

**Remarks by Ambassador K. Nagaraj Naidu,
Deputy Permanent Representative**

at

**High Level World Autism Awareness Day Event
“Autism: Nurturing Care Framework and Family-centered Care”**

ECOSOC Chamber

3 April 2019

Your Excellency Ambassador Alya Ahmed Saif Al-Thani, PR of Qatar
Your Excellency Ambassador Momen, PR of Bangladesh
Excellencies, Distinguished guests, Ladies and Gentlemen

1. At the outset I would like to thank the Permanent Representatives of Bangladesh and Qatar for their leadership in organizing this annual event, aiming at raising the awareness about Autism in the context of inclusive development. India is proud to join as co-sponsor again this year.
2. I also thank ‘Autism Speaks’ for its contribution in fostering understanding of Autism and related challenges.
3. As we mark the 30th anniversary of the Convention of the Rights of the Child, we must fulfill our ongoing commitment to protect the right of every child to survive and thrive. With one in every 160 children worldwide affected by Autism or Autism Spectrum Disorder, we need to develop a comprehensive and rights-based framework to ensure their participation in all aspects of social and economic life.
4. In India, the rights of persons with disabilities including those with Autism has gained strong resonance in policy spheres over the years. The landmark Rights of Persons with Disabilities (RPWD) Act, 2016 has included Autism Spectrum Disorder (ASD) under the category of disabilities and paved way for a rights based approach.
5. With the aim of channelizing the inventive and innovative spirits of persons with disabilities and to make them equal partners in progress, the Act provides for reservation in employment, educational institutions, in

poverty alleviation schemes, as well as allotment of land for housing and concessional loans for setting up businesses.

6. To operationalize the commitments made in the Act and to build a database of Persons with Disabilities, the Government issues Unique Disability ID (UDID) cards to facilitate their access to social protection. Our partnerships with the private sector in ensuring employment for persons with disabilities have been mutually beneficial and fruitful. The Accessible India Campaign has been launched in 2015 for barrier-free access in public spaces and in virtual ecosystems.

7. In India, there is also growing understanding that early childhood interventions are key to diagnosis and care of Autism. The Indian Academy of Pediatrics has recently issued guidelines for screening for ASD at 18 months and 24 months of age, using ASD specific screening tools.

8. To overcome several of the limitations of internationally available tools, and to standardize diagnosis, the India-based International Clinical Epidemiology Network (INCLIN) has developed a diagnostic tool to help detection of autism at an early age. In addition, an assessment procedure has been developed by the Indian Scale of Assessment of Autism (ISSA). In association with the All India Institute of Medical Science, the government has already started to train doctors in the use of these recently developed twin diagnostic tools for issuing disability certificates to people with autism to help them avail benefits like education, scholarships, concessional travel, insurance etc.

9. The estimated number of children with ASD in India is around three million. Providing therapist-mediated services to the patients on a regular basis is not feasible. Parents as co-therapists have become an effective alternative intervention for children with ASD. While we acknowledge the benefits of parent-mediated therapies and role of family support, we must also be cognizant of the higher responsibility and social stigma associated with raising a child with Autism which can put stress on the parents and caregivers.

10. Adults with ASD is a group which is particularly hard to reach. In many cases these individuals have not received therapy in their childhood due to lack of awareness or absence of facilities. With the joint family system which previously provided scaffolding to the parents caring for the child or adult with special needs slowly disintegrating, the need for social

protection for persons with Autism and their family are being felt more acutely.

11. We recognize the crucial role played by civil society in providing care, generating knowledge and awareness about this phenomenon. One such groundbreaking initiative is MSSNG (pronounced 'missing'), a collaboration between Google and Autism Speaks, to sequence DNA of 10,000 families affected by autism. MSSNG will help answer the many questions we still have about and to devise more personalized and effective interventions.

12. New technologies have created opportunities and higher expectations for full inclusion of individuals with autism into all aspects of society, beginning with the classroom. However, barriers still exist to accessing these technologies, including high costs, unavailability and a lack of awareness of their potential.

13. To conclude, there is need for a 'whole of society' approach to ensure that persons with Autism can participate as equal partners in development with their rights and dignity fully protected.

14. The time to act is now.