

Cultural Diversity Committee Newsletter

Volume 5, Issue 3♦ December 2020

Cultural Diversity Committee Updates

Welcome to the third issue of the Cultural Diversity Committee Newsletter! This newsletter features the cultural diversity in autism research award recipient, announcements about upcoming RFAs, most recent research articles on the topics of cultural diversity in autism spectrum disorder (ASD), and resources .

In August, our committee hosted a webinar titled "Building Capacity to Increase Cultural Diversity in Autism Research: Insights from the INSAR Summer Research Internship in Autism and Cultural Diversity". This webinar showcased the experiences of the 2019 summer interns and their faculty mentors as part of the INSAR Summer Research Internship in Autism and Cultural Diversity program. The recording of the webinar is available here.



If you would like to be featured or would like to nominate someone to be featured in the Spotlight section of our newsletter, have any upcoming publications, or know of any resources that are related to cultural diversity and autism, let us know! Contact email: culturaldiversitycommittee@autism-insar.org

Researcher Spotlight: 2020 Cultural Diversity Research Award Recipient



Dr. Waganesh Zeleke, a licensed, bilingual clinical mental health counselor and certified National counsel, is an Associate Professor in the department of Counseling, Psychology and Special Education at Duquesne University. Her research is in the area of identifying, understanding and treating mental health disorders in individuals who are from impoverished communities, where school and community services can be uninformed about the needs of diverse groups. Dr. Zeleke's work has a particular focuses on advancing the needs of **children with autism** and the importance of understanding multicultural experiences. Her research results in recommendations that are relevant for policy makers addressing the needs of children with autism in the US and in Ethiopia. Dr. Zeleke's work also explores the epidemiology, diagnosis, and treatment of autism in Ethiopia and Zimbabwe and has started to right the imbalance of knowledge about autism worldwide.

Dr. Zeleke's work has been embraced by the local community. Not only has she helped with service provision at Joy Center for Children with Autism, one of the pioneer organizations in Ethiopia opening in 2002, they have also served as a community partner. The Joy Center has been instrumental in designing outreach initiatives for families to determine how to best reach individuals with ASD – which included a television information campaign aimed at reducing stereotypes. Additionally, Dr. Zeleke provided educational workshops partnering with two autism centers to ensure parents and service providers' voices are being represented in prioritizing the needs of their community. Her research and professional insight have been featured in the newsletter the *Spectrum*.

A critical component of Dr. Zeleke research agenda focuses on children with Autism in the low-resource areas of the world. Given that minority children with Autism are disproportionately represented in health care access and utilization, Dr. Zeleke analyzed a large national dataset of children with ASDs and other developmental disorders. Her focus on disparity research emphasizes detecting, understanding, and reducing the level of disparity in mental healthcare access and utilization of children with ASD from minority background.

Dr. Zeleke's track record is extensive as it includes 28 peer-reviewed publications, five book chapters, and more than 50 peer-reviewed national and international presentations as well as several grants. All her work address the needs of disenfranchised groups including children with disabilities (especially, autism), immigrant families in the US and African families in Ethiopia. Samples of Dr. Zeleke's publications include (a) <u>Disparities in Diagnosis and Service Access for Minority Children with Autism Spectrum Disorder;</u> (b) *Healthcare and Educational Services Used by Children with Autism Spectrum Disorders in Poverty*; c) <u>The Path to an Autism Spectrum Disorders Diagnosis in Ethiopia: Parent Perspective;</u> (d) *Autism service providers report: Behavioral and educational interventions used in Ethiopia;* (e) <u>Children with Autism in Ethiopia: Diagnosis, legal, and educational services and (f) The experiences of Zimbabwean children with Autism and their families in terms of the process of diagnosis and access to services: Parents' views, (g) Assessing the effectiveness of professional development training on Autism and culturally responsive practice in Educators and practitioners in Ethiopia, and (h) Examining the effectiveness of Behavioral Treatment and Intervention Received by children with Autism.</u>

Stay Tuned: 2021 Cultural Diversity Research Award

INSAR Cultural Diversity Research Award

Call for nominations: Early January, 2021

Nominations due date: Early February, 2021

The Cultural Diversity Research Award seeks to support and recognize research with significant impact on culturally diverse and underserved communities. The goal of the award is to support investigators who conduct community-based or community partnered research that seeks to leave a lasting impact on underserved and under-researched communities beyond the scope of a single research study. For more information, visit this link.

Stay Tuned: 2021 Cultural Diversity Research Internship

INSAR Research Internship in Autism and Cultural Diversity

Call for applications: Early December, 2020

Application due date: Late January, 2021

In recognition of the increased need for the field of autism to incorporate global perspectives and issues of cultural diversity in scientific research, the INSAR Cultural Diversity Committee invites research proposals from highly qualified undergraduate and graduate students interested in cultural diversity issues relevant to autism spectrum disorder (ASD). For more information, visit this <u>link</u>.

Recent Publications

Open Access Articles

Broder-Fingert, S., Mateo, C. M., & Zuckerman, K. E. (2020). <u>Structural Racism and Autism</u>, Pediatrics, 146(3), e2020015420. https://doi:10.1542/peds.2020-015420

Cardon, A. & Marshall, T. (2020). <u>To raise a child with autism spectrum disorder: A qualitative, comparative study of parental experiences in the United States and Senegal.</u> *Transcultural Psychiatry*, 1-16. https://doi.org/10.1177/1363461520953342

Chang, J., Kochel, R. (2020). <u>Vaccine Hesitancy and Attributions for Autism among Racially and Ethnically Diverse Groups of Parents of Children with Autism Spectrum Disorder: A Pilot Study</u>. *Autism Research*. https://dx.doi.org/10.1002/aur.2339

Constantino, J. N., Abbacchi, A. M., Saulnier, C., Klaiman, C., Mandell, D. S., Zhang, Y., ... Geschwind, D. H. (2020). <u>Timing of the Diagnosis of Autism in African American Children</u>. Pediatrics, 146(3), e20193629. https://doi:10.1542/peds.2019-3629

Jones, D. R., & Mandell, D. S. (2020). <u>To address racial disparities in autism research, we must think globally, act locally.</u> Autism, 24(7), 1587–1589. https://doi.org/10.1177/1362361320948313

Lilley, R., Sedgwick, M., Pellicano, E. (2020). <u>Inclusion, acceptance, shame and isolation: Attitudes to autism in Aboriginal and Torres Strait Islander communities in Australia</u>. *Autism*. https://dx.doi.org/10.1177/1362361320928830

Neece, C., McIntyre, L. L., and Fenning, R. (2020) Examining the impact of COVID 19 in ethnically diverse families with young children with intellectual and developmental disabilities. *Journal of Intellectual Disability Research*, 64, 739–749. https://doi.org/10.1111/jir.12769.

Paula, C., Cukier, S., Cunha, G., Irarrázaval, M., Montiel-Nava, C., Garcia, R., Rosoli, A., Valdez, D., Bordini, D., Shih, A., Garrido, G., & Rattazzi, A. (2020). <u>Challenges, priorities, barriers to care, and stigma in families of people with autism: Similarities and differences among six Latin American countries</u>. *Autism*, 1-15. https://dx.doi.org/10.1177/1362361320940073

Shochet, I.M., Orr, J.A., Kelly, R.L. *et al.* (2020). <u>Psychosocial resources developed and trialled for Indigenous people with autism spectrum disorder and their caregivers: a systematic review and catalogue</u>. *Int J Equity Health*, *19*(134). https://doi.org/10.1186/s12939-020-01247-8

Regular Access Articles

Abaoud, A. A., Almalki, N. S., Bakhiet, S. F., & Ateik Al-khadher, M. M. (2020). <u>Psychometric properties of the Autism Treatment Evaluation Checklist in Saudi Arabia.</u> *Research in Autism Spectrum Disorders*, 76, 101604. https://doi.org/10.1016/j.rasd.2020.101604

Columna, L., Felizola, G., Prieto, L., Myers, B., Streete, D., & Lightburn, A. (2020). <u>The experiences of Hispanic families of children with autism spectrum disorder regarding physical activity.</u> *Research in Developmental Disabilities, 107,* 103785. https://doi.org/10.1016/j.ridd.2020.103785

Recent Publications

- Gordillo, M. L., Chu, A., & Long, K. (2020). <u>Mothers' Adjustment to Autism: Exploring the Roles of Autism Knowledge and Culture.</u> *Journal of Pediatric Psychology*, *45*(8), 877–886. https://doi.org/10.1093/jpepsy/jsaa044
- Idris, S. B., Jagersma, G., van Pelt, B. J., Jacobs, S., Laugeson, E. A., Hillegers, M.H.J., van Haren, N., & Greaves-Lord, K. (2020). <u>Development and preliminary testing of the Dutch version of the Program for the Education and Enrichment of Relational Skills (PEERS®)</u>. *Research in Autism Spectrum Disorders*, 78, 101629. https://doi.org/10.1016/j.rasd.2020.101629.
- Kang, J., Han, X., Jon-Fan, H., Feng, H., Li, X. (2020). <u>The study of the differences between low-functioning autistic children and typically developing children in the processing of the own-race and other-race faces by the machine learning approach. *Journal of Clinical Neuroscience*, 54-60. https://doi.org/10.1016/j.jocn.2020.09.039</u>
- Kember, S. M., & Williams, M. N. (2020). <u>Autism in aotearoa: Is the RAADS-14 a valid tool for a new zealand population?</u> *European Journal of Psychological Assessment,* http://dx.doi.org.proxy1.cl.msu.edu/10.1027/1015-5759/a000598
- Khara, R., Kalankesh, L.R., Shahrokhi, H., Dastgiri, S., Gholipour, K. & Feizi-Derakhshi, M.-R. (2020). <u>Dilemmas of empowering families of children with autism spectrum disorders: a qualitative case study.</u> *Advances in Autism.* https://doi.org/10.1108/AIA-05-2020-0028
- Kim, S., Kim, J., Yan, M., & Kang, V. Y. (2020) <u>Korean-American Mothers' Perceptions of Self-Determination of Primary School Children with Autism Spectrum Disorder</u>. *International Journal of Disability, Development and Education*. https://doi.org/10.1080/1034912X.2020.1821873
- Lee, R. & Zhu, Y. (2020) <u>Diagnosis as a sociocultural practice: critical personal narratives of Asian immigrant mothers with Autism-Spectrum Disorder children in Canada.</u> *Disability & Society.* https://doi.org/10.1080/09687599.2020.1804326
- Lilley, R., Sedgwick, M., & Pellicano, E. (2020). <u>Inclusion, acceptance, shame and isolation:</u> <u>Attitudes to autism in Aboriginal and Torres Strait Islander communities in Australia</u>. *Autism*, https://doi.org/10.1177/1362361320928830
- Padilla-Petry, P. & Saladrigas-Tuà, M. (2020) <u>Autism in Spain: Parents between the medical model and social misunderstanding.</u> *Disability & Society*, 1-22. https://doi.org/10.1080/09687599.2020.1828043
- Richa, S., Khoury, R., JRouhayem, J., Chammay, R., Kazour, F., Khalil, R. B., Kheir, W., Choueifaty, D., Kouba-Hreich, E., Gerbaka, B., & Adib, S. (2020). Estimating the prevalence of autism spectrum disorder in Lebanon. L'Encéphale. https://doi.org/10.1016/j.encep.2020.05.015

Recent Publications

Rios, K., & Burke, M.M. (2020). <u>Facilitators and Barriers to Positive Special Education</u>
<u>Experiences and Health Among Latino Families of Children with Disabilities: Two Systematic Literature Reviews.</u> Review Journal of Autism and Developmental Disorders. https://doi.org/10.1007/s40489-020-00220-z

Rivard, M., Millau, M., Mello, C., Clément, C., Mejia-Cardenas, C., Boulé, M., & Magnan, C. (2020). Immigrant Families of Children with Autism disorder's Perceptions of Early Intensive Behavioral Intervention Services. Journal of Developmental and Physical Disabilities. https://doi.org/10.1007/s10882-020-09764-8

Shilubane, H. & Mazibuko, N. (2020). <u>Understanding autism spectrum disorder and coping mechanism by parents: An explorative study.</u> *International Journal of Nursing Sciences*. https://doi.org/10.1016/j.ijnss.2020.08.003.

Tromans, S., Chester, V., Gemegah, E., Roberts, K., Morgan, Z., Yao, G.L. and Brugha, T. (2020). <u>Autism identification across ethnic groups: a narrative review.</u> *Advances in Autism*, https://doi.org/10.1108/AIA-03-2020-0017

Publications related to COVID-19

Cahapay, M. B. (2020). <u>How Filipino parents home educate their children with autism during COVID-19 period</u>. *International Journal of Developmental Disabilities*, 1–4. https://doi.org/10.1080/20473869.2020.1780554

Colizzi, M., Sironi, E., Antonini, F., Ciceri, M. L., Bovo, C., & Zoccante, L. (2020). <u>Psychosocial and behavioral impact of COVID-19 in autism spectrum disorder: An online parent survey</u>. *Brain Sciences*, *10*(6), 341. https://doi.org/10.3390/brainsci10060341

Esentürk, O. K. (2020). <u>Parents' perceptions on physical activity for their children with autism spectrum disorders during the novel Coronavirus outbreak.</u> *International Journal of Developmental Disabilities*, 1–12. https://doi.org/10.1080/20473869.2020.1769333

Jeste, S., Hyde, C., Distefano, C., Halladay, A., Ray, S., Porath, M., Wilson, R. B., & Thurm, A. (2020). Changes in access to educational and healthcare services for individuals with intellectual and developmental disabilities during COVID-19 restrictions. *Journal of Intellectual Disability Research*, 64(11), 825–833. https://doi.org/10.1111/jir.12776

Majoko, T., & Dudu, A. (2020). <u>Parents' strategies for home educating their children with autism spectrum disorder during the COVID-19 period in Zimbabwe</u>. *International Journal of Developmental Disabilities*, 1–5. https://doi.org/10.1080/20473869.2020.1803025

Resources

Global Research in Autism and Neurodevelopment (GRAND) – "GRAND is an online worldwide community enabling people working on autism and neurodevelopmental disorders to share knowledge, tools, and resources, raise awareness and develop innovative strategies and interventions." The network is a free resource, you can learn more by visiting: **The Global Health Network**.

Global Partnerships on Children with Disabilities (GPcwd). "The GPcwd provides a platform for collective action and advocacy to ensure that the rights of children with disabilities are included in and prioritized by both the disability and child rights agendas at the global, regional, and country levels." For more information, please visit their website: **GPcwd**. To access their recent Early Childhood Taskforce Newsletter, please visit: **Early Childhood Development Task Force**

DisabilityMeasures.org has developed a website (<u>www.disabilitymeasures.org</u>) for sharing freely available disability assessment and measurement tools. We are seeking collaborators to recommend measures for inclusion and provide feedback for the future development of this tool.

Sesame Street and Autism: See Amazing in All Children. The website http://autism.sesamestreet.org/ (English & Spanish) contains videos for children and parents, along with daily routine cards, storybooks, and other resources for children, families, and friends.

Co-Chairs:
Marshalyn YearginAllsopp
Sandra Vanegas
Gulnoza Yakubova
Shoba S. Meera

Volunteer Interns: Jasper Estabillo Zoe M. Sargent Aksheya Sridhar Follow us on social media!





