

CULTURAL DIVERSITY COMMITTEE NEWSLETTER

International Society for Autism Research (INSAR)

2024



INSAR
International Society for Autism Research

Cultural Diversity Committee



COMMITTEE UPDATES

Welcome to the 2024 Cultural Diversity Committee Newsletter!

This newsletter features one our 2024 Cultural Diversity Research Awardee and Spotlight Research Interns! Also included, are 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!



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SPOTLIGHT: 2024 RESEARCH INTERN

Ms. Imene Kassous

EDUCATIONAL BACKGROUND

Imene Kassous recently completed her PhD from University of Glasgow. Her doctoral research focused on the knowledge that current/prospective Algerian teachers have about autism; their attitudes towards inclusive education, and how these are shaped by different factors such as societal attitudes, cultural perspectives and institutional training. She has received her MA in language and communication from Abdelhamid Ibn Badis University in Algeria, and her dissertation project focused on the role of digital storytelling in enhancing students' emotional intelligence.



INSAR INTERNSHIP PROJECT

In the Arabic speaking countries, the interest in researching the experiences of parents of autistic children and young adults has been increasing (e.g. Daghistani and MacKenzie, 2021). Most of the studies have been engaging with experiences of parents of autistic children in general with no particular focus on autistic girls or their parents' experiences. Also, there has not been much recognition of the differences in autism traits between the two genders in the region or other parts of the Global South. In this respect, Imene's INSAR project examined the experiences of mothers of autistic females in Algeria. It also sought to understand the different aspects of these experiences and the factors involved in shaping them.

INTEREST AND BACKGROUND IN CULTURAL DIVERSITY RESEARCH

Dr Imene Kassous is interested in autism research and the effect of culture and context in shaping individuals' understanding of autism as well as experiences. She has written a letter to the editors in Women's Health Journal discussing autism research in the Global South (MENA region) and the inclusiveness of Western autism research (Kassous, 2023).

Kassous I.Z. (2023) Researching autism in the Global South (MENA region): To what extent is Western autism research inclusive towards the Global South? Women's Health. 19. doi:10.1177/17455057231156315

FUTURE CAREER GOALS

Imene Kassous aims to conduct research about autistic females from ethnic minority groups in United Kingdom and other international contexts. She hopes to also focus on autism research in the Global South and the different ways diagnostic tools can be improved to become more culturally inclusive.

SPOTLIGHT: 2024 RESEARCH INTERN

Ms Malavi Srikar

EDUCATIONAL BACKGROUND

Ms Malavi Srikar is a fourth-year doctoral candidate in the department of speech pathology and audiology at the National Institute of Mental Health and Neurosciences (NIMHANS), Bangalore, India, under the mentorship of Dr Shoba S Meera. At her current lab (LiL': <https://ssm-lab.org/researchers>; PI: Dr Meera), she serves as the primary interventionist and a core team member conducting a feasibility randomised control trial for 'LiL' STEPS' an online caregiver-mediated early support program for infants at elevated likelihood for autism (<https://doi.org/10.1002/aur.3217>). In addition to her research responsibilities, she dedicates several hours a week to clinical work. Prior to beginning her doctoral journey, she completed her masters in speech-language pathology from the All India Institute of Speech and Hearing (AIISH), Mysore, India and worked in tele-rehabilitation.



INSAR INTERNSHIP PROJECT

Under the mentorship of Prof. Jonathan Green and Dr. Ming Wai Wan at the University of Manchester, UK, Malavi conducted a study to explore the feasibility, utility and preliminary validity of measuring caregiver-infant interaction in infants at elevated-likelihood for autism in India. She is the first to apply the Manchester Assessment for Caregiver-Infant Interaction (MACII), a Western tool, on an elevated likelihood for autism population in South Asia. For this, she first adapted the instructions to be culturally relevant to caregivers in India and translated them to Indian languages (Hindi and Kannada). She collected and analysed caregiver interviews to understand feasibility and caregivers' attitude towards remotely collecting self-recorded caregiver-infant play videos in their home setting and devised a protocol for remote collection of the same. Next, she examined similarities and differences in caregiver-infant interactions between neurotypical and elevated likelihood for autism dyads. These findings were presented at the cultural diversity workshop and as a poster at the INSAR Annual Meeting, 2023 and 2024 respectively. The manuscript for this study is under preparation. She hopes to compare these findings with similar cohorts across the globe.

INTEREST AND BACKGROUND IN CULTURAL DIVERSITY RESEARCH

Malavi, being raised and educated in India, a country known for its rich diversity, appreciates the nuances involved in working with socially, culturally, and linguistically diverse families, in both clinical and research settings. She is constantly considering the applicability and adaptability of global research for autistic children in India, especially in the early intervention space. She has developed several caregiver support materials with infographics to support families with limited literacy. In a country where multilingualism is prevalent, she strongly advocates for bi/multilingual exposure both at home and in intervention settings. In addition to co-writing a review paper and delivering talks to various stakeholders, she also served as a student co-lead for a special interest group on "Improving Global Autism Research for Multilingual Communities" at the INSAR Annual Meeting in both 2023 and 2024.

FUTURE CAREER GOALS

Malavi aspires to build a career in academia while continuing to do clinical work with autistic children which informs her research interests. Her immediate next step is to apply for a post-doctoral program that focuses on implementation science or deepens her understanding of intervention research, with the aim of advancing her career as an intervention scientist.

2024 CULTURAL DIVERSITY RESEARCH AWARDEE



The COMPASS (Communication centered Parent mediated intervention for South Asia) Consortium

The COMPASS consortium was awarded the Cultural Diversity Research Award 2024, for their 12-year history of innovative cross-cultural and diversity work.

Sangath, a public health research not-for profit in India, had conducted an exploration of caregiver experience which reflected need for providing evidence-based interventions. This led to a collaboration with the University of Manchester where the Paediatric Autism Communication Therapy (PACT), had demonstrated efficacy in the UK. This initial adaptation (2012-14), funded by Autism Speaks, as the PASS Project, had two key innovations. The first systematic cross-cultural adaptation of this kind in the field and an adaptation that aimed at task-sharing the intervention with non-specialists but was able to preserve the key mechanistic aspects of the original PACT intervention. This initial work had partners in the University of Liverpool as well as in the Institute of Psychiatry in Rawalpindi and a pilot trial of the Parent-mediated Autism Social communication intervention for non-Specialists (PASS) in India and Pakistan showed excellent acceptability, feasibility, non-specialist intervention fidelity and, crucially, preserved UK efficacy-levels on the outcomes.

In a next step the team developed additional non-specialist provider delivered evidence-informed modules to support co-occurring conditions such as sleep, toileting, feeding challenges and parental stress, to provide community-based advice in contexts with no other service provision. This package of care (PASS-Plus), was evaluated through a comparative design in a rural setting in India; further demonstrating feasibility, acceptability and efficacy.

For a truly scalable solution the team moved from project-employed non-specialist providers to embedded health system worker: the Accredited Social Health Activist (ASHA). With a UK MRC Global Health Trial grant for 'COMPASS'; a scale-up trial of PASS-Plus in New Delhi allowing care for difficult to reach semi-urban populations. This COMPASS trial (<https://sangath.in/compass-2/>) is unique in autism global health to date in its ambition, scale, and adaptive innovation; with a supervision and peer support cascade model supporting the frontline workers to deliver PASS Plus. Trial progress was sustained through the pandemic, the intervention phase was completed in 2023, and results are expected at the end of 2024.

The COMPASS Consortium has demonstrated that high quality science in autism using innovative rigorous methodologies in both adaptation and comparative testing to the highest standards can be conducted in low- and middle-income countries, that we need innovative approaches to address the needs of underserved and diverse populations in low resource settings and that participatory approaches at all stages help in increasing the acceptability of these new approaches.

The COMPASS consortium has been led by Jonathan Green from the University of Manchester and Gauri Divan in Sangath with support from Richard Emsley (Kings College London), Kathy Leadbitter (University of Manchester) and Vikram Patel (Harvard University). This work has been sequentially supported by Autism Speaks, Grand Challenges Canada and MRC UK.

RECENT PUBLICATIONS

Open Access

Aftab, M. J., Haider, N., & Amjad, F. (2024). Investigating Socio-Cultural Factors affecting the Diagnosis of Children with Autism Spectrum Disorder (ASD) in South Punjab. *Annals of Human and Social Sciences*, 5(2), 295–304. [https://doi.org/10.35484/ahss.2024\(5-II\)28](https://doi.org/10.35484/ahss.2024(5-II)28)

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Chang, YC., Shire, S., Shih, W. et al. Brief Report: An Exploratory Study of Young Dual Language Learners with Autism in a School-Based Intervention. *J Autism Dev Disord* 54, 3567–3572 (2024). <https://doi.org/10.1007/s10803-022-05765-y>

Buffle, P., Cavadini, T., Ortega, M. de L., Armijos, C., Soto, P., Gentaz, E., & Crane, L. (2024). Journeys towards accessing an autism diagnosis and associated support: A survey of families of autistic children in Ecuador. *Autism*, 0(0). <https://doi.org/10.1177/13623613241281029>

Franco, M., Costa, A.P. Correction: Should Parents Only Use One Language with Their Autistic Children? The Relations between Multilingualism, Children's Social Skills, and Parent-Child Communication. *J Autism Dev Disord* 54, 3574 (2024). <https://doi.org/10.1007/s10803-024-06465-5>

Frigerio, A., Knight, T., Rella, R., Sinigaglia, E., Camussi, E., & Montali, L. (2024). Experiences of parenting for autistic children in Australia and Italy: A qualitative cross-cultural comparison. *Frontiers in Psychology*, 15. doi:10.3389/fpsyg.2024.1409234

Jensen de López, K. M., & Thirup Møller, H. (2024). Prevalence of Autism in Scandinavian Countries (Denmark, Norway, Sweden), and Nordic Countries (Finland, Iceland, the Faroe Islands, and Greenland). *Neuropsychiatric Disease and Treatment*, 20, 1597–1612. <https://doi.org/10.2147/NDT.S466081>

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Nedungadi, P., Shah, S. M., Stokes, M. A., Kumar Nair, V., Moorkoth, A., & Raman, R. (2024). Mapping autism's research landscape: Trends in autism screening and its alignment with Sustainable Development Goals. *Frontiers in Psychiatry*, 14.

<https://doi.org/10.3389/fpsy.2023.1294254>

Smith, J., Aulich, A., Bent, C., Constantine, C., Franks, K., Goonetilleke, N., ... Hudry, K. (2024). "We go through trauma": South Asian parents' experiences of autism diagnosis and early supports for their autistic children in Australia. *Research in Autism Spectrum Disorders*, 114, 102408. doi:10.1016/j.rasd.2024.102408

Teixeira, M. C., Lowenthal, R., Rattazzi, A., Cukier, S., Valdez, D., Garcia, R., Candela, G. G., Murillo, A. R., Leite, F. P., Pinheiro, G., Woodcock, K., Chung, J. C., Mevorach, C., Montiel-Nava, C., & Paula, C. S. (2024). Understanding emotional outbursts: A cross-cultural study in Latin American children with autism spectrum disorder. *Brain Sciences*, 14(10), 1010.

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Wang, Y. (2024). Research on the culture and awareness of autism. *Transactions on SocialScience, Education and Humanities Research*, 6, 303–311.

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Closed Access

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Dahl, E., Moody, E.J., Barger, B. et al. Differential Performance of Social Communication Questionnaire Items in African American/Black vs. White Children. *J Autism Dev Disord* 54, 1820–1833 (2024). <https://doi.org/10.1007/s10803-023-05931-w>

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Krupa, M., Boominathan, P., Sebastian, S. et al. Joint Engagement in Mother-Child Dyads of Autistic and Non-Autistic Children Among Asian Indian Tamil Speaking Families. *J Autism Dev Disord* 54, 3436–3448 (2024). <https://doi.org/10.1007/s10803-023-06062-y>

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Lee, J.D., Kim, C.K., Yoon, C.D. et al. Exploring Intersections of Culture and Challenging Behaviors: Perspectives from Korean Caregivers. *J Dev Phys Disabil* (2024).
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Lindsay, S., Li, Y., Joneja, S., & Hsu, S. (2024). Experiences of racism and racial disparities in health care among children and youth with autism and their caregivers: a systematic review. *Disability and Rehabilitation*, 1–20.
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INSAR2025
APRIL 30 - MAY 3

**Seattle, Washington
U.S.A.**

SAVE THE DATE

CULTURAL DIVERSITY PRE-CONFERENCE

will be held on

APRIL 30th, 2025



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/>

DisabilityMeasures.org has developed a website (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/>

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