

Autism spectrum disorder diagnosis across cultures

Tafla, Tally Lichtensztein; Teixeira, Maria Cristina Triguero Veloz; Woodcock, Kate Anne;
Sowden-Carvalho, Sophie

DOI:

[10.1177/27546330241226811](https://doi.org/10.1177/27546330241226811)

License:

Creative Commons: Attribution-NonCommercial (CC BY-NC)

Document Version

Publisher's PDF, also known as Version of record

Citation for published version (Harvard):

Tafla, TL, Teixeira, MCTV, Woodcock, KA & Sowden-Carvalho, S 2024, 'Autism spectrum disorder diagnosis across cultures: Are diagnoses equivalent?', *Neurodiversity*, vol. 2. <https://doi.org/10.1177/27546330241226811>

[Link to publication on Research at Birmingham portal](#)

General rights

Unless a licence is specified above, all rights (including copyright and moral rights) in this document are retained by the authors and/or the copyright holders. The express permission of the copyright holder must be obtained for any use of this material other than for purposes permitted by law.

- Users may freely distribute the URL that is used to identify this publication.
- Users may download and/or print one copy of the publication from the University of Birmingham research portal for the purpose of private study or non-commercial research.
- User may use extracts from the document in line with the concept of 'fair dealing' under the Copyright, Designs and Patents Act 1988 (?)
- Users may not further distribute the material nor use it for the purposes of commercial gain.

Where a licence is displayed above, please note the terms and conditions of the licence govern your use of this document.

When citing, please reference the published version.

Take down policy

While the University of Birmingham exercises care and attention in making items available there are rare occasions when an item has been uploaded in error or has been deemed to be commercially or otherwise sensitive.

If you believe that this is the case for this document, please contact UBIRA@lists.bham.ac.uk providing details and we will remove access to the work immediately and investigate.

Autism spectrum disorder diagnosis across cultures: Are diagnoses equivalent?

Neurodiversity
Volume 2: 1–3
© The Author(s) 2024
Article reuse guidelines:
sagepub.com/journals-permissions
DOI: [10.1177/27546330241226811](https://doi.org/10.1177/27546330241226811)
journals.sagepub.com/home/ndy



Tally Lichtensztein Tafla¹ , Maria Cristina Triguero Veloz Teixeira¹,
Kate Anne Woodcock² and Sophie Sowden-Carvalho³

In an increasingly interconnected world, the recognition of autism spectrum disorder's (ASD) global prevalence demands a deeper understanding of its diagnosis within diverse cultural contexts. Approximately 1 in 100 children are diagnosed with ASD around the world, with prevalence estimates increasing in recent years (Zeidan et al., 2022). The fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5-TR) and the 11th revision of the International Classification of Diseases offers standardized criteria, but the interpretation of ASD behaviors within cultural frameworks raises intriguing questions about the equivalence of diagnoses across cultures.

Over time, psychiatric diagnostic systems have tried to capture ASD heterogeneity, including intellectual and language levels, the presence of cooccurring mental health conditions, and genetic, neurological, and other medical conditions. However, no diagnostic biomarkers for core features of autism exist (Myers et al., 2020), making observation-based diagnosis pivotal. This includes clinical evaluation by parents, professionals, and standardized instruments like the Autism Diagnostic Observation Schedule, 2nd Edition and Autism Diagnostic Interview, Revised.

ASD is defined by recognizable behavior and socio-emotional patterns, but diverse cultural contexts can impact the interpretation of these behaviors, leading to differences in identification (de Leeuw et al., 2020). Culture influences how parents and caregivers perceive ASD symptom severity due to varying child development expectations (Hus & Segal, 2021; Matson et al., 2017). Assessing 'social communication difficulties' relies on deviations from culturally defined 'typical' social communication, potentially leading to disparate interpretations. Thus, assigning 'social communication impairments' to children across cultures may lack equivalence, potentially overlooking crucial cultural differences in ASD assessments.

The International Test Commission (2017) underscores the significance of cross-cultural validations, advocating for equivalence analysis involving experiential (contextual understanding) and idiomatic (natural translation) equivalence. These precautions mitigate relying solely on single

translations, ensuring assessments transcend language barriers and encompass cultural intricacies (ITC, 2017). Despite the ITC's work to guide the quality of cross-cultural validations, a lack of focus on the validity of some behavioral assumptions across cultures means there is still something missing in this validation.

Cross-cultural comparisons are vital for ASD, as cultural views on appropriate behaviors and 'typical' development can impact parent/caregiver reports and ASD diagnoses (Matson et al., 2017). Carruthers et al.'s study (2018) analyzing parent-reported data from India, Japan, and the United Kingdom found universal autistic traits, along with potential cross-cultural differences in traits like spontaneity and social conversation (Carruthers et al., 2018). Cultural influence on autistic traits extends to ethnicity (Athar et al., 2021) and even race within a country (DSM-5-TR; Aylward et al., 2021), affecting epidemiological rates and the perception of social communication difficulties.

Our focus is not to challenge standardized assessments measuring intellectual and language skills, but rather to scrutinize observational and medical evaluations. We may consider if 'social communication difficulties' carry uniform connotations across countries with distinct social norms. We may also question the sensitivity and accuracy of screening instruments, especially with respect to detecting mild difficulties. Interpretation of peer interactions and eye contact differ across cultures; a Western ASD trait (lack of eye contact) contrasts with Asian cultures, where direct eye contact can be impolite. Moreover, cultural variability

¹Center for Research on Childhood and Adolescence, Postgraduate Program in Human Development Sciences, Mackenzie Presbyterian University, São Paulo-SP, Brazil

²Centre for Applied Psychology, School of Psychology & Institute for Mental Health, University of Birmingham, Birmingham, UK

³Centre for Developmental Science, School of Psychology, University of Birmingham, Birmingham, UK

Corresponding author:

Tally Lichtensztein Tafla, Graduate Program in Human Developmental Sciences, Mackenzie Presbyterian University, Rua da Consolação 896, Prédio 28, 1º andar, Consolação, São Paulo, Cep: 01302-000/ SP, Brasil.
Email: tafla.tally@gmail.com



Creative Commons Non Commercial CC BY-NC: This article is distributed under the terms of the Creative Commons Attribution-NonCommercial

4.0 License (<https://creativecommons.org/licenses/by-nc/4.0/>) which permits non-commercial use, reproduction and distribution of the work without further permission provided the original work is attributed as specified on the SAGE and Open Access page (<https://us.sagepub.com/en-us/nam/open-access-at-sage>).

in adaptive functioning, intrinsic to diagnostic criteria, is pivotal. Acknowledging culture as integral to the autism evaluation process (Golson et al., 2022; Hus & Segal, 2021; Matson et al., 2017) is crucial.

Discussions of cultural aspects of the behavioral and socio-emotional phenotype underlying an ASD diagnosis are therefore necessary and this is in line with other recent calls for research prioritizing cultural factors (Carruthers et al., 2018; Golson et al., 2022; Hus & Segal, 2021). Cross-cultural studies can illuminate context-based criteria shaping the global understanding of ASD diagnosis and enhance its comprehension around the globe. Research strategies considering diverse cultural factors influencing diagnosis promote a broader view across cultures.

Expanding our lens beyond ASD, it is imperative to consider other neurodevelopmental conditions within the context of cross-cultural diagnosis. While each condition has its unique features, the challenges posed by cultural nuances in assessment are likely to be common. For instance, conditions such as attention deficit hyperactivity disorder (Chan et al., 2022) and some aspects of intellectual disabilities (Gangavati et al., 2023) may manifest differently across cultures, impacting the accuracy of diagnoses. What is socially expected for an individual and consequently seen as a delay or deficit in adaptive functioning, for example, may vary across different cultures, and need to be considered when assessing for an accurate diagnosis.

Navigating ASD's intricate landscape demands cross-cultural research. Embracing diverse cultural perceptions of social behaviors enhances accurate and sensitive diagnoses not only for ASD but for a spectrum of neurodevelopmental conditions. Collaborative efforts among clinicians, researchers, and policymakers bridge assessment tools and cultural nuances, ensuring appropriate care worldwide.

Declaration of conflicting interests: The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding: This work was financed in part by the Coordenação de Aperfeiçoamento de Pessoal de Nível Superior – Brasil (CAPES-PrInt) – Finance Code: CAPES/AUXPE: 2739/2018, Process: 88881.310344/2018-01 and by the CAPES/Coordination for the Improvement of Higher Education Personnel – CAPES) – PROEX – Process Number: 2020/07992-2, and the Conselho Nacional de Desenvolvimento Científico e Tecnológico (CNPq) (the National Council for Technological Development – Research Productivity Grant PQ-1C – Process Number 308665/2021-0. We would also like to thank Fundação de Amparo à Pesquisa do Estado de São Paulo (FAPESP) for the PhD Fellowship support (Process number: 2020/07992-2).

ORCID iD: Tally Lichtenstejn Tafla  <https://orcid.org/0000-0002-8782-8905>

References

- Athar, M. E., Ebrahimi, A., Karimi, S., Esmailzadeh, R., Mousavi Asl, E., Azizi, M., Heidarzadeh, S., Siahkamari, E., Sharifi, A., & Ramezani Farani, A. (2021). Comparison of autistic traits between Iranian students with different ethnic backgrounds: A cross-cultural study. *Frontiers in Psychiatry*, 12(12), 744180. <https://doi.org/10.3389/fpsyg.2021.744180>
- Aylward, B. S., Gal-Szabo, D. E., & Taraman, S. (2021). Racial, ethnic, and sociodemographic disparities in diagnosis of children with autism spectrum disorder. *Journal of Developmental and Behavioral Pediatrics: JDBP*, 42(8), 682–689. <https://doi.org/10.1097/DBP.0000000000000996>
- Carruthers, S., Kinnaird, E., Rudra, A., Smith, P., Allison, C., Auyeung, B., Chakrabarti, B., Wakabayashi, A., Baron-Cohen, S., Bakolis, I., & Hoekstra, R. A. (2018). A cross-cultural study of autistic traits across India, Japan and the UK. *Molecular Autism*, 9(1), 52. <https://doi.org/10.1186/s13229-018-0235-3>
- Chan, W. W., Shum, K. K. M., & Sonuga-Barke, E. J. (2022). Attention-deficit/hyperactivity disorder (ADHD) in cultural context: Do parents in Hong Kong and the United Kingdom adopt different thresholds when rating symptoms, and if so why? *International Journal of Methods in Psychiatric Research*, 31(3), e1923. <https://doi.org/10.1002/mpr.1923>
- de Leeuw, A., Happé, F., & Hoekstra, R. A. (2020). A conceptual framework for understanding the cultural and contextual factors on autism across the globe. *Autism Research: Official Journal of the International Society for Autism Research*, 13(7), 1029–1050. <https://doi.org/10.1002/aur.2276>
- Gangavati, S., Hewage, C. G., Nayar, A., & Chaturvedi, S. K. (2023). Perception of intellectual disability across cultures. In C. Kapugama, R. Alexander, S. Bhaumik, S. Tromans, & S. K. Gangadharan (Eds.), *Psychiatry of intellectual disability across cultures* (pp. 122–135). OUP Oxford.
- Golson, M. E., Ficklin, E., Haverkamp, C. R., McClain, M. B., & Harris, B. (2022). Cultural differences in social communication and interaction: A gap in autism research. *Autism Research: Official Journal of the International Society for Autism Research*, 15(2), 208–214. <https://doi.org/10.1002/aur.2657>
- Hus, Y., & Segal, O. (2021). Challenges surrounding the diagnosis of autism in children. *Neuropsychiatric Disease and Treatment*, 17(17), 3509–3529. <https://doi.org/10.2147/NDT.S282569>
- International Test Commission. (2017). The ITC guidelines for translating and adapting tests (2nd edition). <https://www.intestcom.org/>.
- Matson, J. L., Mattheis, M., Burns, C. O., Esposito, G., Venuti, P., Pisula, E., Misiak, A., Kalyva, E., Tsakiris, V., Kamio, Y., Ishitobi, M., & Goldin, R. L. (2017). Examining cross-cultural differences in autism spectrum disorder: A multinational comparison from Greece, Italy, Japan, Poland, and the United States. *European Psychiatry*, 42(42), 70–76. <https://doi.org/10.1016/j.eurpsy.2016.10.007>
- Myers, S. M., Challman, T. D., Bernier, R., Bourgeron, T., Chung, W. K., Constantino, J. N., Eichler, E. E., Jacquemont, S., Miller, D. T., Mitchell, K. J., Zoghbi, H. Y., Martin, C. L., & Ledbetter, D. H. (2020). Insufficient evidence for “autism-specific” genes. *American Journal of Human Genetics*, 106(5), 587–595. <https://doi.org/10.1016/j.ajhg.2020.04.004>

Zeidan, J., Fombonne, E., Scorah, J., Ibrahim, A., Durkin, M. S., Saxena, S., Yusuf, A., Shih, A., & Elsabbagh, M. (2022). Global prevalence of autism: A systematic review update.

Autism Research: Official Journal of the International Society for Autism Research, 15(5), 778–790. <https://doi.org/10.1002/aur.2696>