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Autism in Bangladesh: Reducing Discrimination Through Innovation

By Saima Wazed Hossain

This article is part of a series of stories and op-eds issued by IPS on the occasion of this year's World Autism Awareness Day



Children's Cultural Program / Town Hall Meeting. Dec 14, 2015. Shilpakala Academy. Organized by Parents Forum for the Differently Able. A short play by nearly 30 children and youth with NDDs. Over 100 parents took part in the meeting asking a whole variety of questions and expressing their concerns related to NDDs.

DHAKA, Mar 30 2017 (IPS) - Within the last 5 years, thanks to political support and national education, autism awareness in Bangladesh has grown immensely. Due to a lack of funds and resources, providing full comprehensive evidence based services for those in need is not yet possible, but with a continuation of our current progression, it is certainly an attainable goal. Credit for our tremendous success in providing public awareness and understanding of the challenges faced by families with autism is ultimately, thanks to the dedication and resilience of those very families.

Our mission for families began in the 1990s with the implementation of comprehensive disability policies along with the formation of national forums and disability organizations.

Since 2008, World Autism Awareness Day on April 2nd is recognized and celebrated with a national event in Bangladesh. This event has involved a cultural show performed by PWD's with our Honorable Prime Minister Sheikh Hasina as the guest of honor. Individuals and organizations were recognized for their work, while getting an opportunity to interact with the Prime Minister to express any concerns.

Despite progression of autism awareness in the population, the real turning point for change in South Asia came with the international conference on autism organized in Dhaka on July 25th 2011. What differentiated this conference from others in the region was the integration of various individuals from scientific, personal, and political backgrounds. The presence of prominent political figures such as, Mrs. Sonia Gandhi, Prime Minister Sheikh Hasina, as well as many other First Ladies and ministers from the region, allowed our conference to be truly unique.



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This event brought about an unprecedented change in the societal attitudes about autism and disability. Since then, previously rejected newspaper articles by parents and experts began to be regularly published in Bangladesh daily papers. Talk show discussions on health matters included the topic of disability. The word 'autism', which did not exist in our language has now become a household term, and frequently, if unfortunately, used as a synonym for disability — or as we say in Bangla 'protibondhi'.

The conference was followed by the formation of 4 task forces comprised of parents and experts in the field. Additionally, I appeared in numerous television interviews where I described autism and shared a personal message to end discrimination and shame. At the recommendation of the task force, a parents' forum was established followed by the formation of a national steering committee in 2013, comprised of 8 ministries headed by the highest non-elected government officials, which are supported by senior advisors and technical experts. This multi-faceted approach prioritized the need for early screening and intervention, supportive educational programs, employment training, and social safety net programs. This sent an important message to stakeholders and policy makers explaining how there is no easily addressed solution to autism which could be implemented by altering existing medical practices. Instead, a multi sectorial life span approach would be required to create a more cost-effective, sustainable and supportive program catering to families' needs.

The last four years of multi-sectorial planning by the National Steering Committee has enabled the inclusion of disability in the government's

development and economic planning. With significant political support, the primary stakeholders, i.e. individuals with neurodevelopmental disorders (NDD) and their families continue to play a significant role in shaping policies and implementing programs. This involvement of several ministries ensures significant awareness for autism and all disability matters; however, our unique and comprehensive approach is challenged by a limited growth in human resource development and the lack of a mechanism for monitoring the efficacy of projects and fund disbursement to ensure sustainable evidence-based programs particularly in the social sector.

Global awareness and enhanced understanding of autism has resulted in increased diagnosis, demand for treatment and development of innovative approaches; many of which remain isolated to research settings or unpublished in scientific journals. Additionally, due to the high cost and copyright laws many programs in low resources countries remain similarly isolated and unshared. Moreover, programs requiring linkages between existing infrastructures with

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inter and intra-disciplinary collaboration are a particular challenge for developing countries. Hence why we urgently need a mechanism by which the challenges and success stories of these individuals can be shared among both disability organizations and governments so it may provide further knowledge on effective, sustainable programs and assist in decision making.

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This April, Shuchona Foundation with WHO-SEARO is paving the way towards implementation of international resolutions on autism by organizing a conference in Bhutan for the ministries of Health and Family Welfare of Bhutan and Bangladesh. Experts, self-advocates, caregivers and policy makers will meet for 3 days in Thimphu (visit www.ANDD2017.org) to discuss identification and interventions methods, issues on education and employment and help develop a collaborative comprehensive plan for low resource settings that all countries can emulate.

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