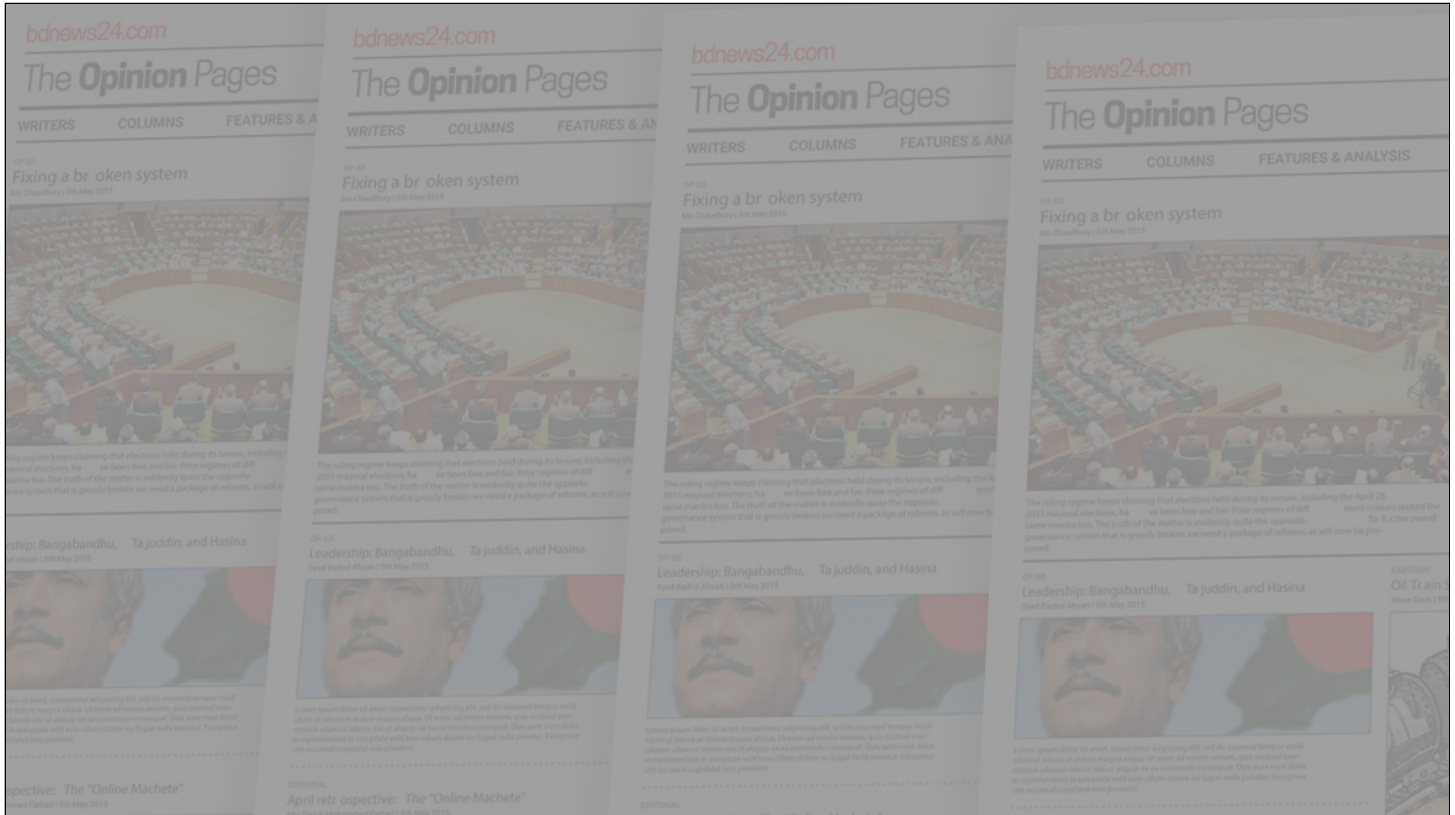


The Opinion Pages

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Of care, culture, customization



Written By **Saima Hossain Putul** (<https://opinion.bdnews24.com/author/saima-hossain-putul/>) | 7th Apr 2011



Your Excellencies, distinguished guests, ladies and gentlemen, good evening. I would like to start by saying how honored I am today to be speaking on behalf of families with special needs particularly autism in Bangladesh.

It's been estimated that 1 in every 110 individuals, or about 1% of the world's population, suffer from an autism spectrum disorder. What does that mean when a country like Bangladesh has a population of 162,220,762? Unfortunately, in many developing countries like Bangladesh we have no data for how many children or adults suffer from this lifelong debilitating developmental neurological condition. Needless to say this and many other scientific and medical questions need to be addressed urgently.

Children are the future of not only the individual country but of an increasingly intertwined global economy. As one of the most populated countries in the world, it is of the utmost urgency that the needs of those with autism be immediately addressed in Bangladesh. In addition to the immeasurable burden experienced by individuals with autism and their families, to society as a whole the economic hardship can be daunting. This is particularly true in a country with limited financial resources such as Bangladesh. While we are yet to have reliable statistic for autism prevalence in Bangladesh, and while resources and infrastructure may be scarce, there is no justification for inaction. In fact, it is the very reason why we need to act now!

Since the independence of Bangladesh in 1971, the constitution mandates the equality, nondiscrimination and creation of equitable measures for all those who are underprivileged under the auspices of the Ministry of Social Welfare. Therefore all programs and services for autism and other disabilities are currently under its jurisdiction. In 1999 during the Awami League government the

National Foundation for Development of the Disabled Persons (NFDDP) was founded in order to ensure that the persons with disabilities have adequate support to participate in the mainstream society. The current government has reactivated the once stalled NFDDP and is currently in the process of updating the Disability Welfare Act of 2001. Since the inception of NFDDP funds have been allocated to provide loans, grants and other services free of cost to persons with disabilities.

During the 2010-2011 fiscal year eighty nine lakh forty five thousand takas (TK 89,45,000) have already been distributed. Through the development program called: Protibondhi Sheba O Sahajya Kendro (organization for the assistance and services of the disabled) created in 2009, 5 main districts across Bangladesh are providing physiotherapy, occupational therapy, counseling, assistive devices and other related services to nearly 15,000 individuals many of whom are diagnosed with autism. It is scheduled to be expanded to 10 more districts by the

end of 2011. A 'One Stop Mobile Service' program has also been introduced in order to reach families that live in villages that lack accessibility to medical services. In April of 2010, 2 hostels were opened in Dhaka in order to help families access medical services in Dhaka. The Autism Resource Center was also established in 2010 to provide free therapeutic services. At present 55 special needs schools are run by the NFDDP through two separate NGO's. 7 of these schools are based on an inclusion model. In June of 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 it aims to provide training of all medical professionals, comprehensive management of services and research on autism and other neurodevelopmental disorders.

Many South East Asian countries share similar social and cultural perspectives. It is a region that values family and education above everything else. Unfortunately in doing so it also tends to leave behind those who may not be easily able to achieve what the average person can so easily do, such as learning to speak and behave in a socially acceptable manner. Often times our instinct to protect our family leads us to shelter these children for fear of being hurt by everything from insensitive remarks to blatant discrimination. Parents of children with autism live in a culture within a culture where sometimes even your extended family often does not know how to interact with you or your child because he or she has autism. I firmly believe that if we work collectively as a region we can not only help design and implement research based interventions in a timely manner, we can also help each and every family gain greater acceptability and understanding in society. Autism in South East Asia is not only a medical issue it is a human rights issue.

The complicated and potentially time-consuming path to a system-wide reassessment of ASD is currently not a national health priority for many countries. Yet, the rising prevalence and the acknowledgment of the emerging public health challenges of autism, developmental disabilities, and child mental health disorders by the United Nations and the World Health Organization demands more immediate relief for the children and families in need around the world.

A major barrier to improving the health and wellbeing of children and families touched by autism is not only the dearth of knowledge and expertise in recognizing the symptoms of ASD but also the absence of effective screening procedures, evidence-based intervention techniques and a lack of social acceptance. In many towns and villages, treatments offered by traditional healers are still the only option for a child with mental health issues and developmental disabilities like autism. This in turn limits access to appropriate and necessary medical care and early interventions which is absolutely critical in reducing the impact on critical developmental milestones.

This July, Sheikh Hasina and her government are partnering with Autism Speaks and the World Health Organization to launch the Global Autism Public Health Initiative (GAPH) in Bangladesh. The mission of the GAPH and the National Advisory Committee will be to develop and implement feasible, effective, and sustainable programs and solutions that are applicable to the Bangladeshi population. It is important to customize the programs based on the culture, social expectations, financial and professional resources, and existing infrastructure within Bangladesh. We plan to achieve these objectives by facilitating collaboration among local stakeholders, community and international experts to work towards a common goal. The development of GAPH will be guided by the National Advisory Committee which will be comprised of both national and international experts on autism and mental health as well as representatives from Autism Speaks. Its vision is to enhance current programs and services and ensure coordination and cooperation between the ministries of Health, Education and Social Welfare so that individuals with autism and other disabilities can become independent and productive members of society.

Bangladesh like many developing Asian countries is poor, overpopulated and agrarian. We therefore need to work in partnership to assist and promote adequate measures for our families with autism. Forming a national committee and implementing programs within Bangladesh is simply not enough. To speed progress and deliver answers to individuals and families, we urgently need the collaboration and cooperation of regional organizations and governments to build partnerships and leverage our collective resources and efforts in order to answer this call to action. Current research gives us hope that if we can identify these children at a very early age, then provide them with evidence-based interventions they are likely to have better developmental outcomes. We urgently need adequate screening for autism, culturally and linguistically appropriate interventions, scientifically based academic programs in inclusive settings, on the job trainings and sheltered accommodations for young adults, as well as a UN appointed spokesperson for autism and mental health disorders who will help launch and monitor social awareness campaigns in every country. With effective programs that provides culturally sensitive and economically feasible solutions there is hope for our children with autism.

I would like to end by saying a special thank you to Secretary General Ban Ki Moon for making the time to come to this event. You and your wife have been staunch supporters of this cause and it is because of your leadership that we are here today to celebrate and honour our families with autism.

I would also like to thank Dr Momen and his team at the Bangladesh Mission as well as Bob and Suzanne and the staff at Autism Speaks for putting together this phenomenal event. Finally, I would especially like to thank Andy and Michael, your dedication and work for those with autism is truly outstanding. Thank you all for making the time to join us at this momentous event today.

Saima Hossain Putul (<http://opinion.bdnews24.com/columnists/saima-hossain-putul/>) is daughter of prime minister Sheikh Hasina, and the article is based on her keynote paper presented on Apr 6, 2011 at the UN conference on autism.

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