



**Notes from the First Meeting of the
RKE ON CRITICAL DISABILITY STUDIES**
Date: SEPTEMBER 27 2024, 12:30-2:00pm

ABOUT THE RKE PROGRAM:

- 24 active groups on health topics
- Read about program here: <https://www.mun.ca/nlcahr/research-and-knowledge-exchange/>
- Groups share knowledge about practice research programming policy anything going on in our communities.
- Recognize everyone is an expert on their own health and we all know what makes us feel well.
- Intentional inclusion: it is not enough for us to say 'everybody is welcome;' we want to try to actively seek and invite people to participate in this program. Please invite anyone you think should be here!
- Low-pressure proposition: your participation is on your terms, at your pace, and as you can.
- NLCAHR will record the meetings. Conveners will take notes as required and we will all do our best to make sure that everybody who signed up to this group will be kept in the loop.
- Groups are great for networking, community programming, collaboration.

CONVENER INTRODUCTIONS:

LAURA PACHECO (she/her)

- Disabled (born and raised with disability) assistant professor in the School Social Work at Memorial.
- Most community based research has been in the field of disability in topics such as:
 - intimate partner violence and institutional violence in the lives of disabled parents who have intersecting identities, which is a term used to take into account the idea that identity can include factors such as gender identity, gender expression, race, ethnicity, class, religious beliefs, sexual identity and sexual expression, among many others
 - reproductive coercion against women with disabilities which refers to behavior that interferes with the decision-making of a person with regards to their reproductive health; and
 - aging and disability.
- A few words about Critical Disability Studies (CDS):
 - There is a lot of knowledge here in this group, so please free to add to this evolving definition:
 - There is great diversity as to how disabled people identify and how disability is defined. Most folks will agree that what binds this community together is often the experience of both ableism (discrimination in favour of the non-disabled, "able bodied," or "able minded") and disableism (prejudice against disabled people, stereotyping, or institutional discrimination) and intersecting forms of oppression in different areas of society, including health and social care settings, institutions, educational settings, policies, practices, and interactions within community settings. The disability community can also be bound together by collective resistance which is a term used when a group of people decide to protest a social injustice together.
 - There are different ideas and tensions in the field of CDS , however most disability scholars and activists would emphasize that CDS is:
 - centered on valuing the experiential knowledge of the disabled community as opposed to the authoritative knowledge of experts or professionals,

- a way to explore disability as an historically, socially, culturally and politically constructed phenomenon- this refers to the idea that things are considered to be "true" on the basis that an idea has been created and accepted by the people in a society, over time, and within a certain culture, without being questioned
- a way of recognizing lived experiences of disabilities within and across contexts
- a way to acknowledge different and overlapping identities, oppression(s) and coalition(s) that is centered on disability justice with the goal of ending injustice and marginalization.

ANDREAE CALLANAN (she/her)

- Works with Memorial's Office of Public Engagement (OPE); recent PhD from Memorial exploring overlap between autistic and poetic forms of language usage, and how autistic cognitive processing can influence the enjoyment of poetry.
- Diagnosed later in life with ADHD and then autism. Lived with disability throughout life and didn't know it— a not uncommon experience for people with adult diagnoses.
- Obtained a Ph.D. through Memorial's English Department. Research employed interdisciplinary critical autism studies and critical studies resources, methods and approaches, but she felt siloed within a single discipline.
- Working at OPE, became more aware of other scholars and researchers and community partnerships within the realm of CDS and adjacent fields (e.g. health, humanities).
- Eager to get everyone together for purposes of sharing ideas and resources, and sharing research in the absence of a designated critical disability studies unit or centre at Memorial.

MEMBER INTRODUCTIONS:

AMANADA GUAY (she/her)

- Social worker in student affairs in a Quebec college, teach a disability course in the School of Social Work at McGill, hoping to enter doctoral studies at Memorial in the coming spring.
- Interests are quite broad in terms of different disability experiences, communities, accessibility. Right now, more of a focus on the students at the college and at the university

ANDREW DIXON (he/him)

- Did Master's work in CDS.
- Now an Interdisciplinary PhD candidate at Memorial, looking at the intersection of neurodiversity and employment.
- Currently embedded at the Autism Society of Newfoundland and Labrador, trying to bring the stories to life of neurodivergent people seeking employment, and the managers who manage them.

ANGIE FOLLETT (she/her)

- Limited mobility and vision,
- Patient Advisor for NL Health Services. Also autistic, ADHD, trauma, traumatic brain injury. Low vision because vision therapy not covered by healthcare.
- Trauma-informed background.
- Member of the Provincial Action Council. Interested to see how new National Autism Strategy goes.
- Thankful to COD-NL [<https://codnl.ca/>] for support and advocacy work, help with tech.
- Starting podcast with two other individuals, launching mid/late October.
- Happy to connect with folks about how to access tech as a low vision individual.

ANNE MALONE (she/her)

- Partially sighted, born with extremely compromised eyesight, passed as sighted until early forties which is a common experience in the sight loss community— to conceal the disability.

- Nearly 70% of people living with sight loss in Canada are unemployed. Highest poverty rate of any disability.
- Loves CDS as a field of study, helpful to understand own experience, and contextualize it.
- For partially sighted people, none of the assistive technology is provided to us. Has to be bought, is incredibly expensive because one particular vendor has a monopoly on all of it in Canada. Therefore, interested in how the 'disability-industrial complex' may in itself be one of the biggest barriers in disabled people's lives.

ANNELIESE ELLIS (she/her)

- Speech language pathologist who works with children with physical disabilities and their families. Tertiary care program that offers services provincially.
- Currently partnering with CanChild [<https://canchild.ca/>], which is a think-tank out of McMaster and several universities in Ontario with international presence in disability research for children.
- Looking at if/how we are offering family centered care. Trying to implement what's called the "F Words of Child Development," which is a reimagining of the World Health Organization's international classification of function, disability, and health into more "family-friendly" wordage.
- Interested in breaking down the barriers between healthcare professionals and families, putting the families and their children first, and us as assistants to them in their function and fun.

ANNETTE MANNING

- Artist, about 15 years working with individuals with various disabilities, mostly seniors.
- Work developed in St. Johns at seniors' complexes, not as a therapist- as an artist.
- Intuitively worked with people where they were, got some amazing results.
- Went to Concordia as a researcher in Fine Arts, did some work at the Cummings Centre [<https://cummingcentre.org/> Individual programs for people with Parkinson's, head Injury, stroke, etc.
- Also has ADHD, late diagnosis, informative to have that.

CAROLYN WHEELER

- Department of Education, Program Development Specialist seconded from the education system to work in the development of policies and guidelines.
- Changes happening at the Department of Education. Looking at teaching and learning now. Diversity of learners more like a continuum of learning, as opposed to, perhaps, some historic practices in education which had a concept of “average” and then, “other.”
- Moving from a medical model to more of a social model in education.
- Challenges in moving a system with thousands of educators and tens of thousands of students and looking at philosophy and practice along those lines.
- Here to listen, to learn, to make connections. Interested in evaluating our work, looking at our work, moving forward. How is the change going? Are we effective in this those types of things?

CHRISTINE TAYLOR FEARING (she/they)

- Neurodivergent, diagnosed as dyslexic since the eighties; original diagnosis was brain damage.
- Attained Master's without an undergraduate degree.
- From St. John's, currently in the interdisciplinary PhD program. SSHRC Doctoral fellowship related to Crip Theory.
- Crip Theory is an intersectional approach to disability which looks at marginalization.
- Passionate about building a larger “crip clubhouse.” Frustrated by experiences of academic ableism.
- Lived experience of being a gifted neurodivergent child forced to be in special needs classes
- Started skipping high school and going to MUN Library and listening to Bob Dylan records and going to art galleries. Created work with Codco and Rick Mercer.
- Has had to approach the medical model with an autism diagnosis and ADHD. Has Scotopic sensitivity or Irlen Syndrome, which affects lighting.
- Arguing in current PhD that these syndromes are within the realm of autism and ADHD and impede my ability to cognitively process.
- Very good writer, but cannot read. Academic ableism is steep.

- Residency at Tangled Art Gallery [<https://tangledarts.org/>], which is one of Canada's think tanks for Crip Theory.
- Passionate about policy, loves reading theory and law.
- Residency at The Rooms and at Yellow House in the Gulf Islands [<https://www.yellowhouseartcentre.ca/yellow-house>]
- Dual citizen of Scotland, and work in ancestral homeland of the Outer Hebrides with the Kinloch Museum [<https://kinlochhistoricalsociety.co.uk/museum/>], looking at ways to decolonize the practice of teaching Gaelic.
- Main theory is what's called “metaphorical research methodology” - taking complicated ideas and packing them into metaphor.
- Researching history of Hallowe’ en—Scottish, Irish roots. Reclaiming the crip and the gothic.
- Trauma related to living through systems as neurodivergent disabled person.
- Do not like the word “inclusive.” as “It means that I'm invited into a system that I don't want to be a part of.” Prefer terms like “equity,” and “access.”
- Wants to unpack how the giftedness of neurodiversity can be looked at without really acknowledging the steps that have to happen. Not into just presenting the mask of that.

DANICA MCPHEE (she/her)

- In Leamington, Ontario. Equity, Inclusion, and Indigeneity coordinator at a small community hospital in Leamington.
- In awe of the stories and experiences in the group!
- Wheelchair user as a result of spinal cord injury.
- Ontario has the AODA – Accessibility for Ontarians with Disabilities [<https://www.aoda.ca/>] AODA goal had been to have a fully accessible Ontario by 2025, January first. Nowhere near where we need to be.
- From the perspective of role within the hospital system: local hospitals don’t even meet threshold.
- Graduate of Critical Disability Studies at Toronto Metropolitan University. Interest in disability as that final frontier of equity work.
- Biggest goal: to have people begin to perceive people with disabilities as a social group with social issues. Untangling the history of how the medical

profession has had such a, such a large role in defining disability, and how that impacts people, defining “normalcy.”

HEALTHER HEWITT (she/her)

- Neurodivergent, mother of two children with a high support needs. Records analyst with Children in Care Inquiry. One of the co-founders of Exceptional Connections—family activities for all ages, all abilities, all exceptional.
- Advocated for non-speaking children, advocating about respite, AAC [Augmentative and Alternative Communication] for son in school.
- Isolated at the moment due to lack of appropriate support.
- Part-time Memorial student, finishing degree in Law and Public Policy

JULIA JANES (she/her)

- Activist academic in the School of Social Work at Memorial.
- Lived expertise of ableism in terms of scholarship. Working with Nicole Schott, doing work with the eating disordered community, theatrical kind of engagement with the community on eating order resistance, and what Nicole is calling Critical Eating Dis/order Studies
- Teaching from an orientation of critical disabilities, justice, decolonizing, and mad studies.
- Organizing with communities has historically been primarily with folks who are harmed by systems while living houseless.
- Hope for this group: to build community and connections with the beautiful diversity of folks in this zoom room.

KATHERINE (KASSIE) WAYNE (she/her)

- Background in philosophy and bioethics, some work in studying different models of disability, and how concepts of disability sort of line up with ideas of health and with practices in medicine.
- Interested in connections with ageism and ableism and speciesism. Ableism specifically in the context of prenatal genetic testing and screening and diagnosis.
- New Master’s student; Master’s of Applied Health Services.

KERRIN RAFUSE (she/her)

- Communications Assistant with Food First NL, background in the fine/media arts.
- Entering the non-profit space coincided with my mental health/AuDHD becoming disabling, and the two happen to overlap in many areas. Pulled to learn more.
- Excited to learn and hopefully take away a few things our group can do to improve experiences of disabled folks around food security.
- Lived experience includes severe anxiety.

LAUREL HUGET (she/her)

- Work at Food First NL. Concerned about poverty, committed to talking the injustices of poverty. Disability at the forefront of that conversation.

LEAH FARRELL (she/her)

- Director of Advocacy and Outreach with the Autism Society of Newfoundland and Labrador.
- Mom of three children, one of who has autism, and he also has what's called Cri-du-chat Syndrome, which is a very rare syndrome. Really been advocating for him and other children like him since he was about four months old. Many, many barriers, but also good people who are listening.

MEL COUGHLIN (she/her):

- Relies on power chair and adaptive software. Homebody, works from home.
- Moved to St. John's from Ottawa in August. So yeah, happy to chat about Ontario's AODA!
- Assistant professor in Philosophy and Religious Studies at Memorial.
- Area of research specialization: modern Japanese Buddhist philosophy. Especially interested in its critique of anthropism (which is the belief that human beings have a spiritual nature beyond the physical body characterized by in-dwelling Divinity), happy to hear the word Speciesism in here.
- Research includes Critical Disability Studies as it intersects with modern Japanese philosophy. Also: ableism in Canadian social movements.
- Next year, teaching bioethics. Will include Critical Disability Studies reader that's come out.

- Looking to get a sense of what is happening at the intersection of Critical Disability Studies, bioethics, and activism in St. John's.

NANCY REID (she/her)

- Executive Director, Coalition of Persons with Disabilities Newfoundland and Labrador, provincial representative for the Labrador on the Council of Canadians with disabilities.
- Acquired disability as an adult, wheelchair user, parent to 27-year-old who has multiple disabilities (intellectual, communication, physical mobility, and others).
- Identifies with disability culture, value of identity as a whole.
- Many interests in the world of disability, mostly interested in truth telling.
- Hopes for this exchange to be an opportunity to share knowledge, share truth and share perspectives.

NICOLE SCHOTT (she/her/ they/them)

- Banting post- doctoral fellow at Memorial University in the School of Social Work, supervised by Julia Janes.
- Critical Eating Dis/Order Studies, making some social action art with the eating disorder community here in St. John's. Having performances in April, and potentially a gallery. Invitation to group to be involved.
- Critical Eating Dis/order challenges the pathologizing of people as having "Eating Disorders," and reorganizes the way we look at it questioning everyday "eating orders" that we are all in relation to. Sees a relationship between Critical Eating Dis/Order and Critical Disability Studies.
- Learning from disabled and neurodiverse folks that are part of the eating order resistance community is so important. (Example, public health notice to "burn more calories, take the stairs" perceived as violence toward wheelchair users and others who cannot access stairs.) Pathologizing folks diagnosed with ARFID [Avoidant Restrictive Food Intake Disorder] is used to justify forced feeding.
- Excited to have conversations with folks mentioning speciesism as well; part of Critical Eating Dis/order studies is also challenging things like what I'm calling the literal "turning beings into food," species hierarchies, etc.

PAUL DE DECKER (he/him)

- Associate Professor in the Department of Linguistics. “Fairly anxious, hard of hearing first generation academic.”
- Experience of academic ableism in the in the university system, looking to challenge and fight back against ableism in in all forms but particularly in in the University
- Produces podcast: “Some Stutter, Luh!” [<https://sometutterluh.ca/>].
- Looking at language and communicative diversity. Started off focusing on people who stutter in the province of Newfoundland and Labrador. Growing into a pro-disability, neurodiversity pride podcast that takes seriously the idea of communicative legitimate diversity.
- Looking forward to this safe space to speak freely about experiences
- Looking forward to learning more about policy

PAUL WALSH (he/him)

- CEO of the Autism Society of Newfoundland and Labrador. Governors’ Council appointment as chairperson of the Board of Directors of Accessibility Standards Canada. Served on the Provincial Advisory Council for the inclusion of persons with disabilities. Currently serving on the Autism Action Council. Per course instructor at the Faculty of Business.
- Lived experience with disability. Diagnosed at birth with cerebral palsy, which resulted in a mobility impairment.
- Deep believer in disability culture. “It’s not something that I came with. It is something I evolved into, and was challenged to recognize the beauty of my disability culture.”
- Background in private enterprise. In about little under four years ago, retired to become the CEO of the Autism Society, and now have the privilege of working with and elevating the voice of the incredible autistic community in this province.
- Here to learn.
- “Equity” is a favourite word, ties back to rights. Rights as disabled people under Section 15 of the Canadian Charter of Rights and Freedoms. Equity as individual right.
- Poverty among the disability community is acute. Something to the effect of a 14% employment rate across Canada. Incredibly disappointed that on September 25th the Parliament of Canada voted down the National Framework Bill, C. 223, an Act to develop a national framework for a

guaranteed livable basic income by a vote of 273 against to 54 being in favour. In this province, only one MP voted in favor, Ken McDonald [Riding of Avalon], which means that Joanne Thompson, Seamus O'Regan, Gudie Hutchings, Yvonne Jones, and Clifford Small all voted against the bill—something that has proof of being both economically sound and justified.

- Accessible Canada stands for a goal of a barrier-free Canada by 2040. Can we truly have a barrier-free society unless people have the economic wherewithal to make their own decisions? Funding is available for researchers working in this area through Accessible Canada.

SARAH WHITE (she/her):

- Individual with ADHD as well, daughter on the wait list for potential diagnoses. Goal is to make things easier for daughter than they were for earlier generation.
- About 20 years in sector, started with ASNL and still very much involved with that organization. Supporting folks with a variety of different diagnosis in Newfoundland and Labrador.
- Last two years with LifeWise [<https://lifewisenl.ca/>]: lived experience organization, team now of 50 across Newfoundland and Labrador. Primary criteria for work at LifeWise is lived experience. Very diverse group.

SHERRIE KOMIAK (she/her)

- Faculty of Business, specialty is a human-computer interaction.
- Husband had almost 10 years of disability before passing away last year.
- Interested in demands on disabled people and caregivers. Aging parents also need support.
- Interest in designing systems to help people with disabilities and caregivers to live and be healthy day to day.

SIBUSISO MOYO (she/her)

- PhD Student at Memorial School of Social Work, supervised by Laura Pacheco.
- Child protection worker in Montreal, Quebec. Has worked with mothers with intellectual disabilities in Southern Africa. Interested in unpacking of the impact of religion and culture on parenting, especially in persons with disabilities.

TA LOEFFLER (she/her)

- Professor in the School of Human Kinetics, avid contributor to many of Research and Knowledge Exchanges.
- Drawing on outdoor adventures to create metaphors that provide new ways to see and transform the inevitable obstacles of life
- TA is dedicated to innovative teaching and community engagement.

CORINA CODNER (she/her)

- Late diagnosis as being neurodivergent. Advocating for people who get missed in the system. Currently engaging with the Department of Health to address gaps and needs.
- Parent of two neurodivergent children. Daughter in grade six when she got her official diagnosis. Experienced struggles as an undiagnosed parent. Not regulated.
- Notes gap in skills training for ND people.
- Learning disabled as well. Happy to connect with people who are able to share resources.

FURTHER CONVERSATION/SUGGESTIONS:

PAUL DE DECKER interested in working together on some sort of group research project.

CHRISTINE TAYLOR FEARING suggests putting together a group Google doc where we can all post our interests, resources, skills to share, etc. Finds Google to be fairly accessible. Directory of group members. Also keen to discuss potential class action suits/human rights complaints with anyone interested. (Rochelle Baker noted that such a directory can certainly be made and we will follow-up as a voluntary effort to respect individual privacy concerns. She can circulate the document link and members can add their information as desired.)

ANGIE FOLLETT backs up shared directory idea. Easy to forget our own experiences and everyone else's if the information isn't documented. Also interested in discussing frustrations/limitations/expectations around disability and employment.

ANNE MALONE would love reading suggestions included as part of directory document. Especially interested in the intersection/mirroring between sensory disability and ADHD/autistic experiences: overlapping traits, shared barriers, etc.

ROCHELLE BAKER loves the idea of a book club/reading list. Will follow up with meeting notes, poll re: themes for discussion and future presentations, participation in directory, etc.

POLLING QUESTIONS:

1. Tell us your top themes for discussions
2. Are you willing to present to this group? What would you like to talk about?
3. Tell us what you are reading/ watching/ listening to and share a link
4. Would you be willing to start an outreach listing for the group that would include names and contact information with details of the kinds of work/ supports you might be able to bring to the table/ willing to contribute?

MEETING STYLES:

- Not Limited by geography
- Presentations on:
 - research
 - practice
 - programs
 - policy making
 - art/ performance
- Collaborative research/ funding opportunities

MEETING FREQUENCY: once a month- Next Meeting

WEDNESDAY NOVEMBER 13 AT 2:00PM NEWFOUNDLAND ISLAND TIME