

## “People, Policy and Practice” The Success Story of Bangladesh in Management of Neuro-Developmental Disability

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The theme “Transformation towards sustainable and resilient societies for all” of International Disability Day 2017 has been buzzing since its declaration and it has been adopted in various National and international declaration and agenda [1]. Bangladesh has approved the rights of a Person disability since its liberation and with the passage of time, the country has extended and Organized coordinated collective efforts for them to make their rights tangible. The government established a series of Acts, for the benefit of the person with a disability to such an extent as National Coordination Committee for the Person with Disability in 1993 followed by the Disability Welfare Act 2001 [2,3]. Later, the latter was replaced with the Rights and Protection of Person with Disability Act 2013, a more right focused approach and more aligned to the provisions of the Incheon Strategy covering their fundamental rights as well as their cultural, social, economic and political rights [4-7]. The acts aim to promote the social inclusion and promote the resilience of the caregivers who frequently encounter stress, depression and social exclusion due to the stigma which is related to disabilities. In the same year, the government enacted “Protection of Persons with Neuro-developmental Disability Trust Act, 2013” to ensure the protection of the rights of the person with Neuro-Developmental Disability and Disorders [5-7]. According to the Act of the country, Autism Spectrum Disorder, Intellectual disability, Down syndrome and Cerebral Palsy is considered as Neurodevelopmental disorders. The trust with the collaboration of various other government and non-government organizations are making a remarkable contribution to transforming the lives of the person with Neuro-developmental disabilities as well as their caregiver.

Bangladesh promotes the active participation of a disable person in every stage of the program focusing them from the planning to implementation. Person with disability gets priority in all the government hospitals and there are a large number of integrated service centres for them all over the country. In promoting their participation in democratic process, special provisions are being created at polling booths. A real time national disability survey system has been established. According to this survey, 1536401 individuals (on 25-11-2017) are facing different types of disabilities like autism, physical disability, intellectual disability, visual disability, vocal disability, hearing disability, multiple disability, cerebral palsy and others [8]. In addition to this system, the government of Bangladesh also received information about the disabled person from the National Census, the Health and Morbidity Status Survey (2014), Education Household Survey (EHS, 2014) [9-15]. However, there is variation on the prevalence of disability and total number of disability among the surveys. From our experience, we can say that the lack of uniform definition and screening system for disability is one of the key reasons behind the inconsistent data. Among the other causes, the low engagement of respondents due to stigma and lack of awareness, the

improper selection of variable and tools, lack of training are noteworthy [15]. Moreover, the lack of universal set of criteria for the data collection method for all these sources and the absence of interoperable electronic health record are other major limitation [12]. The Social Safety Net programs for the person with disability provide monthly allowances for the disabled, stipends for disabled students, grants for the schools of the disabled and so on [13]. The Bangladesh Building Code has provided specific guideline to ensure rights of the person with disability for universal access in all the government buildings and to make all the buildings disable friendly [14]. The use of sign language during the news and major national programs are promoting their rights for information and inclusion through the Information Act 2009 [16]. A holistic activity for national preparedness for disaster for the person with disability is going on based on the Disaster Management Act 2012 that is harmonized with the Incheon Strategy [17,18]. In the country, 5% seats are reserved for the people with disability in all sorts transport and government is also supporting them in their employment by providing quota for them [19-21]. The National ICT Policy, 2009 promote equal rights to access to all electronic technologies and The National Education Policy 2010 and The National Children Policy 2011 promote access to education for children with disability [22-24]. The Bangladesh Bank gives them the opportunity to open account with 0.1 dollar and provides loan up to 8000 USD that is refundable. Many disabled friendly initiatives are going on in Bangladesh that deserves appreciation.

However, the coordination and monitoring of the programs is a key challenge with the widespread stigma related to disability [15]. Another key challenge is lack of organized referral system [25]. The challenge remains in development of an equitable strong and supportive legal and judiciary system [4]. We face continuous challenge of widespread stigma about disability that affects the epidemiological survey while the implementation of a program [15]. With the development of information communication technologies, the protection of rights of a person with a disability in the cyber world is a great emerging challenge [19]. With all its limitation, Bangladesh is making a remarkable process in protecting and advancing the rights of the person with a disability.

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