



SESSION III

Autism & Under-resourced Communities: Opportunities for Change

Dr. Aubyn Stahmer & Vanessa Avila-Pons

July 8, 2021 // 2:00 pm EDT

Course Materials

The purpose of these materials is to help provide an introduction to the INSAR Institute session on understanding autism research and autistic people's experiences in under-resourced communities. The materials were designed to prepare students and trainees who are unfamiliar with this research with the general background to receive the most educational benefit from the session. Toward this objective, we have prepared the following: (1) learning objectives for this session, (2) key terms and concepts, (3) a selection of recommended resources. These materials are considered supplemental to the presentation.

In collaboration with Dr. Aubyn Stahmer and Vanessa Avila-Pons, these materials were developed by **Dr. Nick Fears** (Postdoctoral Research Fellow in the School of Kinesiology at the

University of Michigan, USA; nfears@umich.edu), **Dr. Alana McVey** (Postdoctoral Research Fellow at The University of British Columbia, Canada; amcvey@psych.ubc.ca), **Dr. Jiedi Lei** (First year Clinical Psychology Doctorate student at the Institute of Psychiatry, Psychology and Neuroscience, King's College London, UK; jiedi.lei@kcl.ac.uk), and **Fathima Kodakkadan** (Doctoral Student at Anglia Ruskin University, Cambridge, UK; muhsinak19@gmail.com). Feel free to contact us with questions/comments. Register for this webinar and other sessions in this series at: <https://www.autism-insar.org/page/Institute2021>.

Learning Objectives

The INSAR Institute for Autism Research was established in direct response to requests from students and trainees for multidisciplinary training opportunities. The INSAR Institute team is also working to engage stakeholders. The INSAR Institute priorities are to provide a (1) freely available, (2) multidisciplinary training platform for young scientists and others from various backgrounds that (3) allows for international participation. The overarching goal of the INSAR Institute is to expose junior scientists to topics they are not currently engaged in, with the hope that basic scientists and clinical scientists may learn from each other to ultimately advance the understanding of autism.

The current session, "Autism & Under-resourced Communities: Opportunities for Change," is led by Dr. Aubyn Stahmer & Vanessa Avila-Pons. *At the conclusion of this session, participants will:*

1. **Understand** the intersectionality between poverty and autism
2. **Discuss** the challenges faced by families experiencing poverty and how this impacts access to diagnostic and treatment services
3. **Learn** how to increase access to services for these families

Key Terms

Child Development: The sequence of physical, communication, cognitive, and emotional changes that a child experiences from birth to the beginning of adulthood (<https://childdevelopment.com.au/areas-of-concern/what-is-child-development/>).

Culturally Responsive Practices: Include the acceptance of core cultural beliefs, an emphasis on culturally-related strengths and supports, and validation of the client's experiences of oppression with consideration of the need for environmental change (<https://www.apa.org/pubs/videos/4310900>).

Disability: Any condition of the body or mind that makes it more difficult for the person with the condition to do certain activities and interact with the world around them (<https://www.cdc.gov/ncbddd/disabilityandhealth/disability.html>).

Evidence-based Practices: The intentional use of current best scientific evidence in tandem with one's own clinical knowledge and expertise as well as patient values and preferences to

guide clinical decisions

(<https://accelerate.uofuhealth.utah.edu/explore/what-is-evidence-based-practice>).

Early Intervention: Identifying and providing effective early support to children and young people who are at risk of poor outcomes

(<https://www.eif.org.uk/why-it-matters/what-is-early-intervention>).

Intersectionality: “The term intersectionality refers to the way in which categories such as sex, gender, disability, and ethnicity do not stand alone but rather interact (and intersect) in complex ways that affect individual experience, notably to increase marginalization and discrimination” (see the reference to Cascio et al., 2021 below). In this event, we focus on the intersectionality between autism and poverty, and how they interact and influence individual experience.

Poverty: Not having enough money to meet basic needs including food, clothing, and shelter

(https://www2.gnb.ca/content/gnb/en/departments/esic/overview/content/what_is_poverty.html).

Research Partnership: Research partnership approaches, in which researchers and stakeholders work together collaboratively on a research project, are an important component of research, knowledge translation, and implementation.

(<https://systematicreviewsjournal.biomedcentral.com/articles/10.1186/s13643-018-0879-2>)

Social Determinants of Health: The conditions in the environments where people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks.

(<https://health.gov/healthypeople/objectives-and-data/social-determinants-health>)

Recommended Readings & Resources

Brookman-Frazee, L., & Stahmer, A. C. (2018). Effectiveness of a multi-level implementation strategy for ASD interventions: study protocol for two linked cluster randomized trials.

Implementation Science, 13(1), 1-14. <https://doi.org/10.1186/s13012-018-0757-2>

Cascio, M. A., Weiss, J. A., & Racine, E. (2021). Making Autism Research Inclusive by Attending to Intersectionality: A Review of the Research Ethics Literature. *Review Journal of Autism and Developmental Disorders*, 8(1), 22–36. <https://doi.org/10.1007/s40489-020-00204-z>

Divan, G., Vajaratkar, V., Cardozo, P., Huzurbazar, S., Verma, M., Howarth, E., Emsley, R., Taylor, C., Patel, V. and Green, J. (2019), The Feasibility and Effectiveness of PASS Plus, A Lay Health Worker Delivered Comprehensive Intervention for Autism Spectrum Disorders: Pilot RCT in a Rural Low and Middle Income Country Setting. *Autism Research*, 12: 328-339.

<https://doi.org/10.1002/aur.1978>

Durkin, M.S., Elsabbagh, M., Barbaro, J., Gladstone, M., Happe, F., Hoekstra, R.A., Lee, L.-C., Rattazzi, A., Stapel-Wax, J., Stone, W.L., Tager-Flusberg, H., Thurm, A., Tomlinson, M. and Shih, A. (2015), Autism screening and diagnosis in low resource settings: Challenges and opportunities to enhance research and services worldwide. *Autism Research*, 8: 473-476.

<https://doi.org/10.1002/aur.1575>

Iadarola, S., Pellecchia, M., Stahmer, A., Lee, H. S., Hauptman, L., Hassrick, E. M., ... & Smith, T. (2020). Mind the gap: an intervention to support caregivers with a new autism spectrum disorder diagnosis is feasible and acceptable. *Pilot and feasibility studies*, 6(1), 1-13.

<https://doi.org/10.1186/s40814-020-00662-6>

McClure, L. A., Lee, N. L., Sand, K., Vivanti, G., Fein, D., Stahmer, A., & Robins, D. L. (2021). Connecting the Dots: a cluster-randomized clinical trial integrating standardized autism spectrum disorders screening, high-quality treatment, and long-term outcomes. *Trials*, 22(1), 1-13. <https://doi.org/10.1186/s13063-021-05286-6>

Morgan, E. H., & Stahmer, A. C. (2020). Narratives of single, black mothers using cultural capital to access autism interventions in schools. *British Journal of Sociology of Education*, 42(1), 48-65. <https://doi.org/10.1080/01425692.2020.1861927>

Roman-Urrestarazu, A., Yáñez, C., López-Garí, C., Elgueta, C., Allison, C., Brayne, C., Troncoso, M., & Baron-Cohen, S. (2021). Autism screening and conditional cash transfers in Chile: Using the Quantitative Checklist (Q-CHAT) for early autism detection in a low resource setting. *Autism*, 25(4), 932–945. <https://doi.org/10.1177/1362361320972277>

Stahmer, A., & Brookman-Frazee, L. (2019). Utilizing Community-Based Implementation Trials to Advance Understanding of Service Disparities in Autism Spectrum Disorder. *Global pediatric health*, 6. <https://doi.org/10.1177/2333794X19854939>

Stahmer, A. C., Brookman-Frazee, L., Rieth, S. R., Stoner, J. T., Feder, J. D., Searcy, K., & Wang, T. (2017). Parent perceptions of an adapted evidence-based practice for toddlers with autism in a community setting. *Autism*, 21(2), 217-230. <https://doi.org/10.1177/1362361316637580>

Stahmer, A. C., Vejnaska, S., Iadarola, S., Straiton, D., Segovia, F. R., Luelmo, P., ... & Kasari, C. (2019). Caregiver voices: Cross-cultural input on improving access to autism services. *Journal of racial and ethnic health disparities*, 6(4), 752-773. <https://doi.org/10.1007/s40615-019-00575-y>

Stahmer, A. C., Suhrheinrich, J., & Rieth, S. (2016). A pilot examination of the adapted protocol for classroom pivotal response teaching. *Journal of the American Academy of Special Education Professionals*, 119, 139.

Suhrheinrich, J., Rieth, S. R., Dickson, K. S., Roesch, S., & Stahmer, A. C. (2020). Classroom pivotal response teaching: Teacher training outcomes of a community efficacy trial. *Teacher Education and Special Education*, 43(3), 215-234. <https://doi.org/10.1177/0888406419850876>

Verschuur, R., Huskens, B., & McLay, L. (2019). Classroom pivotal response teaching. In S. G. Little & A. Akin-Little (Eds.), *Behavioral interventions in schools: Evidence-based positive strategies* (pp. 245–261). American Psychological Association. <https://doi.org/10.1037/0000126-014>