SESSION VI
Autism & Neurodiversity: Intersectionality and Social Justice

Dr. Steven Kapp, Dr. TC Waisman, & Dr. Christina Nicolaidis

July 22, 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 of neurodiversity. 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. Steven Kapp, Dr. TC Waisman, and Dr. Christina Nicolaidis, 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. 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), **Dr. Sowmyashree Kaku** (Postdoctoral Clinical Research Associate at St John's Medical College Hospital, Bangalore,

India, sowmeey@gmail.com), and **Desi Jones** (Fourth year Doctoral Student at the University of Texas at Dallas, desi.jones@utdallas.edu). 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 & Neurodiversity: Intersectionality and Social Justice," is led by Dr. Steven Kapp, Dr. TC Waisman, & Dr. Christina Nicolaidis. *The focus of the session is as follows:*

1. **Understand** the importance of examining autism and neurodiversity through an interactional lens that views social justice as a means to frame autism research differently.
2. **Demonstrate** how different intersecting outlooks might better inform autism research by centering on a personal cultural perspective.
3. **Examine** the compatibility of neurodiversity and intersectionality to determine the role that social justice can play in guiding and enhancing respectful autism research.

Key Terms

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).

Intersectionality: "The term intersectionality, coined by Kimberlé Crenshaw in 1989, 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).

Neurodivergence: A neurodivergent person is defined as one whose neurological development and state are atypical compared to "neurotypical development". The term was coined in the neurodiversity movement as an opposite for "neurotypical" - previously the term "neurodiverse" was sometimes applied to individuals for this purpose.
You can read more about it here:
https://www.disabled-world.com/disability/awareness/neurodiversity/

Neurodiversity: is an emerging principle of conceptualising autism and other conditions. It refers to the variation in cognitive functioning etc. within our species. Specifically, it suggests that there is no "right" or "normal" type of brain, but rather a variety of (neuro)diverse types.

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)

Self advocacy Self-advocacy refers to the skills of people from within a specific group to integrate knowledge about their civil rights, relevant laws, and their relative adaptive strengths and weaknesses to effectively communicate their perspectives and needs to the overall community (on an individual level to broader social systems).

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)

Social justice: justice in terms of the distribution of wealth, opportunities, and privileges within a society (https://www.lexico.com/en/definition/social_justice)

Use of language
- **Person-First language**: Person-first language is a method of referring to individuals with disabilities, medical conditions, or functional impairments that emphasizes the person over their disability, condition, or impairment. The term "a child with autism" would be consistent with person-first language, whereas the term "an autistic child" would not.
- **Identity-first language:** Identity-first language is the opposite of person-first language. Saying "Autistic person" rather than "person with Autism" is using identity-first language.
- **Neurotypical**: Description of a medically and psychologically healthy individual demonstrating a normative pattern of neurodevelopment. Typically used specifically in contrast with individuals experiencing an atypical developmental course, such as autism, and often used to describe the control group in clinical research.

Recommended Readings & Resources

Baker, D. L. (2011). *The politics of neurodiversity: Why public policy matters*. Lynne Rienner Publishers.

Bottema-Beutel, K., Kapp, S. K., Lester, J. N., Sasson, N. J., & Hand, B. N. (2020). Avoiding Ableist Language: Suggestions for Autism Researchers. *Autism in Adulthood*. https://doi.org/10.1089/aut.2020.0014

Bury, S. M., Jellett, R., Spoor, J. R., & Hedley, D. (2020). "It Defines Who I Am" or "It's Something I Have": What Language Do [Autistic] Australian Adults [on the Autism Spectrum] Prefer? *Journal of Autism and Developmental Disorders.* https://doi.org/10.1007/s10803-020-04425-3

den Houting, J. (2019). Neurodiversity: An insider's perspective. *Autism, 23*(2), 271–273. https://doi.org/10.1177/1362361318820762

Feldman, D., Gordon, P. A., White, M. J., & Weber, C. (2002). The Effects of People-First Language and Demographic Variables on Beliefs, Attitudes and Behavioral Intentions Toward People with Disabilities. *Journal of Applied Rehabilitation Counseling, 33*(3), 18–25. https://doi.org/10.1891/0047-2220.33.3.18

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

Foreman, P. (2005). Language and disability. *Journal of Intellectual & Developmental Disability, 30*(1), 57–59. https://doi.org/10.1080/13668250500033003

Gernsbacher, M. A. (2017). Editorial Perspective: The use of person-first language in scholarly writing may accentuate stigma. *Journal of Child Psychology and Psychiatry, and Allied Disciplines, 58*(7), 859–861. https://doi.org/10.1111/jcpp.12706

Gillespie-Lynch, K., Dwyer, P., Constantino, C., Kapp, S. K., Hotez, E., Riccio, A., DeNigris, D., Kofner, B., & Endlich, E. (2020). Can We Broaden the Neurodiversity Movement without Weakening It? Participatory Approaches as a Framework for Cross-disability Alliance Building. In A. C. Carey, J. M. Ostrove, & T. Fannon (Eds.), *Disability Alliances and Allies* (Vol. 12, pp. 189–223). Emerald Publishing Limited. https://doi.org/10.1108/S1479-354720200000012013

Gillespie-Lynch, K., Kapp, S. K., Brooks, P. J., Pickens, J., & Schwartzman, B. (2017). Whose Expertise Is It? Evidence for Autistic Adults as Critical Autism Experts. *Frontiers in Psychology*, *8*. https://doi.org/10.3389/fpsyg.2017.00438

Kapp, S. K. (2013a). Social Justice through Research. *Empowering Leadership: A Systems Change Guide for Autistic College Students and Those with Other Disabilities*, 114–121.

Kapp, S. K. (2013b). Social and systems change on campus. *Empowering Leadership: A Systems Change Guide for Autistic College Students and Those with Other Disabilities*, 122–125.

Kapp, S. K. (2020). *Autistic Community and the Neurodiversity Movement: Stories from the Frontline*. Springer Nature. https://library.oapen.org/handle/20.500.12657/23177

Kapp, S. K., Gillespie-Lynch, K., Sherman, L. E., & Hutman, T. (2013). Deficit, difference, or both? Autism and neurodiversity. *Developmental Psychology, 49*(1), 59–71. https://doi.org/10.1037/a0028353

Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., & Pellicano, E. (2016). Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism, 20*(4), 442–462. https://doi.org/10.1177/1362361315588200

Lei, J., Jones, L., & Brosnan, M. (2021). Exploring an e-learning community's response to the language and terminology use in autism from two massive open online courses on autism education and technology use. *Autism,* 1362361320987963. https://doi.org/10.1177/1362361320987963

Nicolaidis, C. (2012). What Can Physicians Learn from the Neurodiversity Movement? *AMA Journal of Ethics, 14*(6), 503–510. https://doi.org/10.1001/virtualmentor.2012.14.6.oped1-1206.

Nicolaidis, C. (2018). Autism in Adulthood: The New Home for Our Emerging Field. *Autism in Adulthood, 1*(1), 1–3. https://doi.org/10.1089/aut.2018.28999.cjn

Nicolaidis, C., Raymaker, D. M., Ashkenazy, E., McDonald, K. E., Dern, S., Baggs, A. E., Kapp, S. K., Weiner, M., & Boisclair, W. C. (2015). "Respect the way I need to communicate with you": Healthcare experiences of adults on the autism spectrum. *Autism, 19*(7), 824–831. https://doi.org/10.1177/1362361315576221

Nicolaidis, C., Raymaker, D., McDonald, K., Dern, S., Boisclair, W. C., Ashkenazy, E., & Baggs, A. (2013). Comparison of Healthcare Experiences in Autistic and Non-Autistic Adults: A Cross-Sectional Online Survey Facilitated by an Academic-Community Partnership. *Journal of General Internal Medicine, 28*(6), 761–769. https://doi.org/10.1007/s11606-012-2262-7

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

Pellicano, E., & Stears, M. (2011). Bridging autism, science and society: Moving toward an ethically informed approach to autism research. *Autism Research*, *4*(4), 271–282. https://doi.org/10.1002/aur.201

Sinclair, J. (1999). Why I dislike 'person-first' language. http://web.archive.org/web/20090210190652/http://web.syr.edu/~jisincla/person_first.htm