of the project has been delayed.

The SUCCEED project will have linked activities in five regions of the country: Sylhet, Rajshahi, Khulna, Barisal, and Dhaka divisions. In each region, Save the Children will select an area known as a "Learning Hub" where "*Beacons of Success*" will demonstrate best practice examples for early childhood development and primary education initiatives and advocacy. SUCCEED's targeted interventions aim to improve children's learning in early childhood, grades one and two.

The SUCCEED project will collect data through house to house surveys on children with disabilities, and implement program planning to serve children, ages 5 to 8, with disabilities, primarily with physical handicaps, in the beginning stage. Children who can be educated in the mainstream (regular classes) with accommodations will be served. The project will promote the concept of inclusive education in the formal schools, making adaptations as necessary for those with mild disabilities; outreach to ethnic communities is also planned.

The capacity of selected institutions will be strengthened through curriculum and material development in order to better serve children with special needs. Through national awareness campaigns, national and regional workshops, and other activities, the SUCCEED project will promote education equity for all.

Beneficiaries at the preschool level are expected to be 72,000 children, 72,000 parents, 600 teachers, and 600 institutions and groups. A door-to-door survey will be conducted to identify children in the community with disabilities. Only children with disabilities allowing them to be mainstreamed (mild to moderate) will be targeted. Children with physical disabilities will be targeted initially for services.

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<sup>54</sup> BRAC Education Program (2003-2004): Progress Report. NFPE Phase III, (Dhaka, BRAC Center), 8.

















Taking the examination in two parts is allowed for these special students. HI-CARE also is used as a student teaching placement for the Special Education Department, Institute of Education and Research, Dhaka University.

In the Dhaka center, fees are generated from the audiology center. Since the NGO receives no funding from the government, it is dependent on fund raising and donations for program sustainability. Services include awareness building (“deaf campaign”), hearing assessment, counseling, and support to other NGOs as a referral base. Students may be referred to the normal government school or to a special school depending on need. The auditory-oral method is used; this means that sign language is not taught. HI-CARE staff provides technical assistance to teachers in the regular schools and serve also as advocates to obtain a placement for the child if appropriate. A constraint is their severely limited capacity to serve more children with hearing impairments.

*Society of Assistance to Hearing Impaired Children (SAHIC)*. SAHIC, founded in 1989, provides education and rehabilitation, using oral auditory methods, special education, and awareness raising on prevention and treatment for deafness, including assistive devices. A top priority of this NGO is prevention, early identification and detection of hearing problems. Resources include highly trained audiologists and technicians, trained teachers, and qualified medical personnel (doctors). SAHIC works in two districts in Bangladesh and has provided services to 127 children, as well as adults.

*Deaf Children’s Welfare Association of Bangladesh (DeCWAB)* is an education center, located in Dhaka, for the area of deafness and hearing impairments. It was started initially as a center for hearing impaired children by the parent of a deaf child, but has expanded its service to children with multiple disabilities. The Center accommodates 34 children (seven girls and 27 boys), ages two to 18 years. Among the 34 students, there are seven or eight with Downs Syndrome and one or two with autistic spectrum disorder. There are 12 students on the waiting list.<sup>82</sup> The formal primary level curriculum is used for the hearing impaired students and an individual education program for the non-HI students. The Center is privately funded.

#### Intellectual Disabilities (ID)

*Society for the Welfare of the Intellectually Disabled, Bangladesh (SWID-B)* is an NGO, a voluntary social service organization started over 25 years ago by a few parents and some professionals. For 18 years (until 2000) it received funding from the Norwegian Association for the Mentally Retarded (NFU). Its many activities include parent training, research, counseling, clinical services (each year more than 350 children receive services), training for teachers in inclusive education, and, through its organizational development program, awareness building and advocacy. SWID-B works with other NGOs, especially BRAC, to promote inclusive education. There are 40 schools (units/branches) that provide special education and vocational training and other programs for children with intellectual disabilities, in addition to the National Institute for the Intellectually Disabled (NIID) and the BRAC schools.<sup>83</sup>

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<sup>82</sup> Based on telephone interview conducted by the study’s national consultant, January 2005.

<sup>83</sup> *25 years of SWID Bangladesh*, (Dhaka: Society for the Welfare of the Intellectually Disabled Bangladesh, December 24, 2002).

*The Bangladesh Protibondhi Foundation (BPF)* has spearheaded initiatives in many areas that have served to improve the quality of life and increase educational opportunity for children with disabilities. The BPF has been serving the intellectually disabled and children with neurological damage (e.g., cerebral palsy) since it was founded in May 1984. It serves the urban poor and children with disabilities in five districts, eight “thana,” and 29 villages throughout the country. The work is accomplished through its medical centers, sheltered workshops, and community-based rehabilitation (CBR) programs. As of December 2004, the beneficiaries of its various programs were a total of 11,370 children, of whom 5,085 were girls.<sup>84</sup> There are many on the waiting list for services.

The BPF runs a special school for the intellectually (cognitively) disabled; the Kalyani-Special School. In Dhaka there are two special schools at which these children, after screening and diagnosis, are placed in different classes for education and training according to their age levels. The special classes are named after Bangla flowers:

Komolkoli (4 to 8 years)  
Champakoli (9 to 12 years)  
Korobi (13 to 17 years); and  
Madhobi (18 years and older).

In addition to the school, BPF has two clinics; the Shishu Bikash Clinics for screening, identification, medical and therapeutic intervention, counseling, and training. One clinic is located in Dhaka, and the other in Dhamrai. A mother-child stimulation program, Dishari-Special Unit, has been developed for children with cerebral palsy. This program provides educational and therapeutic services for school age children with cerebral palsy, as well as the mother-child stimulation program for preschool age children with cerebral palsy. Services are also provided to these mothers and their children in the rural areas through the Rural Multipurpose Project.

BPF also has a distance-training program that includes booklets for the parents on motor development, communication, speech development, and cognitive development. Mothers from all over the country are served through these training manuals known as “Distance Training Manuals.” This center also is used for student teaching by the special education department, Institute of Education and Research, Dhaka University.

### Physical Impairments

*The Center for Rehabilitation of the Paralyzed (CRP)*. CRP, founded in 1979, is widely recognized for its outstanding programs serving children and adults with severe physical impairments and paralysis. Located in Savar, currently with three functioning sub centers,<sup>85</sup> it also operates a 100-bed hospital and outpatient services.

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<sup>84</sup> (Short title) *Directory of Organizations Working in the Field of Disability in Bangladesh*, 38.

<sup>85</sup> Gonokbari (Savar), Dhaka City Center (Mohammadpur) and Gobindapur (Mouvlibazar District) and, in addition, the CRP is constructing a new rehabilitation center at Mirpur in Dhaka.

The CRP offers large-scale rehabilitation programs, vocational training, and health education. It has community-based rehabilitation (CBR) programs in 49 thanas or counties.

CRP has a special vocational training and employment-generation project for disabled girls and women. Their philosophy is that successful rehabilitation is not only a physical process. Social, economic, and psychological aspects must be given equal importance.

*Special Education Needs Unit (CRP).* The CRP runs a special school, established in 1993 primarily for children with cerebral palsy. The school serves a total of 27 children between 5 and 15 years of age. The classes are divided into four units based on the student's degree of disability: mild, moderate, or severe. The class time consists of 4 hours in the morning for academic study, followed by 3 hours in the afternoon for therapy. In addition, a total of 34 students are placed in mainstream classes that follow the regular national curriculum. The school also provides vocational training (e.g., carpentry, mat making, block printing). Fees are charged.<sup>86</sup> in the amount of 4500 taka (\$75) per month. Residential students pay an additional 1600 taka (\$27).

A certificate in special education (a two-semester program) is awarded to students to upgrade their skills as teachers. An impact assessment of the program in August 2003 indicated that the training could provide support, guidance, and motivation for the teachers. Further, it was found that the training should be conducted on a long-term, and short-term, basis to develop trained personnel at different levels.

*Center for Rehabilitation of the Paralyzed (CRP)* offers training for physiotherapists, occupational therapists, rehabilitation nurses, special education teachers, and community-based rehabilitation workers and others.

Both long- and short-term training are provided through the CRP's academic institute; the Bangladesh Health Professions Institute (BHPI). Courses related to special education include the Certificate in Education for Special Education (a 12-month course); orientation one-week workshops for teachers, two-day workshops for head teachers, and a one-day workshop for policy makers on inclusive education.

*Autism Welfare Foundation (AWF).* The AWF, a recent NGO founded by a mother<sup>87</sup> of an autistic child, provides a number of services including a thorough medical checkup and psychological assessment in conjunction with the Child Development Center (CDC) located in the Children's Hospital. CDC is well known and considered by many to be the best hospital in Bangladesh. An all-day educational program is provided for 53 children ages 3 to 15 based on parental interview, developmental history, and results of other assessments such as CHAT; a Childhood Assessment Checklist.

The AWF also sponsors a home-based program where 60 children, including children on a

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<sup>86</sup> The fees for residential students are Tk4300 (\$72) on admission plus a monthly charge of Tk600 (\$10). Non-residential students pay an admission fee of Tk1500 (\$25) plus a monthly fee of Tk300 (\$5).

<sup>87</sup> Chairperson, Autism Welfare Foundation, Dhaka, Bangladesh.





children had cataracts in addition to other conditions associated with loss of sight, such as retinal detachment and glaucoma.

In addition to the study per se, which included the finding that approximately 40,000 children have bilateral problems, the research team performed eye operations on 830 children (1,275 operations including both eyes). A one-year follow-up study indicated that full recovery of sight is possible; the younger the child the better the outcome. This finding underscores the importance of early medical intervention. Dependent on receiving funding, future plans include integrating blind children--those whose sight cannot be restored--in regular primary schools.

### Intellectual, Multiple Disabilities

The BPF runs community-based rehabilitation (CBR) programs in the rural areas of Dhamrai, Savar, Kishoregonj, Narshingdi, Faridpur, Nabinagar, and Comilla, and one in the slum areas of Mirpur. Door-to-door surveys are conducted to identify children with disabilities. They are diagnosed if appropriate and then provided with an educational or training program. All BPF's CBR centers have started "inclusive schools" that include children with disabilities, the disadvantaged, and normal children.

### Physical Handicaps, Multiple Disabilities.

The Bangladesh Council for Child Welfare (BCCW) uses CBR and CAHD approaches to rehabilitate children who have physical disabilities, cerebral palsy, and hearing and speech impairments. Over its long history (it was established in 1957), BCCW has provided physiotherapy and rehabilitation therapy, and other services, for a total of over 80 percent of its 8,514 children.<sup>91</sup>

### Hearing Impaired Children.

ADESH is an NGO that uses CBR approach to help children with hearing impairments and other disabilities. ADESH does informal community surveys and, if any hearing-impaired child is found, ADESH sends the child to HI-CARE in Dhaka for audiological and hearing aid assessment. ADESH buys the hearing aid for the child and then facilitates the child's inclusion in a regular school; the World Concern school (an NGO-run school in Savar). If they find an HI child who wants to go to school in the locality and child is rejected, then ADESH serves as advocate for enrollment. VI children are referred to World Concern Savar. Foreigners train teachers and monitor the teaching; there is no government involvement. ADESH provides home service physical therapy, free of cost. ADESH also provides assistive devices free of charge.

### Training for CBR.

The Center for Disability in Development (CDD) has effective community-based worker training programs for existing community-based development workers in the areas of women,

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<sup>91</sup> (Short title) *Directory of Organizations Working in the Field of Disability in Bangladesh*, 30.

children, aging, poverty, and economic development in order to empower persons with disabilities at the community level. CDD has developed teaching and awareness campaign materials, including picture and cartoon communication, which are effective for guiding disability workers who have not had opportunities for formal education.

*“A researcher just returned from an eight hour rickshaw, boat and trekking trip to a very remote union (cluster of villages) to our research site. He was enthusiastic and talkative about what he had just seen; it represented the best of CBR: Kurigram Disabled People’s Organization for Development (KDPOD) is a self-help NGO, a member of the Bangladesh Protibandhi Kallyam Somity (BPKS), located in the Kurigram district. KDPOD envisions that all persons with disabilities live independently, with dignity in a barrier-free family and community, and that they are in a position to contribute to their own and society’s development. The goal of the organization is to ensure equality in occupations for persons with disabilities through equal rights, opportunity, and full participation in society. This NGO works to develop other grass roots organizations, to empower people, to eliminate discrimination, and to actualize development for all. The director of KDPOD<sup>92</sup> reported that a local survey of persons with disabilities had been completed, and it identified 681 persons with disabilities from birth in Fulbari, Borovita and Vangamor village clusters (“unions” in Bangladesh). Activities of the NGO include leadership development, advocacy and lobbying, and surveys. The KDPOD assists children with disabilities by bearing some of the costs, such as for books, fees, clothing, and assistive devices, as well as providing some training for the teacher on awareness building and positive attitude formation. They help train the visually impaired on ways to ensure personal safety such as how to walk safely on roads and highways and for the physically disabled how to use a wheel chair. Some of the causes of disability identified by this NGO include malnutrition, heavy work done by pregnant women, and their use of antibiotics, and a lack of awareness on the part of families about disability and its prevention.”<sup>93</sup>*

## Assistive Technology

Educational opportunity for children with disabilities is severely constrained in Bangladesh due to a lack of appropriate teaching aids, facilities, and assistive devices and technology.

Some NGOs have been successful in addressing this situation, which benefits adults with disabilities, and children, to the extent linkages are established with the NGOs that run the special schools. For example, the Bangladesh Protibandhi Kallyan Somity (BPKS) established an Assistive Devices Production Center in 1988 and has been producing different types of assistive devices. Maintenance support also is provided to users. The Center produces various types of wheelchairs, crutches, white canes and calipers, and long leg braces. The BPKS has developed innovative varieties of wheelchairs as well.

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<sup>92</sup> Md. Ayub Ali, Director of Kurigram Disabled People’s Organization for Development (KDPOD), personal communication, January 2005.

<sup>93</sup> Case study prepared from notes provided by project research assistant Md. Akhter Hossain.

The Assistive Device Network (ADNet) was started in August 1998 to assist and support organizations serving adults and children with disabilities. By November 1998, eight government and NGOs were members of ADNet. These member organizations, government agencies, and NGOs (there were eight as of November 1998) produce and distribute orthotics and prosthetics, standing and walking devices, special seats, wheelchairs, tricycles, hearing aids, toys, assistive devices for activities of daily living, protective footwear, tools and equipment for work, simple devices for communication, and Braille books. They also assist in adaptations of homes and other premises to increase accessibility.<sup>94</sup>

### Hearing Aids.

Mild to moderately disabled children with hearing, visual, and physical impairments could be integrated in regular schools if appropriate assistive devices were available at low-cost or no cost for poor families. The government, however, does not provide any assistance for assistive devices, unlike neighboring India, where assistive devices are not only available but also free if parents cannot afford to pay for them. In Bangladesh, it is only those children who have parents with means who have access to hearing aids.

One of the NGOs, (HI-CARE), assists, to the extent feasible, children in obtaining hearing aids, but the process is not systematic. A constraint is the necessity for adjusting the size of the hearing aid as the child gets older, a recurring cost. The cost of replacing batteries is also a consideration. Bangladesh imports hearing aids due to lack of domestic production capability.

### Braille-Writing Machine

The Government of Bangladesh operates a national Braille press, through the Social Services Department. It has not been functional, however. Some NGOs have also initiated computerized Braille printing services, but these are limited in scope. With private funding from the Baptist SANGHO, a school for blind girls, a Braille computer system has been set up with capacity to print books, but not on a large scale. A Braille printing press would help increase access to the general curriculum. It is not known how many blind persons in Bangladesh could utilize the output of a Braille press.

### Low Vision Aids

With support of Sight Savers International, a low vision laboratory has been established in the Department of Special Education to help prepare teachers serve children with low vision. The facility allows students to gain experience in low vision aids and conduct research using large print formats (television and computer based), assessment materials (“assessment kits” for low vision), and other teaching aids such as Braille writing machines. Capacity to produce books in Braille requires a special printing press.

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<sup>94</sup> JICA: Asian-Pacific Development Center on Disability (APCD) Bangkok, Thailand.

## Sign Language and Augmentative Devices

Children with disabilities such as deafness, cerebral palsy, or autism typically have great difficulty in communicating. Sign language and augmentative communication devices provide vehicles for receiving and expressing language. Bangladesh has made some strides in promoting sign language and augmentative communication systems.

*Sign Language.* The Department of Special Education, Institute of Education and Research, Dhaka University was energized by the late Dr. N. Anam, who worked with her students in the hearing impairment department. With her leadership, the students developed a vocabulary for common functions and translated those into signs. A video was made of the gestures and an artist was enlisted to draw pictures of each sign. The CDD provided logistical support for the project. Using a participatory approach, approximately 30 hearing impaired “stakeholders” validated the product, item by item. A dictionary of signs was printed in early 2003. Two volumes have been published.<sup>95</sup>

*Augmentative Communication.* The BPF has taken the lead in promoting the use of augmentative communication systems for children with intellectual disabilities and for those with cerebral palsy, working on its initial development with a British expert.<sup>96</sup> A number of Bangladeshi girls have been trained in the use of augmentative communication systems through BPF-funded training for them in India, in collaboration with the Spastic Society of Eastern India, which has special expertise in that area.

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<sup>95</sup> Available from the CDD, based on personal communication with the national consultant, February 1, 2005.

<sup>96</sup> Margaret Walker, Bangladesh Protibondhi Foundation (BPF).

## V

### What Stakeholders Say About the Educational Needs of Disabled Children

No study of the educational needs of disabled children is valid without input from the stakeholders themselves. In this case, stakeholders include children with disabilities and/or their spokespersons, families of children with disabilities, teachers who work with both disabled and non-disabled primary-aged children, and the administrators of schools facing a responsibility to educate children with disabilities.

This study focused on three questions:

1. What are the educational needs of preprimary and primary-aged children with disabilities?
2. What are the current obstacles to obtaining these needs?
3. What recommendations might be made for the improvement of the Bangladesh society and educational system to educate young disabled children?

#### Methodology

In this study, the majority of the stakeholder population was rural, representing therefore, the majority of the Bangladesh population (76.61 percent in 2001<sup>97</sup>). Ten researchers at the senior and research assistant level, trained and monitored by the Senior Consultants, conducted interviews, focused group discussions (FGD), and descriptive literature searches. Although research sites were originally targeted for five locations, unforeseen extended holidays and six days of general strikes (hartals) limited the flexibility of the researchers to travel. Kurigram thus produced data from the most people because it combined visits to both agencies in Kurigram and a visit to a neighboring village with a large group of stakeholders—Ulipur. Data from both Ulipur and Kurigram were consolidated because demographics were similar. This report presents all data that were gathered from four districts. The districts were picked for their demographic and statistical heterogeneity and their generalizability to the Bangladeshi population.<sup>98</sup>

- *Jessore*, to the west and south of Dhaka by about six hours, has an area of 1,158 sq. km. Over 128,000 students are between 6-10 years of age.
- *Savar* is a suburb of Dhaka, the capital city. This site was chosen because it contained an exemplary program of Project SUCCEED, of Save the Children, USA, and the Center for the Rehabilitation of the Paralyzed (CRP), a service organization of Bangladesh.
- *Kurigram*, 9 hours north of Dhaka, has an area of 2,296 sq. km and over 306,000 6 to 10 year olds. It has as many non-government schools as government schools serving children.

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<sup>97</sup> (Short form) *Bangladesh Census, 2000*.

<sup>98</sup> *Primary Education Statistics in Bangladesh*, (Dhaka: Directorate of Primary Education, Primary and Mass Education Division, Government of the People's Republic of Bangladesh, May, 2002).





- No educational program could be effective for children with disabilities and their families if there are not parallel medical services available. Parent/child dyads and administrators recognized that parents and schools can be much more effective in working with disabled children if the children have been appropriately assessed and given medical treatment when necessary, and if families have been counseled about short- and long-term care and maintenance of the child.
- A child cannot be expected to reach his/her full potential when assistive technology is missing. Many children with disabilities can function significantly better when they have proper eyeglasses, hearing aids, mobility prosthetics, orthotics, wheelchairs, augmentative equipment, or other such devices. All realized that assistive technology would have to be free or affordable--another complication in the provision of these needed aids.
- Teachers and administrators recognized that children with disabilities need more than academic work. To be rounded, rewarded, and accepted, children with disabilities also needed “non-academic” courses such as music, arts, sports, and other forms of planned recreation. These offerings will tend to “normalize” the school offerings to the child with a disability, and help that child fit into his peer culture. Probably the strongest case for these subjects, however, is their intrinsic motivation for studying them. Everyone likes arts, sports, and recreation. They are also great “mixers” of disabled and non-disabled children on a social level.
- Teachers and administrators reminded the researchers that no educational program would work if children could not get to it. Therefore, they recommended that a revised educational intervention also include provision for adequate and free transportation from home to school.
- Disability is treated and education will be effective if the disability condition has been adequately assessed. An assessment program that gives data to both teachers and family is needed, say the administrators.
- Along with assistive technology, adjunctive therapies such as speech therapy and physical therapy are needed to help a person with a disability become fully functioning in the school and at home. These therapies are recognized as needed by the child/parent dyads.
- Food has to be supplied at school, say the administrators. Its need is self-evident. Education does not take place when hunger pains and malnutrition prevent proper attention and focus.
- Schools in Bangladesh usually use uniforms—for all the reasons that any school has uniforms. Because children with disabilities are more often poor, uniforms become prohibitive. Thus an educational need is for free or low-cost uniforms for all children with disabilities. Administrators recognize this importance.

- Of course, say the administrators, there needs to be a continual local contribution of finances. Current educational financing does not encourage this. Administrators want either better laws or enforcement of the current ones.
- Transportation, a problem already described, would be enhanced by special vans. This is a specific request of administrators.

## Obstacles

When the data on reported obstacles were consolidated, there were some surprises. The most obvious response would have been the reluctance of the traditional school to make infrastructure needs and trained personnel available to accommodate children with disabilities. That was not the case.

- The major obstacle to pre-primary and primary education for Bangladeshi children with disabilities is what American sociologists call stigma. Stigma is a negative and hostile attitude on the part of society toward anyone perceived as different. Stigma, it is postulated, is bred in superstition, fear, traditions of inequality, misconceptions and ignorance of facts. Stigma is stronger than attitude because it causes actions that restrain or inhibit the stigmatized person, who is usually of a lower class or in poverty. Stigma is behind the statistic of 90 percent abuse of children with disabilities. It generates the shame that a parent feels when he or she generates a “defective” child. It is responsible for the often-heard statement by parents of children with disabilities that “my child is hopeless. He/she will never have any happiness in life; and therefore neither will we.” If accepted without question, there can be no education for the child by the parents; the school accepts the negativism because it has no way of offering special education. The child keeps the family in poverty—and the cycle of poverty to deprivation to dependence and non-marriage to everlasting poverty rolls on. Almost twice as many respondents named this negativism as an obstacle than responses to any other obstacle.
- The second obstacle is the failure of the State to prevent or alleviate poverty. Only when awareness is overcome through societal education, coupled with financial independence from poverty, can the obstacles to a free public education be addressed. The questions of poverty alleviation are seen by most economists and developmentalists as a function of the State: only the State has the resources and the obligation to do the most good for the most citizens. The responders agreed to this statement across the board.
- The current state of education in Bangladesh is unfriendly to children with disabilities unless radical changes are made. Classrooms often contain 70 children to one teacher. Teachers are not trained in inclusion or special provisions for persons with disabilities. There are no supplementary professionals to offer special tutoring, Braille instruction, speech therapy, mobility, and activities of daily living. The government schools do not currently have the money to change the system, and if they did, there would be a severe shortage of trained teachers and specialists. Thus

overcoming school resistance to educating children with disabilities is a major governmental problem. This was an observation given primarily by children/parents and by teachers.

- Stigma is not just for persons outside the family of a person with disabilities. The parents often “buy in” to the stigma premises because they know nothing different. They feel their children are “hopeless” because they have never seen a successful or coping adult with disabilities. They do not understand their child’s condition—they don’t even know a name for it—and they therefore envision it as a curse, “bad luck”, or a punishment for bad deeds. Education to prevent family negativism should prioritize families before the general public, but both are strongly needed in order to make societal pathways to education. Teachers and administrators recognized this obstacle more than did parents.
- There are few if any governmental schools, either segregated or inclusive, that can handle more than a fraction of the children with special educational needs, say the teachers. This lack of services cannot be blamed on stigma; schools cannot be built fast or large enough to keep up with the rate of population growth.

**“I want to go at the school with my classmates.  
But I did not get admission anywhere.”**  
Student comments at Solidarity, Khalilgonj, Kurigram.

- Most of the schools serving children with disabilities are funded by the central government, NGOs, or INGOs. There is no local flow of educational funds, thus preventing local groups, such as parent groups, from exerting pressure for the education of known local children with disabilities. Even if the State were to provide disability education through Government Schools, it would be split between two Ministries, Social Welfare and Education, so that many children, and their families, would lose services in jurisdictional squabbles. This was a comment mostly made by school administrators.
- Most children have to be transported to government schools. The current system in rural areas offers little to no specialized transportation from home to school. Children with disabilities are also not eligible for assistance with rickshaw transportation as are children without disabilities. This is a poignant complaint by parents of children with disabilities.
- At the current time, families noted, there are no books or other educational materials available to educational programs or to families that have children with disabilities. There are no books containing the issues of successful living with a

disability, no books portraying heroes who are disabled, nor books written in large print, Braille, or recorded in order to meet special needs of children with disabilities.

- Parents noted that almost no child with a disability, particularly if they are poor, has assistance with aids and appliances, orthotics and prostheses. Therefore children with mobility problems and sensory problems are even more severely constrained in school systems than they need to be. Their efforts have to be greater than those of the non-disabled child.
- Some educational administrators noted that the laws assisting young children with disabilities in Bangladesh are few and, when they exist, inadequately monitored. Although there is a special education law, the State feels more bound to conventions of the UN to which Bangladesh is a signatory. In any case, there is little or no enforcement of these legislative initiatives.
- In the rural areas of Bangladesh, there is almost no medical assistance to assess, counsel, or treat disabilities and their consequences. Families in particular suffer from this lack of knowledge.

## Recommendations

Most of the recommendations were derived from themes of the “needs” data. However, many of the recommendations often showed knowledge of successful practices in other districts, other NGOs, or other countries and were incorporated into the recommendations.

- The major recommendation was the building of a “traditional” special education program in all government schools. This meant that all the respondents wanted a program that would offer special education classes mainstreamed in each school. All classes containing children with disabilities should have a reasonable teacher/student ratio, about half the current one. Teachers should be especially trained in disability methodology and content, especially those teachers who taught children with visual impairments, hearing impairments and intellectual disabilities. There needs to be useable space for the varied needs of instruction in the schools, the age of entry and leaving from the special classes should be flexible, and the schools should be equipped with appropriate teaching materials. In addition to education, each school should have an aggressive program that seeks disabled students, provides safety measures for children with disabilities (to protect them from stigma-related abuse), provides at least one meal per day, and builds home-school cooperation through family meetings. Although parent/child dyads wanted these schools, it was the teachers and administrators that articulated the concepts most cogently.
- Child/parent dyads and teachers strongly advocated for the concept of free education for children with disabilities. Because so many children with disabilities were in poverty, they explained that “free” meant that there should be no costs for expenses like clothing and books. There should be scholarships and/or stipends for children with disabilities (as there are for children without disabilities). Families who

have children with disabilities should be helped so that the child does not become an economic liability to that family.

- Besides government schools and the inclusion of children with mild disabilities, there is great need for special and segregated educational programs for children with multiple disabilities, reported teachers and administrators. Many of the schools needed should be residential schools so that children with severe disabilities can be unimpeded in their educational pursuits by negative family and social conditions and given effective special education. This was a recommendation of both families and educators.
- Awareness campaigns, i.e., campaigns of public education through all media including printed and broadcast material, theater and dance, should be aggressive and started immediately. The purpose of these awareness efforts would be to minimize (if not eliminate) stigma and the deprivation of rights of persons with disabilities. Included in the awareness campaigns should be stories of successful coping and success by persons with disabilities, and an open forum of disability issues. All respondents mentioned this recommendation as an absolute necessity.
- No educational programs should be started without a corresponding medical service program, responded the parents. They needed to know what the medical basis for the disability was, whether it could be prevented in the future, and if and how it could be treated. They needed to know if what they were doing to nurture a disabled child were in actuality hurting that child's chances for future adjustment or if they were providing an environment that would stimulate growth and development. These medical services would, of course, have to be free to all families.
- Teachers discussed the curriculum for children with disabilities and articulated that such a curriculum should be well-rounded and as close to the non-disability curriculum as possible. They recommended that the curriculum should contain sports, fine arts, recreation, and vocational preparation as well as academic content. The academic curriculum should also contain specialized methods in teaching Braille and sign language.
- All the respondents agreed that transportation should be provided to children with disabilities attending school. It should be free to those who cannot afford it.
- Children, parents and teachers insisted that assistive devices should be provided all disabled children who could use them. Because Bangladesh citizens cannot afford such assistive technology, the State should consider funding such technology development and providing it, free, to children with disabilities and their families.
- Children and parents as well as teachers remarked that they are more functional and effective in raising and educating their children if they have information about their children, such as the nature of the disability and the strengths and weaknesses of the







## VI Parenting and Parent Education

Being a parent of a child with a disability in Bangladesh is often a full time occupation—and a severe test to a family’s economic and psychological stability. The data about parenting and potentials for parent education contained in this report are qualitative and represents the personal testimony and opinions of parents interviewed both singly and in groups during the field visit part of the investigation. As has been noted in previous chapters, the largest majority of children with disabilities are in poverty conditions—conditions that not only cause disability through malnutrition, disease, and lack of medical attention, but also inhibit education through stigma, negative beliefs, and lack of transportation, attentive care, and inadequate home schooling among many factors. With a poverty rate of 64.3 percent<sup>99</sup> and three fourths of the population rural, it is likely that the overall figures heretofore quoted are conservative; the number of disabled children in Bangladesh will be greater than these estimates, and their population lies mainly below the poverty line and in rural areas. It is from these populations that these observations are drawn.

Parenting a disabled child has many dimensions.

- **Care.** A disabled child of any variety requires more intensive care than any non-disabled child. Often, the first task of caring for a disabled child is geared towards survival. The child must learn to eat, eliminate, communicate and thrive—all of which may require, in severe cases such as acute malnutrition or diseases, round-the-clock vigilance and nurturing by the family. Trained medical help is often not available, so neighbors and semi-medical personnel are needed. Medicines are often too costly to afford, and specialized treatments such as physiotherapy or speech pathology or assistive technology such as braces, crutches or hearing aids are non-existent. The child will receive only what the parents and family have to give—a little food, perhaps some breast milk, holding and comforting, and little more. The mother will, by tradition and unspoken law, be the main caretaker of the child, and, although the grandmother may help (many rural families live three generations to a house), the secondary caregivers will be the siblings of the child. The father, the extended family, and the neighbors may help the mother with the care of the child, particularly if the mother is working, but it is the mother who must make the caregiving decisions about the child.
- **Beliefs.** One of the first thoughts of a parent when he or she knows that the baby is disabled is, “What have I done to deserve this?” Is my disabled child a message from Allah? Often there is guilt: “I am receiving punishment for past transgressions.” A life is sacred, however, and most parents usually realize eventually that they must accept this “burden” and try to help the child as much as possible. Behind their thinking, however, is a fatalistic attitude: “A disabled child has no future.” They know of no persons with disabilities who have been educated or are successful. They know that the Government schools will not

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<sup>99</sup> (Short form) *Bangladesh Census 2000* .

accept their child for education and, if they did, the child would soon drop out because there are so many other children in the class that the teacher cannot teach their child. They know that other children and adults will make fun of the child, and possibly even abuse her or him. They know that there will be no financial help or extra food for this child, as there are for non-disabled children who go to school, because none of these institutions believes that a disabled child has promise. Parents may grow to love their child, as was seen in almost all of the interviewees of this study, but such love must be unconditional: their child has no future. Now.

**“When my child goes to school, we get inspired.  
We hope one day he will get rid of this situation.”**

Mother’s comments at SWID Bangladesh  
Kurigram

- **Economies.** In poverty conditions, all members of the family must work for the common good. In many families, poverty or non-poverty, the wife also works to add to the standard of living. Because the woman of the house must raise the children in it, she must also be responsible for the care of the disabled child. This usually prevents her from working. In the poverty situation, this eliminates the chance to be released from the poverty cycle; therefore a disability in a family has grave economic consequences. If a child receives proper medical care, including prostheses, orthoses, medical treatment, medicine, assistive technology, or any of the numerous supports given disabled children in developed countries, the cost is overwhelming to the Bangladeshi family; there is no relief from these expenses except from a handful of NGOs—and then in a very limited way. Most families bear the task of caring for their disabled children without ever knowing the name of the disabling condition, actions to be taken to help the child become more self-sufficient, or the medical or educational resources are needed and/or available to the family. For most families, this little knowledge is a blessing; they cannot afford more than they have to offer from their meager incomes.
- **Practices.** The interviewees seemed to have no generalized set of parenting practices for disabled children. What shaped the parenting practices was the nature of the disability, the obvious needs of the child, and the behaviors of the parents according to their degree of acceptance and their concepts of stigma. Most mothers, feeling that the child had no future, were content to concern themselves with food, cleanliness, and survival, developing routines of care, and training siblings and extended family members to watch the child when the mother had a need to be absent. In many cases, however, there were antagonisms towards the child in the village—or even in the home. Several parents told of disabled children abused by the father, the siblings, healers, or neighbors. Girl children were especially vulnerable. Often the shame of having a disabled child (stigma) manifested itself in the home by isolating the child from the community, sometimes even locking the child in the house. Wife and husband often disagreed on the care of a child, and the resulting

friction eroded the family stability. In only one interview, that of a father and his bright, deaf, but attractive son, was seen pride in a disabled child and a concurrent shard of hope for the future. (The child had applied to the Government School for Hearing Impaired children, but only 4 children could be selected from a waiting list of 114.) This view of a disability, obviously involving both the mother and father, was the only positive interview in over 100 such conversations.

- **Gender.** In the studies of gender and disabilities, more females than males are identified as disabled.<sup>100</sup> In the field visits, this ratio seemed skewed toward more parents with girl children than males. This is attributed to the fact that girls with disabilities are seen as bigger liabilities than male children with disabilities because stigma drastically reduces their chance for marriage (and consequent dowry income for the family plus more freedom from her care). Male children are trained more often to do menial tasks to help the family, thus becoming economic producers. Interviewed parents and girls revealed the high rate of abuse, both physical and sexual reported in studies.<sup>101</sup> In the values of the Bangladesh family, male children with disabilities are more likely to receive the advantages of lessened stigma. That child can possibly go to school (if they will take him). Although one would expect an equal ratio of male to female children with disabilities, the discrepancy between males and females reported with disabilities may reflect a more liberal and or positive attitude towards males than females in the culture. This, however, is speculation.
- **Parent Education.** In the search for projects of parent education about disabilities, very little effort is apparent. Project SUCCEED, in its equity program thrust, mentions providing knowledge to people and organizations about disability and disability rights, but does not describe parent education. Community Approaches to Handicap and Disability (CAHD) is a movement fueled by an organization, The Center for Development and Disability (CDD) and mentions, as an activity, the provision of knowledge to people and organizations about the roles of family members in creating handicaps (vs. disabilities). The researchers found no examples, however, of focused efforts to teach parents how to help or provide home education to their children with disabilities. Yet, this need was articulated at all the field visits. Parents want to know about their child's disability. They want to know its name. They want to know how best to help that child. They want to know how to reduce stigma in the community. And they want to be able to talk to someone about their child. So far, that knowledge and the ways of teaching it or providing it to parents with simplified written or broadcast resources, is not on any known organization's priority list. Project SUCCEED may initiate it in the future. Sesame Street has a chance to work in this area but has not programmed it yet. The BRAC schools promise to refer students with disabilities, thus providing parents with some information—but no agency could be found that undertakes the task of educating all parents about disabilities. When such programs are started, they

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<sup>100</sup> (Short form) Kabir, *Four Baseline Surveys on Prevalence of Disabilities*. A study of 12,578 disabled persons from a population of 94,260 concluded that 41 percent were males and 59 percent were females, a statistic very close to that of the 1999 Census sample study conducted by the Bangladesh Bureau of the Census, 2000.

<sup>101</sup> (Short title) *A documentation of good practices on inclusive education for UNICEF, CSID*.

will provide valuable information about new methods of educating disabled children—as they have done in developed countries.<sup>102</sup>

In the field, working to gather information for this report, groups of parents, holding their disabled children, met with the researchers to discuss their opinions on educational needs, articulate the obstacles to education for disabled children, and make wishful recommendations. The energy among the parents, as described by the researchers, was palpable. Parents finally had a professional to talk to, and they were grateful—and demanding—and tearful—and angry—and verbal—and articulate. Their stories were sometimes terrifying, sometimes heroic, and always unique. They wanted medical help, educational advice, and general knowledge. They wanted enough knowledge to allow hope. They were willing to come long distances, with great hardships, to talk about their children. If they could work together, they might achieve systemic change, but they had no idea how to do that. All the researchers saw them as a potential force for helping not only their disabled children, but improving the stigma and removing some of the barriers of disability in their cities and villages. Parents are still an untapped force in the education of disabled children in Bangladesh.

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<sup>102</sup> The US has been particularly aggressive in parent education, funded by governmental funds. The results have shown remarkable improvements in the education of children with disabilities. An overview of the US parent training system may be found at <http://www.pacer.org>.





- **Involving Parents.** Parents of children with disabilities have energy in search of an outlet. Time after time, they asked the research team “what can I do?” not “what can a doctor or a teacher do for me?” They would function in an active mode if they had some knowledge, some leadership, and some incentives to work for their families and their disabled children within them. They need information. They need examples of what can be done for disabled children and the raw materials with which to replicate useful practices. They need to enlist the help of their elders and their neighbors. They need friends who are sympathetic and helpful to them and not condemning or exploitative. They want to make informed decisions. They want knowledge. Perhaps USAID can develop such an informational system. Perhaps SISSIMPUR can assist with this.
- **Building Self-Esteem.** Families are frequently stifled by the hostility of their community, but undoubtedly they also are constrained more frequently by their own lack of self-esteem. If the community finds their children hopeless, disfigured, or non-responsive, they may turn on them. They do not, however, turn against members of the community who show their creativity, their athletic prowess, or their determination to be “just like all the others”. All the players in education and most of the parents remarked on the need for programming in sports, entertainment, and also the arts. Many children can participate in the arts or sports, particularly through the excellent programs offered by the Special Olympics or Very Special Arts, and many children have been literally “saved” from frustration and abuse by their performances and their integration into society through these extra-curricular activities. A comprehensive arts and sports program can be started in Bangladesh and taken into the rural areas. The voices, the drums, and the arts are there. The project team has seen and heard them. USAID could work with existing international organizations to start or increase programs like that in Bangladesh.
- **Medicine and Food.** Finally, there are models of rural medical services and food distribution that bring very needed information, treatment, and referral as well as nutrition to disabled children and their families. In the phases of systemic change in the rural areas, free medical help and food play crucial roles. They attack poverty cycles and the stigma of ignorance, and they offer a glimmer of hope after treatment. They offer nutrition that facilitates learning and reduces the burden of household feeding. These are actions that will start a powerful movement of parents of children with disabilities (who might be as many as 30 percent of the population). Demonstrations and diffusion of model medical/educational assessment and referral centers could be made possible through the education and health sectors of USAID.
- **The Facts.** It is obvious that precise planning, particularly when the stakes are high and the investment is heavy, is much better when the statistics on status and trends are stable and well founded. There have been attempts to get accurate counts of children with disabilities, but they have not used the most efficient methods and are often internally and externally non-comparable. A question in the last National census now appears to have been worthless; it has never been reported. Good sampling, accurate

instruments (such as the Ten Plus Questions), or the functional measures of the CY-ICF would give the most useful data for positioning oneself as a multiplier of change in the education of children with disabilities in the future. Because of the inadequacy of previous attempts at finding disability and disability economic figures for both the urban and rural, poverty and non-poverty sectors of Bangladesh, fact-finding is still a high priority in the paradigm of change. There are examples from the past on which to learn the lessons that will make future counts more accurate. USAID could provide some of that needed research.

Bangladesh has many donors contributing many studies and coordinating with few others. The scramble for data and studies and explanations of disability education in Bangladesh was very difficult, particularly because there was no central repository for it. The area of preschool education for children with disabilities was particularly difficult. It is hoped that with USAID's good library facilities, that it may develop into a valuable archive of important data in this area.



Investment in early childhood interventions, pioneered and championed by the USA, is now seen worldwide as a logical first step in systemic educational reform for children with disabilities and their families. Early intervention prevents what is now an increased dependency and economic liability of persons with disabilities as they grow older. Early intervention also shows the citizenry that all people can be valued, not diminished, by stigma or vulnerability. Only with increased independence and the acquisition of skills by all family members can poverty cycles be broken. Early medical, nutritional, educational, and awareness efforts are crucial components of an early intervention model for Bangladesh.

USAID has a unique opportunity to stimulate early childhood intervention systems in a country that literally has almost no offerings in this area. Already USAID is funding two projects that directly address stigma reduction and the setting up of models for early educational inclusion. There is more that can be done through these projects, and also through careful planning and execution of other projects.

What this study has found, however, is the deadly apathy of exemplary projects without replication or diffusion targets or resources. INGOs and NGOs are the major providers of educational interventions for young children with special needs. Where are the efforts and resources that should be provided from public education and health systems?

USAID has the chance to use its investments to leverage both public and more private interventions. It can plan these interventions wisely and with multiple resources. Sustainability is possible when educational reform occurs and successful models are in place to show value and to train needed personnel. USAID has an opportunity, through its actions in Bangladesh, to model strategies and programs for young disabled children in other developing nations. This study shows that change is possible in Bangladesh—slowly. The Study Team views USAID as a potential accelerator.

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# **IX APPENDICES**

**APPENDIX I  
THE STUDY TEAM**

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