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Fighting ignorance: SEN in Bangladesh

Details

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*Changing attitudes and government investment can do much to improve the lives of children with SEN in Bangladesh, says **Saima Hossain***

The Constitution of Bangladesh (Article 28) says that the state shall not discriminate against any citizen on the grounds of religion, race, caste, sex or place of birth and that no person shall be subjected to any disability, liability, restriction or conditions with regard to access to any place of public entertainment or resort or admission to any educational institution. Despite this constitutional protection, the nearly one million people with disabilities in Bangladesh are suffering from limited employment and educational opportunities, social discrimination and stigma. Bangladesh's situation is compounded by inadequate financial support, insufficient services, a limited number of trained professionals, and fragmented policies and procedures. Without a comprehensive government-monitored program to address these issues, those with disabilities and special needs cannot hope to become active participating members of society.

South-east asian countries share similar social and cultural beliefs: college education is highly valued, families are close-knit and interdependent, and social structures are more intricate than in western societies. This can be both a source of support and a cause of greater complexity. Unfortunately, what often happens for many with complex genetic conditions, such as autistic spectrum disorders (ASD), is that fear, misunderstanding and lack of information lead to social isolation and economic hardship. Families with disabled children often experience insensitive remarks, discrimination and humiliation. In Bangladesh, parents of children with special needs live in a culture within a culture where sometimes even the extended family does not interact in a positive and supportive manner. Parents, particularly mothers, are often blamed and shunned, and sometimes even abandoned, for having a child with a disability. The lack of understanding, coupled with the condemnation and personal guilt that parents are made to experience, is outrageous and appalling. In South-East Asia disability is not just a medical issue; it is a human rights issue.

In Bangladesh, we have yet to conduct a comprehensive nationwide epidemiological study that would accurately portray the number of children and adults with debilitating neurodevelopmental disorders such as autism. We need to develop a cohesive and reliable educational classification system for special needs, adequately monitor services and programs, develop standards and goals, and also set up a system of ongoing training for professionals serving this population. In many towns and villages, treatments offered by traditional healers are still often the only option for a child with mental health or developmental issues. As a result, access to appropriate and necessary medical care and early interventions, which are absolutely vital in reducing the impact on critical developmental milestones, is severely limited.

Beginnings of government intervention

Due to the foresight of its founding father, Bangabandhu Sheikh Mujibur Rahman, women, children and those who are disabled were given equal rights and opportunities in the Constitution of Bangladesh; however, little was done to define those rights. The Ministry of Social Welfare and the Ministry of Women and Children were created but, from 1975 to 1997, they received little attention or funding. It was not until 1997, due to the leadership of Prime Minister Sheikh Hasina, that the Government refocused its attention onto issues of rehabilitation and services for those with disabilities and special needs. In 1999, the National Foundation for Development of the Disabled Persons (NFDDP) was founded under the Ministry of Social Welfare. The purpose of the NFDDP was to ensure that persons with disabilities received adequate support and services in order to become active participants in mainstream society. The NFDDP was responsible for allocating funds for loans, grants and other services free of cost to persons with disabilities. The Disability Welfare Act was passed in 2001 and the current Government is in the process of updating it.



During the 2010-2011 fiscal year, more than 18 million US Dollars was allocated and distributed for programs, services, stipends and loans for those with disabilities. Approximately 21 million US Dollars have been allocated for the current financial year. In 2009, the development program “Protibondhi Sheba O Sahajya Kendro” (Organization for the Assistance and Services of the Disabled) was created to provide physiotherapy, occupational therapy, counselling, assistive devices and other related services to nearly 15,000 individuals across Bangladesh. A one Stop Mobile Service program was also introduced in order to reach families living in villages that lack access to medical services. In April 2010, two hostels were opened in Dhaka helping families access medical services in the capital, and the Autism Resource Centre was established to provide free therapeutic services.

School provision for special needs

At present, 55 special needs schools are run by the NFDDP through two separate non-governmental organisations (NGOs). Seven of these schools are based on an inclusion model, including the children with special needs in regular classes. In June 2010, the Center for Neurodevelopment and Autism in Children (CNAC) was inaugurated. It is the first government initiative that is linked to a medical university. In partnership

with the Bangabandhu Sheikh Mujib Medical University (BSMMU) it aims not only to provide training to parents, teachers, therapists and all medical professionals, but also to engage in the comprehensive management of services and research on autism and other neurodevelopmental disorders.

Out of the 55 schools educating children with disabilities, the following schools target children with specific needs:

Schools for the blind and visually impaired

There are four schools for the blind, located in 4 Divisions of the country. They serve approximately 500 children, 180 of whom have been provided with residential facilities. There are 64 government-sponsored integrated schools for the visually impaired at the secondary level which have a resource teacher and a resource room in each school.

Schools for the deaf and hearing impaired

There are seven government run schools for the deaf providing services to 700 children, of whom 180 are provided with residential facilities. Residential students also receive stipends and free room and board.

Schools for the intellectually disabled

At present, there are two special schools, subsidised by the Ministry of Social Welfare that have a total enrolment of 100 children with intellectual disabilities. The Society for the Welfare of the Intellectually Disabled, Bangladesh (SWID-B), an NGO, is the pioneer organisation for the education and advocacy of the intellectually disabled in Bangladesh.

Children with physical disabilities and neurological impairment

There are no government educational services for pre-primary or primary age children with physical disabilities. However, in 2011, all new government buildings and schools have been mandated to make their buildings wheelchair accessible. The Government does not provide specialised schooling for those with neurological impairments such as cerebral palsy (CP) or ASD. These children are integrated with children with intellectual disabilities, primarily through programs of the SWID-B, BPF and other NGO's working with children with different categories of disability. The Society for the Welfare of Autistic Children (SWAC) is currently the only NGO that is providing education exclusively to those with ASD.

Research suggests that if we can identify these children at a very early age, and provide them with intense evidence-based interventions, they are likely to have better developmental outcomes. In Bangladesh, we urgently need adequate screening for neurodevelopmental disorders, culturally and linguistically appropriate interventions, scientifically based academic programs in inclusive settings, on the job training and sheltered accommodation for young adults. With effective programs that provide culturally sensitive and economically feasible solutions, there is hope for all children with disabilities and special needs.

In order to bring greater focus onto children with neurological impairments and developmental disabilities, the Government has partnered with Autism Speaks and the World Health Organization to launch the Global Autism Public Health Initiative in Bangladesh (GAPH-BANGLADESH) and formed the National Advisory Committee on Autism in Bangladesh (GAPH-NAC). The purpose of the GAPH-NAC is to develop and implement feasible, effective and sustainable programs and solutions that are applicable to the Bangladeshi population. It is important to customise the programs based on the culture, social expectations, financial and professional resources, and existing infrastructure within Bangladesh. The GAPH-NAC plans to achieve these objectives by facilitating collaboration among local stakeholders and community and international experts to work towards a common goal.

The NAC is comprised of both national and international experts on autism and mental health, as well as representatives from Autism Speaks. Its vision is to enhance programs and services and ensure coordination and cooperation between the ministries of Health, Education and Social Welfare, so that individuals with autism and other special needs can become independent and productive members of society. GAPH Bangladesh intends to increase public and professional awareness of ASD, enhance research expertise, improve service delivery, build

capacity for better service implementation and conduct a national epidemiological study of the autistic population in Bangladesh. In addition, the formation of the South Asia Autism Network (SAAN) will enhance regional collaborations through a high level political and social network, foster partnerships between organisations, and leverage collective resources to address the needs of families.

The GAPH and SAAN came into being at the First International Conference on Autism Spectrum Disorders and Related Disabilities in South Asia, in Dhaka in July 2011. All 11 countries from the region who participated in the conference unanimously ratified the Dhaka Declaration on ASD. The Dhaka Declaration provides a guideline to increase awareness and understanding, build capacity, establish evidenced-based practices and encourage governments in the region to work in partnership with one another in order to address the needs of those with neurodevelopmental conditions.

As this is one of the most heavily populated regions of the world, it is of the utmost urgency that the needs of those with special needs are immediately addressed. In addition to the immeasurable burden experienced by the individuals concerned and their families, the economic hardship associated with dealing with these issues can be particularly profound in countries with limited financial resources, such as Bangladesh. The only way that the needs of those with special needs will be adequately addressed is if policy makers, government bodies, professional organisations and parents work together in partnership. Only through regional collaborations between organisations and political leaders can those with special needs hope to become productive members of society. International organisations, such as the United Nations and the World Health Organization, also need to urgently prioritise the needs of children with special needs and their families.

Further information

Saima Hossain, licensed school psychologist and the daughter of the Prime Minister of Bangladesh, is an international autism campaigner who spoke at the World Autism Day event at the United Nations in New York in 2011. She is currently chair of the National Advisory Committee for GAPH-Bangladesh and has launched an autism information service at:

www.globalautism.org

She is also associated with the research organisation Autism Speaks:

www.autismspeaks.org

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