NNDR 2023

Session Title: Critical Rehabilitation Studies: Intersections and Tensions with Disability Studies

May 11/23 @1425. [Hilton Room G]

Talk 1: Re-Orienting Rehabilitation to Critical Disability Studies: A call for Radical Reform - Barbara E Gibson

Slide: Session Title:

- I am Barbara Gibson. My co-presenters are: Donya Mosleh, Yani Hamdani, Katie Mah, Kelly Fritsch, Gail Teachman
- We are all from Canada: University of Toronto, Western University, Carleton University

Slide: Who We Are:

- We are a mix of rehabilitation clinicians and disability studies scholars
- All engaged with 'critical rehabilitation studies' (CRS)
- Commitment to change the status quo in allyship with disabled people
- Along with many of you, my colleagues and I demand a revolution in healthcare. And to that end, we are excited to be sharing our vision of CRS here at a disability studies conference.
- My positionality: Non-disabled, white, cis-woman. Physiotherapist who worked clinically for 10 years, mostly in child health.
- My Academic career for the past 15 years - focused on bringing DS to rehab.

- I position myself as an ally but am aware I might get it wrong/still have much to learn.
- I add that as knowledge producer embedded in colonial and ableist epistemologies, my first battle will always be internal with myself. This is a life-long process of reflection.

Slide: My Intro Talk is…

Re-Orienting Rehabilitation to Critical Disability Studies: A Call for Radical Reform

- In this session I will give you an overview of CRS. It is by no means monolithic.
- In the talks that follow my colleagues will do a deeper dive into some of the work they are doing in the field.

Slide: Overview

- My plan is this: I will review some of rehab's core assumptions particularly around normalization. I will then sketch out some parameters of CRS, and then finish with some broad applications.

Slide: Ableism Operates Systemically in Healthcare

- As I will explore, rehab reproduces ableism even while striving to support disabled people. This is because ableism operates systemically in healthcare. Its embedded in everything that rehab does – its programs, policies, principles, training programs, organization, funding mechanisms, assessment measures, and the research questions that are deemed relevant.
- Also Rehab has also largely ignored disability studies and disability advocates.

- Having said this, I want to avoid demonizing individual clinicians or rehab generally. Practitioners are embedded in the same disability discourses that pervade societies and contribute to processes like internalized ableism. I also want to avoid oversimplifying rehab's assumptions and their effects… Rehab is and does many things and CRS focuses on unpacking and addressing its harms, but also its potential benefits.

Slide: Rehab Should Be a Site of Radical Change…

What we need is to address entrenched systems of thought and how they are operationalized in practice. CRS suggests that Rehab should be a site of radical change, working in allyship with disabled people.

Slide: What is rehab? - Medical Definition

What is rehab? Rehab is a multidisciplinary enterprise that is delivered primarily by health professionals including therapists, SWs, nurses and doctors.

- Miller-Keane and O'Toole's (2003) medical encyclopaedia defines rehab as: ‘The process of restoring a person's ability to live and work as normally as possible after a disabling injury or illness.’

Slide What is Rehab? -CDS Description

Disability studies scholar Colin Goble describes rehab this way:

> ‘The assumption (is) that the problem lies within the person, and the solution is a technical intervention from a professional expert who helps the person achieve a greater level of independence, and thus moves them closer to a

more socially and culturally accepted level of normality.’

- Both of these descriptions refer to normalization processes. This one is obviously leading to a critique.

Slide: Rehab’s Core Assumptions: Normalization

- The slide has a pic of a brochure that reads:’ ‘Rehabilitation services - get back to normal’ w an image of a clinician and older man.
- There are multiple assumptions that pervade rehab, but I suggest the most damaging is the assumption that disability is a problem that needs to be fixed through normalization.
- Rehab is historically and ideologically aligned with biomedicine. It is not oriented to cure but rather to re-establishing physical and social function… Following injury this represents a return to previous function, or the closest possible approximation.

- For those with life-long impairments it is also an approximation towards something - which is normalcy: normal bodies, normal activities, and/or normal social roles.
- [New Slide] Normality as a goal in rehab is positioned in opposition to disability which is constructed as the problem requiring intervention.
- Acknowledge complexities…Normalization manifests in many ways, not always harmful. Not always the practitioners pushing for normalization etc.

Slide: Intersectionalities & Effacement

- Ableist notions of normalization interlink with racism, sexism, heteronormativity, and coloniality.
- The dominant knowledge in health care is Euro-American/Western. It is techno-scientific, and positivist in orientation. These masquerade as universal truths which displace and dismiss

alternative epistemologies such as those from the Global South.

- Consistent with other oppressions, rehab seldom reflects on its view that to be and do ‘like everybody else’ is the best possible outcome.
- Stiker (1999) has suggested that, in the name of equality, rehab attempts a kind of erasure of disability that strives to ‘efface’ differences.
- These approaches to disability thus limit professional imaginations rather than illuminating the ways that people could and do resist these notions; or the ways they could support people to live differently, and build countercultures.

Slide Progress + Problems

- The rehab folks + others in the audience may object to some of these ideas
- Rehabilitation preceded other health fields in recognizing the social determinants of disability.

- It has progressed to refocus interventions away from ‘fixing’ impairments towards enabling function…

  … - most notably through embracing the International Classification of Functioning (ICF), PCC, and, in children’s rehab, the so-called 6 f-words of function, family, fitness, fun, friends, future.
- This is good! However, while I do not have time to critique each of these, but I will echo the suggestions of others, that, at least in their applications these well-meaning approaches continue to rely on:
  - particular notions of what constitutes a good life,
  - continue to prioritize biomedical aims,
  - and continue to largely promote normalization -albeit in different forms: ie Function, future, fitness etc

Slide: Do we need rehab?

- Yes, Rehab can help people in many ways.
- As Tom Shakespeare and colleagues have noted: 'The danger surely lies in a blanket dismissal of a whole area of healthcare and human experience. A more nuanced approach is required.'
- I add- The issue is not whether rehab has positive effects, but rather what are its insidious negative effects. How does Rehab reproduce ableism and what can be done to eliminate it?

Slide: Critical Rehab Studies

- So where did CRS come from? Some writings from within Rehab in the last two decades beginning w KWH's 2006 book, Perspective on Disability and Rehab, and is pictured on the slide. but only in the last few years has CRS been named as an emerging field of study. This includes my 2016

book, Rehabilitation: A post critical approach, pictured on the slide

- There are now people around the world doing this work. Some at this conference.

Slide: Others doing CRS

- There is also an emerging body of work from outside of Rehab that overlaps with CRS. In DS, sociology and STS. Some of it is led by disabled people.
- This includes important empirical research by Shakespeare, Bezmez, Cooper, Papadimitriou, Strukhamp and others. Their research has examined and re-theorized the doings of clinical practices and the 'adjustment' work done by people experiencing rehab.

Slide: Critical Rehab Studies

- What is CRS?

- Like disability studies, CRS is a transdisciplinary field that resists definition.
- We are deliberately NOT sketching out a set of principles, aims, or methods for CRS. We maintain that it must remain an open-ended enterprise - to allow for innovation and inclusion of diverse perspectives.
- We can say this: Like all critical work, CRS investigates the taken for granted, attends to power, and critiques the dominance of positivism and other Eurocentric modes of knowledge production. (neoliberalism + biomedicine)
- This will always include an imperative to end Ableism +an imperative for disabled people to lead +/or partner in reforming rehab

Slide: CRS Practice, Education, Research

Let me finish with some broad applications that CRS can and is addressing in Practice, Education & Research

- Training in disability studies + epistemic reflexivity – rehab students and practitioners
- Questioning medical(ized) outcomes + measures (in policy, practice and in research)
- Addressing ingrained structures + systems (ie not just micro level)
- Retheorizing disabled childhoods + development
- Research oriented to ending ableism (explicit focus)

Slide: Session Talks

The next talk in our session is from Donya Mosleh who will be discussing posthumanism in her CRS research

- De-territorializing rehabilitation - D Mosleh
- Disabled by 'normal development'? -Y Hamdani
- Reorienting constructions of concussion 'recovery'- K Mah & G Teachman

- Re-orienting childhood disability - G Teachman & K Fritsch

Talk 2: De-territorializing rehabilitation: Experimenting with posthuman disability studies- Donya Mosleh

Slide 1: Introduction

My name is Donya, and I am a PhD candidate at University of Toronto.

- Today, I would like to explore the idea of an experimental, life-affirming posthuman critical rehabilitation studies.

- I will draw on a Posthuman Disability Studies epistemology to discuss how rehabilitation logics and practices enact particular types of subjects and objects.

- I will do this by presenting an example from my doctoral study, of boy I call Nazeem. I consider how

Nazeem, and his family, can be re-imagined as emergent and temporary assemblages; as made and unmade within the context of a neuromuscular rehab clinic.

- I argue this context-specific connectivity enables a consideration of people beyond prescriptive categories of difference, such as normal/abnormal, or disabled/non-disabled, and creates lines of flight for thinking and doing otherwise in critical rehab studies (CRS).

- Like my colleagues, my aim is not to advance a distinct or singular trajectory for the field of CRS, but rather, to highlight how posthuman disability studies creates space for experimentation and therefore, affirmation of multiple ways of living, doing and being in the world.

Slide 2: Posthuman Disability Studies (PDS)

Posthumanism is a diverse theoretical orientation that de-centers the human, and by extension, the supremacy of Western knowledge and truth. Primarily influenced by the works of Deleuze and Guattari, posthumanism posits that the world (which includes people), is always already radically connected and constantly in flux.

- Posthuman disability studies is an intersectional field of ideas, theories and debates that advances a more affirmative and nomadic reading of human subjects by considering how people with ascribed differences are produced, or made and unmade across time and space.

Posthuman disability studies (posthumanism for brevity) reconfigures subjects as assemblages; that is, as active and contingent, and always in the process of

changing, depending on the entanglements of forces through which they are produced.

- D&G use the term assemblage to refer to the always shifting connectivities between entwined human and nonhuman, animate and inanimate and abstract forces (e.g, discourses, objects, technologies, social emotions, places, social meanings, etc.)

- Assemblages are temporary and dynamic, and come together in specific arrangements to produce objects and subjects that have the illusory appearance of permanence/stability

Slide 3: Subject positions

Critical disability studies scholars, such as Goodley, Shildrick, Kafer and others, highlight how this shifting subject challenges essentialist and oppressive identity categories by affirming that all bodies differ by virtue of being in a continual process of change.

- Subjects are not encased by skin and organs nor are they defined by static binary categorizations, such as dependent/independent, abled/disabled, male/female, or even person/thing, or myself/other.

- Posthumanism views these categories as subject positions'—they are outcomes of generative processes. They don't describe people as they are; they MAKE people in certain ways.

To demonstrate the productive potential of posthumanism for thinking and doing otherwise in CRS, I will now present an example from my doctoral study.

Slide 4: Study and observation context

My research used a posthuman virtual ethnography to investigate the production and resistance of subject positions in relation to children diagnosed with Duchenne muscular dystrophy (DMD).

The following example includes a boy I call Nazeem, and his encounters with an outpatient rehab clinic.

- Nazeem was diagnosed with DMD.

- DMD is medically defined as a life-limiting condition, characterized by progressive muscle weakness, which leads to a loss of function and eventual respiratory failure. Life expectancy ranges from 25-40 years, but varies greatly. Every 4-6 months, Nazeem and his mother, Zina, attended an outpatient clinic at a children's rehab hospital. These appointments were ~ 3-6 hours, during which a team of health care professionals took turns performing various assessments, and provided medical care oriented to preserving function and managing medical symptoms.

Slide 5: Nazeem

Nazeem was a 12-year-old boy who enjoyed art, reading, and building lego, but most of all, he LOVED

school—he loved learning, socializing and playing. At school, he worked closely with an Educational assistant, whose primary responsibility was to help him with daily routines, including toileting.

In the summer of 2022, Nazeem lost the ability to walk. Because of this, he was no longer able to go to the toilet without help. At school, the new toileting process required, two EA's a lift, a barbercape, and a small travel-sized urinal bag. This intricate process took roughly 25-30 minutes, and on any given school day, happened between 3-4 times (=~1.5-2 hours out of his 6 hr school day). In order to reduce the frequency of bathroom breaks and minimize interruption to his school day, Zina, Nazeem's Mum decided to limit how much water he drank at school.

Zina discussed this decision with the neuromuscular team at a clinical appointment I observed. The following is an exchange between Zina and Harper, a nurse. Harper is concerned about the side effects of

dehydration which can lead to kidney issues for people dx'd with DMD.

Slide 6: Data

I recorded the following in my observation notes:

Harper started talking about the frequency of "brown pee" Nazeem was experiencing. She noted that this was "myoglobinuria" [a condition that can lead to acute kidney injury] and tried to convince the family it was serious. Zina pleaded "but it goes away after drinking water". Harper replied "it doesn't matter. It's better and safer to get it checked out by a professional. It's also helpful for us to have these things documented". Harper asked Zina how often this had happened in the past month. Zina replied, "between 2-3 times".

Slide 7: Data part 2

Harper asked if Nazeem ever felt hot or sweaty. When Zina replied yes, Harper swiftly replied "well, if he's

hot, and he’s not getting enough water, that’s going to lead to rhabdomyolysis [a condition that can cause kidney failure]. If this is the case, he needs to be taken to the hospital, immediately. Next time, please don’t wait. It’s not worth the risk”.

Slide 8: My Posthuman reading

My posthuman accounting of the event, considers the enactment of the subject position, ‘child with dmd’ in the clinic space and the implications for critical rehab studies.

- The diagnosis of DMD acts as a catalyst, and enables different ways of knowing and doing, of Nazeem and his family. The space, politics and practices of the clinic are embedded within the institution of medicine, which regulates and affects what kinds of approaches and understandings are deployed. Among these forces, Harper draws on her professional expertise, medical discourses, and logics

to relay [so-called] objective information, in attempt to "educate" Zina of the ways her decisions affect Nazeem's body.

- In this Harper is enacted as the 'responsible clinician' who performs in accordance with the entangled webs of knowledge, practices, values and conventions that permeate clinic spaces and extend into the worlds of families and diagnosed children.

- The underlying assumption, that the family lack the [supposed] necessary information to make "safer" choices, positions Zina as the "irresponsible / uneducated parent".

Slide 9: Nazeem-as-symptom

- As productive forces, habitual practices, clinical discourses and ableist ideas intra-act with the materiality of the body to produce notions of decline, loss, and tragedy. Brown pee is regarded as a symptom, output, or extension of Nazeem. Disability is

produced a problem that inheres in a body, exacerbated by [what are construed as] poor individual choices.

- Nazeem-as-symptom becomes the object of care, or a problem to be addressed. Nazeem is produced as a collection of symptoms that poses a problem in the pursuit for certain capacities and not others, including the clinical imperative to extend lifespan.

Slide 10: Physical health prioritized

These entities and forces thus temporarily interact to produce care that reinforces or as Deleuze would say "territorializes" certain ideas and not others.

- The clinical and ableist imperatives to preserve function and extend life automatically overrules any consideration of enjoyment of life, of having more time to participate at school.

- The dx of DMD, clinical imperatives, brown pee, safety discourses, the hierarchization of professional

over experiential knowledge, (etc) all conspire to produce these subject positions and the imperative for Zina to make the supposed 'right' choice, where only one option is presented/allowed.

But, there are other ways of understanding people and impairments.

Slide 11: An affirmative reading

A posthuman disability studies approach involves 'a re-thinking of the problem itself'.

Perhaps, a more affirmative approach might begin with an appreciation for other ways of doing and being in the world, like for example, the here-and-now experiences of playing and learning and the practical concerns of timing.

Slide 12: doing rehabilitation otherwise

Could clinical and rehab imperatives be re- oriented? What becomes possible when both bodily concerns and

opportunities to live well in the present, are considered alongside, simultaneously? How could people, get produced in more affirmative ways? What other possible subject positions, or different Nazeems, Zinas, & Harpers, could be produced?

Slide 13: Other possibilities

To be clear, I am not naively suggesting that rehab ignore risk of kidney failure, nor am I implying that the idea of living a shorter life is in itself desirable.

- On the contrary, my aim is to expose the opportunities and potentials enabled, when both realities are kept equally open for consideration.

Just as examples,

- Is there a way to increase water consumption while also going to the washroom less?

- Can the toileting process, as Mol would say be "tinkered" with, so that it doesn't take as long?

- Or perhaps, this is an opportunity to pursue more profound systemic changes, like re-organizing class schedules, or making public bathrooms more accessible…

Slide 14: Concluding

The example I presented today highlights how subject positions emerge in the extension of clinical imperatives and logics into daily life.

- In employing posthumanism, CRS can "deterritorialize care", by adopting a more affirmative reading of people as multiplicities; as potentials to form and reform, rather than as patients, or collections of symptoms and problems to be addressed.

- Deleuze and Guattari use the term deterritorialization to refer to an affirmative and experimental unfolding along "uncharted territory". Deterritorialized care is morality that does not precede action- it is a doing and failing, a "tinkering" with the

ideas of what it means to live well, beyond pre-determined logics and ideals, and creates different kinds of subjects and objects.

Slide 15: Implications

Like others in this session, I believe radical change can only happen if we shift the way we think and talk about people, disability and what it means to live well. As a modality of CRS, posthuman critical rehab studies, offers an opportunity to engage in this endeavour, and to re-imagine more affirmative possibilities for living, doing and being in the world.

Our next speaker is Yani Hamdani: going to talk about developmentalism, its role in rehab, and its effects on disabled people.

Talk 3: Disabled by ‘normal development’? Challenging ablism and developmentalism in rehabilitation for young people with ‘developmental disabilities’ – Yani Hamdani

Slide 1: Disabled by ‘normal development’? Challenging ableism and developmentalism in rehabilitation for young people with ‘developmental disabilities’

- I am Yani Hamdani, an Assistant professor in the Department of Occupational Science and Occupational Therapy at the University of Toronto and a researcher at the Centre for Addiction and Mental Health in Toronto, Canada.
- I’m part of a research unit focused on health services, experiences, and policies relevant to adults labeled with developmental disabilities.

- Regarding my positionality, I am a nondisabled, mixed race, cis-women, Canadian by citizenship.
- I practiced as an occupational therapist in children's rehabilitation for 16 years before completing graduate training in social sciences and public health.
- I bring critical rehabilitation studies (or CRS) perspectives into my work as a qualitative researcher.

Slide 2: Critical Rehabilitation Studies (CRS)

- In this talk, I discuss how notions of normal development function to label and disable young people whose developmental and social trajectories differ from the norm by drawing on examples from two qualitative studies that draw on critical rehabilitation studies (or CRS) perspectives.
- I examine the ways in which ableism and developmentalism underpin the aims of rehabilitation and explore their disabling and intersecting effects

for young people labeled with so-called 'developmental disabilities', such as intellectual disability, Down syndrome and autism.

- First, I discuss the notion of developmentalism that oriented the analyses for these studies and served as a lens for examining the 'hidden' social consequences of policies and practices for the health and daily lives of young disabled people and their families.

Slide 3: Developmentalism

- Developmentalism can be described as the particular logic wherein children are presumed to follow a relatively predictable trajectory of progressively achieved physical, intellectual, emotional and social milestones from childhood to adulthood.

- The goals and expected outcomes of so-called '<u>normal</u>' development are defined by pre-conceived norms and competencies for adult life. Examples

include independent living, employment, and financial self-reliance.

Slide 4: Developmental checklists

- There are a variety of checklists available (such as the one on this slide) that focus on promoting and supporting ‘normal development’, which attests to its significance in guiding not only rehabilitation practices, but also health and social care, education and parenting practices more broadly.
- Children are expected to progress along a ‘normal’ social and developmental trajectory, to the extent possible, on the journey to adulthood.
- That is, an adulthood of a particular kind that is generally accepted as the right and natural goal of child development - one in which independence, productivity (mainly in the form of paid work) and contribution to society are valorized.

Slide 5: ‘Adults-in-the-making’

- Critical scholars argue that young people who do not or cannot ‘successfully’ achieve particular ‘adult’ skills related to independence and productivity, remain as ‘adults-in-the-making’, experiencing exclusion from full citizenship and social participation in adult life.

Slide 6: Study 1: Transition to adulthood

- I now provide examples from two qualitative studies that examined assumptions about disability and normal development to illustrate the ways in which CRS research can advance thinking in rehabilitation for young disabled people.
- The first study arose from my experiences as an occupational therapist (or OT for short) of developing and implementing transition to adulthood programs for young disabled people in a children’s rehabilitation hospital.

- This study interrogated practices, policies and family experiences oriented to improving transitions from child to adult services, and to adult life.
- It involved analyzing three policy documents on transitions in Ontario, Canada and 13 interviews with parents of young people labeled with developmental disabilities.
- We were guided by a Foucauldian-inspired critical policy analysis approach called What's the Problem Represented to Be? proposed by Carol Bacchi of the University of Adelaide.

Slide 7: (quote on slide)

- In the policy documents, on the surface, the problem was construed as a service transfer issue – an issue of transferring from child to adult services.
- A discursive analysis of these texts revealed implicit assumptions about proper and socially expected

ways of being, becoming and conducting oneself as an adult citizen.

- For example, a document from the Ministry of Education stated:

  "Almost all students will need or wish to engage in productive employment, supportive employment, or meaningful volunteer work" (MEDU, 2002).

Slide 8: (quote on slide)

- Suggested transition goals included:

  "Independent living in the community" and "daily living skills for independence" (MEDU, 2002).

- These statements, reflected in all of the documents, suggested the relative importance and value placed on particular traits and activities in adulthood; that is, productivity (mainly in the form of work) and independence, of which all students were expected to achieve or at least approximate.

- An emphasis on achieving independence to the extent possible reflected its high social value as an adult trait, implying that dependence is acceptable in childhood but less desirable and to be avoided in adulthood.
- Thus, the service transfer 'problem' rested on an implicitly understood problem in which the social and developmental trajectories of young disabled people were judged inadequate or at risk of failure because they deviated from pre-conceived norms.

Slide 9: (quote on slide)

- Parents in the study also reproduced ideas about the idealized outcomes for adult life following high school. For example, a mother I called Evelyn, said:

> "It's always the same route. You graduate from high school and you continue on with education in school to have some training in order to position yourself in society".

- Evelyn’s comment revealed an inherent assumption that the ‘same route’ or trajectory from school to further education and eventual employment was expected.
- Her comments suggested that it was important to pursue this path to establish oneself financially and socially in adult life.
- Yet, she did not question or consider if another route might be more realistic, feasible or better for her daughter (who was 27 years old and labeled with an intellectual disability).
- Rather, her account reflected that she had internalized social values and beliefs about a productive, independent adulthood, which shaped her transition planning goals toward these ends for her daughter.

Slide 10: 'Normal' ways of being and conducting oneself as an adult shaped implicit understandings of the 'disabled child' as 'in need of' intervention

- Sensitized by lenses of ablism and developmentalism, this analysis revealed that taken for granted assumptions about 'normal' ways of being, becoming and conducting oneself as an adult shaped implicit understandings of the 'disabled child' as problematic and conceptually as an object of interest for intervention compared to the 'nondisabled child' because of their risk of not achieving an independent, productive adulthood.

Slide 11: Study 2: Critical reflexive dialogues

- The second study arose from my roles as an OT educator and researcher at the Azrieli Adult Neurodevelopmental Centre, which is linked to a clinical mental health service for adults labeled

with developmental disabilities aged 16 years and older.

- This study examined assumptions about disability and development underlying occupational therapy and their effects on assessment and intervention practices, and thus for disabled adults.
- A group of eight OT students, clinicians, postdoctoral fellows and researchers participated in a series of four dialogue sessions to critically reflect on and discuss their clinical practices and training.

Slide 12: Navigating biomedical assumptions

- The OT participants in this study talked about navigating normalizing assumptions about developmental disability in their training and work with disabled adults.

- These prevailing assumptions embedded in healthcare systems and practices positioned developmental disability as inherently caused by neurodevelopmental deficits and biological impairments, which reflected prevailing biomedical framings of disability and normal development.
- This framing placed emphasis on ‘fixing’ impairments and minimizing or addressing deviations from ‘normal’ developmental milestones as a path to ‘normal’ functioning in ‘normal’ everyday life activities (commonly categorized as self-care, productive and leisure activities in occupational therapy).

Slide 13: (quote on slide)

- Participants discussed how these assumptions reflected broader social values and beliefs about disability and development.
- For example, one participant stated:

"It's these broader social values embedded in [our work]… Always comparing to normal: how is that helpful and not so helpful? If we're interested in meaningful occupations and client centeredness, are we really doing that to the extent we can? Are we just sort of bringing in these social values and ideas into our practice?"

- This example highlighted the participants' reflections on how the aims and focus of OT interventions are shaped by prevailing societal values and expectations.

Slide 14: (quote on slide)

- The group discussed the benefits of pursuing goals, such as employment, associated with a typical adulthood.

- For example, a participant said:

"we don't want to deny that there's some people that this really helps support... maybe it is about

getting supported or even competitive employment and they feel happy to be part of the world and society in that way".

Slide 15: (quote on slide)

- They also discussed unintended harmful consequences for those who could not achieve a typical adulthood.
- One participant stated:

  "I wonder how those labels can affect their development and trajectory, the ways these people feel about themselves, the ways others see them... how that might lead to a mental health concern".

- This led to discussions about emotional and social consequences, such as depression, anxiety and stigma, of labeling and of pursuing normal functioning as a goal for adults labeled with developmental disabilities who have been compared to developmental norms throughout their lives.

- It also led to discussions about ways to navigate both the benefits and harms of OT practices guided predominantly by biomedical thinking.

Slide 16: CRS Perspective

- Consistent with other CRS and critical disability studies research, these two studies suggest that:

  When embedded in rehabilitation practices, assumptions about normal development and disability may reproduce and perpetuate ableism through developmentalism, and have hidden consequences, such as stigma, oppression and marginalization, for disabled adults.

Slide 17: CRS: Rethinking rehabilitation

- CRS research has implications for rethinking the traditional indicators of adulthood in Western societies as guiding principles for rehabilitation and considering other possibilities for supporting young people labeled ‘disabled by their development’.

Slide 18: Implications

- First, these critical rehabilitation studies illuminated the need for rethinking the emphasis on 'normal' – normal bodies, normal functioning, normal development - towards ending ableism by embracing diverse ways of being, becoming and doing for young disabled people.
- Rehabilitation may unintentionally de-emphasize other possible, atypical ways of living a good life as an adult that may be healthier, more feasible, desirable or suited to the life circumstances of young disabled people and their families.
- More emphasis can be placed on engaging in social and recreation activities as valuable goals in their own right, rather than pursuing independence and employment as the main or only goals.
- Second, rehabilitation can direct attention to fostering positive disability identities and drawing on

strength-based rather than deficit-focused approaches.

- Shifts in thinking about ‘normality’ as the guidepost for disability, development and transition to adulthood programs are beginning to emerge.
- Such approaches would support young disabled people to create and lead lives that are relevant to their own desires, goals and life circumstances.
- To clarify, I am not suggesting that conventional rehabilitation approaches focused on addressing impairments and developmental differences are unimportant or unnecessary, or that pursuing traditional adult indicators be abandoned or avoided.
- Rather, I suggest that a variety of traditional and alternative options for living a good life can be discussed, supported and given equal attention and consideration in rehabilitation encounters, including sensitive discussions with young disabled people and

their families about the potential benefits and harms of any option.

- Young disabled people and their families should be exposed to a number of ways for living a good life into adulthood and be given opportunities to evaluate the goals and options that make sense for their lives.

Slide 19: Adulthood – It's not for everyone

- I conclude with this idea:

  "Adulthood – It's not for Everyone!"

- Perhaps adulthood of a particular kind may not be available, accessible or desired by everyone.

- The notion of an idealized adulthood characterized by independence and productivity may inadvertently function to marginalize and exclude some people and produce unintended harms on their health and well-being.

Slide 20: Takk

- Takk! I also thank the participants in these studies.
- I now introduce Dr. Katie Mah, who will talk about disability studies perspectives on concussion ‘recovery’.

Talk 4: Re-orienting constructions of concussion recovery through a critical disability studies lens – Katie Mah

Slide: Session Title:

· (no spoken words)

Slide: Concussion Statistics:

· An estimated 125,000 children in Canada and 750,000 in the US will sustain a concussion each year

· Up to half will experience a prolonged recovery.

· These statistics might prompt biomedical scientists to question how the injured brain might be restored to its preinjury status. Or rehabilitation scientists to question how they might better design interventions to facilitate recovery

- From a CRS perspective, however, these statements about concussion are not taken as fact. They become our objects of inquiry, prompting us to look beyond the surface meaning and to ask different questions
- Good afternoon, my name is Katie Mah. I’m a Postdoctoral Fellow at Western University in Canada, working in the Childhood Rehabilitation Ethics and Disability Lab with Gail Teachman
- My positionality: Non-disabled, multi-racial cis-woman. Worked clinically as a nurse, then an occupational therapist, completed PhD in the rehabilitation sciences
- Acknowledge that our substantive area of concussion might seem out of place at a DS conference. I would tend to agree- when and if concussion is contemplated through biomedicine.

- In biomedicine, concussion is understood in terms of biomechanics, pathophysiology, and clinical signs and symptoms

  Slide: Earlier research:

    - Concussion is, as much or more, a social phenomenon as it is biological, that young people come to know concussion through how they experience it in the social world,
    - These experiences have disabling effects

Slide: Concussion Statistics Revisited:

- when I see statistics and statements about concussion recovery, I am drawn to reframe them, to ask other questions of them, including:
- what does it mean to 'recover' from concussion?

What assumptions underlie current medical conceptualizations of concussion recovery? And what

do these assumptions do for and to the recipients of care?

Slide: Concussion Statistics Amended:

- Our team is currently conducting a project exploring these questions through a Foucauldian discourse analysis of the concussion literature
- We have found that when recovery is constructed in reductive biomedical terms, as a return to normal bodies, and normal function, young people who don't recover as expected are constituted as abnormal, as failed subjects
- In this talk I will share our preliminary analyses. I will demonstrate how the literature constructs what we have termed a 'typical recovery discourse'. And I will discuss how this discourse organizes practices, contributes to anxieties of young people and their parents, and ultimately equates disability with failure

Slide: Doing Recovery:

- straying from positivist conventions that convince us that the production of knowledge is always linear
- This is a small act of resistance to the constructed linearity of concussion recovery which is imposed on young people from the moment they are diagnosed
- We suggest that this imposed linearity contributes to the high levels of anxiety experienced by many young people
- My earlier research suggests that young people are (in the words of a participant) ”freaked out” by concussion
- Not by its pathophysiology and clinical signs and symptoms. But by the many responsibilities that are thrust upon them by a host of therapists, doctors, teachers, coaches and family members once they are injured

- One participant described this process as “doing recovery”
- “Doing recovery” is an intricate practice that involves the young person diligently monitoring their bodies for the signs and symptoms of concussion, modifying their energy expenditure, sleep, and what they eat to find that so-called ‘just right’ balance between rest and activity that keeps the symptoms at bay
- And, importantly, is oriented toward future progress and expected adult futures
- This earlier research made me aware of the urgent need to explore recovery *conceptually.* And to investigate what other effects the intense ‘doings’ of recovery have on young people

Slide: Recovery: a reductive ableist concept:

- Ableist notions of normality are deeply ingrained within rehabilitation

- Emerging analysis suggests that recovery is a reductive ableist concept
- I will now present some examples from the literature and our analyses:
- This quote is from a clinical guideline for the management of concussion, it reads: “Clinical recovery is defined functionally as a return to normal activities, including school, work and sport, after injury. Operationally, it encompasses a resolution of post-concussion-related symptoms and a return to clinically normal balance and cognitive functioning.”
- In this quote, recovery is constructed as a “getting back”, to normal bodies, free from symptoms, and able to balance, to normal cognitive function and normal activities
- And importantly, although not stated, normal is equated with good, with the right way to be.

Slide: Producing normal/abnormal

- Campbell and colleagues reproduce this normativity when they write: “An estimated 33% of children who seek medical care for a concussion will have persistent symptoms (occurring beyond 28 days postinjury) including headaches, dizziness, foggy thinking, sleep problems, and emotional distress, which can cause significant disruptions to their daily lives. Previous studies have found that children with prior concussions are at risk for recurrent concussion which, in rare instances, can result in acute life-threatening injuries with potentially lifelong consequences. For the majority of children however, recovery occurs within 1-4 weeks postinjury”
- Variations of this statement are found at the beginning of nearly all studies in the concussion literature

- In this statement – and others like it - the typical recovery timeline is constructed as linear and time-limited, beginning when the young person encounters the medical system at day 1 and ending by 28 days postinjury
- Typical recovery is also produced as the norm, the way recovery is expected to progress ---"for the majority"
- Typical recovery is **normal** recovery, it is straightforward, and unproblematic.
- In contrast, prolonged recovery is accompanied by distressing symptoms, life-threatening injuries, and lifelong consequences. It is abnormal. It incites a moral panic

Slide: A typical recovery timeline:

- Our analyses suggest that the concussion literature constructs a 'typical recovery discourse'. I've taken the creative liberty to visually represent this typical

recovery discourse here as a horizontal line extending across the slide

- The timeline is marked in 3 spots, with a vertical line at the far left, labelled day 1. A second vertical line cutting down the center of the timeline, labelled week 4. And an arrowhead at the far right that is unlabeled and represents a timeline with no definitive end
- Along this linear recovery timeline **typical** recovery begins at diagnosis or day 1 and ends at precisely 4 weeks post-injury
- Prolonged recovery picks up where typical recovery left off, at the 4-week mark and extends indefinitely
- This construction of recovery as typical or prolonged, is so pervasive in the field of youth concussion that it is taken-for-granted as “just the way” concussion and recovery proceed

- However, this timeline is not value-free. It is not an objective descriptive of a so-called natural process
- It imposes notions of what counts as typical, and what counts as prolonged

Slide: A typical recovery timeline shapes practice:

- In the field of youth concussion, the typical recovery timeline is reified. It functions as truth, organizing the ways that clinicians think and talk about how recovery **should** progress
- To recover "on time" and as expected is to recover the status of 'normal'
- To take longer than is expected, to cross the 4-week threshold from typical recovery to prolonged recovery is to become 'abnormal'
- Just as the categories of typical and prolonged are not neutral, neither are the categories of normal and

abnormal. They are ethically loaded categories, where normal equals good and abnormal equals bad

- And they form the basis of clinical decision-making
- Young people who recover “well” and return to their preinjury developmental trajectories are no longer under the purview of rehabilitation
- Young people who do not, become the objects of rehabilitation

Slide: Intervening on abnormal: Doing recovery:

- They are introduced to the doings of recovery. The intricate practices of monitoring their bodies, modifying their activities, balancing their energy demands, engaging in complex calculations of energy in versus energy out
- Through these doings of recovery, the body is made into an object of surveillance

- The clinician surveils the young person's body through initial assessments, and ongoing evaluation. When abnormalities are located that cannot be addressed by the clinician, the young person is referred on to others who specialize in surveilling more discrete parts of the abnormal body, and so the number of surveyors increases
- Importantly, this surveillance of the body is not the job of clinicians alone
- The responsibility to monitor the body is downloaded onto parents and young people themselves
- As active members of the care team, parents and their children are taught to monitor the body through administering symptom checklists at regular intervals, they familiarize themselves with "red flag" symptoms that require urgent care. They enter a cycle of monitoring and adjusting, surveilling and responding

- And through this process of doing recovery and doing it well, clinicians, young people, and their parents are made subjects of a preferred way of being
- 'Good' patients comply with the expert guidelines that teach them this monitoring and modifying.
- 'Good' parents monitor their children's bodies, and their own responses to their children's bodies. They ensure that they, and their children, remain active partners in care, who adhere to this strict regimen of doing recovery
- 'Good' clinicians oversee this strict regimen and in doing so, 'good' clinicians produce recovered patients and normal children

Slide: Locating ableism in youth concussion:

- When Barb introduced this session, she shared that the imperative of CRS is to end ableism

- In this talk, I've shared our preliminary analysis as an example of CRS's commitment to examining rehabilitation's ableist ideologies and practices, and the effect of these practices on young people, their parents, and clinicians
- In this example, the recipients of care aren't necessarily labelled as disabled
- But ableism operates nonetheless to produce typical recovery and normal bodies, prolonged recovery and abnormal bodies
- As currently oriented, concussion recovery is a reductive ableist concept. But could it be otherwise?

Slide: Re-orienting concussion recovery?

- Our task moving forward in this work is to contemplate this question, and to consider what we might learn from other fields

- Including mental health, where recovery is not a static end point or result, or the remission of symptoms and a return to a previous ‘normal’ state free from mental illness. Instead, decades of advocacy and scholarship have resulted in a conceptual evolution with recovery in relation to mental health being re-conceptualized in varied ways, including as an ongoing and individual journey during which one can be ‘in recovery’ while continuing to live with a mental health diagnosis.
- We suggest that re-orienting concussion recovery toward ‘living well’ might better reflect young people’s lived experiences. We are eager to explore the potential of re-orienting recovery in this way, or perhaps abandoning the concept of recovery altogether in favour a different concept. But we know that we cannot undertake this work alone. As CRS scholars we know that such a reimagining must

integrate diverse perspectives, including those of young people themselves. Thank you.

- Our next speakers are Gail Teachman and Kelly Fritsch who will be discussing their study, re-orienting childhood disability.

Talk 5 (Final): Re-orienting childhood disability: Critical discourse analysis in the fields of disability studies and children's rehabilitation.

Slide. Title Slide

- Good afternoon. My colleague Kelly Fritsch and I will be sharing early results from an ongoing study titled: Re-orienting childhood disability: Critical discourse analysis in the fields of disability studies and children's rehabilitation.
- I am Gail Teachman, a non-disabled white cis woman. I practised as an occupational therapist in

children’s rehabilitation for many years before transitioning to an academic role. My teaching and research activities bring a critical rehabilitation studies lens to issues concerning childhood, ethics, disability and rehabilitation.

- Three further panel members – Barbara, Yani and Katie are members of our study team which includes academics from disability studies and critical rehabilitation studies across multiple institutions, alongside trainees. Several team members identify as disabled. We are supported by an Advisory Panel of 5 individuals contributing perspectives from disabled persons, parents of disabled children, clinicians, and disability advocates.

Slide. Study Background and Aim

- Our study is concerned with the ways that dominant societal discourses situate childhood

disability as a problem of individual children and their families, and as a tragic burden to society. Such ubiquitous assumptions shape practices related to disabled young people in profoundly detrimental ways.

- Rehabilitation remains one of the most enduring societal responses to childhood disability and has conventionally placed emphasis on fixing or 'overcoming' individualized 'deficits'. However, this focus fails to acknowledge the societal norms and conditions that continue to constrain disabled children.
- We also note that relatively little research in disability studies has focused specifically on children. Insufficient attention has been paid to how some discourses underpinning disability studies can further marginalize some disabled children.

- We aim to unpack dominant discourses and bridge valuable knowledge across these siloed disciplines given that each has significant implications for the flourishing of disabled children and our understandings of disabled childhoods.

Slide. Study Methodology

- Following initial discussions with the advisory panel, we sampled and analyzed published texts from both fields, including journal papers, course syllabi, and websites as well as texts generated through interviews.
- Oriented by a Foucauldian approach to critical discourse analysis, we interrogated representations of childhood disability in and across the texts in our overall sample.

Slide. Sample Analytic Questions

- For example, questions we asked of the texts included:
    - What assumptions underpin these representations?
    - Whose perspectives are authorized or represented as legitimate, and whose are discounted, or silenced?
    - What does the text do? What are it's effects? Does it reproduce or reformulate dominant conceptions of childhood disability? and
    - What tensions or contradictions are present in the text?
- Next, Kelly will speak to some of the tensions identified across our analyses to this point in the study.

Slide. Constraints in children's rehabilitation

- Thanks Gail. I’m Kelly Fritsch, a disabled cis white woman and assistant professor in Sociology at Carleton University in Ottawa, where my research and teaching is focused within critical disability studies.
- The results that we are sharing with you today focus on the social mechanisms, underlying logics, and organizing principles that structure the fields of disability studies and children’s rehabilitation. Mindful of our limited time today, we will shed light on just a few tensions between these fields that are illuminated through our analysis.
- One tension relates to the constraints of dominant discourses and subject positions within each field. In children’s rehabilitation, clinicians bump up against a limit to how critical they can be of professional practice and values. Dominant discourses in the field make alternative practices unthinkable and unimaginable.

- As one rehab participant commented: "…there's an unspoken agreement - you identify the issue, and you resolve or fix the issue… I felt there was room to expand my role while staying in my college guideline scope of practice to be something that more closely aligned with what I think children and families were wanting. Which wasn't necessarily a fix for their child, but it was development for their child…".
- This quote illustrates how hard it is to think outside of the confines of the discourses of normal development and family-centred care, logics that reinforce 'normalcy' even as they resist 'fixing' impairments.

Slide. Constraints in disability studies

- In disability studies, one subject position constraint is most apparent in the way the field has predominantly focused on disabled adults rather

than children, articulated this way by a disability studies participant:

- "…all of the courses I myself taught or knew of, were focused on adult worlds… I felt like there was a big lack within disability studies talking about disabled childhoods. Because in part, that requires either people to kind of reflect on their own experiences as disabled children or to speak on behalf of. Which is not something…done easily in disability studies, right, because it requires a certain kind of engagement with power."
- Expanding, this participant noted: "Disability studies is so often defined as, you know, like nothing about us without us, right? And so disabled childhood asks us to think not just about our own personal experiences of the past, but also the experiences of others - other children - who might not be able to be telling the stories that we're telling in adult worlds, right, in academic spaces."

- Here we see a few ways constraints of discourse are raised in disability studies, largely revolving around scholarship coming from adult perspectives, and often intersecting with notions of activism, agency, and communicative fluency. What can be said or written is constrained by the power differentials associated with not only speaking on behalf of but also related to the different kind of stories disabled children might tell, and the different ways they might communicate such stories.

Slide. Tensions: Translation of critical approaches across fields

- Another tension involves the difficulties in translating critical approaches across fields. In children's rehabilitation, our analysis demonstrates shifts away from a totalizing biologically based cure or fix paradigm towards a more social model

approach of setting meaningful goals under the rubric of the F words. This shift was mentioned earlier in this panel by Barb Gibson. However, this move toward framing disability as a difference that is socially produced remains tethered to assumptions that disability as difference can be alleviated through sufficient supports and technology. It assumes that such an alleviation is to be embraced, is desirable.

- This framing misses the important critical disability studies intervention whereby disability is a form of culture, politics, and a difference that matters and that cannot be erased through technological and environmental supports. As one DS participant commented; "disability studies' aim is to recognize that disability is a site of oppression, and it is also a site of joy and identity… Disability is an experience of feeling that your body, your mind, your emotions, your communication are different

from other peoples, and that that difference leads to exclusion from the mainstream but can also lead to community with other people who share your characteristics."

- What emerges out of community is forms of disability culture and politics, specific ways of doing and being that are different than nondisabled ways and constitute a form of difference that has meaning and value that exceeds accommodation.

Slide. More Tensions

- There is also a tension relating to what kind of child and childhood is being desired by disability studies and children's rehabilitation. The emphasis in children's rehabilitation is on hope for the individual child to change. Here we find that the goals set within children's rehabilitation are frequently premised on the desire to create future productive citizens and so-called 'normal'

childhoods. Such goals are reinforced by the ways that funding in rehabilitation is linked to judgments about a child's potential to progress. One rehab participant stated: "…I don't always know that [outcome measures] are in alignment with the family or the child. And we're kind of forcing them into these little boxes when we do things like…these outcome measures… But insurance wants to see outcomes, and hospitals and facilities want to see outcomes."

- Critiquing these goals, a disability studies participant commented: "I hear over and over and over again, parents saying, "I just have to put those checklists away. I cannot look at those checklists anymore. All they do is tell me that there's something wrong with my child. It is so harmful."

- In disability studies, we find that this tension about what kind of child and childhood is being desired is

articulated in the ways the field primarily theorizes about disabled childhoods rather than childhood disability. Discussions of disabled childhoods tend to focus on power and structural levels of social and political critique, with relatively less emphasis on individual children and living with impairment as a child. Our analysis illustrates that embedded in advocacy for disabled children, notions about children's rights to participate in some form of putatively normal childhood risk reproducing conventional ideas about what it means to flourish as a child.

- In both fields, our analysis raises questions about which children are being talked about, thought about, and desired. We find a need for engaging more deeply with children who may be multiply disabled, experience communication barriers, and who may not steadily progress or improve, or be able to work as an adult. In thinking about which

children are frequently left out of both fields, we see the ways that disability studies can benefit from paying more attention to disabled childhoods and childhood disability, and that children's rehabilitation needs to more deeply grapple with power analyses coming out of disability studies.

Slide. Risky engagement across fields

- The final tension we want to highlight today relates to the constraints and risks that both fields face by deeply engaging one another. One participant

noted: "My feeling…is that both the rehab people and the disability studies people are responding to the cultures that they find themselves in. And that noticing that is part of the solution… just noticing that there are different ways of understanding and experiencing the world would be a start, wouldn't it?"

- Another posed this question: "Can we make parallel lines meet?? … I think they're parallel

mostly because people haven't talked to each other because they've been fighting rather than listening and trying to clarify…”

- We feel acknowledging these tensions opens up tremendous potential for collaborating across disability studies and children’s rehabilitation. As we complete our study analysis and consult with our advisors, we aim re-orient children’s rehabilitation to critical disability studies and disabled children’s childhood studies.

Slide. Conclusion

- I’d like to sum up our panel by revisiting some of the commitments involved in advancing critical rehabilitation studies or CRS. Across our presentations, we have illustrated some of ways that CRS aims to shift practices in ways that involve not only thinking differently but acting differently. We invite feedback and critiques,

acknowledging that we might not be ‘getting it right’.

- In this work, we are mindful of the power differential between children’s rehabilitation and disability studies. Children’s rehabilitation draws authority from the broader sphere of biomedicine, and as we have shown, it’s alignment with dominant social discourses concerning disability. By contrast, disability studies is a small, marginalized, and under resourced field.
- Critical Rehabilitation Studies involves commitments to:
    - Move forward with humility in allyship with disabled persons
    - Engage in life-long reflexivity and ‘thinking otherwise’
    - Foster an ethic of openness

- Call for and enact radical reforms in the field of rehabilitation

Slide. Thank you.