4. Autism Spectrum Disorders: Prevalence in India and Way Ahead

Prelims Syllabus: Governance

Mains Syllabus: GS-II Governance | Health & Education

Why in News?

- In India, the prevalence of autism spectrum disorders (ASD) is a widely debated issue due to a lack of systematic estimates. Most estimates have been derived from studies based on school children, revealing that over one crore Indians may be on the autism spectrum. However, there are notable cultural differences in diagnosing autism between countries, which highlights the need to assess the prevalence of autism spectrum disorders specifically in the Indian context.

What is Autism?

- **Spectrum disorder:** Autism, also known as Autism Spectrum Disorder (ASD), is a neurodevelopmental disorder that affects communication, social interaction, and behaviour. It is called a spectrum disorder because the symptoms and severity can vary widely between individuals.

- **Common symptoms:** Some common symptoms of autism include difficulty with social interactions, such as maintaining eye contact or understanding nonverbal cues, delayed speech and language development, repetitive behaviors, and sensory sensitivities.

- **Cause:** Autism is believed to be caused by a combination of genetic and environmental factors, but the exact cause is not yet fully understood.

- **Cure:** There is currently no cure for autism, but early interventions and therapies can help individuals with autism lead fulfilling and independent lives.

Prevalence of Autism in India

- **Lack of systematic estimates:** Autism is a global issue and affects individuals of all cultures, ethnicities, and socioeconomic backgrounds. However, there is a lack of systematic estimates of autism prevalence in India.

- **Methos failed:** Researchers have attempted to estimate prevalence through government hospitals, but this method failed due to the absence of central medical registries.

- **Conservative estimates:** As a result, prevalence was estimated through school-based assessments. According to conservative estimates, well over one crore Indians are on the autism spectrum. This highlights the need for further research and attention to address the prevalence of ASD in India.

Cultural Differences and Diagnosis of Autism:

- Notable cultural differences exist in the diagnosis of autism spectrum disorder. In the US and UK, the majority of children with autism spectrum diagnosis are verbal, with average or higher IQ, and attending mainstream schools.

- However, in India, a significant majority of children with a clinical diagnosis of autism also have intellectual disability and limited verbal ability.

- This difference is driven by sociological factors, such as access to appropriate clinical expertise, provisions for inclusion in mainstream schools, and availability of medical insurance coverage.

Challenges in Assessing Autism

- **Assessment tools:** Assessment of autism spectrum disorder is primarily behavioral, and most widely used autism assessment tools are not available in Indian languages.

- **Indigenous autism assessment tools challenges:** There has been a rise in the development of indigenous autism assessment tools. Despite the development of these tools, it can be challenging to compare across different assessment measures.

Demand and Supply in India

- **Shortage of mental health professionals:** Most autism assessment tools need to be administered by specialist mental health professionals. However, there is a significant shortage of mental health professionals in India, with less than 10,000 psychiatrists, a majority of whom are concentrated in big cities.

- **Delay is costly:** Delay in interventions can be costly for neurodevelopmental conditions such as autism.

- **Demand and supply gap need to be met:** This gap between demand and supply cannot be met directly by specialists alone, and parallel efforts to widen the reach of diagnostic and intervention services through involving non-specialists is required. Emerging evidence suggests the feasibility of involving non-specialists in autism identification and intervention through digital technology and training programs.

Way ahead: Need for an All-India Program

- **National program on autism:** The need of the hour is to develop a national program on autism in India that links researchers, clinicians, service providers to the end-users in the autism community.

- **Essential components:** This program needs to have three essential components that are joined up: assessment, intervention, and awareness.

- **Assessment:** Research is needed to develop appropriate assessments and design efficient implementation pathways.

- **Intervention:** Clinical and support service workforce needs to be expanded by training non-specialists such that a stepped-care model can be rolled out effectively across the nation.

- **Awareness:** Large-scale initiatives need to be launched to build public awareness that can reduce the stigma associated with autism and related conditions.

Conclusion:

- There are challenges in diagnosing and assessing autism in India which highlights the need for a comprehensive and coordinated effort to address them. By expanding the clinical and support service workforce, training non-specialists, and developing appropriate assessments and interventions, India can improve outcomes for those on the autism spectrum and reduce the stigma associated with the condition. This national program needs to be informed by consultation with different stakeholders, with a primary focus on end-users within the Indian autism community.

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