

## Perspective

Xiang Yu\* and Xiu Xu\*

# The future of care and clinical research in autism – recommendations from the 2021 Lancet Commission

<https://doi.org/10.1515/mr-2022-0015>

Received May 31, 2022; accepted June 2, 2022;

published online July 1, 2022

**Abstract:** At least 78 million people worldwide are affected by autism, a neurodevelopmental disorder characterized by deficits in social interactions, and repetitive behaviors and/or interests. Autism typically manifests in early childhood, and affects social communications and behaviors throughout the lifespan of the individual. Under the umbrella of autism spectrum disorder, it is a highly heterogeneous disorder, with some individuals profoundly affected and needing care every day, while others can live highly independent lives, with some adjustments. The past 60 years has seen a major influx of interest in autism, and significant advances in many areas. However, a large gap remains between current scientific knowledge and the help and support that people with autism and their families need. To address these concerns, the Lancet commissioned a report on the “future of care and clinical research in autism”. The Commission calls for government coordination between health-care, education and social sectors, as well as active participation from people with autism and their families. The Commission proposes personalized, evidence-based assessments and intervention, that is accessible and affordable to all, and call for increased appreciation of neurodiversity and prioritization of research that can improve the lives of people with autism and their families. How to support each and every autistic individual and their families is highly challenging. The 64-page Lancet Commission Report, published on December 2021, was

written jointly by 32 authors from 6 continents and 13 disciplines, including clinicians, other health-care providers, researchers, advocates, autistic individuals and their parents.

**Keywords:** autism; autism spectrum disorder; neurodevelopmental disorder.

## Understanding heterogeneity and recognizing diversity

Autism is a highly heritable and heterogeneous neurodevelopmental disorder that can co-occur with other conditions. The estimated prevalence of autism worldwide is 1%–2%, meaning that at least 78 million people in the world have autism [1, 2]. In the fifth edition of Diagnostic and Statistical Manual of Mental Disorders, several different categories of autism were grouped under the umbrella of autism spectrum disorders [3]. The Commission Report uses the term autism, rather than autism spectrum disorder, because it is shorter and more acceptable to many autistic people [4].

Within the spectrum of autism, are individuals with substantial intellectual disability, are non-verbal or have minimal language, cannot take care of own basic daily needs, and need lifelong care and support. The Lancet Commission introduced the term “*profound autism*” to describe these individuals, not as a diagnostic subtype, but as an administrative term, to urge government, as well as clinical and research communities, to prioritize the need of this vulnerable group. In three different cohorts, the proportion of individuals meeting the criteria of profound autism varied between 18% and 48% [5].

At the other end of the spectrum are individuals who are can live largely independent lives, with some adjustments. They may face exhausting daily life situations, due to excessive sensory stimuli, constant struggle to decipher social cues and to communicate, and needing to deal with unexpected changes. Increased awareness of autism in the community, and more accommodations in the

\*Corresponding authors: **Xiang Yu**, State Key Laboratory of Membrane Biology, School of Life Sciences, Peking-Tsinghua Center for Life Sciences, IDG/McGovern Institute for Brain Research, Peking University, 5 Yiheyuan Road, Haidian District, Beijing 100871, China; Autism Research Center of Peking University Health Science Center, Beijing 100191, China; and Chinese Institute for Brain Research, Beijing 102206, China, E-mail: yuxiang01@pku.edu.cn. <https://orcid.org/0000-0003-1225-7666>; and **Xiu Xu** Department of Child Healthcare, Children’s Hospital of Fudan University, Shanghai 201102, China, E-mail: xuxiu@shmu.edu.cn

environment, can help ease those impairments and possibly turn them to strength. Some individuals with autism have average or above-average intelligence and language abilities, are college-educated, have profession jobs, are married and have children. Some members of this group consider autism to be neurological difference, rather than a disorder, and are opposed to research on the causes of autism [6]. The Commission notes and respects these voices, but also emphasizes that all individuals with autism need to be attended to, with respect to their specific needs.

Heterogeneity in autism is not only between individuals, but also across different life stages of the same individual. During childhood, adolescent and adulthood, autistic individuals and their families likely have different needs and priorities. Over the past ten years, studies show that behavioral and psychosocial interventions can lead to improvements that significantly mitigate the difficulties that autistic people experience [7]. In addition to differences between individuals at the time of diagnosis, variability in response to treatments may add to differences at later stages of life.

The Commission proposed a novel, stepped-care approach to assessment and intervention in autism, personalized for each individual, taking into account the costs, burden and preferences of autistic individuals and their families. This new type of “person-centered” care requires information on the skills and needs of each autistic person and their family. For example, for a 5-year-old with profound autism, providing daily care and ensuring the safety of the child are likely priorities; for another child of similar age, but with less severe symptoms, the priority may be to help him/her to be able to attend regular school. Priorities depend on the individual’s ability, age, severity of symptoms, cognitive and language skills; the acceptance, general motivation and ability of the family, as well as the availability of resources and treatment strategies [5]. The treatment goal is to fully inform and to provide the best possible care, given the available means, based on the need and preferences of the individual and their family. The Commission also emphasizes follow-up monitoring, based on changing needs of the individuals, as they develop through adolescence into adults.

## Improving services in lower-resource settings

The Lancet Commission proposes an evidence-based, stepped-care and personalized approach for intervention and assessment in autism, involving governments, health-care systems and service providers working in concert, to provide services that meet the needs of autistic people and

their families, ensuring equity, equality, diversity and inclusion [5]. 95% of children under the age of 5 with developmental disabilities, including autism, live in low-income and middle-income countries (LMIC) [8]. Yet most research is done in high-income countries.

Due to competing health priorities [9], insufficient health-system capacity, and inadequate diagnosis and awareness of autism, services for autism in lower-resource settings are uneven and generally lacking. The Commission highlights the importance of building national and international infrastructure and of developing research strategies to help autistic individuals in LMIC. The recommendations reiterate the pressing need to increase investment in autism research in lower-resource settings, to identify what interventions work, for whom, when, how, with what general outcome, and at what cost. They also emphasize the importance of working within the context of the local communities.

Providing parents with sufficient training and guidance to enable parent-delivered intervention is one feasible possibility in lower-resource settings, and progress has been reported in some Asian and African countries [10]. Supporting autistic children, especially those with good intellectual and language abilities, in regular schools is a major challenge, but one that is critical to the development of these children. Accepting students with disabilities into regular schools requires more teachers, and especially more special education teachers with training in autism; these teachers are generally lacking, especially in LMIC. In some countries, regular schools do not have support for individuals with disabilities altogether. Thus, building a work force with more teachers specializing in autism is the ultimate goal, for both regular and special education schools. In the interim, more autism awareness in teachers in regular schools, working together with special education teachers, can help bridge the gap. It is also very important that other students and the broader community become more autism aware, and provide a more welcoming and accepting environment for autistic children. For typically developing children, being aware of disabilities and learning to help others will also help them to become more caring and more well-round individuals.

## Prioritization of clinical research into effective treatment strategies

The past several decades have seen major advances in autism research, mostly basic and translational research. The Commission calls for prioritization of clinical research that addresses the immediate needs of autistic individuals and their families, especially those that can be put into effect in the next 5 years. The most urgent concerns are to

identify which interventions are effective, for whom, when and at what intensity. This is especially important for developing scalable interventions worldwide.

The Commission calls for randomized controlled trials for short-term interventions, including both medication and behavioral trials, to measure the effectiveness of treatment strategies. It also calls for consideration for factors outside the clinic, including how age, developmental levels, socioeconomic and cultural backgrounds affect outcome, as well how required training is implemented by parents and caregivers. For treatments to be effective in lower-resource settings, both the treatment itself and the system that implements it need to be robust and cost-effective.

Double-blind, gold-standard, randomized control trials are not always feasible in evaluation of long-term, multicomponent and complex trials, especially those involving behavioral training. Alternative trial approaches thus need to be developed. The goal is to develop effective and affordable treatment strategies that can be implemented worldwide, including in lower-resource settings. The Commission also notes the importance of culture adaptation and tailed intervention approaches.

At the other end of the spectrum are individuals who can live. Over the past several decades, we have learnt much about what autism is, how it differs between individuals and how we can support the development of autistic people. We know that early treatment strategies can significantly improve the prognosis of individuals with autism, and hope that future research and improved implementation of research findings can help more people worldwide.

**Research funding:** None declared.

**Author contributions:** All authors have accepted responsibility for the entire content of this manuscript and approved its submission.

**Competing interests:** Authors state no conflict of interest.

**Informed consent:** Not applicable.

**Ethical approval:** Not applicable.

## References

1. Baxter AJ, Brugha TS, Erskine HE, Scheurer RW, Vos T, Scott JG. The epidemiology and global burden of autism spectrum disorders. *Psychol Med* 2015;45:601–13.
2. Maenner MJ, Shaw KA, Baio J, Washington A, Patrick M, DiRienzo M, et al. Prevalence of autism spectrum disorder among children aged 8 Years—autism and developmental disabilities monitoring network, 11 sites, United States, 2016. *MMWR Surveill Summ* 2020;69:1–12.
3. American Psychiatric Association. *Diagnostic and statistical manual of mental disorders*, 5th ed. Arlington, VA: American Psychiatric Publishing, 1993.
4. Kenny L, Hattersley C, Molins B, Buckley C, Povey C, Pellicano E. Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism* 2016;20:442–62.
5. Lord C, Charman T, Havdahl A, Carbone P, Anagnostou E, Boyd B, et al. The Lancet Commission on the future of care and clinical research in autism. *Lancet* 2022;399:271–334.
6. Frankish H, Horton R. A way forward to improve the lives of autistic people. *Lancet* 2022;399:215–7.
7. Sandbank M, Bottema-Beutel K, Crowley S, Cassidy M, Dunham K, Feldman JJ, et al. Project AIM: autism intervention meta-analysis for studies of young children. *Psychol Bull* 2020;146:1–29.
8. Global Research on Developmental Disabilities C. Developmental disabilities among children younger than 5 years in 195 countries and territories, 1990–2016: a systematic analysis for the Global Burden of Disease Study 2016. *Lancet Global Health* 2018;6:e1100–21.
9. Scherzer AL, Chhagan M, Kauchali S, Susser E. Global perspective on early diagnosis and intervention for children with developmental delays and disabilities. *Dev Med Child Neurol* 2012;54:1079–84.
10. Kakooza-Mwesige A, Bakare M, Gaddour N, Juneja M. The need to improve autism services in lower-resource settings. *Lancet* 2022;399:217–20.