Committee Updates

Welcome to the 2024 Cultural Diversity Committee Newsletter!
This newsletter features one of our 2023 Cultural Diversity Research Awardee and Spotlight Research Interns! Also included, are our current committee activities and the most recent research articles on the topics of cultural diversity in ASD and resources.

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
**SPOTLIGHT: 2023 RESEARCH INTERN**

Sadaf Khawar, M.A.

**EDUCATIONAL BACKGROUND**

Ms. Khawar is a fifth-year doctoral candidate in the clinical psychology program at Montclair State University, New Jersey, under the mentorship of Dr. Erin Kang. She is a board-certified behavior analyst who has extensive experience in conducting assessments and delivering evidence-based interventions in a variety of home, school, and mental health settings across the United States. During her doctoral years, she has received clinical training at prestigious sites like the Autism Spectrum Disorder Service at the New York University's Child Study Center and Kennedy Krieger Institute at Johns Hopkins University School of Medicine Pediatric Developmental Disabilities clinic. Sadaf will be starting a 2-year postdoctoral fellowship in assessment, intervention and research in autism and related conditions under the mentorship of Dr. Amy Esler at the University of Minnesota's Masonic Institute of the Developing Brain in Fall 2024. Prior to starting doctoral studies, Sadaf graduated with a master's in clinical psychology from University of Houston-Clear Lake in Houston, Texas and has an undergraduate degree from the University of Houston as a psychology major and philosophy minor.

**INTEREST AND BACKGROUND IN CULTURAL DIVERSITY RESEARCH**

In addition to her clinical work, Sadaf is seeking to explore barriers to autism diagnosis and treatment access as well as disparities in service use in underrepresented ethnoracial minorities through her research. Further, she is particularly vested in community based participatory research methods as it involves stakeholders and community engagement which increases recruitment from diverse groups. Sadaf is engaged in various community service outreach projects and advocates to mobilize resources at the grassroots level to support families.

**INSAR INTERNSHIP PROJECT**

Under the mentorship of Dr. Amy Esler (University of Minnesota), Sadaf designed a mixed-method study to assess trends in service use, met and unmet needs, and barriers (familial, cultural, structural) to diagnosis and treatment access in historically underrepresented ethnoracial groups in the United States – South Asian, Middle Eastern North African (MENA) and East African. The aims of this project also included identifying social determinants of health impacting the access to care and quality of service use. Sadaf completed semi-structured interviews and used reflexive thematic analysis to complete the qualitative analysis. The internship project became the foundation of Sadaf’s dissertation. The preliminary findings of this endeavor were presented at the Cultural Diversity Workshop at INSAR’s annual meeting in Stockholm, Sweden in May 2023. Numerous conference presentations and publications are anticipated from this data.

**FUTURE CAREER GOALS**

Sadaf is committed to her goal of developing accessible, effective, and culturally sensitive interventions and assessment tools that would improve the quality of life of differently abled youth, caregivers, and families, particularly from minoritized backgrounds. She aspires for a career integrated with research and clinical practice which includes cross cultural collaborations. She hopes to expand the scope of her research to include dissemination of evidence-based interventions to South Asia and other low- to-middle income countries to promote accessibility and bridge the research-to-practice gap.
EDUCATIONAL BACKGROUND
Mrs. Terol is a Doctoral Candidate in the Department of Special Education at the University of Illinois Urbana-Champaign. She received a Bachelor of Arts in Speech and Language Pathology and Audiology from the Universidad Autónoma del Paraguay, in Asunción Paraguay, her home country. After four years of clinical experience providing services to young autistic children and their families in Paraguay, Mrs. Terol pursued a Master’s in Education in Early Childhood Special Education at the University of Illinois Urbana-Champaign. While pursuing her master and doctoral studies, Mrs. Terol collaborated in several projects in the Meadan Family Lab under the advisement of Dr. Hedda Meadan, and in the Burke Lab under the supervision of Dr. Meghan Burke. These projects focused on cultural adaptation of interventions, caregiver training, and measures to better support families of children with autism from marginalized backgrounds.

INTEREST AND BACKGROUND IN CULTURAL DIVERSITY RESEARCH
Mrs. Terol is interested in the cultural adaptation and sustainable implementation of evidence-based practices for young autistic children and their families in low-resourced communities. She is interested in the use of implementation science and the optimization of cultural adaptation strategies to build the capacity of community members and increase the availability of high-quality services and resources for young autistic children in their communities. Mrs. Terol has established community-academic partnerships with community-based organizations of caregivers of autistic children in Paraguay and has conducted the cultural adaptation of caregiver training interventions to support caregivers in such settings. She has also collaborated in the cultural adaptation of measures of empowerment and advocacy for the Latino population in the United States.

INSAR INTERNSHIP PROJECT
Under the mentorship of Dr. Sandy Magaña at the University of Texas at Austin, and Dr. Hedda Meadan at the University of Illinois, Mrs. Terol conducted a study focused on the cultural adaptation of the Parents Taking Action caregiver training to be implemented with caregivers of young autistic children in Paraguay. For this purpose, Mrs. Terol conducted six focus groups and two individual interviews with 28 community members from Paraguay. Participants provided their perspective to identify needs of caregivers of autistic children and reviewed and suggested adaptations to the Parents Taking Action curriculum. Based on participants’ suggestions and following the Cultural Adaptation Checklist (Lee et al., 2023) framework for cultural adaptation, Mrs. Terol adapted the Parents Taking Action caregiver training to be used in Paraguay. The adapted intervention is currently being piloted with caregivers in Paraguay. The manuscript is currently under review in a peer-reviewed journal.

FUTURE CAREER GOALS
Mrs. Terol wishes to pursue a career in higher education, where she can continue to develop community-academic partnerships with minoritized and underserved communities. She hopes to continue to collaborate with community members to culturally adapt and develop culturally responsive interventions and support that meet their needs. Furthermore, she hopes to develop international collaboration to continue to support families of autistic children in low-to-middle income countries.
In 2020, researchers and community stakeholders from Ethiopia, Kenya, the UK, and the World Health Organization came together to create the SPARK project. Their aim is to support communities in improving the mental health and well-being of children with developmental disabilities and their caregivers in Ethiopia and Kenya. The project also seeks to co-develop an integrated care model that promotes the identification and referral of children with Developmental Delays, community-based support, and inclusion.

The SPARK project is conducted in four urban and rural Ethiopia and Kenya sites. After extensive community consultation, a Community Identification of Developmental Disabilities (CIDD) tool was developed and piloted in each of the four sites to improve the identification of developmental delays and encourage help-seeking. The SPARK project hopes to work across 16 clusters in each of the four sites (a total of 64 clusters). The SPARK project is being carried out in four urban and rural sites in Ethiopia and Kenya. However, due to security concerns, work in rural Ethiopia has been suspended for now. Currently, the project is working in only three sites but the preparatory work, including a pilot, was performed in all four sites.

The tool is currently being implemented; families of children identified with the tool are invited to participate in a hybrid type I pragmatic effectiveness clustered randomized controlled trial of the WHO Caregiver Skills Training. Effectiveness is measured in terms of child behaviors and parents’ quality of life.

The ultimate goal of this project is to generate evidence on how to implement a sustainable model of care for children with developmental delays in a context of high need and minimal resources. These findings could guide the implementation of similar models in other underserved and under-resourced communities in Africa and abroad. The SPARK project is funded by the UK’s National Institute for Health and Care Research (NIHR) and co-led by Prof Amina Abubakar (Aga Khan University, Kenya) and Dr Rosa Hoekstra (King’s College London). For information about the program and its publication, visit https://www.thesparkproject.net/
INSAR 2024 CULTURAL DIVERSITY ACTIVITIES

INSAR Cultural Diversity Committee Pre-Conference Workshop
Theme: Diverse Perspectives in Autism Research: Insights from Asia-Pacific Communities
★ Wednesday, May 15th at 12:00pm-4:00pm ★
The workshop will include presentations by researchers doing projects related to cultural diversity in the Asia and Oceania regions.

Happy Hour Meet & Greet
★ Wednesday, May 15th at 4:30pm ★
New to INSAR? Want to reconnect with other members before the conference? Join us for a meet and greet/before the Opening Reception.

Cultural Diversity Networking Luncheon
★ Friday, May 17th at 12:30pm ★
Are you interested in autism and cross-cultural/diversity related topics? The INSAR Cultural Diversity networking lunch is the place to do it! Bring your lunch and join this opportunity to network!

Diverse Perspectives in Autism Research: Insights from Asia-Pacific Communities

1. Monitoring children’s social-communication development using the Social Attention and Communication Surveillance (SACS) tool in Nepal and China- Dr. Rena Shrestha, Dr. Josephine Barbaro, Dr. Chongying Wang
2. Research studies from Malaysia: A Southeast Asian Perspective- Dr. Subhashini Jayanath
3. Yarning with Aboriginal communities in Western Australia- Dr. Aarti Saiganesh
4. Culturally and Linguistically Diverse Researchers - a top-tier approach to conducting research within Culturally and linguistically Diverse Communities in Australia- Dr. Ifrah Abdullahi
5. Drawing on mātauranga Māori in the design and delivery of supports in Aotearoa New Zealand- Dr. Jessica Tupou, Dr. Hannah Waddington
RECENT PUBLICATIONS

Open Access


**Regular Access**


Pillay, S., Duncan, M., & de Vries, P. J. (2024). ‘We are doing damage control’: Government stakeholder perspectives of educational and other services for children with autism spectrum disorder in South Africa. Autism, 28(1), 73-83.


RESOURCES

Anti-Black Racism Resources for Autism Clinicians

"Given the well-documented disparities in access to assessment, diagnosis, and high-quality services for Black autistic individuals, Autism clinicians have a duty to educate themselves about the intersection of anti-Black racism and autism services. Many clinicians wonder what they can do to address anti-Black racism in their settings." This website provides some concrete recommendations and resources: [https://autismlab.psy.msu.edu/resources/anti-racism-resources/](https://autismlab.psy.msu.edu/resources/anti-racism-resources/)

DisabilityMeasures.org has developed a website ([www.disabilitymeasures.org](http://www.disabilitymeasures.org)) 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.

The Academic Autistic Spectrum Partnership In Research and Education (AASPIRE) is a partnership between the academic community and the autistic community. It offers guidance and resources to conduct research projects using the principles from the Community Based Participatory Research (CBPR) framework, relevant to the needs of autistic adults. [https://aaspire.org/](https://aaspire.org/)

Committee Co-Chairs
Shoba S. Meera, Ph.D. & Sandra Vanegas, Ph.D.

Chair Elect
Lisa Joseph, Ph.D.

Board Liaison
Connie Kassari, Ph.D.

Secretary
Shuting Zheng, Ph.D., BCBA

Communications
Cecilia Montiel-Nava, Ph.D. & Jonathan Safer, Ph.D.

Awards
Chongying Wang, Ph.D. & Serene Habayeb, Ph.D.

C-CAP
Amy Esler, Ph.D.

Members
Salam Salloum Asfar, Ph.D.
Ivy Giserman-Kiss, Ph.D.
Imene Kassous
Sivapriya Santhanam, Ph.D., CCC-SLP
Audrey Thurm, Ph.D.

Past Co-Chair
Marshalyin Yeargin-Allsopp, M.D.
Gulnoza Yakubova, Ph.D.

@AutismINSAR
facebook.com/autismINSAR