



SESSION V

Power Shift: Participatory Approaches to Autism Research

Dr. Melanie Heyworth (Macquarie University, Reframing Autism) & Dr. Liz Pellicano (University College London)

July 25th, 2022 // 7:00 am ET

Course Materials

The purpose of these materials is to help provide an introduction to the INSAR Institute session on participatory approaches to autism research. 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. Melanie Heyworth and Dr. Liz Pellicano, these materials were developed by **Molly McCabe** (MSc student at the IOE, UCL's Faculty of Education and Society, UCL, UK; molly.cabe.21@ucl.ac.uk), **Dr. Nick Fears** (Postdoctoral Research Fellow at University of Michigan and incoming Assistant Professor in the School of Kinesiology at Louisiana State University, USA; nfears@umich.edu), **Gabrielle Agnew** (second-year doctoral candidate in Clinical Psychology at University of Texas Southwestern Medical Center in Dallas, USA; gabrielle.agnew@utsouthwestern.edu), **Tori Haar** (Engagement Officer [Autism MQ] at the Macquarie School of Education, Macquarie University, Sydney, Australia;

tori.haar@mq.edu.au), **Dr. Sowmyashree Mayur Kaku** (Post-Doctoral/Clinical Research Associate at the Center for Advanced Research and Excellence in Autism and Developmental Disorders [CAREADD], St. John's Medical College Hospital, Bangalore, India; sowmeey@gmail.com), and **Mallory Stevens** (fifth-year doctoral candidate in School Psychology at the University of Missouri, USA; mashx5@umsystem.edu). Feel free to contact us with questions or comments. Register for this webinar and other sessions in this series at: <https://www.autism-insar.org/page/Institute2022>

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's 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, "Power Shift: Participatory Approaches to Autism Research," is led by Dr. Melanie Heyworth and Dr. Liz Pellicano. *At the conclusion of this session, participants will be able to:*

1. **Discuss** examples of participatory approaches to autism research
2. **Identify** why research priorities from the autistic community have yet to be consistently centered in autism research
3. **Understand** ways in which the involvement of autistic partners can play a crucial role in enhancing autism research and making its outcomes meaningful and relevant

Key Terms

Community engagement: Community engagement in research is a process of inclusive participation that supports mutual respect of values, strategies, and actions for authentic partnership of people affiliated with or self-identified by geographic proximity, special interest, or similar situations to address issues affecting the well-being of the community of focus (Ahmed & Palermo, 2010). (<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2901283/>)

Co-production: Co-production happens when researchers, participants, and collaborators share power and contribute to the research process without privileging one type of knowledge over another. The knowledge is 'co-produced' and the ownership of the project is shared among all people involved.

(https://www.cardiff.ac.uk/_data/assets/pdf_file/0003/881571/Introduction-to-Co-Production-and-Participatory-Research-5.pdf)

Double empathy problem: According to the double empathy problem, empathy is a two-way process that depends a lot on our ways of doing things and our expectations from previous social experiences. Differences in experiences can create communication barriers between autistic and non-autistic people and make it more difficult for them to connect, share experiences, and empathize with one another (Crompton et al., 2021).
(<https://kids.frontiersin.org/articles/10.3389/frm.2021.554875>)

Neurodiversity paradigm: An approach that highlights diversity in human neurobiology, emphasizes that all people are treated with dignity and respect as there is no superior/inferior neurodevelopment, and recognizes disability as a result of barriers and obstacles in the larger social and environmental context (Pellicano & den Houting, 2022).
(<https://acamh.onlinelibrary.wiley.com/doi/10.1111/jcpp.13534>)

Participatory research: working together with the community that is affected by the research to elicit their views on what and how the research should be conducted (den Houting et al., 2021). This emphasizes co-production, relationships, supportive environments, and balanced power structure. (<https://journals.sagepub.com/doi/full/10.1177/1362361320951696>)

Priority perspectives: A term used by the Australasian Autism Research Council to refer to viewpoints considered particularly relevant to discussions about particular research priority areas for example prioritizing the inclusion of the perspectives of autistic people who don't use verbal speech and autistic people and their family members from Culturally and Linguistically Diverse (CALD) backgrounds for focus group discussing research priorities in the area of communication (Poulsen et al., 2022).
(https://www.autismcrc.com.au/sites/default/files/aarc/AARC_2020-21_Research_Priority_Update.pdf)

Supportive environments: A necessary factor to build a culture where autistic people and their allies can take on active, meaningful roles in research. Includes shifting language and perspectives of autism and eliminating physical and nonphysical barriers for autistic involvement in research (Fletcher-Watson et al., 2019).
(<https://journals.sagepub.com/doi/full/10.1177/1362361318786721>)

Recommended Readings & Resources

- Benevides, T. W., Shore, S. M., Palmer, K., Duncan, P., Plank, A., Andresen, M.-L., Caplan, R., Cook, B., Gassner, D., Hector, B. L., Morgan, L., Nebeker, L., Purkis, Y., Rankowski, B., Wittig, K., & Coughlin, S. S. (2020). Listening to the autistic voice: Mental health priorities to guide research and practice in autism from a stakeholder-driven project. *Autism*, 24(4), 822–833. <https://doi.org/10.1177/1362361320908410>
- Cascio, M. A., Weiss, J. A., Racine, E. & the Autism Research Ethics Taskforce (2020). Person-oriented ethics for autism research: Creating best practices through engagement

- with autism and autistic communities. *Autism*, 24(7), 1676–1690. <https://doi.org/10.1177/1362361320918763>
- den Houting, J., Higgins, J., Isaacs, K., Mahony, J., & Pellicano, E. (2021). ‘I’m not just a guinea pig’: Academic and community perceptions of participatory autism research. *Autism*, 25(1), 148–163. <https://doi.org/10.1177/1362361320951696>
- Fletcher-Watson, S., Adams, J., Brook, K., Charman, T., Crane, L., Cusack, J., Leekam, S., Milton, D., Parr, J. R., & Pellicano, E. (2019). Making the future together: Shaping autism research through meaningful participation. *Autism*, 23(4), 943–953. <https://doi.org/10.1177/1362361318786721>
- Grinker, R.R., Chambers, N., Njongwe, N., Lagman, A. E., Guthrie, W., Stronach, S., Richard, B. O., Kauchali, S., Killian, B., Chhagan, M., Yucel, F., Kudumu, M., Barker-Cummings, C., Grether, J., & Wetherby, A. M. (2012). “Communities” in Community Engagement: Lessons Learned From Autism Research in South Korea and South Africa. *Autism Research*, 5(3), 201–210. <https://doi.org/10.1002/aur.1229>
- Nicolaidis, C., Raymaker, D., Kapp, S. K., Baggs, A., Ashkenazy, E., McDonald, K., Weiner, M., Maslak, J., Hunter, M., & Joyce, A. (2019). The AASPIRE practice-based guidelines for the inclusion of autistic adults in research as co-researchers and study participants. *Autism*, 23(8), 2007–2019. <https://doi.org/10.1177/1362361319830523>
- Pellicano, E. & den Houting, J. (2022). Annual Research Review: Shifting from “normal science” to neurodiversity in autism science. *Journal of Child Psychology and Psychiatry*, 63(4), 381–396. <https://doi.org/10.1111/jcpp.13534>
- Pellicano, E., Dinsmore, A., & Charman, T. (2014). What should autism research focus upon? Community views and priorities from the United Kingdom. *Autism*, 18(7), 756–770. <https://doi.org/10.1177/1362361314529627>
- Pellicano, E., Dinsmore, A., & Charman, T. (2014). Views on researcher-community engagement in autism research in the United Kingdom: a mixed-methods study. *PloS One*, 9(10), e109946. <https://doi.org/10.1371/journal.pone.0109946>
- Pickard, H., Pellicano, E., den Houting, J., & Crane, L. (2022). Participatory autism research: Early career and established researchers’ views and experiences. *Autism*, 26(1), 75–87. <https://doi.org/10.1177/13623613211019594>
- Poulsen, R., Brownlow, C., Lawson, W., & Pellicano, E. (2022). Meaningful research for autistic people? Ask autistics! *Autism*, 26(1), 3–5. <https://doi.org/10.1177/13623613211064421>

Roche, L., Adams, D., & Clark, M. (2021). Research priorities of the autism community: A systematic review of key stakeholder perspectives. *Autism*, 25(2), 336–348.
<https://doi.org/10.1177/1362361320967790>