

## 2024 KT Online Conference

### Understanding and Addressing Access Barriers from Youth and Young Adults with Mental Health-Related Disability: A Mixed-Methods Study

*Presenter:*

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Sponsored by AIR's Center on Knowledge Translation  
Disability and Rehabilitation Research (KTDRR)  
<https://ktdrr.org/conference2024/index.html>

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Sandy Rao: Well, hello everyone. My name is Sandy Rao, PhD candidate at the University of Calgary. I use she her pronouns. I'm a brown skinned woman in her early forties with dyed blonde hair and a long sleeve purpleish pink blouse. I also want to take the time to acknowledge my incredible supervisors, Dr. Gina de Metropolis and Scott Patton, for which this research would have not been possible. And finally, I am just one representative of the larger heart study team for whom I've had the privilege on presenting on behalf of next slide please. So this is just a little journey map for our time together. I will try to stick to it, but I have been known to off-Road. That said, I'll start with the research problem and the gap. This study addresses aligning our discussion with the theme of this conference, disability inclusion, and then we'll engage in a deep brief, rather interactive activity. Just something you can reflect on to ground this discussion and center the people with the lived realities. Then I'll cover the research methodology, share some key core findings, and then conclude with some take homes. Next slide please.

I will say I believe this is applicable across geographies, but the focus of my research is the Canadian context. And what we're finding is despite advancements in mental health and addiction services, young adults with mental health related impairments and disabilities, especially mood and anxiety disorders, still encounter significant barriers to care. And traditional frameworks often overlook the unique challenges related to disability, particularly at the intersection of mental health and functional impairments. And so for this work, we've really relied upon the incredible insights of disability studies that highlight the importance of viewing these impairments as distinct dimensions. Next slide, please. And so early investigations suggest in what I've coined an access paradox where young adults with mood and anxiety related disabilities must use the same functions to access healthcare that would actually be impaired by the same illness for which they sought treatment. If that sounds like a mouthful, it's because it is, and it shows the paradox between you're getting care for what you're ill for and you have to do the things you can't do because you're ill. So it is quite confusing. So next slide please.

So I wanted to ground this discussion with a quick activity, and so if you could just take a time to reflect or if you have a pen and paper just to walk through this with me. Next slide, please. Imagine designing a rehab center for a person that just broke their leg. So most likely if you were the designer of this rehab center, you'd prioritize accessible features like ramps, elevators to accommodate that limited mobility because they broke their leg. Next slide please. Now try to imagine building a system for young adults with mood and anxiety disorders. Their impairments and challenges may be less visible but no less impactful. This exercise challenges us to think beyond what's observable and to consider the invisible barriers these young adults may face. It also directly relates to the scheme of disability inclusion by inviting us to consider how these systems can adapt to invisible disabilities and support diverse needs. Back to the exercise in the interest of time, instead of building the whole system, let's just focus on getting to the front door. What might that look like for most people, often people that are designing these systems, it looks a little like this. Next slide, please.

Yeah, it looks like a leisurely jog to the finish line. However, over the past decade as a health system executive, before I went and started my PhD, and as a clinician, we learned through the eyes of young adults with mood and anxiety disorders. It looks a lot more like this. Next slide, please. Pretty treacherous. Healthcare access may seem straightforward, but for young adults with mood and anxiety disorders, it can feel like a full on obstacle course. This perception gap often leads to, while not quite hostile architecture, it does lead to environmental, structural and systemic disabling designs that are not compassionate to the lived realities of young adults with mental illness. Bridging this gap is essential for fostering genuine inclusion and enabling the possibility of healthcare. You can have all the most impactful evidence-based interventions and treatments you want, but if young people can't access them, it doesn't really matter. Next slide, please.

So what I do want to highlight here is so functional limitations impact every aspect of healthcare access for young adults with mood and anxiety disorders. And it's rarely if ever discussed. There is a primacy in healthcare on symptoms and impairments are often maligned. So according to the World Health Organization's disability assessment schedule, so these may include things like challenges with cognition, mobility, self-care and social participation as just some of the examples that come alongside mental illness. The World Health Organization calls it "What you cannot do when you are ill." By exploring quantifying, understanding and highlighting these specific areas, we can advocate for intersectional policies and practices that acknowledge and accommodate the full scope of young adults experiences. To further illustrate the WHO-DAS tool, which is the acronym for what I said earlier, breaks things down into six key sections, which you'll see on the slide. So let's focus on one just to illustrate a little bit more. Next slide please.

So cognitive impairments, like difficulties with concentration, memory, and problem solving are common barriers for young adults with mood and anxieties disorders. Consider how difficult it would be to access healthcare if you struggled to remember an appointment or couldn't fill out the intake forms. These cognitive barriers highlight the need for accessible adaptive healthcare processes that support mental health related disabilities. Next slide please. So remember back to our interactive activity. The person

with the broken leg, they can usually walk, but their injury impairs them from doing some things they used to be able to do before, activities they could do before. Similarly to those young adults with mood and anxiety disorders, filling out forms, organizing appointments, talking to strangers, figuring out how to get to new places are all the things required for a healthcare visit, and especially even more if it's a new healthcare visit. And that can be extremely difficult based on their mental illness.

That said, and I want to be very clear, despite these impairments due to their illness, young adults with mood and anxiety disorders demonstrate incredible feats of tenacity, grit, and fortitude. And it's incredible the amount of strength, but they really shouldn't have to do these types of things in order to get care when they feel ill from the healthcare system. Next slide, please. So we're trying to imagine a healthcare system that focuses on the strengths of these young adults rather than the limitations that come along with illness. Such a model would improve and would move beyond stigmatized and discriminatory perspectives and consider alternate ways to engage persons based on what they can do or young adults based on what they can do. Next slide, please.

And that's ultimately what this research is in service to. It is engaged scholarship, which basically means doing the research in partnership with people with lived experiences, co-researchers. So every step of the way has been done with young adults with mood and anxiety disorders and mental health related disabilities across equity deserving and equity owed groups through what's called the critical methodological pluralism. So we can get both the broad information but also the deep nuanced contextual information that really gets to the core of understanding access issues as related to health system utilization through the direct perspective of young adults with mood and anxiety disorders, building on what's working and refining what's not. Next slide please. Next slide please. So I think what I really want to get across is what I said before and what some of the presentations have alluded to also is that these things are largely invisible and as a result, they're not just easy to observe and then figure out, we have to use different methodologies in order to be able to see the unseen.

And that's what this approach is really about. It's grounded in the philosophy of critical realism. And while technically it may be considered a mixed method study, this framework goes beyond combining quantitative and qualitative methods. Critical methodological pluralism allows us to explore the unseen aspects of healthcare barriers that may not be hidden or immediately evident. And also, instead of relying on just conventional methods like deduction and induction that are common in research, we incorporate things like retrodiction, retrodiction, and abduction. And these approaches are key for uncovering underlying mechanisms that shape access barriers. Next slide, please.

And so in the interest of time, I won't go through this in great detail, but again, as I said, we are using this sort of intensive and extensive design. So we're starting with national quantitative data to take that big broad look. And then we're drilling down into who do we really need to talk to through participant or qualitative interviews to get that more depth, nuance and contextual information to be able to put those two together. Next slide please. The research paradigm we've used draws from a Canadian research team, Rovex conceptual model of access and integrates critical disability perspectives. So this

framework breaks down into dimensions like approachability, affordability, appropriateness, to really understand not only those environmental barriers at that sort of structural access perspective, but also looking at the determinants of health from that lived experience or that service user's perspective. Usually models of access are more on supply and demand.

And you'll see in the slide here it's so much more nuanced than that. And there's literally three decades of research on access, and we're trying to do something a much more innovative to be able to move beyond the barriers that we continue to have today. Next slide please. And so this again, is just a view of what the study looks like because again, it is a new model that we are attempting to do here that's engaged scholarship and brings that sort of criticality with both the quantitative and the qualitative and put it together. Next slide please.

I've included the slide so that folks can see that we both have quantitative questions. So really looking at that biopsychosocial and contextual factors for unmet healthcare needs. Next slide please. And the qualitative sort of questions to get into that much more deeper insights. Next slide please. I also wanted to take a moment to highlight the ethics that were integral in the study such as this and it went far beyond procedural requirements. Very frequently if you're attached to an institution, you go through sort of a research ethics board. But by doing engaged scholarship, we don't consider our folks vulnerable by any stretch of the means. We see them for their full and robust strengths. But we do need to be mindful that we are in structures and systems that can harm and have harmed. And so we wanted to ensure that this research is inclusive, respectful, and safe. And this aligns with a transformative research paradigm that includes an axiological imperative, which is really an ethical commitment to benefit co-researchers, participants, and communities. This isn't research on them, it is research with them and that which they need to benefit directly from. And so knowledge translation from this research is therefore rooted in equity, respect, and inclusivity. Next slide, please.

So we just wanted to share some brief results to date, and I will provide links in the chat for where you can actually see the manuscripts on a lot more of these details that I won't be able to cover in our time. So next slide please. And maybe I'll skip to the next slide, please, in the interest of time. Thank you. So our findings really reveal that young adults with mood and anxiety disorders do in fact experience much more severe functional impairments such as difficulty with daily tasks, memory and concentration, self-care, communication, and weaker community connections compared to their peers without mental health related disabilities. So this data actually finally gives us that support that we need to prove to policy makers to prove to those program designers that we need healthcare systems to adopt inclusive practices that respond to the specific functional and social challenges faced by young people. Next slide please.

And to summarize the key points, individuals with mood disorders and anxiety disorders just experience a range of functional and social impairments to compare to those without. And all the individuals in Canada, because of our healthcare system, are accessing things through the same door, but they have very, very different experiences. And I think that what I'm presenting to most folks on this call, I presume is not going to

be new knowledge, but I think we're now actually starting to get the evidence and the data to prove that something needs to be done about this. Next slide. And in my last second, if I can get to the next slide also to just sort of say the call to action. Next slide, please. Ultimately, why does this matter? Who cares? So what? Mood and anxiety disorders is something that is really, it's already so prevalent, but it's even then it's under reported.

And so in Canada it is the highest rate among young adults who are at the highest risk for suicide. And this is a system where one in three are not getting the care that they need and in some cases are being harmed by the system that's intended to serve. So my hope is that this research, this study contributes to meaningful actionable insights and creating accessible healthcare pathways. And as Robert said before me, when we know better, we can do better. And now we actually know better. Okay. At time, thank you so much. And I'll bring it back to all of the panelists for the Q&A.