

AUTISM : THE CHALLENGE AND GLOBAL AUTISM PUBLIC HEALTH(GAPH) INITIATIVE : BANGLADESH

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Summary

Autism spectrum disorder (ASD) is a developmental neurological disorder characterized by deficits in social behavior & communication, and a restricted range of activities. ASD transcends social, cultural & geographic boundaries. At least 1 in 150 individuals are affected with autism. In Bangladesh there has been a dramatic increase in the visible number of children with Autism. It is estimated by the Ministry of Social welfare that the total number could be as high as 1.4 million, of whom only a few hundred have been diagnosed. Another estimation is that 1 in every 500 children in Bangladesh has Autism, meaning that the approximate number of children with Autism Spectrum Disorder(ASD) in Bangladesh is no less than 280,000. Autism symptoms range from mild to severe. Some individuals have strong intellectual & language abilities, whereas others require lifelong care. Many suffers from medical problems along with autism. The American Academy of Pediatrics(composed of over 60,000 pediatrician) has recommended mandatory autism screening for all children between 18 and 24 months of age because there is compelling evidence that early intervention can result in significant gains in language and cognitive and impact long term outcome. A major barrier to improve the health & wellbeing of children and families touched by autism is the lack of knowledge and expertise. This limits access to care & early intervention and impedes the development of appropriate public health programs that can improve the quality of life for individuals with ASD & their families. These challenges are further complicated by a shortage of experts & trained professionals.

Key words

Autism; autism spectrum disorder; Bangladesh

Background

Bangladesh emerged as an independent and sovereign country in 1971 following a nine month war of liberation. The State is governed by the National Constitution which is based on the principles of "equality, human dignity & social justice for all citizens" as declared in the "Proclamation of Independence" of Bangladesh.

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Despite this constitutional protection, the nearly one million people with disabilities in Bangladesh are suffering from limited employment & educational opportunities, social discrimination & stigma. Bangladesh situation is compounded by inadequate financial support, insufficient services, a limited number of trained professionals and fragmented policies & procedures. Without a comprehensive government monitored program to address these issues, those with disabilities & special needs can not hope to become actively participating member of society

From the administrative point of view, Bangladesh is divided into 7 Divisions, 64 Districts, 6 City Corporations, 308 Municipalities, 481 Upazillas, 599 Thanas and 4498 Unions¹.

Prevalence

- Prevalence studies, with disparate sample designs, are very few in number, varied in design, and not always comparable and reliable in terms of findings.
- Prevalence by type of disability reveals that the developmental disabilities including Autism have been completely neglected (except intellectual disabilities)
- There is significantly higher prevalence in rural areas than in urban areas
- That the moderate group is larger than the mildly or the severely affected groups
- That prevalence among females is higher than among males
- That NGO data varies from 5.6% to 8 % prevalence in the general population
- That a Government HIES survey in 2010 identified 9.07 % of the population as being affected by some form of disability
- The only study on autism in Bangladesh, was conducted jointly by the WHO country office and National Institute of Mental Health, in Dhaka Division, for the 0-18 yrs. age group ; this limited study showed a prevalence of Autism to be 0.84%(details are waited) among children.
- The center for autism and neurodevelopmental disorders (CNAC), set up in BMSSU, is considering a prevalence study on Autism, in the very near future.
- The ESTEEM II study,² conducted by the Primary and Mass Education Division (PMED) with the support of DFID and the technical support of the Cambridge Consortium in 2001-02, found that out

of an estimated 1.6 million children with disabilities within the primary school going age in Bangladesh, a staggering 96% had never gained any access to education at all. Among the small number of enrolled children with disabilities only 48% are in formal education, while 23% are in integrated schools, 15% in special education, 5% in inclusive education and 9% in other types of education.

• An USAID study on education for persons with disability in Bangladesh reveals³: Analysis of existing statistics on disparate sample studies offer only an approximation of the configuration of types of disabilities, and their proportionate prevalence.

Most indicate

- ◆ physical disabilities have the greatest reported incidence (41.5 percent)
- ◆ visual disabilities (19.7 percent),
- ◆ speech and hearing (19.6 percent),
- ◆ intellectual disabilities (7.4 percent),
- ◆ cerebral palsy (7.0 percent),
- ◆ multiple disabilities (3.4 percent) and
- ◆ mental illness (1.4 percent).

Current international trends in understanding the magnitude of Autism reveal 1:90 in the USA and in a few studies in the Asia-Pacific region (Japan, Hong-Kong and Korea) show sharply increased figures as high as 1:47⁴.

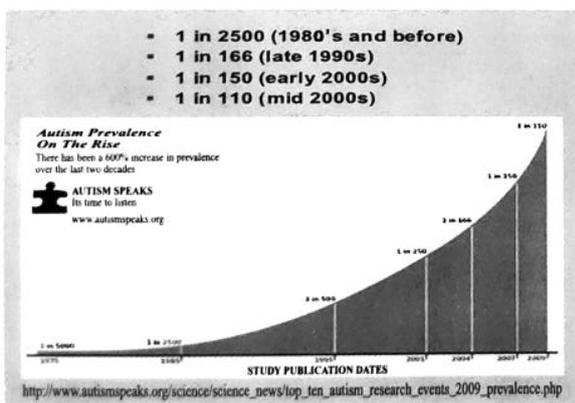


Fig 1 : Changing Prevalence of ASDs over time

In Bangladesh, attention to Autism and other developmental disorders has been disproportionately low (other than intellectual disabilities); there is a shifting burden of health from communicable diseases to non communicable diseases and better medical advances are now saving many more high risk NICU patients (with possibly compromised quality of life). In Bangladesh, 80% of deliveries are conducted at home.

Interventions that could reduce social, financial and psychological costs of disability to individuals, families and the nation need to be considered and factored into the existing mechanisms. The current situation

The current situation of disability in general in Bangladesh is clearly reflected in the chart below, sourced from (CDD)⁵.

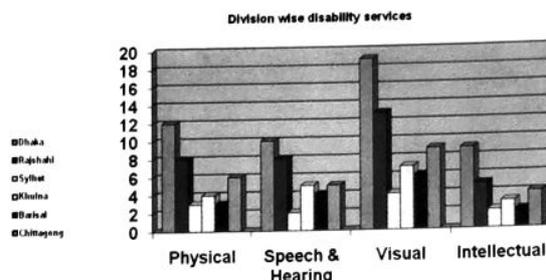


Fig 2 : Division wise disability services

In 6 divisions, the disability-specific services reflect that other than in Dhaka, services in intellectual disability are fewer as compared to the other three disabilities; that Rajshahi and Chittagong are the other two divisions which fare better than the others. Even in these 3 divisions, services, few as they clearly are, serve largely the urban and the peri-urban populations.

There are very few autism-specific services like the Society for the Welfare of Autistic Children (SWAC), Autism Welfare Foundation (AWF), Autistic Children's Welfare Foundation, Creative World of Autistic Children, Smiling Children and Alokito Shishu, some of whom have centers both in Dhaka and in Chittagong, Most of them are parent-driven, and offer a range of excellent services. From the government sector, only one center is available in the Ministry of Social Welfare, based in Protibondhi Unnayan Foundation, and the other is housed within CNAC, BSMMU.—both in Dhaka city⁶.

Initiative of Autism Speaks

Autism Speaks, in collaboration with Government of Bangladesh and WHO, conducted an International Conference in July 2011 in Dhaka, Bangladesh on Autism and Developmental Disabilities, attended by over 1000 persons, with Mrs. Sonia Gandhi of India as Chief Guest and many First Ladies of the Region as Guests of Honor. The Dhaka Declaration was a landmark document for the Region and has set off a chain reaction with an Autism Conference held in Delhi in November 2011, jointly by the Health Ministry in India and the WHO Country Office.

Autism Speaks Global Autism Public Health (GAPH) Initiative is an innovative, integrated approach that focuses on three goals:

Parental concerns, as documented from 2 meetings in Dhaka and Chittagong, and mail exchanges, are given below

- Future safety and security
- Protective legislation
- Legal Guardianship
- Parity in access to civil, political, social, economic and cultural rights
- Recognition of legal capacity
- Property/Inheritance rights and right to pension of children of Government personnel (both parents)
- Increasing coverage, improving quality and standardization of training and life-span services
- Regulatory body for standardization of services and service-providers
- Grievance redressal mechanism/disability commissioner (awareness raising of existing system at district-level) to be an autonomous body
- Mechanism for protection against abuse
- Access to trained doctors and reliable diagnosis and feed-back mechanisms
- Access to a range of educational options and addressing parental concerns
- Awareness towards dismantling of negative attitudinal and informational barriers

- Sensitization of police judiciary medical and education personnel in government
- Continuum of services to include respite , residential and independent living centers
- Disability certificates, tax exemptions, health insurance
- Income Tax exemptions for donations to special schools, services
- Modifications inIncome-Tax exemptions for parents under section 82bb of the IT ACT 1984
- Priority in queues,alloction for beds etc at hospitals, doctors clinics etc.

Parents of persons with Autism and other DDs, are particularly vulnerable to anxiety because their group of children are currently not promoted as self-advocates. Empowering and enabling them with knowledge, skillsand leadership, will result in the emergence of a massive workforce to guide, support and monitor decisions and activities which directly and indirectly benefit their children, as well as the nation as a whole. Conversely, marginalizing them will lead to loss of a highly motivated cadre of key resource persons.

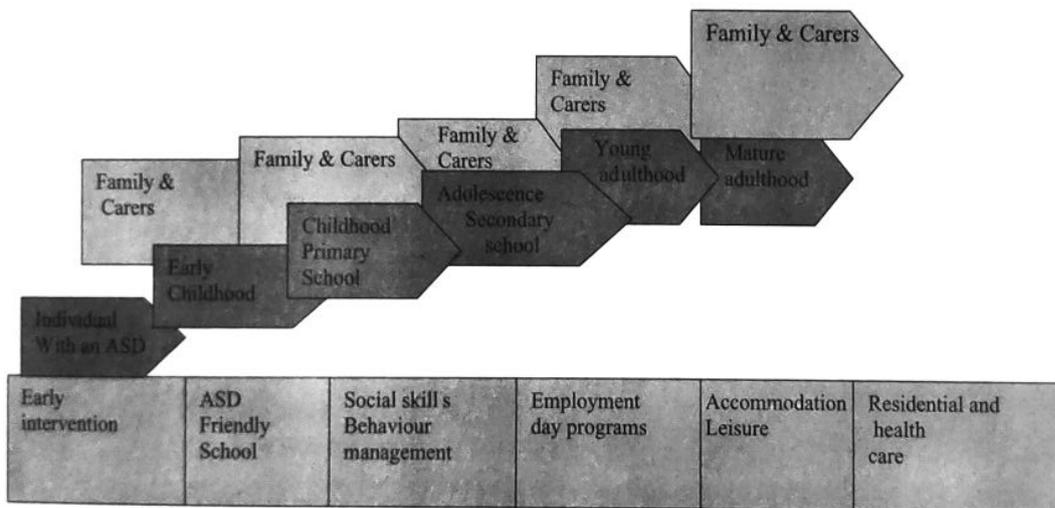


Fig 3 : Lifelong support: whole family approach. Accessible support skilled, compassionate workforce

(Source:Victoria State Plan on Autism, Australia)

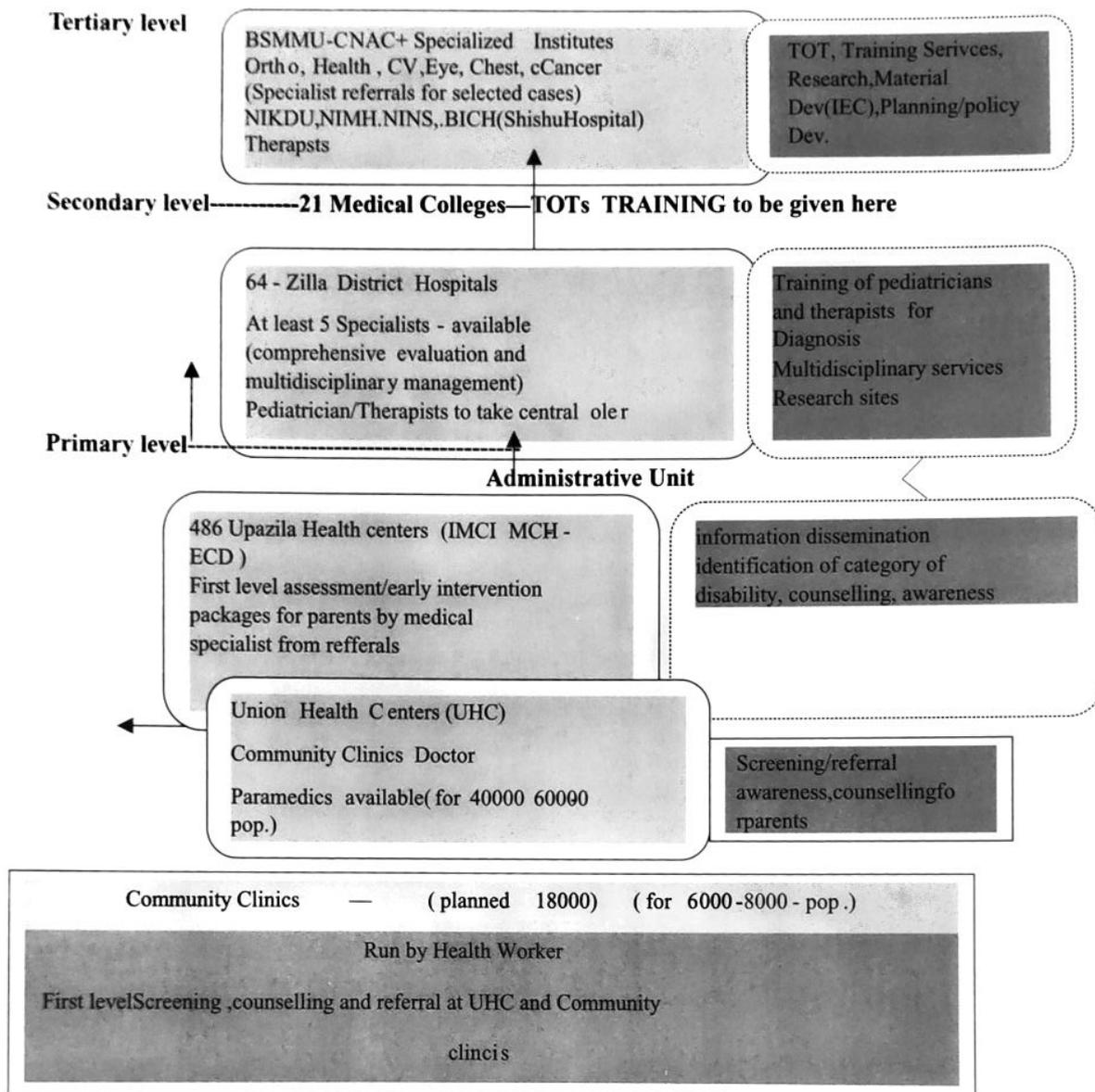


Fig 4 : Creating Synergy with the Health System in Bangladesh

(Source: SEARO-WHO workshop on Autism in Bangkok, Thailand, 2010)

Conclusion

The development of a Strategic Action Plan on ASD and DDs is seen as critical to the sustainability, synergy and success of any efforts to address the needs of this group in terms of Research, Advocacy, Services (in detection, diagnosis, interventions, capacity building etc.) along with the provision of a range of educational and vocational options. Regardless of the concerns about the availability and absolute reliability of prevalence studies in the country, it is evident that there is a huge upsurge of interest in training, services, awareness and information about Autism and the other Developmental Disabilities in the last few years, more particularly in the last few months.

It is becoming increasingly clear, even within a short span of 6-8 months, that the GAPH-Bangladesh program is breaking old barriers and treading new paths. The development of four Task Force groups on Awareness and Advocacy, Education, Services and Research, has led to the mapping of existing resources and identification of gaps thereof. Detailed planning, evidence-based practices and planned new prevalence studies will further strengthen the new initiatives on Autism and other developmental disabilities in the very near future. Most certainly, it will place Bangladesh as a pioneer and leader in the South East Asian region. A Nobel prize-winning Bengali poet and visionary, Gurudev Rabindranath Tagore, had said that “The problem is not how to wipe out the differences, but how to unite with all the differences intact”...that is exactly what the challenge ahead will be.

Special

Disclosure

The author declared no competing interestes

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