



Promoting Child Rights



Children with disabilities: Discrimination impedes development

JAMIL MAHMUD

DISCRIMINATION in the family, the community and the workplace is at the core of most violations of the rights of children with disabilities in Bangladesh. Beliefs are that disability is a curse and these social beliefs are deeply rooted at all levels. While progress is slow, changes have been noted due to policy modifications and social mobilisation.

Unicef's report "The State of the World's Children 2013", which was unveiled in Bangladesh recently and especially dedicated to children with disabilities, strongly recommends building more inclusive societies for them.

Bangladesh is among the first countries to ratify and bring into force the two most significant global documents that protect the rights of children with disabilities—the UN Convention on the Rights of the Child (CRC) and the UN Convention on the Rights of Persons with Disabilities (CRPD).

Rehabilitation services in Bangladesh are provided by the government under the direction of the Ministry of Social Welfare. The country has taken a number of legislative and policy actions towards national adoption of the global commitments including the Children Policy 2011 and the Rights of Persons with Disabilities Act 2012.

However, the act, a key factor for taking further actions, is pending enactment. Social Welfare Secretary Suraiya Begum said the bill was vetted by the law ministry. At present the ministry is waiting for sending it to the cabinet.

Knowing the exact number of children with disabilities and the types of problems they are facing is another issue for further actions. However, till date the government is

Knowing the exact number of children with disabilities and the types of problems they are facing is an issue for actions. Till date the government is in the dark in this regard, as no nationwide survey on children with disabilities was held in the past.



PHOTO: AMRAN HOSSAIN

Recently the government has started a survey to count the number.

The survey was started in June and will end in August. The result will be known not before September, said the social welfare secretary.

Challenges to realisation of the rights of children with disabilities need to be understood within the context they live in Bangladesh. Bangladesh is one of the most densely populated countries and over 31

percent of the total population live below the national poverty line.

To make an inclusive society for the children with disabilities, the government has mandated the schools to build ramps. The government has a programme of awarding the children with stipends as well.

Children with disabilities at primary, secondary and higher secondary levels received Tk 300, 450 and 600 per month respectively in the fiscal year 2012-13. A total of 18,620 students with disabilities, including those who enrolled for higher studies, received the stipend, a source from

the social welfare ministry said.

Kalyani is a special and inclusive education system for children with disabilities under Bangladesh Protibandhi Foundation. It has three centres in Dhaka.

Momtaz Begum, principal of the Malibagh school said 157 students including 76 regular children are enrolled in the school. The school has 15 staffs.

Children usually enjoy times here because, alongside study, the school has good entertainment facilities for them. Behaviour of the teachers and staffs are also good, said Nilufar Aktar, mother of a child with a disability.

A major initiative in the development of health for children with disabilities is the establishment of Shishu Bikash Kendra (child development centre) in government medical colleges.

Ten centres with trained multi-disciplinary professionals are located in as many government medical hospitals with three in Dhaka.

The government has a plan to establish similar centres in its other medical hospitals as well, said Dr Naila Zaman Khan, national co-ordinator of the programme.

The Centre for Neurodevelopment and Autism in Children (CNAC) is another initiative where children with disabilities receive services. CNAC was launched in 2011 and is the first governmental initiative to establish a nationwide paediatric neurodevelopment and autism related management.

At present 100 to 150 children take services from the centre each day, said Professor Shaheen Akhter, executive director of the centre. She said 15 children can take services at its Day Care centre for five days in a week.

Prof Shaheen said they have further plan to turn the centre into an institute.

Key recommendations

International commitment to building more inclusive societies has resulted in improvements in the situation of children with disabilities and their families, but too many of them continue to face barriers to their participation in the civic, social and cultural affairs of their communities. Realizing the promise of equity through inclusion will require action to:

1. Ratify -- and implement -- the Convention on the Rights of persons with Disabilities and the Convention on the Rights of the Child.
2. Fight discrimination and enhance the awareness of disability among the general public, decision-makers, and those who provide essential services for children and adolescents in such fields as health, education and protection.
3. Dismantle barriers to inclusion so that all children's environments -- schools, health facilities, public transport and so on -- facilitate access and encourage the participation of children with disabilities alongside their peers.
4. End the institutionalization of children with disabilities, starting with a moratorium on new admissions. This should be accompanied by the promotion of and increased support for family-based care and community-based rehabilitation.
5. Support families so they can meet the higher costs of living and lost opportunities to earn income associated with caring for children with disabilities.
6. Move beyond minimum standards by involving children and adolescents with disabilities and their families in evaluating supports and services designed to meet their needs.
7. Coordinate services across all sectors so as to address the full range of challenges facing children and adolescents with disabilities and their families.
8. Involve children and adolescents with disabilities in making decisions that affect them -- not just as beneficiaries, but as agents of change.
9. Promote a concerted global research agenda on disability to generate the reliable and comparable data needed to guide planning and resource allocation, and to place children with disabilities more clearly on the development agenda.

Cost of treating impairments too high

ZYMA ISLAM

SONIA, 15, from Kamalganj in Sylhet, was first diagnosed with deafness as infant when she did not respond to any sound, but never received therapy afterwards.

This means, she is wholly incapable of lip-reading or understanding sign language.

Being unable to cope up in a normal school, she has also never learnt how to read or write.

She was never given any therapy because there are no services within their area, claimed her father Borhan Miah, a farmer by profession.

"I had taken her to the Sylhet city hoping to find a cure, but they told me that she will have to take therapy for several years. I could not afford such a program. Besides, how will a farmer survive in the city?" said Borhan Miah.

For children with hearing impairments, a cochlear implant can cost as much as Tk 20 lakh, said Dr Shorifa Shahjadi, Assistant Professor of Physiology Department at Bangabandhu Sheikh Mujib Medical University.

Occupational therapy, directed at rehabilitation, is given to patients with both physical and mental special needs, and can cost up to Tk 300 per session at private organizations, said Shariful Islam, Secretary of Bangladesh Occupational Therapists Association.

"This therapy is important because it acclimatizes the patients to their surroundings, and makes them self-reliant. It focuses on improving both physical capabilities as well as social skills," added Shariful.

Children with other physical impairments also have to go through extensive therapy processes to improve their situation, said Krishno Sen, Monitoring and Evaluation Officer of the Research and Evaluation Division of Centre for the Rehabilitation of Paralyzed (CRP).

"In the initial stage, a cerebral palsy patient is given a month-long therapy at a stretch, while spinal cord injury and stroke patients are kept



PHOTO: AMRAN HOSSAIN

"The government-run community level clinics are unable to provide medical intervention to patients with special needs, because it is difficult to recruit good doctors in rural areas."

for three months, but, they require consistent follow-ups and lifelong attention. Many patients have to go through recurring periods of long-term therapy throughout their lives," he

added.

The burden of the costs involved may make many drop out of these medical procedures, said Krishno Sen.

A wheelchair would cost around Tk 15,000, stated Shariful Islam.

Children with behavioural or psychiatric illnesses also do not usually get fully treated, and medicine costs may be as much as Tk 2000 per month said Badrul Mannan, General Secretary of Welfare Society for Mental Health and Rehabilitation (WSMHR).

Depending on the severity of the intellectual impairment, the child may be fit for rehabilitation within a couple of years, or may have to take lifelong sessions of therapy and training, said Director of Society for the Welfare of the Intellectually Disabled (SWID), Nurul Islam.

Centre for the Rehabilitation of Paralyzed (CRP) in Savar, on the outskirts of the capital, provides medical care at discounted rates, or even free, according to the financial need of the patients, said Sen.

"However such services cannot be delivered to patients all over the country," he added.

Our primary medical care system consisting of community clinics, are not equipped with such services, although such patients exist everywhere, maintained Badrul Mannan.

"The government run community level clinics are unable to provide medical intervention to patients with special needs, because it is difficult to recruit good doctors in rural areas. At best, patients are referred on to hospitals which can provide such facilities," admitted secretary to the Ministry of Health and Family Welfare, NM Nijaluddin.

Nevertheless, the ongoing nationwide survey of people with special needs being undertaken by the government will help identify children with developmental problems all over the country, and make it easier to extend medical intervention to them, said Professor Naila Zaman Khan, of Dhaka Shishu Hospital.

Overcoming challenges

Brought home two silvers and a bronze in Badminton in the Special Olympics World Summer Games in 2007



PHOTO: AMRAN HOSSAIN

ZYMA ISLAM

SPORTSWOMAN Shihuli Shathi recently became a common face within the country, courtesy of a Grameenphone campaign disseminating her achievements.

The telecom company, which has aired a television commercial and set up billboards all over the capital featuring her, introduced Shihuli as a girl with special intellectual needs who had been able to overcome her learning barriers and become an international athlete.

"I brought home two silvers and a bronze in Badminton in the Special Olympics World Summer Games in 2007," said Shihuli.

Other than that Shihuli claims to have also won five gold medals in bocce, a ball game, internationally, three during the national special Olympics meet held in Brunel in 2003, and two more again in 2009.

"I was first introduced to bocce and badminton at the age of ten. It was a play my teachers used to keep me in school, because I was afraid around the other children and had dropped out," said Shihuli, who studied in a school for children with special needs run by Society for the Welfare of the Intellectually Disabled, Bangladesh (SWID).

Children are allowed to concentrate on whatever areas they want at the school, and Shihuli chose to train in sports, stated the Director of SWID.

Shihuli claims to have been receiving training for ten years in bocce and badminton, from her coaches at SWID, Bangladesh.

"The Special Olympics Committee Bangladesh also gave me training prior to events," said Shihuli.

Shihuli Shathi has completed training and therapy and currently serves as a teaching assistant for autistic children in SWID, Bangladesh.

She is also the primary caretaker of her parents, because her father has a long-term foot injury and is currently unemployed, and her mother is a housewife.

However, the meagre salary of Tk 1,800 per month she gets is barely enough to make ends meet, said Shihuli.

"It is also going to be difficult for me to get a job elsewhere, because of my autism," she said.

Shihuli Shathi hopes to attend more international sporting events in future.

Family awareness must for their mental development

TAMANNA KHAN

HER clear light-green eyes looked away in the distant, as people showered her with questions. She remained quiet as if she could not hear them speak. "She is not talking today but she does when she feels well," her mother Nasima insisted. Dressed in royal pink, twelve-year old Cynthia was waiting at the corridor of the department of Child, Adolescent and Family Psychiatry section in the National Institute of Mental Health (NIMH), Bangladesh.

"She was a adorable child, born after two brothers so we hardly let her down from our lap," recalled her mother explaining why it took her some time to understand that Cynthia was different than her other children. Initially, she did not notice that Cynthia repeats words or sentences and becomes restless among strangers. She was more concerned about Cynthia's continuous fever and cold which at times turned her blue.

"We have been to many doctors but no one could diagnose the illness. Lastly a doctor referred us here," she said.

Early detection of impairments among children is a challenge in our country. Professor Shaheen Akhter, Program Coordinator, Centre for Neurodevelopment and Autism in Children (CNAC), Bangabandhu Sheikh Mujib Medical University (BSMMU), said, "In villages, a child suffering from mal-nutrition often walk and speak late. People often mistake an autistic child for a quiet child, who likes to be left alone."

"In a similar manner, a hyper-active child is seen as a naughty boy or girl and absence seizures in children are often mistaken for inattentiveness and goes undiagnosed," she said adding that because of failure of early detection and intervention, teaching development skills to children with mental disabilities becomes difficult.

CNAC, which started its journey on September 1999, provided treatment to about 22,000 children. Among them roughly 24 percent suffered from epilepsy, 19 percent from cerebral palsy, 23 percent from growth and speech delay, nine percent from autism spectrum disorder, 2 percent from Down's syndrome and rest from other intellectual disability, headache etc.

Though there is no comprehensive data on the prevalence of mental disabilities among children in Dhaka, Dr Md Faruq Alam, Associate Professor of Child, Adolescent and Family Psychiatry, NIMH, said "A study conducted with support from World Health Organisation in 2008-2009 in Dhaka division showed prevalence of mental disability in children below 18 years is 18 percent."

"Among them 3.8 percent children suffered from mental retardation and 2.2 percent from epilepsy," he said giving a brief idea about the findings of the report. "Severe autism, conduct disorder, hyperactivity are prevalent among boys whilst girls suffer mostly from hysteria, depression and anxiety disorder." According to Dr Alam, prenatal

birth injury and birth complications often lead to mental disorder at a later stage.

In Bangladesh most child births take place at homes. Unicef's report on the state of world's children -2013 shows that only 32 percent births are attended by skilled health personnel (doctor, midwife, nurse).

Dr Alam said parents in general have less patience when it comes to treatment. "Most of the time they ask for medicine for quick recovery and fail to understand psychological treatment and counseling. As a result follow-up rate is very low." Drop-out rate is higher after 8-10 sessions, he informed.

Often parents refuse to accept diagnosis of the impairment. Dr Farzana Islam, child and adolescent mental health specialist, Child Development Centre

(CDC), Dhaka Shishu Hospital, said, "We noticed that when we tell parents about the diagnosis they reject it. Mothers become mentally distressed when they hear their child have developmental problems from birth." "So we rather tell parents about the strengths and skills of the child, so that parents feel positive about their child's ability to develop life skills," she said.

However, things have started to change. Dr Farzana said that community awareness have been raised through Meena cartoon and in many villages through traditional theatre, with the help of Ministry of Social Welfare. They are also planning to impart training to field level health workers about child development to increase early detection and intervention of impairment.

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PHOTO: AMRAN HOSSAIN

Regular schools better for them

Specially trained teachers can help them study alongside other children

AKRAM HOSEN

SEAM Ull Karim, a 19-year-old student, does not let his attention deficit hyperactivity disorder throw him off track. "I'm trying really hard for the oncoming exams and the load of homework," he says with a broad smile and apologizes for not being available for a long interview.

He does not go to a school specifically aimed for students with learning disabilities. Rather, he goes to a school where the authorities make arrangements with specially trained teachers to give him lessons.

His single mother Sajida Rahman usually spends more than Tk 120,000 every three months for his tuition fees alone—perhaps more than any other schools in the country.

However, being an autistic, Seam may not understand the concept of money. "But I'd spent all my savings and done everything I could just to see him equipped to survive without my support," she says.

When Sajida tried to get Seam admitted, at least 30 schools refused to take him.

While doctors suggest that children with special needs be admitted to regular schools to study alongside other children, the school authorities do not take them.

Commenting on the available opportunities of education for children with disabilities, Dr Nafeesur Rahman, director, National Forum of Organisations Working with the Disabled, says that although primary education is a must for all children in the country, schools refuse to take children with disabilities through the loopholes of the law.

Although the Compulsory Primary Education Act 1990 makes primary schooling mandatory for children, it states that the schools are not bound to take students with disabilities, he says.

Moreover, not many parents in Bangladesh have the means to provide the high expenditure needed for the schooling of children with disabilities.

Apart from the handfuls of cen-



PHOTO: AMRAN HOSSAIN

"Parents sometimes do not try and get their children admitted to schools because they become extremely disappointed and frustrated when they give birth to children with disabilities. In the primary stages, most parents go through a stage of denial and do not bring their children to specialists harming the child's development."

tres run by National Disabled Development Foundation and several NGOs providing education to these children, there are about 60 government run schools for children with disabilities in the country. Besides these, there are no opportunities for them.

"Despite forming 10% of the country's population, these children are hardly paid any heed to by their families and the state," says Shahidul Haque, chief executive of Social Assistance and Rehabilitation for the Physically Vulnerable (SARPV).

Farzen Ferdous Alam, president of Oggro, an organisation aimed to extend educational support to visually impaired girls, points out that Braille books are very expensive.

She says the cost of Braille books needs to be sold at reduced price or distributed free of cost to encour-

age more visually impaired students in studies.

Nazrana Yasmin Hira, programme manager of Manusher Jonno Foundation says,

"There is no specially-designed curriculum in schools for the children with disabilities. Besides, the school premises, including the lavatories, are not made with considerations to the needs of the physically challenged."

Pointing out that teachers need training to teach children with special needs, Nafeesur Rahman suggests that training of primary school teachers should include a course on special education.

He adds that graduates from the Department of Special Education, Dhaka University, can easily work as teachers' trainers in such courses.

Parents sometimes do not try and get their children admitted to schools because they become extremely disappointed and frustrated when they give birth to children with disabilities. "Many people believe that disabled children are outcome of their parents' sins, making the parents suffer from a sense of guilt," he adds.

In the primary stages, most parents go through a stage of denial and do not bring their children to specialists harming the child's development. He said, even when they come to terms with the truth, they remain too frustrated to try and get their children admitted to a school.

"People need to understand that these children can be turned into skilled human resources through the right kind of schooling at the right time," he said.

Discrimination has to be avoided

British born philanthropist and physiotherapist Valerie Taylor spent most of her life in Bangladesh treating and rehabilitating the people suffering from neurological disorders and running the Centre for the Rehabilitation of the Paralyzed (CRP) which was founded by her. She came to Bangladesh with a charity organization in 1969 for 15 months, but decided to devote her life to serving the paralysed here, among whom, the poor were especially vulnerable.

CRP, which started with 4 patients in a warehouse, is now a 100-bed hospital and serves about 1500 patients at its outdoor.

For her humanitarian work, Valerie won Rotary International award this year. Recently, The Daily Star (TDS) interviewed her about the prospects of children with disabilities in the country. What follows are excerpts of the interview.



TDS: Children with special needs are often considered a financial burden in Bangladesh. Is this a retrospective of how expensive specialized services for them are?

Valerie: Children with special needs being considered a financial burden will in many cases reflect the fact that specialised services are often expensive for their families. Service centres will vary in price and some will provide services free of cost if the family cannot afford these. The majority of services will be found in Dhaka and other cities causing the majority of children with special needs from across the country to be unable to access these. Also many families are unaware of the places that might be able to assist their children with special needs.

TDS: Children with special needs being abused both physically and mentally, is a common reality. Why is this such?

Valerie: I think that abuse of children with disabilities can occur anywhere in the world. I believe that you will always find some parents and relatives who are devoted to their child with a disability and others who abuse them both physically and mentally. To help remedy this awareness raising about the problem and the solution should be spread across the general public and the print media is a wonderfully powerful tool to spread the positive messages necessary. Television and radio should also be employed to help reinforce these messages more vigorously. We are very grateful to The Daily Star for focusing on these problems in an effort to resolve them.

TDS: Do you support providing specialized services for children with special needs in regular schools, or creating separate schools for them?

Valerie: Whichever possible the ideal would be to have able and disabled children studying at school along side each other. In this way everyone benefits and this introduction of disabled children in regular schools can help change the attitude towards disability in the next generation. Of course, children with a severe disability are some times unable to manage in a regular school and would ideally need individual help and tuition to meet their potential. My feeling is that segregating children in different schools, depending on their physical or mental disability, is a backward step but at all costs they need the chance of schooling.

VICTIM OF VIOLENCE Society must play the saviour's role

STAFF CORRESPONDENT

MUNIR, an eleven-year-old who limps around on his club foot at the Farmgate traffic signal begging for alms, says that being beaten up is a part of his daily life. He gets beaten around at home by his elder brothers, or on the street by other beggars, policemen, or even regular pedestrians.

"Maybe they hurt me because I cannot fight back, or maybe they find my foot ugly," he says, brushing off the gravity of the issue.

Such children living on the streets are regular recipients of verbal, physical or sexual abuse because it is easier to hurt them, said Dr Khurshed Alam, Chief Executive of Bangladesh Institute of Social Research (BISR), which had conducted a study on the violence faced by such children last year.

Sexual abuse and rape usually occurred to the girls, he stated. However, Valerie Taylor, founder of Center for Rehabilitation of Paralyzed (CRP) states that, "The stigma of having a child who is disabled seems to happen amongst all social levels in the society".

Abul Kalam Azad, co-chairperson of the Welfare Society for Mental Health and Rehabilitation (WSMHR) said that his son developed psychiatric disorders during high school, could not complete his education within the country because the environment was not friendly.

"He managed to pull through high-school, and got admitted to East West University in the capital, but dropped out within six months because of the behaviour of his peers," he added.

Those with special psychiatric, mental or intellectual needs are often called "lunatic", a word bearing a negative connotation about mental capacities, thereby negatively affecting their impression about themselves, said Dr Mahtab Khanam.

Badrul Mannan, General Secretary of WSMHR, who has a son with special psychiatric needs said that his son was hit with an onion by a shopkeeper who thought it would be funny.

"But it had a negative effect on his self-esteem to know that people think of him as a lunatic who can be abused", added Badrul.

Furthermore, children with special needs can be abused at home because they require extra services, making them a financial liability, said Dr Mahtab Khanam.

Everyone in the community can do something about in order to alleviate the stigma, recommended Valerie Taylor.

Initiatives can be taken to conduct a national awareness campaign focusing on children with special needs, said Promode Mankin, State Minister for Ministry of Social Welfare.



PHOTO: AMRAN HOSSAIN