Autism and Neurodiversity: Intersectionality and Social Justice



Dr. Steven Kapp

Lecturer, University of Portsmouth

Dr. TC Waisman

Founder of Adapt Coach & Autism Training Academy

Dr. Christina Nicolaidis

Professor, School of Social Work, Portland State University

22nd July 2021

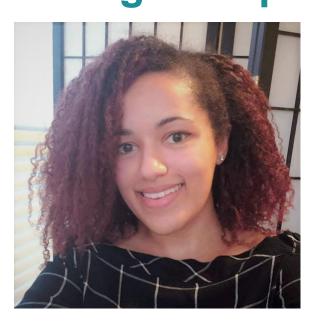
Moderator: Dr. Nick Fears
Student & Trainee Committee Chair: Dr. Alana McVey

INSAR

Autism and Neurodiversity: Intersectionality and Social Justice Working Group



Dr. Sowmyashree KakuSt John's Medical College
Hospital, Bangalore, India



Desi JonesUniversity of Texas - Dallas,
USA



Dr. Jiedi LeiKing's College London, UK



Autism and Neurodiversity: Intersectionality and Social Justice

Speaker



Dr. Steven KappLecturer, University of
Portsmouth

Speaker



Dr. TC WaismanFounder of Adapt Coach &
Autism Training Academy

Speaker



Dr. Christina NicolaidisProfessor, School of Social
Work, Portland State University



Session VI - Autism & Neurodiversity: Intersectionality and Social Justice

Presenters: Dr. Steven Kapp & Dr. TC Waisman with Dr. Christina Nicolaidis

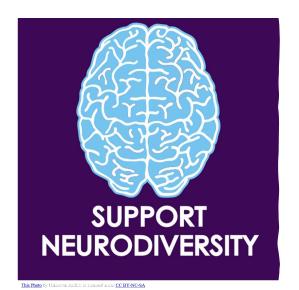
Introductio n

- Steven: Define Neurodiversity
- TC: Intersectionality
- Steven: further discussion of overlap of ND/autism and intersectionality
- Christina: synthesize and reemphasize what was said
- Q&A



Dr. Steven Kapp

Neurodiversity



What is neurodiversity?

(Gillespie-Lynch, Kapp, Pickens, Brooks, & Schwartzman, 2017)

- The 'fact' of neurocognitive differences: "variations in brain function that lead to differences in perception and bodily experience"
- A framework that values those differences:
 "Acceptance of neuroatypical people, like people with autism or depression or schizophrenia"
- A movement advocating for the *neurodivergent*: "An advocacy movement for people with neurological disabilities, based on acceptance and civil rights."

Autistic Community and the Neurodiversity Movement Stories from the Frontline Edited by Steven K. Kapp



What is neurodiversity?

"Neurodiversity, to me, means both a fabulous celebration of all kinds of individual minds, and a serious, holistic acknowledgment of the necessity of diversity in order for society to survive, thrive, and innovate. It means identity, belonging, and community. It means I am not broken, not alone, and neither are my siblings standing with me beneath that huge, multi-colored neurodiversity umbrella: we the autistic, the mad, the weirdly-wired, the queer, the crippled, and the labeled with neurodivergent diagnoses like flowers that glorify our beautiful bodies and minds." (Raymaker, 2020, p. 142)

Autism is a way of being. It is pervasive; it colors every experience, every sensation, perception, thought, emotion, and encounter, every aspect of existence.

> (Sinclair, 1993)



Judy

History of neurodiversity movement

- Autism rights movement began in 1992 led by Jim Sinclair (Pripas-Kapit, 2020)
- Neurodiversity coined by autistic sociologist Judy Singer (1998) (Dekker, in Kapp, 2020), as a rhetorical frame for autism rights movement
- Movement has since expanded to intersectional cross-disability rights activism

Contested realities



(Broderick & Ne'eman, 2008)



Autism as































The *neuro*- in *neurodiversity*

8 years, 6 months, 4 days, 16 hours, 19 minutes, and 20 seconds

The Autistic Genocide Clock

Estimated time remaining before prenatal testing and routine abortion:



- Neurodiversity framework positions autism as essentially biological
 - Feature of being autistic, not supporter of the movement (Kapp, Gillespie-Lynch, Sherman, & Hutman, 2013)
 - Autistics more likely to define autism internally (Gillespie-Lynch et al., 2017)
- Autism as 'hard-wired' part of the self (Ortega & Choudhury, 2011)
 - Autistic traits heavily overlap with personality traits (Schwartzman, Wood, & Kapp, 2016)

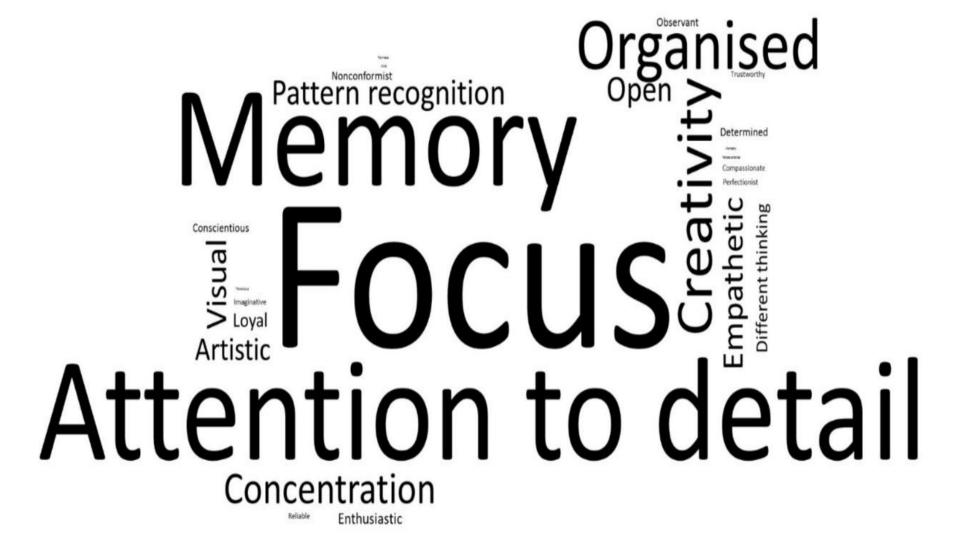
The *diversity* in neurodiversity



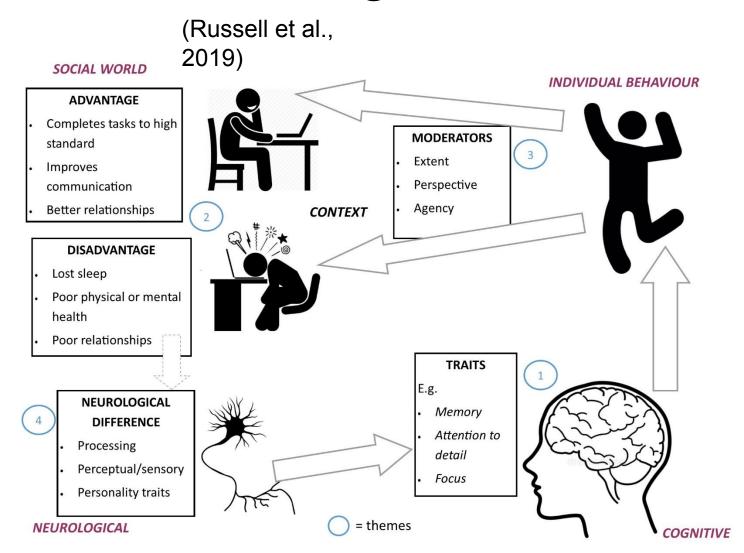
- Autism viewed as a complex difference (Russell et al., 2019)
- Values experiential expertise and leadership of autistic people
 - Autistics had highest autism knowledge, related to lower stigma (Gillespie-Lynch et al., 2017)
- Quality of life (QoL), not 'cure', supported (Ne'eman, 2010; Robertson, 2010)

Word cloud of advantageous traits

(Russell et al., 2019)



Conceptual map of whether or not traits were experienced as advantageous

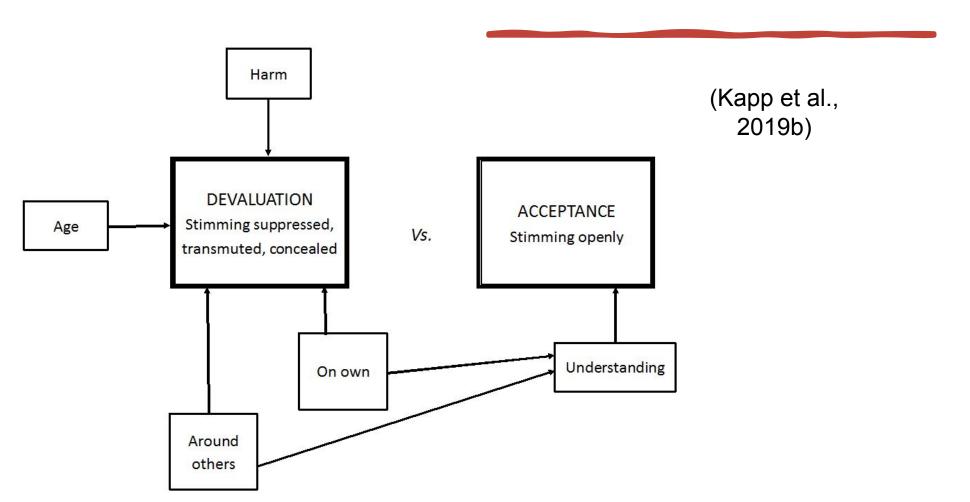


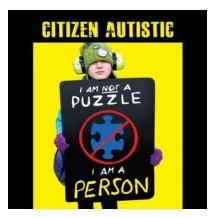
Overwhelming **Environment** Noisy Sensory **Thoughts** Overload **UNCONTAINABLE** Calming Calming **EMOTION STIMMING**

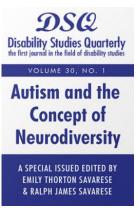
Traits as coping mechanisms: stimming

(Kapp et al., 2019b)

(De)stigmatisation of stimming









(Kapp,

Neurodiversity as an integrative disability model

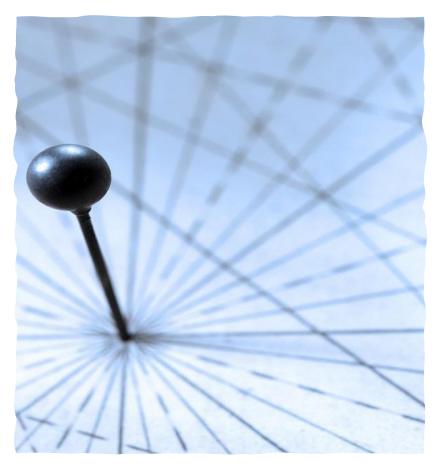
- Advocates support celebrating and ameliorating autism (Kapp et al., 2013)
 - Autistic people often define autism in nuanced ways (Kapp et al., 2017)
- Neurodiversity scholars critique social-first views of autism
 - Critique social motivation (Kapp, Goldknopf, Brooks, Kofner, & Hossain, 2019) and social cognition theories of autism (Dinishak & Akhtar, 2013)
 - Support for dynamic brain-body, person-environment interactions



Dr. TC Waisman

Intersectionality

Intersectionality



DEFINITIONS

- N. American focus
- Where two or more lines intersect when defining one's identity
- Where multiply-marginalized individuals experience multi-issue realities
- Analytical framework: interlinking systems of power and how they afford us dis/advantages, gives us power or oppresses us

"There is no such thing as a single-issue struggle because we do not live single-issue lives" **Audre Lord**

Sojourner Truth 1797-1883

History

• Roots in 19th century Black feminist thought from Sojourner Truth to contemporary feminists including Kimberle Crenshaw, Angela Davis, Audre Lorde, Nikol Alexander-Floyd etc.

 Term used in critical studies: gender studies, queer studies, ethnic studies, disability studies, sociology, literature, history etc.

Intersectionality & power

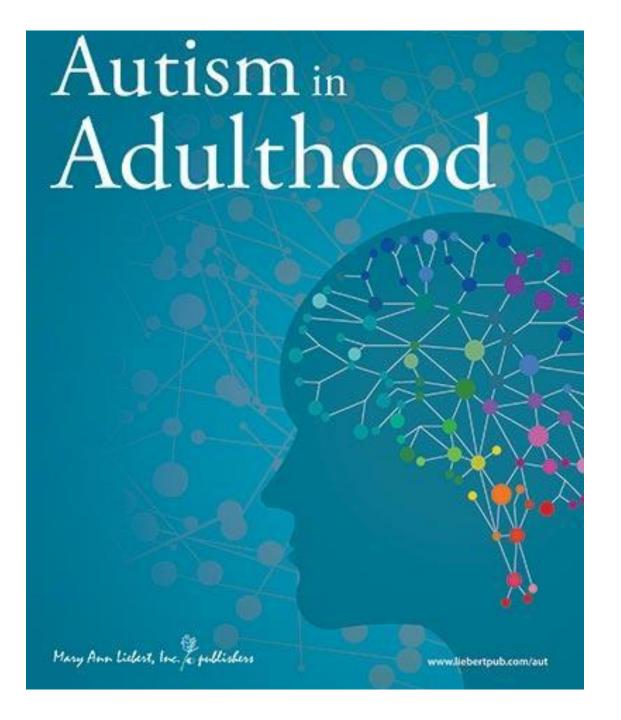


- Connected to the concept of intersectionality is the question of power
- Historical systems of power constitutively uphold themselves in a way that continues to oppress marginalized individuals in society
- Intersectionality is not about flipping power role
- Intersectionality is about giving equal room for voices of those traditionally oppressed to create more egalitarian society and find innovative solutions to current barriers

Intersectionality & disability



- Intersectionality essential to discourse about inclusivity
- Intersectional view of disability:
 - Those with disabilities often have other intersections that need to be considered in research, policy making, and implementation of practices
 - Challenges associated with disability is not the fault of the individual but rather a systemic issue
 - Promotes equity and social justice for disabled individuals



Intersectionality & autism research

- intersectionality is not meant to reduce Autistic individuals to a singular identity called disability
- Intersectionality is consistent with social model of disability, concept of neurodiversity, and adds clarity regarding how multiple social identities interact with a disabled and Autistic identity.
- Community-based participatory research



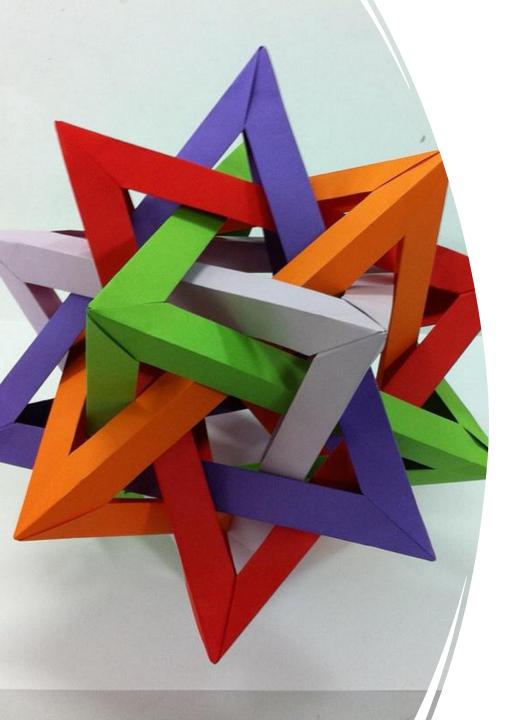
Intersectionality & autism in practice

Diagnosis:

 Autism underdiagnosed in Black and Hispanic people; limited access to support services when diagnosed

Higher education:

- Relegated to autism awareness day/week
- Focused on perspective of autism that rarely includes intersectional perspectives e.g. LGBTQ+, Black, Asian, Latinx, Indigenous, or other co-occurring medical challenges



Intersectionality & autism in practice

- Safety: Cultural stereotypes can make it doubly dangerous to be Autistic and Black, Latinx, Indigenous, or have co-occurring medical identities such as schizophrenia etc.
- Academia: emotional & professional burden to be token, symbol, icon, 'natural experts' on all things autism (especially intersecting with race, LGBTQ+ etc.)
- Research: questionnaires designed by researchers from non-marginalized communities can be skewed towards particular privileged perspective and may not accurately represent intersectional autism community

Furthering the Intersectionality narrative



- Not all oppression is equal "ain't I a woman?"
- Liberation on one road can oppress individuals on another road
- Love (not just oppression) should be considered in narratives of intersectionality



My story

The story of intersectionality is the story of *love*

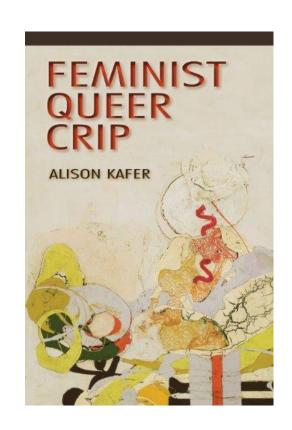


Dr. Steven Kapp

Neurodiversity and Intersectionality

Neurodiversity and Intersectionality

- Gender, sexual intersections with autism prominent among neurodiversity activists, scholars
 - No cis men among founding members of autism rights movement, "neurodiversity" coiner
- Participation in advocacy, research high among women, gender and sexual minorities
 - Coined "neuroqueer" to recognize intersection, subvert ableism, heterosexism (Egner, 2019)
- Indeed, biological attribution of causality reduces stigma against gay people (Haider-Markel &



to be pro NEURO DIVERSITY is to be ANTI RACIST



Further intersections for autism, neurodiversity

- Concepts used in neurodiversity activists that originate with people of color
 - Participatory research, which uses an emancipatory perspective for Autistic people
 - "Passing" as neurotypical (somewhat akin to passing as white, straight, etc.)
- Yet more work to welcome those disadvantaged by race, immigration, class
 - e.g. Black autistic college students less likely to identify as disabled but also to feel self-efficacious (Shattuck et al., 2014)



Dr. Christina Nicolaidis

Take Home
Messages for Autism
Researchers

Intersectionality Lens

Status Quo

- Centers dominant group (e.g., white, middle-class, cis males in US) or UK)
- Ignores issues of diversity or power

Disparity

- Focus on individual marginalized identities
 - E.g., race, gender, sexual orientation, SES, county

Intersectionalit y

- Additive: Multiply marginalized = greater barriers
- True: Multiply marginalized = totally different experience

Neurodiversity Paradigm

Status Quo

Autism as Disease

Medical Model of Disability

Deficit Focus

Focus on Individual (or parent)

Neurodiversity

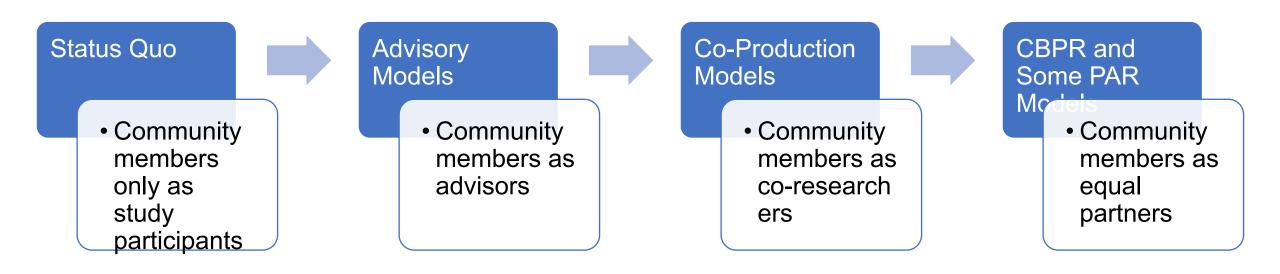
Autism as Identity

Social Model of Disability

Strength-Based

Individual in Context

Participatory Approaches*



^{*} In addition to efforts to increase diversity in academia / support insider researchers

Intersectionality **Participatory** Neurodiversit **Approaches**

Putting it All Together

Can you think of an autism study in each part of the diagram?

Where do you want your own research to fall?

What will it take to make that happen?

References & Resources

A decolonial critique of intersectionality | Decolonial International Network. (n.d.). Retrieved July 1, 2021, from https://din.today/a-decolonial-critique-of-intersectionality/

Alexander-Floyd, N. G. (2012). Disappearing acts: Reclaiming intersectionality in the social sciences in a post-black feminist era. Feminist Formations, 24, 1-25.

Begeer, S., El Bouk, S., Boussaid, W., Terwogt, M. M., & Koot, H. M. (2009). Underdiagnosis and referral bias of autism in ethnic minorities. *Journal of autism and developmental disorders*, 39(1), 142.

Berger, M. and Guidroz, K. (eds.) (2009): The Intersectional Approach. Transforming the Academia Through Race, Class & Gender. University of North Carolina Press. Chapel Hill.

Broderick, A. A., & Ne'eman, A. (2008). Autism as metaphor: narrative and counter-narrative. *International Journal of Inclusive Education*, *12*(5-6), 459-476.

Buchanan, N. T., & Wiklund, L. O. (2020). Why clinical science must change or die: Integrating intersectionality and social justice. *Women & Therapy*, 43(3-4), 309-329.

Burkett, C. (2020, January 20). 'Autistic while black': How autism amplifies stereotypes. Spectrum | Autism Research News. https://www.spectrumnews.org/opinion/viewpoint/autistic-while-black-how-autism-amplifies-stereotypes/

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, 22-36.

Crenshaw, K. (1990). Mapping the margins: Intersectionality, identity politics, and violence against women of color. Stan. L. Rev., 43, 1241.

Decolonial Intersectionality and a Transnational Feminist Movement – The Feminist Wire. (n.d.). https://thefeministwire.com/2014/04/decolonial-intersectionality/

Dekker, M. (2020). From exclusion to acceptance: Independent Living on the Autistic Spectrum. In S.K. Kapp (Ed.), *Autistic Community and the Neurodiversity Movement: Stories from the Frontline* (pp. 41-49). Palgrave Macmillan: Singapore.

Dinishak, J., & Akhtar, N. (2013). A critical examination of mindblindness as a metaphor for autism. *Child Development Perspectives*, 7(2), 110-114.

References & Resources

Garcia, A. (2019, September 23). *Intersectionality, Autism & STEM College Outcomes*. Stairway to STEM. https://www.stairwaytostem.org/intersectionality-autism-stem-college-outcomes/

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*, 438.

Haider-Markel, D. P., & Joslyn, M. R. (2008). Beliefs about the origins of homosexuality and support for gay rights: An empirical test of attribution theory. *Public Opinion Quarterly*, 72(2), 291-310.

Hira, S. (n.d.). *A Decolonial Critique of Intersectionality*. Films for Action. Retrieved July 3, 2021, from https://www.filmsforaction.org/articles/a-decolonial-critique-of-intersectionality/

Jones, D. R., Nicolaidis, C., Ellwood, L. J., Garcia, A., Johnson, K. R., Lopez, K., & Waisman, T. C. (2020). An expert discussion on structural racism in autism research and practice. *Autism in Adulthood*, *2*(4), 273-281.

Kapp, S. K. (2013). Empathizing with sensory and movement differences: Moving toward sensitive understanding of autism. *Frontiers in Integrative Neuroscience*, 7, 38.

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.

Kapp, S. K., Goldknopf, E., Brooks, P. J., Kofner, B., & Hossain, M. (2019a). Expanding the critique of the social motivation theory of autism with participatory and developmental research. *Behavioral and Brain Sciences*, *42*, e94.

Kapp, S. K., Steward, R., Crane, L., Elliott, D., Elphick, C., Pellicano, E., & Russell, G. (2019b). 'People should be allowed to do what they like': Autistic adults' views and experiences of stimming. *Autism*, 23(7), 1782-1792.

Knudsen, S. V. (2006). Intersectionality—A theoretical inspiration in the analysis of minority cultures and identities in textbooks. *Caught in the Web or Lost in the Textbook*, 53(1), 61-76.

Lykke, N. (2010): Feminist Studies. A Guide to Intersectional Theory, Methodology and Writing. Routledge. New York.

Lylasaxena. (2020, November 10). *Intersectionality and Disability-Inclusive Development*. Inclusive Sustainable Development. https://disabilitydevelopment.com/2020/11/09/intersectionality-and-disability-inclusive-development/

Mirza, H. S. (2014). Decolonizing higher education: Black feminism and the intersectionality of race and gender. Journal of Feminist Scholarship, 7(7), 1-12.

References & Resources

Moradi, B., & Grzanka, P. R. (2017). Using intersectionality responsibly: Toward critical epistemology, structural analysis, and social justice activism. *Journal of Counseling Psychology, 64*(5), 500–513. https://doi.org/10.1037/cou0000203

Ne'eman, A. (2010). The future (and the past) of Autism advocacy, or why the ASA's magazine, The Advocate, wouldn't publish this piece. *Disability Studies Quarterly*, 30(1).

Ortega, F., & Choudhury, S. (2011). 'Wired up differently': Autism, adolescence and the politics of neurological identities. Subjectivity, 4(3), 323-345.

Pripas-Kapit, S. (2020). Historicizing Jim Sinclair's "Don't mourn for us": A cultural and intellectual history of neurodiversity's first manifesto. In *Autistic Community and the Neurodiversity Movement* (pp. 23-39). Palgrave Macmillan, Singapore.

Racial and Ethnic Differences in Children Identified with ASD. (2020, October 2). Centers for Disease Control and Prevention. https://www.cdc.gov/ncbddd/autism/addm-community-report/spotlight-on-closing-racial-gaps.html

Raymaker, D. M. (2020). Shifting the system: AASPIRE and the loom of science and activism. In *Autistic Community and the Neurodiversity Movement* (pp. 133-145). Palgrave Macmillan, Singapore. Palgrave Macmillan: Singapore.

Rice, C., Harrison, E., & Friedman, M. (2019). Doing justice to intersectionality in research. *Cultural Studies* ↔ *Critical Methodologies*, *19*(6), 409-420.

Robertson, S. M. (2009). Neurodiversity, quality of life, and autistic adults: Shifting research and professional focuses onto real-life challenges. *Disability Studies Quarterly*, 30(1).

Russell, G., Kapp, S. K., Elliott, D., Elphick, C., Gwernan-Jones, R., & Owens, C. (2019). Mapping the autistic advantage from the accounts of adults diagnosed with autism: A qualitative study. *Autism in Adulthood*, *1*(2), 124-133.

Saxe, A. (2017). The Theory of Intersectionality: A New Lens for Understanding the Barriers Faced by Autistic Women. *Canadian Journal of Disability Studies*, 6(4), 153–178. https://doi.org/10.15353/cjds.v6i4.386.

Schwartzman, B. C., Wood, J. J., & Kapp, S. K. (2016). Can the five factor model of personality account for the variability of autism symptom expression? Multivariate approaches to behavioral phenotyping in adult autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 46(1), 253-272.

Shattuck, P. T., Steinberg, J., Yu, J., Wei, X., Cooper, B. P., Newman, L., & Roux, A. M. (2014).. Disability identification and self-efficacy among college students on the autism spectrum. *Autism Research and Treatment*.

Sinclair, J. (1993). Don't mourn for us. Our Voice, 1(3). Retrieved from http://www.autreat.com/dont_mourn.html.

Women's Rights National Historical Park. (2017, November 17). Sojourner Truth: Ain't I A Woman? (U.S. National Park Service). Nps.gov.

Autism and Neurodiversity: Intersectionality and Social Justice

Questions & Answers



Dr. Steven Kapp
Lecturer, University of
Portsmouth, UK



Dr. TC Waisman
Founder of Autism
Training Academy,
Canada



Nicolaidis
Professor, School of
Social Work, Portland
State University, USA

Dr. Christina



Dr. Nick Fears

Postdoctoral Research
Fellow
University of Michigan,
USA

To Join INSAR Visit: http://autism-insar.org/membership Email: studentcommittee@autism-insar.org







JUNE 17 - JULY 21, 2021



Thank you to all our speakers for volunteering their time and knowledge as well as the INSAR Board and staff for supporting this year's INSAR Institute.

Coming Soon: INSAR STC Anti-racism Resources Repository Email <u>StudentCommittee@autism-insar.org</u> for more information

Presentation Discussion Resources

https://autisticadvocacy.org/resources/books/empowering-leadership-a-systems-change-guide-for-autistic-college-students-and-those-with-other-disabilities/#:~:text=About-,Empowering%20Leadership%3A%20A%20Systems%20Change%20Guide%20for%20Autistic%20College%20Students,our%20Empowering%20Disabled%20Leaders%20project

https://link.springer.com/chapter/10.1007/978-981-13-8437-0_1

https://erikengdahl.se/autism/isnt/index.html

https://www.frontiersin.org/article/10.3389/fpsyg.2021.635690

https://www.liebertpub.com/doi/full/10.1089/aut.2020.0014

https://acamh.onlinelibrary.wiley.com/doi/full/10.1111/jcpp.13315

https://journals.sagepub.com/doi/10.1177/13623613211031403

http://www.autismtraining.academy/

https://www.facebook.com/groups/184927248725729

https://www.facebook.com/groups/236272016838118

https://aaspire.org/collaboration-toolkit/

https://home.liebertpub.com/cfp/special-issue-on-intersecting-identities-in-autistic-adults/345/

Steven Kapp email: steven.kapp@port.ac.uk

TC Waisman email: tc@adaptcoach.com or tc@autismtraining.academy

Christina Nicolaidis: nicol22@pdx.edu