

Experts set out future of autism care and treatment with focus on personalised and lifelong approaches

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A new, comprehensive model of autism care and treatment that prioritizes personalized, stepped care approaches is urgently needed,

according to a new international report published in *The Lancet*.

The authors of The Lancet Commission on the future of care and [clinical research](#) on autism call for global coordination between governments, [health care providers](#), education, financial institutions, and social sectors to reform research, care, and treatment for autism that will include individualized treatments throughout a person's life with active participation from patients and their families.

The Commission was formed in 2018 by international experts, including clinicians, healthcare providers, researchers, advocates, self-advocates, and parents of children with autism. The report identifies urgent actions required in the next five years to address the current needs of people with autism and families worldwide and to build a foundation for improved care and treatment in the future. The report sets out a new standard of care that all services and social care systems worldwide should adopt to best support the needs of people with autism and their families.

The Commission also calls for global research efforts to expand beyond basic science toward developing evidence-based practical interventions tailored to the heterogeneous needs of people living with autism and could be applied to other neurodevelopmental conditions.

Personalized, stepped model approach to care

At least 78 million people are living with autism worldwide, the majority of whom do not receive adequate support or care services, especially those living in low-and-middle-income countries or other low-resource settings. Given the heterogeneous nature of autism, a new personalized, stepped care approach is urgently needed. This new approach moves away from a categorical diagnosis toward a focus on support to improve the quality of life for individuals and their families centered around their

unique concerns, needs, characteristics, and circumstances that can be adjusted throughout their lives.

"Although numerous well-tried interventions and treatments for autism exist, not enough is known about which treatments or services should be offered, when, to whom, for how long, with what expected outcomes and for what cost," says Commission co-chair Dr. Catherine Lord of the University of California, Los Angeles (U.S.). "Autism is an incredibly heterogeneous condition and treatment approaches must vary not only between people living with autism but throughout a person's lifetime. This stepped care approach requires coordination on a global scale between governments, social sectors, healthcare providers, education and finance institutions, and among people living with autism and their families."

The Commission also reiterates the value of neurodiversity among people with autism—or the natural variability within human brains and minds—to create stronger, wiser communities and positive social values. At the same time, the Commission proposes that the designation of 'profound autism' be adopted for people with autism who are minimally verbal or non-verbal, are not able to advocate for themselves, and require 24-hour access to an adult who can care for them. The authors propose that the designation be used for administrative purposes (rather than a formal diagnosis) in order to encourage both the clinical and research global communities to prioritize the needs of this vulnerable and underserved population. The authors validated the designation of profound autism against three databases, and found that it would apply to anywhere between 18% to 48% of people with autism.

Prioritizing meaningful research and clinical practice

National and international infrastructures should be developed to help prioritize research that goes beyond biology and studies of single

interventions to focus instead on those that integrate care across systems over time and take into account individual differences within the autism spectrum that lead to better outcomes.

Recent high-quality trials among young children with autism have identified psychosocial interventions that can result in changes that could mitigate the influence of autism on development for some people. Research is now needed to identify what factors enable people with autism to live positive, fulfilling lives, the key elements of effective interventions for children and adults, and the wider environmental barriers to change for people with autism.

"Basic science is often prioritized over more practical knowledge, leaving people living with autism, families, and providers without evidence-based guidance. Individuals with autism are a valued part of society. We urge commitment to greater investments in what can be done for people living with autism and their families now, with a focus on how to build on existing information to answer specific practical questions that will then better inform interventions and services to help people living with autism achieve their fullest potential," says Commission co-chair Prof Tony Charman of King's College London (UK).

Overcoming global inequities in assessment, care, and treatment

The needs of families who live with autism worldwide are universal. The World Health Organisation (WHO) has recognized autism as a global health priority, with key recommendations for all member states to implement. But many individuals with autism remain undiagnosed, especially in low-resource settings, where surveillance is rarely done for any neurodevelopmental disorder. Families often have limited access to

evaluations and other resources to assess and treat autism or other neurodevelopmental conditions. In addition, many families may not seek out assessment or treatment due to limited awareness about autism, social and cultural stigma related to neurodevelopmental conditions, and financial barriers.

"It is imperative that we tackle the scarcity of resources that exist for autism care and treatment worldwide, especially for individuals and their families living in resource-limited settings where autism and other neurodevelopmental conditions may be stigmatized, or overlooked, leaving children undiagnosed until adulthood or in many cases never diagnosed. In these settings, where most of the world's children live, individuals should not have to wait for months or years to start treatment because they are unable to find an appropriate assessment, and once identified as having specific needs, their geography, socio-economic and social status and access to services should not be a barrier for receiving care. Women, minority ethnic populations, people living with profound autism, and people with other co-occurring conditions such as anxiety, depression, behavior challenges, or sleep disorders are also often further marginalized from services. We must do more for these populations and hold our governments and health systems accountable for providing life-changing support that will ultimately better our entire society," says co-author Dr. Gauri Divan of Sangath, India.

Improved care today and for the future

The authors write that much more can be done now for people living with autism that will lay the foundation for improved, comprehensive care in the future to ensure more equitable care and social justice for people living with autism. The Commission's recommendations for both clinical practice and systems change are based on beginning with an individual's needs and with continual involvement of stakeholders, including people with autism, families, supportive community members,

and providers, at each step of the way. Capacity building is essential to strengthening care systems, particularly in [low-resource settings](#) and underserved communities. These multi-dimensional approaches will yield personalized, dynamic models of intervention and services that will be the key to a better future for individuals with [autism](#) and other neurodevelopmental conditions.

Writing an introductory Comment for the Commission, Dr. Richard Horton, Editor-in-chief of The Lancet and Helen Frankish, Executive Editor of The Lancet say "The Commission's recommendations emphasize improving the quality of life for all autistic people and their families through seeking better information about the needs, strengths, and most effective services for autistic individuals across the lifespan and developmental stages. Ultimately, the message of the Commission is one of hope. Studies have shown that much can be done to improve the life outcomes for autistic individuals. But concerted action is needed without delay to answer fundamental questions about the care for autistic people, together with the development of policies and programs to improve the lives of all autistic individuals across the globe."

More information: The Lancet Commission on the future of care and clinical research in autism, *The Lancet* (2021). [DOI: 10.1016/S0140-6736\(21\)01541-5](#)

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