Complicating Normalcy: Disability, Technology, and Society in the Twenty-First Century

Welcome to the University of Rochester’s first Disability Studies Cluster Symposium. Themed “Complicating Normalcy: Disability, Technology, and Society in the Twenty-First Century,” the symposium is organized around the documentary film *FIXED: The Science/Fiction of Human Enhancement*. The film explores the meaning of “disability” and “normalcy” in contemporary times through the examination of technological and pharmacological advances designed to “fix or enhance the human body” and the bioethical implications and social tensions that arise from these scientific advances.

THANK YOU!

Many, many, many thanks to our co-sponsors, without whose support this symposium would not have been possible:

- University Committee on Interdisciplinary Studies (UCIS)
- University of Rochester School of Nursing
- Center for Excellence in Teaching and Learning
- Warner School of Education
- Strong Center for Developmental Disabilities
- Teaching and Curriculum Program at the Warner School
- Institute for Innovative Transition
- Film and Media Studies Program
- Training Program in Cellular Biochemical and Molecular Sciences (NIH Grant T32 GM068411)
- Department of Biochemistry and Biophysics
- UR Office of Human Resources—Organizational Development and Staff Diversity
- ASL Interpreting Services Provided by Interpretek

Many thanks also to those who gave their time and expertise to secure space and technology, publicize the symposium, and help with logistics:

- Jonathan Wetherbee
- Chris Penders
- Laura Brophy
- Laura Robinson
- Pam Kaptein
- Brian Harrington
- Theresa Danylak
- UR Cinema Group
- Bonnie Reda
Symposium At A Glance

8:30 - 9:00  Registration/Light Breakfast  SON Atrium
9:00 - 10:30 Welcome, Film Screening, Keynote  SON Auditorium
10:30 - 10:45 Break  SON Atrium
10:45 - 12:00 Panel Session 1  SON 1W501
12:00 - 1:15 Lunch and Poster Session  Evarts Lounge
1:15 - 2:30 Concurrent Panel Session 2  SON 1W501 / 1W502
2:30 - 2:45 Break  SON Vestibule
2:45 - 4:15 Concurrent Panel Session 3  SON 1W501 / 1W502

Film Screening and Keynote

Presented by Regan Brashear, Producer/Director of FIXED, and Dr. Gregor Wolbring, Associate Professor at the University of Calgary
9:00–10:30 a.m.
School of Nursing Auditorium (1W304)

(Image: head shot of woman with reddish hair, smiling)

Fixed producer/director, Regan Brashear, has been working on disability, economic, racial, LGBTQ and youth justice issues for over twenty years now through documentary film, theater, union organizing, community forums, and grassroots activism. Previously, Brashear served as a producer and community engagement coordinator at Open Eye Pictures, a documentary production company in Sausalito, CA, doing community engagement for the Academy Award-shortlisted film, Under Our Skin and as co-producer for The Grove, a film about the National AIDS Memorial Grove. Both films aired across the country on PBS stations in 2011. She is the founder of Making Change Media is a documentary production company based in Oakland, CA, which specializes in educational media on urgent and complex social issues of our time.

(Image: head shot of man with glasses and a beard, smiling)

Dr. Gregor Wolbring is an Associate Professor in Community Rehabilitation and Disability Studies within the Department of Community Health Sciences at the University of Calgary, Alberta, Canada. In addition to his position at the University of Calgary, Dr. Wolbring is a Visiting Professor of Ability Expectation and Ableism Studies at American University of Sovereign Nations (AUSN); scientific staff at the Institute for Technology Assessment and Systems Analysis in Karlsruhe, Germany; a Fellow at the Institute for Science, Policy and Society at the University of Ottawa, Canada; adjunct faculty in Critical Disability Studies at York University, Toronto, Canada; and Affiliated Scholar at the Center for Nanotechnology and Society at Arizona State University. He serves on a number of boards including the Council of Canadians with Disabilities, Thalidomide Victims Association of Canada, the Centre for Disability Studies in Winnipeg, Canada and the Society for Disability Studies, USA. He is past-President of the Canadian Disability Studies Association, and has also served on the board of the Canadian Commission for UNESCO to name two Past appointments. On November 11 2013, Dr. Wolbring was awarded the Queen Elizabeth II Diamond Jubilee Medal by the Government of Canada in recognition of his work, which was cited as “tireless and of benefit to the greater community.

Thank You!

We would like to thank the members of the Disability Studies Cluster for their roles in this symposium:
Angela Clark-Taylor, Bryan Harrison, Cayla Jimenez, Beth Jorgensen, Jessica Keith, Maria Lynch, Martha Mock, Laura Robinson, Kristen Totleben, Elizabeth Ballard, Beverly Buscemi, Bonnie Smith, Missy Pfohl-Smith, Amanda O’Hearn

Special thanks to our Conference Planning Committee:
Elizabeth Carpenter  Caroline Nestro
Jenny Hadingham  Jonathan Wetherbee
Brian Harrington  Julia M. White
Susan Hetherington
**Panel Session 1: 10:45 – 12:00**

**Identity, Identifying, and “Care”: Political Constructions of (Dis)Dis/Ability**

Room: School of Nursing Flaretti Room (1W501)

Chair: Kristen Totleben

Participants:
- Attendants as Assistive Devices: Independent Living and Technologies of Care. *Christine Kelly, Institute of Feminist and Gender Studies, University of Ottawa*
- Implications for Treating Ultra High-Risk States for Developing Psychosis. *Gerald Jordan and Srividya Iyer, PhD, Douglas Mental Health University Institute, Prevention and Early Intervention Program for Psychoses, McGill University*
- The End of Normal?: De-Regulating Disorder in the DSM-5. *Anne McGuire, PhD, New College, University of Toronto*

**Posters, During Lunch, 12:00-1:15**

Room: Helen Wood Hall, Evarts Lounge

- The relationship between contact and attitudes: Reducing prejudice toward individuals with intellectual and developmental disabilities. *Jessica Keith, University of Rochester*
- The Use of Online Coursework to Increase Accessibility for Deaf Students in Higher Education. *Nicole L. O’Dell, Warner School, University of Rochester*

**Ongoing**

Rooms: SON Vestibule; Helen Wood Hall, Evarts Lounge

- The Opportunity Project: Changing How We Frame Disability. *Martha Mock, Ph.D., Institute for Innovative Transition, Warner School of Education, University of Rochester, and Catherine Branch Lewis, Rochester Center for Community Leadership, University of Rochester*

---

**Panel Session 2: 1:15 – 2:30**

**Stigma, Control, and Change: Historical Perspectives of (Dis)Dis/Ability**

Room: School of Nursing Flaretti Room (1W501)

Chair: Dr. Susan Hetherington

Participants:
- Structural and Public Stigmas in the American Probation Models: Effects of Deinstitutionalization on Criminalization of Mental Illness. *Babatunde Oluwaseun Adekson, Warner School, University of Rochester*
- When the Deaf Hear: Cochlear Implants Reconsidered. *Dr. Rebecca A.R. Edwards, Department of History, Rochester Institute of Technology*
- Schools of Social Control: Organized Oppression at the Intersection of Indian Boarding Schools and Mental Hospitals. *Kelsey John, Syracuse University*

**Access and Accommodation: (Dis)Dis/Ability in Higher Education**

Room: School of Nursing Classroom (1W502)

Chair: Elizabeth Carpenter

Participants:
- Guidelines for Total Classroom Inclusion in Higher Education Settings A Practical Perspective. *Christina Goodermote, Warner School, University of Rochester*
- Online Resources for Deaf Students in Learning Foreign languages. *Ting Huang and Xia Wu, Warner School, University of Rochester*
- Toward the Transformative Inclusion of Students with Disabilities in STEM Fields. *Lauren Rose Strand, The Ohio State University*
Panel Session 3, 2:45-4:15

Governance of Body and Mind: Resistance and (Dis)Dis/Ability Activism
Room: School of Nursing Flaretti Room (1W501)
Chair: Maria Lynch
Participants:
The National Body and Cinema’s Prosthesis: Disability and Affective Production in Hara Kazu’s Documentary Encounters. Joel Neville Anderson, Visual and Cultural Studies, University of Rochester
Disability Activists Challenge Negative Disability Bias in Advance Care Planning and the Broader Culture. Diane Coleman, JD, Not Dead Yet, Rochester, NY, and Bruce Darling, Center for Disability Rights, Rochester, NY
“For Your Own Good”: The Need for Youth Rights in the Disability Justice Movement. Shain M. Neumeier, Esq., PADD Staff Attorney, Disability Rights New York
Anticipatory Advocacy and Anticipatory Governance of Scientific Research and Technology Development: What Does It Mean for Ability-Impaired Labeled Groups? Lucy Diep and Dr. Gregor Wolbrin, Cumming School of Medicine, University of Calgary

Inclusive Spaces and Places: (Dis)Dis/Ability and Community
Room: School of Nursing Classroom (1W502)
Chair: Laura Robinson
Participants:
Bullying and Individuals with Disabilities: Needs and Future Directions. Kathleen P. Allen, Ph.D., Jilynn Werth, University at Buffalo, SUNY, Alberti Center for Bullying Abuse Prevention
Move to Include: How Beth Adams and Big Bird are Changing the Way We Think About Disabilities. Ann Costello, Golisano Foundation, and Elissa Marra Orlando, WXXI Public Broadcasting
Salud Para Todos: Addressing the Health Needs of Persons with Disabilities through the Global Medical Brigades Model. Nichole Roxas, University of Rochester School of Medicine and Dentistry
Vorsprung Durch Technik: the Creation of Caring Church-Communities through Technological Aids. Mike Walker, Knox College, University of Toronto, Toronto School of Theology

About the UCIS Disability Studies Cluster

Mission
Disability Studies holds the perspective that disability is a social, cultural, and political phenomenon and challenges the deficit model through which disability is typically understood. The mission of the Disability Studies Cluster (DiSC) is to engage in scholarship and service that promotes: (1) the study of disability in social, cultural, and political contexts that rejects deficit models; (2) greater awareness of the interests and experiences of individuals with disabilities; and (3) the inclusion of individuals with disabilities in all areas across the University of Rochester and the greater Rochester community. The Disability Studies Cluster consists of individuals from all areas of the University, as well as community agencies and partners that represent people with disabilities, or that have an interest in contributing to the mission of this group.

Goals
The University of Rochester has undertaken a bold journey to define, establish, and maintain an inclusive and productive environment for all people; students, staff, faculty, volunteers, contractors, and vendors. Toward this end, the UR has several goals, one of which is to create an inclusive community. “Members of the University’s community come from different geographical areas, represent differences in ethnicities, religious beliefs, values, and points of view; they may be physically different, have different intellectual interests, or have different abilities.” DiSC supports UR’s goals by:

• providing faculty and staff at the U of R with opportunities for increased awareness of the contributions of and challenges encountered by people with disabilities, as well as the resources with which to promote the contributions and mitigate the challenges;
• dispelling the myths about disability while highlighting the achievements of people with disabilities,
• affording members of the University community ways to be allies to people with disabilities,
• providing opportunities and organizing events for scholars to network and collaborate on interdisciplinary, interdepartmental, and intercollegiate research related to issues of disability; and
• designing the infrastructure necessary to create and sustain an undergraduate interdisciplinary minor in disability studies.
Presenter Bios:

**Babatunde O. Adekson** is a 4th year PhD student in the counselor education and supervision program at the Warner School of Education and Human Development at the University of Rochester. He obtained a bachelor’s degree in psychology from St. Bonaventure University and holds a master’s degree in community mental health counseling from the Warner School of Education. His primary research interest is focused on the stigma of mental illness, deviance and criminal behavior.

**Kathleen P. Allen, Ph.D.** is the training and evaluation specialist for the Alberti Center for Bullying Abuse Prevention at the University of Buffalo. She is the co-author of the Alberti Center’s Dignity for All Students Act program for new or repeat education certifications for NYSED. Allen is also an adjunct at the Graduate School of Education at SUNY Buffalo, and Monroe Community College. She is currently a co-investigator on a study to assist the New York State Developmental Disabilities Council in formulating a strategic plan to address the problem of bullying of and among children and adults with developmental disabilities. Allen’s research interests include bullying in schools and adolescent social drama.

**Joel Neville Anderson** is a filmmaker and scholar working in independent cinema and visual culture. He is pursuing a PhD in the University of Rochester’s graduate program in Visual and Cultural Studies and is an alumnus of Purchase College’s Conservatory of Theatre Arts & Film. His film and video works have been screened at Anthology Film Archives, Bronx Museum of the Arts, as well as school campuses and community events. As an educator Joel has worked with the Museum of the Moving Image, Jacob Burns Film Center, Purchase College, the New School, and DCTV. He recently curated the eighth edition of JAPAN CUTS: The New York Festival of Contemporary Japanese Cinema at Japan Society July 10-20, 2014, and co-programs Rochester’s thematic avant-garde film series “On Film.” He served as Managing Editor of *Invisible Culture: An Electronic Journal for Visual Culture* for the 2013-2014 term, and his article “Cinema in reconstruction: Japan’s post-3.11 documentary” will be included in *Film on the Faultline*, a collection of essays on cinematic responses to earthquakes due out from Intellect, Ltd. in 2015. Joel was a 2013 Robert Flaherty Film Seminar Fellow, and is based in New York City and Rochester.

**Diane Coleman** is the founder, President and CEO of Not Dead Yet, a national disability rights group organized to give voice to disability rights opposition to legalization of assisted suicide and euthanasia in the U.S. In addition to using traditional advocacy strategies such as public testimony, friend of the court briefs, and community education through various media, Not Dead Yet also uses direct action tactics like rallies and protests. Diane has a law degree, has co-taught graduate courses in medical ethics at the University of Illinois at Chicago, and uses a motorized wheelchair as well as breathing supports.

**Ann Costello** is Director of the Golisano Foundation, the nation’s leading foundation dedicated to helping individuals with intellectual disabilities. Ann has more than 25 years of service in the non-profit sector, in human service administration, strategic planning, fund distribution and organizational policy development. Under her leadership the Foundation has supported and launched many innovative partnerships and programs to build a more inclusive community by inspiring and motivating people to embrace different abilities and include all people in every aspect of community life. Ann earned her Master’s Degree from the University of Pennsylvania, School of Social Policy and Practice, and also served as a Research Fellow at the School’s City and Regional Planning.

**Lucy Diep** is a master’s student in the Department of Community Health Sciences, Program of Community Rehabilitation and Disability Studies at the University of Calgary under the supervision of Dr. Gregor Wolbring. Her thesis work is exploring the linkage of anticipatory governance especially around emerging scientific processes and technological products and people with disabilities. Her thesis work is supported by the Social Sciences Humanities Research Council of Canada, Canada Graduate Scholarship - Master's award (766-2014-0759).

Christina Goodermote is a student at Warner Graduate School of Education in the Accelerated EdD program for Higher Education. She has an MBA from Simon Business School and is employed by the University of Rochester as a Project Manager in the River Campus Facilities and Services Department. She is a three-time stroke survivor with multiple infarcts on the brain, including the inner central portion. Her perspective comes from a personal triumph over partial impairment of the motor skills area which led her to continued pursuit of her lifelong goal to obtain masters and doctorate degrees. She is a community health advocate for stroke awareness with television appearances and speaking engagements. Christina’s guidelines offer faculty alternative methods for bettering the classroom experience for students with cognitive impairment who show no outward signs of disability.

Ting Huang is a PhD student in teaching and curriculum at Warner school and a senior lecturer teaching Chinese language classes at UR. Her research interests include foreign language learning and teaching, Chinese as a foreign language pedagogy, Chinese literature and culture, and Classical Chinese.

Kelsey John is a PhD student at Syracuse University in the Cultural Foundations of Education Department. She is a National Science Foundation Graduate Research Fellow. Her research interests include post-disciplinary inquiry around issues of identity and institutions. She is interested in utilizing multiples methods and philosophies to provide a holistic approach to research on the concept of identity and how it functions in various institutions.

Gerald Jordan is a PhD student in Psychiatry at McGill University. His research activities take place at the Prevention and Early Intervention Program for Psychoses, which is located at the Douglas Mental Health University Institute in Montreal, Canada. His research interests include political and social participation among people with mental health issues, and ways people thrive following an experience with first episode psychosis.

Jessica Keith is a first-year Clinical Psychology graduate student in the department of Clinical and Social Sciences in Psychology. Her research and clinical interests focus on better understanding and helping individuals with autism spectrum disorder and their families.

Christine Kelly is a Banting Postdoctoral Fellow in the Institute of Feminist and Gender Studies at the University of Ottawa. Informed by feminist disability studies, her research explores tensions around ‘care’ through qualitative studies of attendant services and training for unregulated care workers. Christine also has expertise and research projects exploring the current status of Canadian disability movements.

Catherine Branch Lewis is a passionate advocate of integrating disability advocacy and the arts. As a flutist with cerebral palsy, she holds a unique perspective on music’s ability to act as an instigator of positive change. Ms. Lewis is founder of the “Music of Difference” project: a concert series whose goal is to encourage positive conversations about disability and diversity. Two Music of Difference albums have been released and the project has been presented at venues including Harvard University and the VSA International Disability Arts Convention in Washington, DC. Ms. Lewis graduated from Rice University in 2008 and completed her Master of Music degree at the Eastman School of Music in 2009. In 2014 she completed a fellowship with the national Leadership Education in Neurodevelopmental and Related Disabilities (LEND) program at University of Rochester Medical Center. Currently, in addition to working toward her Doctor of Musical Arts degree at the Eastman School of Music, Ms. Lewis works as Assistant Director at Rochester Center for Community Leadership at University of Rochester. There, she focuses on programs supporting inclusive higher education for students with intellectual disabilities as well as political and community engagement among college students.

Anne McGuire is a Lecturer in the Equity Studies Program at New College, University of Toronto, where she teaches and researches in the area of disability studies. Her research and teaching draw on interpretive perspectives in disability studies, cultural studies, critical race and queer theory and feminist epistemology. Her book, The War on Autism: On Normative Violence and the Cultural Production of Autism Advocacy (forthcoming in 2015 from University of Michigan Press) analyzes the cultural production of autism and the ideological and material effects of contemporary discourses of autism advocacy. It explores such themes as: neoliberalism, consumerism and autism; biopolitics, race and disability; capacity, vitality and precarity; systemic ableism and normative violence.
**Martha Mock**, Ph.D., is an Associate Professor at the University of Rochester, in the Warner Graduate School of Education and is also the Director of the Institute for Innovative Transition. She has worked with and been an advocate with people with disabilities and their families for over 25 years in educational and community based settings. Under her leadership the Institute has secured grants totaling over $6 million dollars, focusing on teen and adult age individuals with intellectual and developmental disabilities from federal, state, and private foundation funders. Some funders include the U.S. Department of Education, NYS Developmental Disability Planning Council and the B. Thomas Golisano Foundation. Her areas of expertise include the following: individuals with intellectual and developmental disabilities, transition, employment, inclusive higher education, person-centered planning, and systems change. She is a former special education teacher and holds her Ph.D. in Special Education from the University of Wisconsin-Madison.

**Shain Neumeier** is a disabled person, a survivor of coercive treatment, and an attorney. Shain has been involved in advocacy against abuse, neglect and involuntary treatment in institutional settings, with a focus on the "troubled teen industry" of residential behavioral modification facilities for youth. This has included advocating for stronger laws against aversive interventions, restraint and seclusion; helping to organize protests against programs that rely on these practices; and assisting with a lawsuit against a residential facility for its systematic abuse and neglect of the youth in its care for a period of over 20 years. Shain now works as a staff attorney with a New York disability rights organization.

**Nichole O’Dell** received a Bachelor’s Degree in Sociology from SUNY Brockport and a Master’s Degree in Library Science from the University at Buffalo. Ms. O’Dell has been a Senior Information Analyst with the University of Rochester Clinical and Translational Science Institute (CTSI) since 2007, where she fills the role of Evaluation Program Manager. Ms. O’Dell is currently a Doctoral student at the Warner School in the Teaching and Curriculum program. Her research interests focus on online teaching and learning in higher education.

**Elissa Orlando** is Senior Vice President, Television and News at WXXI Public Broadcasting, where she oversees Television programming and production for WXXI’s television stations. Elissa also leads the WXXI news team in television, radio, digital and mobile news coverage and supervises the news staff and regional collaborative journalism projects. Elissa serves as executive producer of the national health series *Second Opinion*. She has been the recipient of several journalism and community service awards, including a citation for courage under fire for television news reporting in Somalia, Africa. Elissa earned a bachelor’s degree from Nazareth College, and a master’s degree in Public Administration from Syracuse University.

**Nichole Roxas** is a second year medical student at the University of Rochester School of Medicine and Dentistry. She received her Bachelor of Arts from New York University's Self-Designed Honors Major track, concentrating in Global Health Education. Her medical anthropology lens and her passion for social justice have led her to engage and collaborate with local and global communities as they explore issues of addiction, homelessness, disaster relief/recovery, and global health equity.

**Lauren Strand**’s current research examines intersectional identities of students with disabilities in STEM fields, including the interplay between disability, gender, socioeconomic background, and race. Such research is needed in order to better understand the unique experiences and multifaceted identities of students with disabilities. The ultimate goal of this work is to communicate with educators and program developers to ensure the full inclusion of students with disabilities in STEM fields, measured by increased retention in STEM majors and graduation rates.

**Mike Walker** is a fourth-year doctoral student at Knox College at the University of Toronto. His research interests include disability studies, liberation theologies, and the Christian sacraments. Mike likes to sing and write poetry; he’s very excited to share his passion for church and community with a larger group of people!
**Jilynn Werth** is a current third year doctoral student in the Combined Counseling and School Psychology program at the University at Buffalo, where she also earned her M.A. in General Psychology. She has been a graduate research assistant for the Preschool Social Development lab studying bullying, aggression, and prosocial behavior and is currently a graduate assistant at the Alberti Center for Bullying Abuse Prevention. She is a co-investigator on a research grant funded by the New York State Developmental Disabilities Planning Council on bullying prevention and individuals with developmental disabilities. Jilynn has worked with youth and adults with disabilities in variety of settings including colleges, school districts, and outpatient services.

**Xia Wu** is a doctoral student in Warner School, University of Rochester, Teaching and Curriculum program (expected, 2019), and graduated from the Warner School in 2014 with an M.S in TESOL.

**Rachael Zubal-Ruggieri** serves as the Center on Human Policy’s Information Coordinator. She is responsible for technical layout and design of informational materials, the management of dissemination databases, the tracking of information dissemination, and managing the Center on Human Policy’s websites. She has received advanced training in web-based information technology and has expertise in web design and Internet communications. She is also co-creator and co-coordinator of “Crippling” the Comic Con, an annual symposium at Syracuse University, providing participants with the opportunity to engage in a broad array of reflective discussions about the representations of disability that exist “beneath the surface” and explicitly within mainstream popular cultures both nationally and internationally, particularly the popular culture phenomena that are comic books, graphic novels, and manga.