Thank you for attending the Disability in the Disciplines Conference!

Conference Organizing Committee

Chair: Marion Quirici Staff and Faculty: Katherine Berko (Health Humanities Lab Manager), Kevin Caves, Daniel Ellison, Jehanne Gheith, and Jules Odendahl-James Students: Simran Prakash, Logan Welborn, and the executive board of Duke Disability Alliance

Special thanks to Arts Access, BrailleSmith, Communications Access Partners, Duke Parking and Transportation, Duke Performances, the Duke Student Disability Access Office, the Durham Audio Described Art Project, and the staff of the Rubenstein Arts Center for your help making our conference as accessible as possible!

AN EXTRA THANK YOU TO OUR VOLUNTEERS!



Disability in the Disciplines Conference

April 25-26, 2019 | Rubenstein Arts Center



Image by: Maria Lulo Abinader, Duke '21

Sponsored by: Health Humanities Lab at the Franklin Humanities Institute, Duke Disability Alliance, and Disability & Accessibility Initiative

Accessibility Statement

In organizing this conference, we recognize disability access as a basic, yet essential, foundation for social justice. This conference has a quiet space you may visit in **room 128**. We have ASL interpretation, assisted listening devices, audio description, and a few extra wheelchairs on hand.

For assistance of any kind, ask a volunteer! You can identify conference volunteers with their white shirts and black aprons. Or find someone at the welcome desk!

We recognize that even with our best efforts, accessibility is an ongoing process of improvement. Please let one of our conference volunteers know if there is anything we can do better, or email marion.quirici@duke.edu.

#AccessIsLove

Schedule At-A-Glance

Day 1: April 25, 2019

5:00 – 6:00 PM: Keynote Lecture by **Lennard Davis** (Film Theater) **6:00 – 6:30 PM**: Catered Reception by Comfort Cuisine (Multipurpose Studio 124)

6:30 – 8:00 PM: Premiere of *Illness Revelations,* an embodied inquiry into the eugenics impulse and the nature of care, oppression, illness and healing \sim by **Marina Tsaplina** (Von der Heyden)

Day 2: April 26, 2019

8:30 – 9:00 AM: Breakfast by Fosters Market and Coffee by Beyu Blue (Multipurpose Studio 124)
9:00 – 10:15 AM: Breakout sessions

<u>Session 1</u>: Neurodiversity and Mental Health (Von der Heyden) Moderator: Tara Chandrasekhar Speakers: Sam Aldave, Jeff Baker, and Qin Hu

<u>Session 2</u>: Medical Ethics and the Culture of Care (Ruby Lounge) Moderator: Neil Prose Speakers: Jen Ansley, Jennifer Hawkins, and Priscilla Smith

10:15 – 10:45: Break

10:45 – 11:45: Community Engagement Plenary (Von der Heyden)

Moderator: Marion Quirici Speakers: James Davis, Susan McSwain, Chris Rivera, and Ricky Scott

11:45 - 12:45: Lunch by Comfort Cuisine (Multipurpose Studio 124)

12:45 – 2:00: Student-led Plenary on Accessible Pedagogy (Von der Heyden)

Moderator: Logan Welborn Speakers: Victoria Nneji, Simran Prakash, and Andrew Toig

2:00 – 2:30: Break

2:30 - 3:45: Breakout sessions

<u>Session 3</u>: Disability & Design: Experiences in Higher Education (Ruby Lounge) Moderator: Kevin Caves Speakers: Deja Barber, Richard Goldberg, Marisha Madhira, Tara Moore, and Kate Simmons

<u>Session 4</u>: Theater and the Arts (Von der Heyden) Moderator: Jules Odendahl-James Speakers: Dan Ellison, Ann Fox, Monét Marshall, and Kali Quinn

3:45 – 4:00: Break **4:00 – 5:15PM**: Breakout sessions

> <u>Session 5</u>: Disability Law and Human Rights (Ruby Lounge) Moderator: Adam Rosenblatt Speakers: Craig Brown, Cate Reilly, and Ed Rizzuto

<u>Session 6</u>: Language, History, and Representation (Von der Heyden) Moderator: Marion Quirici Speakers: Eileen Anderson, Ashley Elrod, and Ann Millett-Gallant

5:30 - 6:30PM: Student Art and Research Showcase with Catered Reception by Comfort Cuisine (Multipurpose Studio 124)

Featuring the Durham Audio Described Art Project ~and~ Out of the Blue (Duke oldest all-female a cappella group)

Full Schedule (with Speaker Bios)

Day 1: April 25

5:00 – 6:00 PM: Keynote Lecture by Lennard Davis: "Disability Studies Across the Disciplines: Theory and Praxis" (Film Theater)



Lennard J. Davis is a professor in the English department at the University of Illinois at Chicago. In addition, he is a professor of Disability and Human Development in the School of Applied Health Sciences, as well as a professor of Medical Education in the College of Medicine. He is also the director of Project Biocultures, a think-tank devoted to issues around the intersection of culture, medicine, disability, biotechnology and the biosphere.

6:00 – 6:30 PM: Catered Reception by Comfort Cuisine (Multipurpose Studio 124)

6:30 – 8:00 PM: Premiere of *Illness Revelations* by Marina Tsaplina: an embodied inquiry into the eugenics impulse and the nature of care, oppression, illness and healing (Von der Heyden)



Marina Tsaplina is the founder and catalyst of THE BETES. She is a puppeteer, clown, kinesthetic performing artist, and patient advocate. She has lived with Type 1 diabetes since she was two years old, has known severe depression, and is passionate about bringing her artistic vision to the new emerging fields of the Medical Humanities and Narrative Medicine. She is currently a Scholar in the Medical Humanities at the Penn State College of Medicine – Kienle Center for Humanistic Medicine.

Featured Musicians during the Performance

William "Mac" McLaughlin is a retired pharmacist and keyboard player with over 45 years of experience. Widely known throughout the Triangle and beyond as an avid jazz artist committed to keeping the art of jazz alive, especially in communities of color, he is executive director of the Durham Jazz Renaissance Foundation. He can be heard regularly at Arcana and other venues in the Triangle at the helm of The Mac McLaughlin Group.

Dana Thalheimer, drummer, studied percussion at University of North Texas and is a founding member of Durham's award-winning Bull City Blues Band.

Damon Walker, bassist, is a native New Yorker active in large and small groups around the Triangle. He is owner and luthier of Dr. Bass String Instrument Repair, Rental & Sales on Broad St. in Durham.

Robert Zimmerman, trombonist, studied jazz at California Institute of the Arts and developed his style in the smoke-filled dives of Chicago. He covers the arts at Duke for the Office of the Vice Provost for the Arts.

Day 2: April 26

8:30 – 9:00 AM: Breakfast by Fosters Market and Coffee by Beyu Blue (Multipurpose Studio 124)

9:00 - 10:15 AM: Breakout sessions

Session 1: Neurodiversity and Mental Health (Von der Heyden)

Moderator: Tara Chandrasekhar Speakers: Sam Aldave, Jeff Baker, and Qin Hu

Tara Chandrasekhar, MD, is an Assistant Professor of Psychiatry in the Department of Psychiatry and Behavioral Sciences. She is a staff psychiatrist at CAPS and provides clinical care and does research at the Duke Center for Autism and Brain Development. She is co-chair of Duke Neurodiversity Connections, a working group of faculty, staff and students who aim to increase awareness and inclusion of neurodiversity on Duke's campus. She is interested in supporting the mental health, academic, social, and career needs of students who identify as neurodiverse.

Sam Aldave, a North Carolina native, holds a BA in psychology from the University of North Carolina at Chapel Hill and a Master's in Education Policy & Management from Harvard University. After serving North Carolina students for eight years, first as an elementary school teacher and later as a K-12 teacher coach, he was called to ministry. Sam is currently completing a Masters of Divinity at Duke University and hopes to ultimately teach at the university level. In doing so, he strives to bridge the divide between queer trans people of color (QTPOC) and faith communities. Jeff Baker, MD, PhD, is a pediatrician and historian, who has written and lectured around the country on the history of pediatrics, vaccines, and autism. A Professor at Duke University School of Medicine, he directs the Trent Center for Bioethics, Humanities, and History of Medicine. He has had a longstanding clinical focus on children and adolescents with autism spectrum disorders and has been affiliated with the research and clinical programs of the Duke Center for Autism and Brain Development.

Qin Hu, PhD, is a staff psychologist at the Counseling and Psychological Services at Duke University. She is a member of the Neurodiversity Connections at Duke. Qin's educational background includes a PhD in counseling psychology and a Master's in school counseling. Her research interests focus on mental health professionals' attitudes towards students with autism, as well as how the identity of being neurodiverse intersects with race and gender.

Session 2: Medical Ethics and the Culture of Care (Ruby Lounge)

Moderator: Neil Prose Speakers: Jen Ansley, Jennifer Hawkins, and Priscilla Smith

Neil Prose, MD, is a Professor of Pediatrics, Dermatology and Global Health, and co-director of the Health Humanities Lab at Duke. He is a pediatric dermatologist who writes and teaches about empathetic patient-provider communication. He is creating a curriculum in respectful maternity care for midwives and health extension workers in Ethiopia, and for midwifery students in Chilean Patagonia. He is also making a documentary on housekeepers in the Duke Hospital. Jennifer Ansley, PhD, is faculty in the Thompson Writing Program. Their scholarship in both Writing Studies and Queer Cultural Studies is united by questions surrounding the politics of care and caregiving. Ansley's book manuscript in-progress, "Feeling Queer: The Institutionalization of Care & Safety," examines how vulnerable populations—queer and trans people, disabled people, people of color, and the elderly—have rhetorically and discursively responded to interpersonal and state violence, and have used writing and storytelling to imagine nonnormative kinship and caregiving networks that support their survival.

Jennifer Hawkins, PhD, is an Associate Research Professor in the Department of Philosophy and a core member of Duke's Trent Center for Bioethics, Humanities & History of Medicine. Her research area is ethics with a special interest in the philosophy of well-being, as well as disability. She has written about dementia, cognitive disability more generally, and mental illness. She regularly teaches an undergraduate course on the philosophy of disability here at Duke.

Priscilla Smith is a domestic care worker and organizer with the National Domestic Workers Alliance. She is also active with We Dream in Black, Care Workers in Action, and the Durham Workers Assembly.

10:15 – 10:45: Break

10:45 – 11:45: Community Engagement Plenary (Von der Heyden)

Moderator: Marion Quirici Speakers: James Davis, Susan McSwain, Chris Rivera, and Ricky Scott James E. Davis, Jr. is Assistant Director for the Department of Neighborhood Improvement Services, where he provides strategic direction for the Human Relations and Community Engagement divisions. He earned an undergraduate degree in accounting from Knoxville College (TN) and a law degree from the University of Tennessee. He served as a Disease Intervention Specialist for a local health department. His passion is to promote equal access and opportunities for all demographics.

Susan McSwain is the Executive Director of Reality Ministries, a community of adults with and without developmental disabilities who have been working, playing, learning and growing together for the past 11 years. She has been involved with Reality from the start, as a volunteer and then staff, entering her current role 6 years ago. She and her families are part of the North Street community, a neighborhood of people of all abilities living in community together in downtown Durham.

Chris Rivera is the Director of Operations at the Alliance of Disability Advocates (ADA). Before getting a job there, he was a volunteer in the office. He has been at ADA for almost 8 years and earned a degree in 2017. He feels his story captures the importance of community inclusion and the life changing role that Centers for Independent Living (CILs) can play in someone's life. When he's not working, Chris plays on the Triangle Thunder wheelchair basketball team.

Ricky Scott, PhD, is Chair of the Raleigh Mayor's Committee for Persons with Disabilities, and serves on the Advocacy Committee of the governor-appointed North Carolina Statewide Independent Living Council. He earned his undergraduate degree from UNC Chapel Hill, his Master's degree from UNC Charlotte, and his doctoral degree from NC State University. He has served as President of the Governor Morehead School Alumni association, the Second Vice President of NC Council of the Blind, and has been on the board of directors of many other disability rights organizations in the state. 11:45 – 12:45: Lunch by Comfort Cuisine (Multipurpose Studio 124)

12:45 – 2:00: Student-led Plenary on Accessible Pedagogy (Von der Heyden)

Moderator: Logan Welborn Speakers: Victoria Nneji, Simran Prakash, and Andrew Toig

Logan Welborn is a first-year student from Winston Salem, NC studying Public Policy and Global Health. Logan's passion for disability advocacy has led her to serve as the advocacy chair for Duke Disability Alliance and to be a student representative for Citizens United for Research in Epilepsy. On campus, Logan sings with her a cappella group Out of the Blue, performs in musicals with Hoof 'N Horn, and records music with Small Town Records.

Victoria Chibuogu Nneji is a creative strategist and strategic creator passionate about mobility. She was born in Lagos, Nigeria and raised in Durham, NC, but grew up in New York City where she was a mathematician and entrepreneur at Columbia University. Victoria has since returned here to earn her Master of Engineering Management and PhD in Mechanical Engineering-Robotics at Duke University.

Simran Prakash is an undergraduate freshman from Phoenix, Arizona at Duke University studying Visual & Media Studies on a pre-medical track. Both Simran and her brother have grown up with 60% hearing loss and wear hearing aids to cope along with day-to-day life. Her passion for increasing the awareness for hearing-impaired individuals has led her to strongly advocate for ASL as a foreign language on Duke's campus, while also serving as the activism chair for Duke Disability Alliance. Besides her work with disabilities, Simran competes on the Duke Club Swim team, dances with Duke Raas (an Indian dance team) and takes photos for the Duke Chronicle.

Andrew Toig is a Duke Law student in the class of 2020, and the founding president of Law Students for Accessibility. The group is dedicated to advocating on behalf of accessibility issues, providing professional development for students interested in careers involving disability issues, and is the only such group at the law school. Andrew is also a Social Studies teacher in Colorado public schools.

2:00 – 2:30: Break 2:30 – 3:45: Breakout sessions

> Session 3: Disability & Design: Experiences in Higher Education (Ruby Lounge)

Moderator: Kevin Caves Speakers: Deja Barber, Richard Goldberg, Marisha Madhira, Tara Moore, and Kate Simmons

Kevin Caves, MEM, is a Clinical Associate in the Department of Surgery at Duke University. He specializes in Technology and Design for People with Disabilities, Assistive Technology, Augmentative and Alternative Communication (AAC), Rehabilitation Engineering, and Computer Technology. He is also an instructor in the Department of Biomedical Engineering and Clinical Associate in the Department of Medicine at Duke University. His recent research projects include the development of brain computer interface (BCI) technologies, the use of sensors to help older people and individuals with disabilities live more independently and safely at home, and telerehabilitation techniques to improve delivery of assistive technology services. **Deja Barber** is a young disability justice advocate with cerebral palsy. She has a Bachelor's in educational studies from William Peace University, and is planning on going to graduate school to obtain a Master of Science in School or Rehabilitation Counseling. She serves as an executive member on the North Carolina Statewide Independent Living Council, which helps people with disabilities throughout the state. She is also the Vice Chair of the Youth Steering Committee of the Association of Programs for Rural Independent Living, organizing an annual conference for youth to learn about disability advocacy.

Richard Goldberg, PhD, is a Research Associate Professor at UNC Chapel Hill. He received his Bachelor of Science in Electrical Engineering from Bucknell University, and his PhD in Biomedical Engineering from Duke University. His current research is in Rehabilitation Engineering, with projects involving the development of custom devices for people with disabilities.

Marisha Madhira is currently an undergraduate at Duke University. She is a Pratt Research Fellow and is majoring in Biomedical Engineering.

Tara Moore, MSW, is the intellectual and developmental disabilities (I/DD) care coordinator at Alliance Behavioral Healthcare. She received a Master of Social Work from UNC Chapel Hill. She has a passion for people with I/DD and she loves working towards creating a more inclusive and informed community.

Kate Simmons is a hospice volunteer for Wake County, NC.

Session 4: Theater and the Arts (Von der Heyden)

Moderator: Jules Odendahl-James Speakers: Dan Ellison, Ann Fox, Monét Marshall, and Kali Quinn Jules Odendahl-James, PhD, is an adjunct lecturer in Theater Studies at Duke University where she also serves as the Director of Academic Engagement for the Arts and Humanities. In 2016, she was a Kienle Scholar in Medical Humanities at Penn State College of Medicine. A professional theatre director and dramaturg, Jules specializes in work by women playwrights, developing new collaborations across the arts & the sciences, and creating performances about the lived experience of illness from personal narratives/memoirs, interview materials, and adapted from fiction. She has taught courses in medical humanities at Duke.

Daniel Ellison, JD, is an attorney in private practice in Durham, concentrating in arts law and is a leading advocate for the arts throughout North Carolina. His earliest arts accessibility presentation was "Museums and the ADA," presented at the 1992 annual conference of the NC Museums Council. He is a member of the Raleigh Arts Accessibility Learning Community and is a trained audio describer. He is the founder and director of the Durham Audio Described Art Project, and faculty advisor of Hoof 'N Horn.

Ann M. Fox, PhD, is a professor of English at Davidson College, where she teaches classes about modern and contemporary drama, disability studies in literature and visual representation, and medicine in the graphic novel. A disability studies scholar of almost twenty years, her writing on disability in the visual and performing arts has been published widely, and she has co-curated four disability-related visual arts exhibitions on subjects including disability, women, and sculpture; HIV/AIDS; and the lives of disabled citizens in her home state of North Carolina. Her current book project is entitled "Adaptive Activism: How Disability Refigures the Cultural Landscape."

Monét Marshall is a performer, director, writer, cultural organizer and creative consultant whose work sits at the nexus of

equity, creativity and community-based practice. She is presently the Founding Artistic Director of MOJOAA Performing Arts Company, producing new works by and new opportunities for Black playwrights. Last year she received the Mary B. Regan Community Arts Fellowship from the NC Arts Council and is an Independent Weekly Arts Award winner. Most importantly, she is Robin and Bryan's daughter, and Evelyne, George, Zelma and Bob's granddaughter.

Kali Quinn is a performer and musician from Providence, RI. She has taught physical theater at Trinity Rep/Brown University, MIT, and Accademia dell'Arte (Tuscany). She mentors solo performance, emerging artists, and companies around the world based on her teaching memoir/audiobook, *I Am Compassionate Creativity*, and creates performances looking at aging, end-of-life ethics, memory care, patient-provider communication and intergenerational grief. Recently, Kali has been an artist in residence at Duke and Wake Forest.

3:45 - 4:00 Break

4:00 - 5:15PM: Breakout sessions

Session 5: Disability Law and Human Rights (Ruby Lounge)

Moderator: Adam Rosenblatt Speakers: Craig Brown, Cate Reilly, and Ed Rizzuto

Adam Rosenblatt, PhD, teaches in International Comparative Studies at Duke and writes about the intersections of human rights, social justice, and care of the dead. His first book, *Digging* for the Disappeared: Forensic Science after Atrocity (Stanford University Press, 2015), explores how scientific experts exhuming mass graves interact with international institutions, grieving families and their dead loved ones. His next book is about volunteers who reclaim neglected spaces of the dead, including African-American burial grounds and former mental hospital cemeteries. His other disability studies-related work includes an article called "Autism, Advocacy Organizations, and Past Injustice" (Disability Studies Quarterly, 2018).

Judge Craig Brown, JD, served in the North Carolina justice system starting in the 1970s, becoming a judge in 1996. His book *Blind Justice* (2009) shares his experiences on the bench during controversial cases in Durham, while living with Behçet's Syndrome.

Cate Reilly, PhD, is an Assistant Professor of Literature at Duke specializing in Central and Eastern European modernism and the interwoven history of psychiatry, psychoanalysis, and medicine. Her first book project studies the creation of an internationally standardized grammar for the human psyche. In her teaching, she seeks to draw students' attention to the role of language as a site of cultural and historical difference amidst the growing pressures of an (illusory) global sameness.

Ed Rizzuto, JD, is a California attorney and serves as a Pro Bono Out-of-State attorney sanctioned by the North Carolina State Bar to assist Disability Rights North Carolina clients with employment-related disability discrimination claims. Mr. Rizzuto teaches Self Advocacy, Adaptive Technology and Independent Living Skills to visually impaired people under contract with the NC Division of Services for the Blind. He is a co-organizer of Vision InSights, a Durham-based independent advocacy, networking, and support group for visually impaired people. He collaborates with local institutions to enrich the visually impaired community through enhancing access to transportation, art, and recreational activities. Mr. Rizzuto is married and the proud father of three young children.

Session 6: Language, History, and Representation (Von der Heyden)

Moderator: Marion Quirici Speakers: Eileen Anderson, Ashley Elrod, and Ann Millett-Gallant

Marion Quirici, PhD, is a Lecturing Fellow in the Thompson Writing Program, where she has designed and taught courses on Disability and Representation; Literature and Medicine; Neurodiversity, Narrative, Activism; and Modernism and Madness. She is Co-Director of the Health Humanities Lab at the Franklin Humanities Institute and faculty advisor of Duke Disability Alliance. She has published on the autistic genius stereotype as well as several articles on disability studies and Irish literature. She is currently working on a book manuscript entitled "Fitness for Freedom: Disability and Democracy in Irish Modernism."

Eileen Anderson, PhD, teaches language, writing, servicelearning, and culture courses in the Romance Studies Department at Duke University, including a disability studies Spanish course. Her primary area of interest is using technology to encourage students to collaborate more effectively. Her scholarly work provides new insights into the ways in which communities interact. She has a PhD in comparative literature from UNC Chapel Hill and an MA in Digital Teaching and Learning from NC State.

Ashley Elrod, PhD, is Assistant Professor of History at Northeastern Illinois University in Chicago. She earned a PhD in History from Duke University in 2017, and co-founded the Disability and Access Initiative with Marion Quirici. Her research focuses on the intersection of legal culture, disability, and rights in Europe since the sixteenth century. She has volunteered in disability rights advocacy on campus and in the wider community, serving as a faculty advisor and board member with three disability advocacy organizations in North Carolina.

Ann Millett-Gallant, PhD, is a Senior Lecturer at UNC Greensboro, designing and teaching online art history, visual culture, and liberal studies courses. Her research bridges the disciplines of Art History and Disability Studies. Her books include *The Disabled Body in Contemporary Art* (2010); *Re-Membering: Putting Mind and Body Back Together Following Traumatic Brain Injury* (2016); and *Disability and Art History*, co-edited with Dr. Elizabeth Howie (2017). She has also published essays and reviews of art and film, and she enjoys painting and composing mixed-media collages.

5:30 - 6:30PM: Student Art and Research Showcase with Catered Reception by Comfort Cuisine (Multipurpose Studio 124)

Featuring

The Durham Audio Described Art Project ~and~ Out of the Blue (Duke oldest all-female a cappella group)

Students participating in the Exposition: Maria Lulo

Abinader, Laura Benzing, Alex Chan, Robert Franco, Tiana Horace, Dawson Jones, James Tristan Kelleher, Seijung Kim, Siddarth Madala, Nikhita Mahendru, Sujal Manohar, Yasamine Mesri, Ashley Myers, Jaan Nandwani, Megan Richards, Abdullah Shahid, Natalie Tarn, Anna Tupetz, Jacqueline Vicksman, and Lorne Zhang.

Featured Artists

Martha Hoelzer is a photographer who explores the intersection of art and bodily trauma through "What Lies Beneath Concussion." In a series of images and video, she considers how multiple concussions have impacted her visual perception of everyday items. Her work asks the viewer to consider the question of how—and if—we can render our experiences so that others can understand what they cannot see. Hoelzer earned her degree in American Studies and German from UNC Chapel Hill.



Ann Millett-Gallant, PhD, who is a speaker on the Language, History, and Representation roundtable, has contributed four paintings available to be viewed in Studio 124. The four paintings represent the four seasons of the year, including inserts of her amputee hands in acts of writing and making art.