

OCCUPATIONAL THERAPY NOW

VALUING LIVED EXPERIENCE

JULY / AUGUST 2023
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Advocating for Neurodivergent- affirming spaces with lived experience

Kayla Warren

Challenging Intersections
of Critical Disability Studies
and Occupational Therapy

Shayla McMillan

The Two-Way Street of Collaboration:
An interview with Annette McKinnon

Caryn Kwai-Pun

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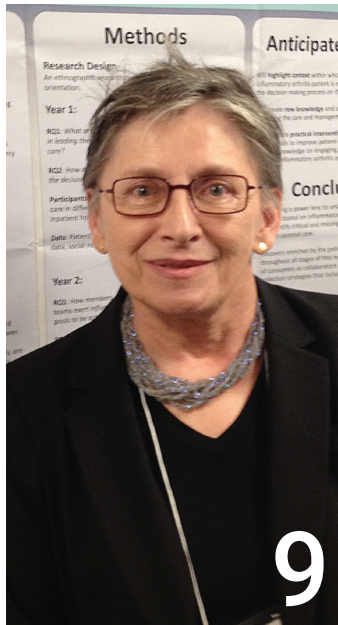
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Cover photo:
Kayla Warren shared this photo taken by Allie MacEachern at a Dalhousie University Occupational Therapy Ball. Her enjoyment of the evening was enhanced by her high-fidelity earphones and offers by peers to accompany her on sensory breaks. An advocate at heart, Kayla encouraged the addition of a quiet area inside the venue for the next special event.

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OCCUPATIONAL THERAPY NOW

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A CONVERSATION BETWEEN DISABLED AND MADDENED OCCUPATIONAL THERAPISTS ON SERVICE USER INVOLVEMENT AND EPISTEMIC INJUSTICE

Susan Mahipaul & Stephanie LeBlanc-Omstead



Susan Mahipaul



Stephanie LeBlanc-Omstead

We are colleagues and collaborators in occupational therapy practice, teaching, and scholarship, in disability, Mad activism, and other supportive communities. We desired to contribute to this special issue (Valuing lived experience) because of our years of conversation around how to bolster the inclusion of critical, experiential perspectives on disability, neurodivergence, and madness/mental distress in the occupational therapy profession. This editorial is a conversation — not to make it informal, but rather invitational and accessible to both you, the reader, and us. Dialogue allows us to discuss our positionalities within this issue and to navigate how our identities intersect with disability theory and occupational therapy with complexity and nuance. It has also served as a *crippled* (McRuer, 2008), mad positive (LeFrançois et al., 2013) writing modality for us. Our process makes space for the realities of disabled occupations, pain, the dwindling of available spoons (Miserandino, 2003), grief, and our many care tasks, in addition to companionship and reflection. Here, we will speak about how we have found epistemic community (a community of knowers) through and with each other, how the topic of this special issue resonated with us and our authors, the importance of visibility for mad, disabled, and neurodivergent occupational therapists and the communities within which we provide care.

SUSAN

I, a visibly disabled woman, and clinician, have practiced, researched, written, and taught in occupational therapy and disability studies for almost 20 years. I say disabled and maddened¹ clinician these days, after years of reflection and discussion. Our education has been similar: my doctorate specialized in Critical Disability Studies (CDS), and yours in Mad Studies. Our individual and collective scholarship has embedded us within rich and vast bodies of scholarship outside of occupational therapy which forefront perspectives on disability, neurodivergence, and madness that I seldom see addressed by occupational therapy literature.

STEPH

Not unlike yourself, I am rooted in mad and neurodivergent communities, and have practiced, researched, written, and educated in occupational therapy and disability studies for nearly a decade. Over the years, you and I have discussed the importance of forefronting our positions as disabled and maddened health professionals as we accept invitations to lecture, supervise, and mentor student occupational therapists. These experiences have made us privy to the tension between educators' approaches, and often very good intentions, and the still uncritical ways we involve service users within the profession. More recently, I've

¹ "A reclaimed, politicized term to describe broader social, cultural, and liberatory approaches to thinking about and responding to medicalized experiences of mental distress and diversity (widely known as 'mental illness' within psy-systems". (LeFrançois, Menzies, & Reaume, 2013, p. 337).

reflected on the similarities between our earliest discussions and the ones we're still having today; they seem linked to matters of visibility, epistemic community, and instances of lateral violence we have experienced or noticed within our mad and disabled communities, occupational therapy, and health professions.

SUSAN

I appreciate how you refer to our collaborations as interactions that create epistemic community. When I first encountered the term, I thought it meant “something to do with knowledge” and it didn't resonate with me. However, thinking of us as *knowers* and our knowledge as valued (valuable) gives me confidence to find a space within occupational therapy. This work relies on tremendous inner reflection. My doctoral work focused on how I could systematically analyze snapshots of my life story/narrative using critical disability theory to compel readers to engage with perceptions of disability and rehabilitation. I started by considering how occupational therapists need to engage different kinds of partnerships with clients and service users, and then realized that it also was about how disabled and maddened occupational therapists engage with their own identities and perceptions of lived experience — what we call *experiential knowledge*. More importantly, it was about how occupational therapy, as a field, fails to engage critically with disability and madness and the profound ripple effects this creates through the entire field, whether you are a clinician, student, or client.

STEPH

I think I experienced those ripples as crashing waves while I was a student occupational therapist and new clinician trying to find a sense of belonging in the profession. I credit the boundary-pushing work of disabled and mad clinician-scholars

like yourself for helping me to see that my fit and flourishing here was possible. After graduating, I went on to conduct doctoral research which examined a practice many refer to as *service user involvement* (SUI), in which an individual (or group) with lived experience of disability, neurodivergence, mental distress, and so on, is invited to share this experiential knowledge with student health professionals. When I began thinking about this special issue, I initially dreamed it might forefront the voices of those actively engaged in CDS, Mad Studies, Critical Autism Studies, and the like, offering us exemplars and tangible strategies for how to engage with service users “well;” that is, with intention, focus on social accountability, prioritization of fair remuneration, with awareness of the ever-present risk of tokenism, etc.

SUSAN

I too had this vision . . . or perhaps expectation? We have spent years talking about how we have had permission and the time to engage with theories and perspectives that we either didn't at first accept or know that we could participate in. As we near the end of putting together this special issue, I recognize the breadth — the heterogeneity — within the critical perspectives that the authors represent. I enjoyed offering feedback on critical language and discussing when to recognize medicalization and psychiatrization in our writing. We have been able to provide mentorship and model how to disrupt, and push back on, traditional perspectives for authors who had never experienced critical disability and Mad Studies-related language, concepts, and mentorship. We have been able to communicate and support the voices of equity-seeking authors accustomed to having their writing and their language changed within occupational therapy school, practice, research, and writing.

STEPH

Yes, and I think that what we have here might be even more meaningful than what we originally set out to curate. Rather than a collection of articles attending to issues identified by CDS theorists, these articles collectively represent the perspectives of (student) occupational therapists and service users actively engaged in practice and advocacy, including in the classroom, and who acknowledge some of these same issues. They speak in their own ways about making space for experiential knowledge and client voice. I am realizing that we have started to widen our epistemic community in the process of putting this special issue together. In addition to the crippled work we spoke of earlier, the *doing* of this special issue has sparked conversations with several contributing authors around centring expertise, CDS, and disabled community. I suspect that some of them have experienced the sort of *hermeneutic triumph* you and I did when we first learned that there were whole words and theories outside of popular medicalized discourse to accurately capture our lived experiences (I'm thinking about concepts such as ableism, sanism, testimonial injustice, neurodivergence, crip time, and spoon theory here). I think our collaboration with these authors represents an expansion of this epistemic community of service-using occupational therapists and allies.

SUSAN

I love the phrase *hermeneutical triumph*. It is hard to explain the sense of belonging that comes with this experience. And this issue includes a precious glimpse into voices within occupational therapy who are wanting to dismantle ableism and sanism around them. In all our work, you and I prioritize the importance to crip our work. Crippin' our teaching, writing, activism, and research means that we focus on our access needs and model for others how to forefront access from

the beginning. We remind each other to pace ourselves and our work, to focus on quality and not quantity, and to challenge our own internalized ableism and sanism. By now, this happens quite naturally between us. If we feel that we cannot keep up or produce in so-called professional ways, then we dare to unsettle those structures and create space to produce in ways that increase access and recognize where ableism/sanism are at work (i.e., for this issue, we extended author deadlines, recognized emotional labour, and used audio notes to draft our conversation for this editorial).

STEPH

One of the things I love most about this special issue is the way it makes visible the presence of disabled, mad, and neurodivergent occupational therapists in our midst. For too long, we have trodden lightly and spoken softly — or not at all — so as not to draw attention to ourselves. But as several authors in this issue have so beautifully illustrated, the liminal positionality that is service user–service provider has so much to offer this profession. As this (epistemic) community continues to grow, it seems that so too does the profession's openness to alternative perspectives: ones which challenge understandings of disability, mental distress and difference, and illness historically held by our profession.

SUSAN

Perhaps this is what brings us back full circle? This special issue allows us to open our conversation — our little epistemic community — to others out there, which our readers will hopefully find meaningful. It also makes visible contributions and collaborations between service users who are not occupational therapists but support health initiatives.

Like you said earlier, without formal CDS educational backgrounds, most of the contributing authors recognized and named a need for: service users and clients' greater involvement in numerous capacities across our profession; the importance of privileging experiential

knowledge in education, research, and practice; and offering tangible examples in the forms of professional partnerships, collaborations, and how this can (and is) being done. All the articles foreground the experiential knowledge our authors bring to this issue and share the advice they have for occupational therapy and others who use health care services.

Woods shares her award-winning watercolours and her painting process following physical changes and increased pain.

Kwai-Pun interviews Annette McKinnon, co-founder of the Patient Advisors' Network, about her advocacy, research, and advice for occupational therapists.

Harold interviews Michael MacDonald about the opportunities he creates for employees with disabilities.

Kitchen shares how her diagnosis of long COVID has changed her experience as a knower and how that now informs her occupational therapy practice.

McMillan makes visible tensions between CDS and occupational therapy theory, calls us in to rich, imaginative, and humanizing ideas of disability, and suggests CDS readings.

Brison-Brown & Amiri highlight the benefits of experiential knowledge within our profession and within our educational settings.

MacLeod Schroeder, in her Helen P. LeVesconte address, provides visibility and advocacy — the kind we longed for as occupational therapy students.

Warren shares the key messages in her work when advocating for neurodivergent-affirming spaces with lived experience.

Lecours provides an example of embedding service user expertise into tool development.

Warnock & Ly highlight the role of occupational therapy with physicians from a service user perspective.

Davidson, an active blogger, presenter, and advocate, shares that occupational therapy is the unsung hero of her rehabilitation team.

We came to this special issue as guest co-editors with a collective vision: more equitable and ethical practice of service user involvement and collaboration in occupational therapy. What has become clearer to us is that there isn't one singular *how* for bringing this vision to life. In numerous different ways, the articles that follow offer us a glimpse into the ways members of our profession are taking steps toward strengthening partnerships, valuing experiential knowledges, and acknowledging (and celebrating) the growing presence of service-using occupational therapists and service-using allies in our midst.

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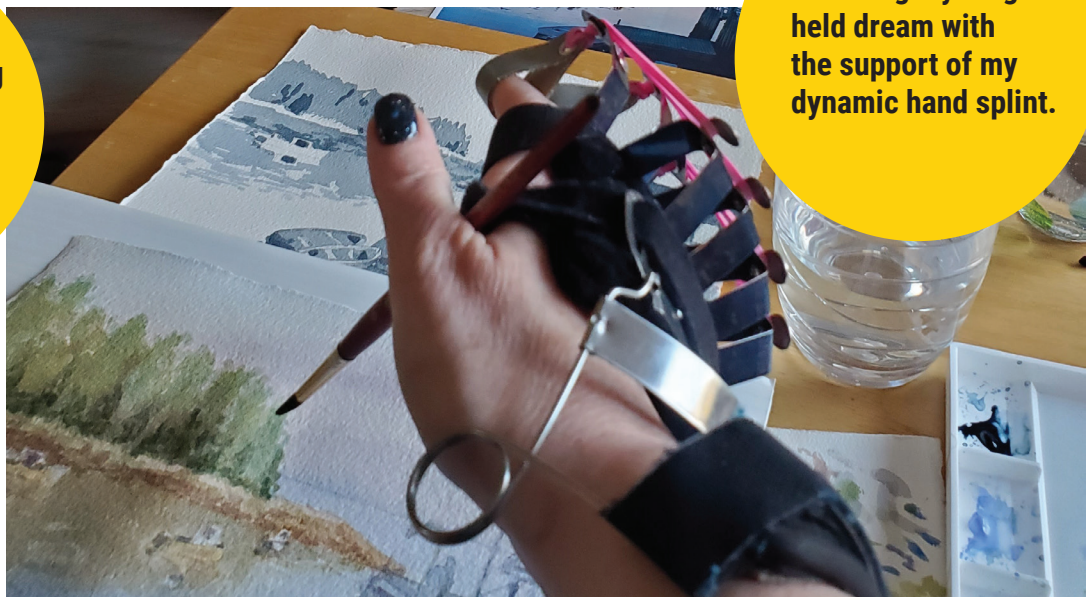
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#ArtDespitePain

Sandra Woods



My plein-air (outdoor) painting set-up when I'm cycling, using my bike as my easel.



Realizing my long-held dream with the support of my dynamic hand splint.

When a person is no longer able to do an activity that they loved, occupational therapists can help explore possibilities, and suggest assistive tools and techniques to keep original interests alive. I can no longer bike with my husband due to complex regional pain syndrome (CRPS), so we've adapted; he does 100+ kilometre routes while I do 30-45 km rides in the same areas. When I need to rest, I'll stop to paint. Later, he'll text me and we'll meet to ride together to one of the cafés along our cycling routes.

ART: My career in bioethics and my experiences with pain inform my artworks. I'd always dreamed of learning to paint with watercolours, but thought my CRPS symptoms would derail that plan. But by holding a paintbrush with my thumb and making some other adjustments, I can do it. I've even won art awards! Now I use my artwork to raise awareness of chronic pain and the benefits of creative activities for pain management.



Echinacea "White Swan": A reminder that sometimes simply spending time outside, enjoying nature, can have beneficial effects for people with chronic pain (and for everyone!).



Moving ahead, with pain: The clouded brain of this piece represents the mental health impacts of chronic pain, along with the "brain fog" or "pain brain" so often reported by people who live with persistent pain.

You can read an overview on my art website, on the page "Art Despite Pain":
https://www.sandrawoods.art/page/art_despite_pain

THE TWO-WAY STREET OF COLLABORATION: **AN INTERVIEW WITH ANNETTE MCKINNON**

Caryn Kwai-Pun

As an accomplished advocate, Annette McKinnon's passion for supporting people with arthritis and partnering with occupational therapists enriches our profession. She is co-founder of the Patient Advisors Network, a member of the Advisory Committee, co-author of a chapter in *Promoting Occupational Participation: Collaborative Relationship-Focused Occupational Therapy* (Kiepek et al., 2022), and co-author of several research papers, including one with Reaching Out with Arthritis Research (ROAR; Leese et al., 2017). Through her participation with councils and boards, Annette has advocated for the importance of patient and caregiver participation. In a recent interview, Annette discussed her connection to occupational therapy and her collaborations to improve health care.

Q Tell me a bit about your experience with occupational therapy.

A When I was 32, and my kids were about 10 and 11, I started having pains in my hands, pains in my feet, and when I went to the doctor, he'd say, "Oh, you're a normal, busy mom!" or "It's because you're standing in your job," because I was working part time in a bank. And he just didn't seem to get it, that what I was saying was more serious. I ended up finding an orthopedic surgeon to look at my feet, and he figured it out within two minutes! By looking at my feet, and listening to the complaints, he thought it was obvious. And so, when I finally got the diagnosis [of rheumatoid arthritis], I was very relieved.

The benefit to being diagnosed back in 1982 was that there was still a team in place — a rheumatology team. And so, I met a pharmacist, an occupational therapist, a physiotherapist...they had an orthotist right in the hospital, and the rheumatologist, and a nurse.

Then I joined a couple of [support] groups, but I kept seeing a physiotherapist with The Arthritis Society, and an occupational therapist, because I had splints that needed maintenance.

And the splints the OT made, made a big difference to me, because my wrists were really badly affected, and I had been wrapping them up in Tensor bandages you use if you sprain your ankle. Having the resting splints that I wore every night really helped. When I woke up my wrists weren't so sore, and my hands felt somewhat better. And so, finding solutions that can help you carry on doing what you want to be doing was



Annette McKinnon presenting at the Arthritis Alliance Canada Conference in Kananaskis AB in 2015: *The Power of the Patient: Exploring Patient-Centered Care within Multidisciplinary Inflammatory Arthritis teams.*

very important to me for my overall quality of life.

Q How did you come to get involved in projects with occupational therapy?

A Well, when I retired [...] I had suddenly 50 hours a week that I could spare! [...] So, I thought, well, “Look at my experiences dealing with arthritis and the things I've learned.” I started writing a blog (McKinnon, 2018), [...] I got onto Twitter, and I started tweeting an article every day, tweeting a link to a research article about rheumatoid arthritis that I thought was interesting. I gradually built-up a following in the arthritis area and a researcher contacted me from Arthritis Research Canada.

She asked me to help them out with an event they called, “Reaching Out with Arthritis Research” or ROAR. They had been doing it in person for years, and they had decided they'd expand it to Twitter and that I would be a good Twitter moderator, because of my experience. And so, I got involved with them through doing that. They asked me to help them, but I didn't realize when they asked for help, that they were doing research! It turned out to be a real research project that I became a co-author on.

Following this experience, Annette began to participate in different conferences and research projects with the Canadian Arthritis Network, the Stanford Medicine X Conference, and the Patient Experience Conference.

I saw that the groups of people who were working on health problems were all enriched by having the patient voice there.

Annette joined the Health Mentor Program at the University of Toronto – now the Centre for Advancing Collaborative Healthcare & Education (CACHE) – a leader and innovator in interprofessional education, an ongoing

program since 2010 (CACHE, n.d.). She also participated in an elective course, speaking to students about living with a chronic health condition.

With the encouragement of the Associate Director of CACHE, in 2016, Annette accepted a Public Member position with the College of Occupational Therapists of Ontario (COTO).

I felt that that my point of view was making a difference to the College, because I was able to help them see the way patient and client perspectives had been changing.

During her three-year term with the COTO, Annette provided feedback on communications and made a point to urge the College to involve more clients.

Q How can occupational therapists better involve client experiences in therapy planning, research, and advocacy?

A Well, [as an occupational therapist,] you're in such a great position to know what the issues are when you're doing advocacy, because you will have spoken to so many people, and you can represent the voices of the people you talk to, and who you help. And they're not all going to be handpicked people who have the time, the leisure, the interest to get involved altruistically.

I think that access to people and their voices is going to help alert you to issues that should be advocated for.

[My] advice for OTs going out to practice, no matter how early you are in your career, or how new you are to practicing, you're still a health professional and people really respect what you have to say to them, and so you can give them encouragement, even if it's a very little thing they've accomplished!

[People with arthritis] need to know that the efforts that they make can make a difference to themselves, to the course of their disease. And I would say I'm much happier being involved, and knowing what's happening, and having conversations with health professionals on a more level field.

The picture has changed dramatically, I think, over these years that I've been doing this. At first, we would have to push to get in anywhere, and now I'm a co-founder of a patient organization called Patient Advisors Network. And we're up to 250 people across the country. It's a community of practice, which can be called upon if you need patients!

One of the key changes needed in health care and health research is the inclusion of people with lived experience in every aspect, from the problem statement to co-creation right up to transferring the knowledge to people who will use it.

CARYN'S REFLECTIONS:

In my occupational therapy program, I've learned about theories, approaches, models, assessments, modalities, ethics, and professionalism. We talk a lot *about* service users in class, but our real opportunities to learn *from* them are during placements. At the heart of it all, this learning is meant to support us to collaborate to promote occupational participation. This conversation with Annette has highlighted three items I will keep in mind in my future practice:

1. Acknowledge effort: People work hard to meet their occupational therapy goals!
2. Encouragement: A few simple words can go a long way.
3. Ask, “What do you think about this?” Input from service users and peers is an invaluable resource.

As I prepare myself to step into the working world and to eventually call myself an occupational therapist, I look forward to listening to each unique person. Speaking with Annette made me feel inspired by her ambition and passion for education and advocacy. Annette has set an example of continued learning and contribution that I hope to follow throughout my career — learning and furthering research with the help of service users and my peers. I plan to take what she has shared to foster a collaborative atmosphere in my workplace, setting an example through my words, actions, and values. I am excited to focus on promoting occupational participation in various contexts throughout my career.

RESOURCES



Annette's recommended resources for working with patient advocates:

Strategy for Patient-Oriented Research by CIHR
<https://cihr-irsc.gc.ca/e/41204.html>

Canadian Patient Partner Study by Julia Abelson
<https://ppe.mcmaster.ca/research/canadian-patient-partner-study/>

Learning Together Framework by the Centre of Excellence on Partnership with Patients and the Public
<https://ceppp.ca/en/uncategorized/learning-together-evaluation-framework-for-patient-and-public-engagement-ppe-in-research/>

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WORKSHOPS AND ONLINE COURSES

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WORKSHOPS AND ONLINE COURSES

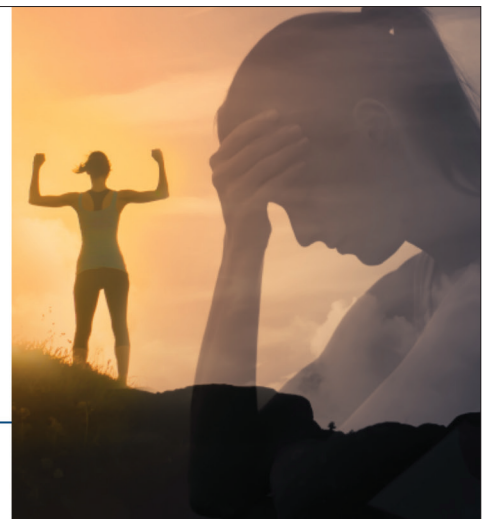
Self-management techniques for chronic pain

This workshop presented by Zara Dureno will increase your understanding of chronic pain and self-management strategies that can be used to support people living with pain.



Online delivery –
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Register for this workshop
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CREATING BETTER OPPORTUNITIES FOR EMPLOYEES WITH DISABILITIES: **LESSONS FROM THE WORKPLACE**

Kristin Harold

Michael MacDonald has given a lot of thought over the years to what creates a positive relationship between a client and a health care provider. As someone with hearing loss and who oversees the disability management team for Jazz Aviation, an airline with 4,500 employees across Canada, he has found the secret to success is embracing flexibility, exploration, and curiosity.

More than 3.8 million Canadians live with a disability, according to Statistics Canada (2015), but Michael has found that many workplace and health care teams still don't receive enough training to help them determine how best to collaborate with clients with disability related needs, including communication, relationship-building, and addressing internalized ableism.

Michael says his workplace at Jazz is a safety-sensitive, fast-paced, and highly regulated environment developed to meet the strict aviation standards. These conditions have created a rigid structure that doesn't leave room for much accommodation for employees with disabilities.

However, Jazz looks for opportunities to help individuals with disabilities succeed with their work goals and optimize their required tasks and roles. Michael, who has a Master of Education, says his team began to ask employees and job candidates how the organization could support them to navigate access needs in current or future positions. With greater attention focused on the physical environment and a more inclusive organizational culture, disabled employees and employees with disabilities were able to obtain positions previously unavailable to them.



“One thing I’m particularly proud of is that we hired a new employee named Madison with a congenital hearing loss who is a graduate of the Atlantic Provinces Special Education Authority,” he says. “She wanted to be an aircraft maintenance engineer, which is unconventional in many ways since it’s a male-dominated industry and there have always been strict requirements about hearing capabilities.”

Michael consulted with occupational therapists, audiologists, and other health care practitioners to determine what accommodations could be made. Then he relied on their expertise to create technical recommendations for Madison. These efforts were documented in an article he co-authored with Dr. Lynn Shaw, Director of the School of Occupational Therapy at Western University, and audiologists Mary Beth Jennings and Janine Verge. Entitled *Use of the Person-Environment-Occupation (PEO) Model as an analytic tool for audiology, occupational therapy, and workplaces in generating solutions to support workers with hearing loss succeed at work*, it appeared in the Canadian Audiologist online journal in 2019.

The article documented several factors that contributed to Madison’s ability to succeed in the role, including the long-standing history of diversity and inclusivity at Jazz and their receptiveness to exploring options to maximize occupational performance. The authors concluded that the PEO model offers a valuable framework for those with hearing loss aspiring to enter, remain, or return to the workplace, while giving professionals and companies concrete solutions which enable workers to achieve the best possible outcome.

“Madison has now been successful in the job for the last eight years and is very well respected,” says Michael. “In

fact, her presence in the workplace has created some changes to the safety procedures that have benefitted all the workers in her area.”

He adds that her achievement is an excellent example of what is possible for deaf and hard-of-hearing people in a safety critical job.

“I’m now in a position where I can help dispel myths and that includes assumptions that both employers and those with disabilities have themselves,” says Michael. “My greatest success has come from when people are curious about what I can do rather than focused on what I can’t do. And then I pay that forward to the clients that I support.”

That’s where occupational therapists are important, Michael adds, because they can effectively identify opportunities and partnerships for clients with disabilities to better create flexibility and social change within existing infrastructure and diagnostic guidelines.

“That is a really important point because as an OT, you can make certain assumptions clinically and it’s best to make sure that you’re listening to what the client actually wants and needs,” says Michael.

He adds that he’s worked hard to create collaborative health care relationships in his personal life, but it hasn’t always been easy.

“The health care community wasn’t really well suited to support me, despite my success being a good advocate, whether its dealing with clinicians who can’t understand that masks make it very hard for me to understand them or audiologists who make unacceptable recommendations.”

He refers to a quote written by a friend and author that aligns closely to his personal philosophy. In the

book, *Curious? Discover the Missing Ingredient to a Fulfilling Life*, Todd Kashdan writes “Curiosity creates possibilities; the need for certainty narrows them” (2009, p. 23). Todd later elaborates, writing: “Curiosity creates energy; the need for certainty depletes. Curiosity results in exploration; the need for certainty creates closure” (2009, p. 23).

Michael says these are the key principles behind his work as he manages his interactions with his clients, and what he recommends to occupational therapists.

“It’s important to keep an open mind and it definitely requires a lot of self-advocacy and self-awareness,” he says. “Every good outcome I’ve been able to make happen is borne from that commitment to curiosity. All my frustrations with clinicians trying to support me have been a direct result of the provider being too fixated on certainty. It’s important that they remember to grant each client their autonomy and agency for self-expression.”

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A STRANGE TIGHTROPE: UNRAVELLING THE DICHOTOMY BETWEEN GIVING AND RECEIVING CARE AFTER COVID-19

Katie Kitchen

In the early morning hours of December 7, 2020, I completed a cross-fit workout in my make-shift home gym. Later that evening, I developed chest pain near my sternum. After failing the employer-required COVID self-screening tool the next morning — due to difficulty taking a deep breath secondary to chest pain — I booked a polymerase chain reaction (PCR) COVID-19 test. Upon arriving at the test site, the test administrator asked me about my symptoms, glanced at me, and remarked, “Well, you look fine,” and begrudgingly administered the test. Now, two-and-a-half years later, I realize this was the first assessment of my credibility as a patient. This comment, surely long forgotten by the test administrator, signaled the beginning of my negotiation for legitimacy and of the journey that would change how I think about service users, health care professionals, and myself.

Following the PCR test, and in less than 24 hours, my function rapidly changed. Getting dressed rendered me breathless and walking a few steps across the room left me gasping for breath. This was vastly different from the conditioned cross-fit athlete I had been only a day before.

Still, on December 10, 2020, I was shocked when I received the PCR test

results indicating I had tested positive for COVID-19. In that moment, I became one of the first people I knew to contract the virus. After describing my now-worsening symptoms to my employer’s occupational health and safety department, I was told to go to a hospital with an intensive care unit. Upon arriving at a local hospital, my person and my environment were literally labelled with signage indicating my COVID-positive status. At that time, I did not require admission and was assured by the attending physician that I was expected to have “a swift and uncomplicated recovery.”

This promise eluded me in the months that followed. In March 2021, I was officially diagnosed with long COVID, otherwise known as post-acute COVID-19 syndrome. Now, over two-and-a-half years later, I continue to live with numerous symptoms and am not alone in this experience. Recent data suggests that 1.4 million Canadians live with long COVID (Statistics Canada, 2022). This term was developed by patients to describe their experiences at a time when the medical community had yet to recognize the influence of COVID-19 on long-term health. (Callard and Perego, 2021). Though considerable progress has been made since that time — both in understanding the condition and in

establishing medical legitimacy — there continues to be fundamental problems in how the health care system and our own profession have approached this complex, episodic health condition.

Though I had worked in health care for 10 years since graduating with a Master’s of Occupational Therapy degree from the University of Manitoba, I had little experience in the role of “patient.” I have worked throughout my career with people who experience severe and persistent mental illness. I have sat with individuals who I felt privileged to know as they travelled through phases of illness and recovery, with moments of despair and periods of hope. I provided people with education regarding illnesses that health care providers still have much to learn about, and often experience only peripherally through our clinical observations and through listening to people who experience the illness. On December 10, with my COVID-positive label firmly affixed, my role shifted. I witnessed the strong divide — and found myself on a strange tightrope — as I navigated the role of a health care provider receiving health care services.

Now, suddenly, I was confronted with startling parallels. A stigmatizing illness that many health care

providers did not understand, while others did not even recognize it. An illness where I struggled to be believed — where my experiences were assessed for their validity and for their truth. In the absence of a concrete diagnostic finding from an imaging test, my symptoms were — at times — dismissed as psychosomatic. I quickly realized that I would need to learn about my own illness. I learned that I could not depend on health care providers to understand the intricacies of this new condition.

In his memoir, neurosurgeon Paul Kalanithi (2016) described the process of releasing himself from the responsibility of his own medical care after being diagnosed with cancer, describing that he could release his “doctor-self [from] remaining responsible for [his] patient-self” (p. 217). As someone living with long COVID, I learned that this was not possible. Like other provinces across Canada, Manitoba has a lack of coordinated long COVID services, with care being delivered in silos instead. I became accustomed to advising one health care professional what the recommendations of another were, following up on promised phone calls and referrals, and often having to bridge communication between service providers. It was not uncommon for me, the patient, to provide education to my own health care providers on the assessment and treatment of long COVID.

Though I felt unable to release myself from my own care, I slowly learned to release the dichotomy of giving help and receiving help, by instead recognizing that I could both provide health care to others while simultaneously receiving it myself. Assuming the role of patient challenged what I thought I understood about power imbalances between client and service provider. I wondered how I was perceived

as a patient. Had I been labelled as a “difficult patient” because I was advocating for myself? Was I being perceived as credible, and if so, would that legitimize my symptoms? This process of negotiating candidacy for health care services was described in qualitative research by Maclean et al. (2023) who noted that people who have long COVID often felt “their claims to candidacy were rejected (adjudicated as not credible)” (p. 7) by health care providers. What role have we, as occupational therapists, played in adjudicating candidacy for our services?

To assess my symptom of brain fog, my occupational therapist asked me to complete a Montreal Cognitive Assessment (MoCA; Nasreddine et al., 2005). After assuring my occupational therapist that I would ace the MoCA by virtue of having administered it dozens of times in my own clinical practice, we moved into a discussion about the disruption of life roles and my social identity. We discussed the occupations that had been radically changed by my course of illness. I sensed that there was less comfort for the therapist here. There were no cut-off scores, no prescribed adaptive equipment. This discussion involved the therapist accepting discomfort, and acknowledging what was not known. Despite this, my symptoms and experiences were validated. She acknowledged that she was not sure how she could help me — in part due to my own knowledge as an occupational therapist, and in part due to a lack of clarity regarding the etiology and trajectory of my symptoms. She treated me as a co-expert of my own condition, which helped me to feel validated and understood. Maclean et al. (2023) note that, “The most positive health care interactions can be experienced as an affirming partnership of discovery in which patient and health care professional ‘co-expert’ to learn more about (treatment for) long Covid

together” (p. 3). As a patient, this rang true. As a health care provider, this issued a challenge.

Occupational therapists have long professed the value and utility of a person-centred approach. We pride ourselves as advocates, communicators, and collaborators (ACOTRO, ACOTUP, & CAOT, 2021). Occupational therapists are expected to “partner with clients in decision making” and “participate actively and respectfully in collaborative decision making” (ACOTRO, ACOTUP, & CAOT, 2021, p. 12). We posit that we engage in co-creation with service users to support occupational participation, and further that we “contribute to the equitable access to occupational participation and occupational therapy” (ACOTRO, ACOTUP, & CAOT, 2021, p. 14). Yet, when confronted with an illness that disrupts life trajectories, social roles, and function, we have been slow to respond. People seeking care have been left feeling invalidated, dismissed, and — at worst — not believed. Assessment of credibility and the dismissal of symptoms is not unique to long COVID and is often experienced by those who have chronic health conditions, such as chronic fatigue syndrome (Blease et al., 2017), pain (García-Rodríguez et al., 2023), and autism (Wodziński & Moskalewicz, 2023). While these experiences are neither specific nor limited to occupational therapy services, I would challenge our profession to consider the role that we have played in the experiences of people seeking health care who live with long COVID and other chronic health conditions.

Kalanithi (2016) asserts that “when there’s no place for a scalpel, words are the surgeon’s only tool” (p. 113). Have our assessments, adaptive equipment, and semi-structured interviews become our scalpels? Can we find comfort in the fundamental tenets of our

profession to respond nimbly to a new health condition, and to accept the uncertainty that comes with that? Can we trust in the stories of lived experiences that describe symptoms that we cannot see, or that we do not yet understand? Can we enter each service user encounter with the expectation of believing our “co-expert?” I am confident that we can. Our strength, as health care professionals, is our capacity to listen, validate, and learn alongside our clients. Will you accept the challenge?

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WORKSHOPS AND ONLINE COURSES

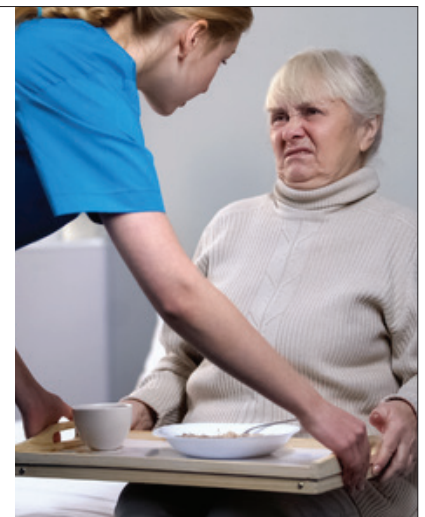
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CHALLENGING INTERSECTIONS OF CRITICAL DISABILITY STUDIES AND OCCUPATIONAL THERAPY

Shayla McMillan

My process of navigating occupational therapy school through a critical disability lens has been nonlinear and confusing. When I began my first occupational therapy class, I was excited to begin a career I have pursued since Grade 11. I was eager to build on my undergraduate knowledge in kinesiology and critical disability studies (CDS) and on years of experience working in rehabilitation. In the first weeks of school, excitement quickly gave way to feelings I wasn't expecting; I feared that I had to abandon my previous understandings of disability to fit into occupational therapy. In this reflection, I summarize CDS and consider challenges I've encountered while applying this critical lens. I highlight how the field can contribute to occupational therapy theory and practice and invite the profession to integrate CDS perspectives into occupational therapy discourse and education.

I preface this reflection by sharing that I believe that occupational therapists are well intentioned and inherently good. This reflection invites you to engage in curious conversation about CDS and build an appreciation for what it can offer occupational therapy research, theory, and practice.

CRITICAL DISABILITY STUDIES: A SHORT INTRODUCTION

CDS is a contemporary field of academic activist scholarship that aims to both uncover what is taken for granted as true, right, and obvious about disability and examine the socio-political relationships between body, mind, and society (Burghardt, 2020; Shildrick, 2012).

Unlike the social model of disability, which views disability as exclusively constructed by disabling social practices (Oliver, 1996), CDS theories centre the embodied experiences of disability by engaging critically with how dominant society fundamentally values conformist bodies and minds at the expense of those who deviate from the able-bodied norm (Hansen & Janz, 2009). CDS moves beyond disability studies of the late 20th century — which outlined disabled people's structural, economic, and cultural exclusion — and is more complex, political, and relational than binary biomedical and social model perspectives (Kafer, 2013; Meekosha & Shuttleworth, 2009). CDS theorists contemplate disability to examine how power and systems of oppressions create and maintain inequalities for all (Goodley, 2013). Ableism, a key concept within contemporary CDS, privileges "typical (usual) bodies, minds, and abilities as superior" (Campbell, 2009; Hammell, 2022, p. 3). Ableism is baked into our societal values, and therefore deviation from the conformist body/mind impacts how all individuals perceive ability, beauty, normalcy, and time in both others and within the self (Clare, 2017; Hansen & Janz, 2009; McRuer & Berube, 2006). CDS scholarship is primarily written by people with lived experience of disability.

CDS AND OCCUPATIONAL THERAPY

The colonial foundations of the rehabilitation sciences, including occupational therapy, favour reductionist approaches to understanding and

addressing a problem (Hammell, 2022). Binary models of disability are favoured and prevail under a colonial agenda, such as the biomedical, social, or charity. Many occupational therapists are beginning to advance more critical perspectives on disability in the profession (Bulk et al., 2020; Burghardt et al., 2021; Hammell, 2022; Mahipaul, 2015; Sibbald & Beagan, 2022). This growing area of scholarship is still young, and occupational therapy still assumes that disability is a problem to fix.

Current research suggests occupational therapy could benefit with greater attention to scholarship aimed at addressing ableism. Friedman and VanPuymbrouck (2021) found that 68% of occupational therapy students in selected American occupational therapy programs graduate with implicit prejudices towards disability. This is a chilling statistic, given that occupational therapists inevitably have the social power to bring their own context and beliefs into their practice (Egan & Restall, 2022; Hammell, 2015). These findings suggest that education programs may fail to influence students' ableist attitudes, which may then reinforce negative biases in their own practice and contribute to ableist stigma in health care at large.

BUILDING A CRITICAL DISABILITY LENS AND NAVIGATING OCCUPATIONAL THERAPY

After several years as a rehabilitation assistant, personal support worker, event director for Motionball for the Special Olympics, and undergraduate kinesiology student, I encountered CDS

in a disability studies elective course. I became enthralled with CDS, and immersed myself in the discipline as a student, teaching assistant, and full-time research assistant. Although I entered occupational therapy education one year ago with a critical lens, my relationship to the concept of disability feels unstable and challenging.

I feel disappointed by the lack of engagement with CDS in my occupational therapy education. Preferences for binary models and classificatory systems dismiss the complexity of disability in occupational therapy education. For example, my classes introduced the World Health Organization's International classification systems of functioning, disability, and health (WHO, 2001) to define disability as a functional limitation related to a body/mind impairment. This set the foundation to not only constrict students' understanding of disability, but also to categorize and measure disablement in relation to the client in question.

Although CDS was mentioned in my education, there was limited dialogue on its relevance to occupational therapy. When I initiated discussions related to CDS, the need to "move on" and get to the important content was made clear. Tight timelines and a high volume of content further restricted opportunities to discuss CDS with peers or instructors. Perspectives that challenged the biomedical or social models of disability felt unwelcome in my classrooms. This rejection of critical perspectives reinforced institutional norms related to the proximity of normality, and communicated that disability is a monistic concept that should not be contested (Hammell, 2022).

I notice that I repress my critical view of disability to fit into education, and I am constantly confronted by the feeling of discomfort that accompanies any resistance. I have adopted narrow definitions of disability as a means

to finish assignments and complete evaluations. I have completed required projects that involve movie characters as case studies to identify occupational performance problems. My work on these projects was limited by socially dominant narratives in media that convey disability as either a tragedy or inspiration (Young, 2014), and I reflected on the assumptions students are instructed to make about disability. Moreover, I thought, how will this contribute to therapists' compulsion to *cure* clients (and more insidiously, the assumption that they wish to be cured) of their experiences (Clare, 2017)?

During observations and placements, I notice that therapists refrain from using language such as "disabled" or "disability" altogether in efforts to preserve the hope that clients can have a "good" life. If disability is an inevitable part of the human experience, why are therapists quick to deny that it exists? Therapists' avoidance of language, such as "disability," insinuates that the disability experience should be shamed and hidden. It communicates that disability is abnormal, and that the only acceptable conversations are underpinned by the assumption of getting back to "normal." This denies the complexity of disabling experiences and produces shame about disabled embodiment and identity. Failing to address this shame in the therapeutic process not only promotes ableism but poses a significant barrier to occupational participation and wellbeing.

Overall, the negotiation of CDS in occupational therapy education has been lonely. Few colleagues in my immediate circles understand the intersections of these disciplines, and I long for the rich conversations I once experienced in my disability studies courses. I feel that my fluency in CDS theory is waning. Although I try to continue to engage with CDS scholarship, the intensity of the program and other contextual demands inhibit me from maintaining my CDS knowledge, especially without proper mentorship. I crave the support

of disabled and critical occupational therapists who have the tools to help me navigate how to practice with CDS theory in mind. Given that disabled therapists are often excluded from the profession (Bulk et al., 2020), it has been difficult to find this collegial support.

REFLECTIONS ON CDS AND OCCUPATIONAL THERAPY

I empathize and resonate with occupational therapists who stray away from critical perspectives. It is undoubtedly easier to operate from the concrete definition of disability, especially as students who are learning how to navigate the profession's inherent breadth. I was in rehabilitation settings long before I encountered CDS, and I too refrained from concepts that were theoretical and abstract.

I believe that identifying ableism is especially challenging for occupational therapists because it requires radical honesty and vulnerability of and within our profession. It is very common for therapists, researchers, and students alike to experience an uncomfortable sense of confrontation when we reflect on the relationship ideals of "normal" bodies/minds and our personal perceptions of worth. It is these ideals, which we covertly hold, that keep us from seeing other possibilities. Within ableism, we fear both being a burden and the loss of doing the things we love when we injure our physical bodies. Ableism teaches us that we should hide ourselves from the ones we love when we are hurting. It fuels the shame we experience when our body changes and deviates from what we know as "normal." The ableism pervasive in occupational therapy may be a result of lack of education on the ways systems of power shape our fundamental and collective understanding of ability and normalcy within ourselves.

Although I've felt pressured and tempted to let go of CDS perspectives to fit into occupational therapy education, the consequences of perpetuating social

inequities that impact both clients and therapists are too great. The hope embedded within CDS feels like a bell I can't un-ring.

I assure you, there is another way about thinking of disability that is much more rich, imaginative, and humanizing than anything I've been exposed to in the rehabilitation sciences.

One may ask, if I'm so concerned about CDS, why occupational therapy? To that, I know my answer is shared by many occupational therapists. I fell in love with the occupational lens, and I continue to value the profession's holistic nature. I find the focus on occupation opens possibilities to appreciate people's complexity beyond what we see in medical settings. Additionally, occupational therapy allows me to reflect on the practical and diverse ways that one can be enabled or disabled from participating in everyday living. Perhaps it's my optimism bias, but I think occupational therapists could just be the squeaky wheel health care needs to challenge ableist ideals at large.

DREAMING A CRITICAL OCCUPATIONAL THERAPY LENS: IDEAS FOR A WAY FORWARD

My hope is for my colleagues to believe that the feeling of possibility I encountered when discovering CDS is something available to us all. I wish for more critical dialogue and education about CDS in occupational therapy programs. I dream of spaces of safety and understanding to learn about the complexity of CDS theories. Ultimately,

I imagine that occupational therapy can understand disability as an opportunity to restructure our ideas and environments to address the ableist undercurrents driving research and practice.

I share this reflection hoping to demonstrate that the process of navigating occupational therapy school through the lens of CDS is nonlinear, arduous, and lonely at times. I have more questions than answers in this moment, and I am thankful to be part of a profession that has evolved to value reflexivity, learning, and growth. Most importantly, I am thankful for the disabled and critical occupational therapists and scholars who have devoted their careers to this work. I encourage occupational therapists to either explore or review some of the CDS scholars' work cited in this paper so we can all participate in the transformation of a more inclusive and equitable occupational therapy together. Please find some of my favourites in the references below.

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OUR DUAL LENS: VALUING SERVICE- USING OCCUPATIONAL THERAPISTS

Meredith Brison-Brown & Armita Amiri



Imagine an occupational therapist who not only holds a deep understanding of their profession but also carries the lived experience of being a service user in health care. Whether you thought of yourself, a friend, an acquaintance, or a hypothetical occupational therapist, the simultaneous view of occupational therapy from both professional and service user perspectives — a dual lens — has the power to transform occupational therapy. We, the authors, each view our world through multifaceted lenses, however this article is a reflection on our experiences as students becoming service-using occupational therapists (SUOT). As such, our focus is on our dual lens of occupational therapy professional and service user. In this article we aim to use our dual lenses to examine and dispel the constructed dichotomy of consumer and clinician that influences the ways we interact with our colleagues and clients. In doing so, we hope to highlight the value of SUOT and advocate for their inclusion in academic and professional spheres.

VALUE OF SUOT

The experiential knowledge that service users possess, combined with core occupational therapy competencies, make SUOT an asset to the field. Occupational therapists who are intimately familiar with the health care system from a user perspective can enhance care by using professional expertise deepened by first-hand experiences (e.g., Bevan, 2014; Chacala et al., 2013; Easterbrook et al., 2015; Jung et al., 2014). A systematic review of literature between 2002-2022 proposed

that occupational therapists with disabilities build empathetic rapport, reduce implicit biases, and expand the professional knowledge base which contributes to better health outcomes (Lindsay et al., 2023).

Student occupational therapists, like ourselves, with experience as service users can enrich our colleagues' learning by offering critical perspectives on, and alternatives to, established theories and practices. The dual lens we offer can make overt what may otherwise remain covert and help advance curricula and institutional policy (Beagan et al., 2022). As Beagan and colleagues (2022) articulate, SUOT challenge norms and power dynamics by bringing to view our "transgressive knowledges and skills that are not only helpful to working with a wide range of clients but also key to transforming institutions and social structures" (p.13). Thus, SUOT and students are key stakeholders with expertise in advancing individual client-care and the profession overall.

SUOT: PROFESSIONAL LEGITIMACY

Despite considerable expertise and value, service-using health professionals are often not meaningfully included in educational and professional spheres due, in part, to doubts regarding their legitimacy as professionals (Jarus et al., 2023). Within health care, service users find that the legitimacy of their accounts is questioned or dismissed (e.g., Costa et al., 2012; Kitchen, 2023). Disabled occupational therapists and scholars have described experiences of bringing critical and experiential knowledge into academia and having its legitimacy questioned when this knowledge does not conform to the normative ways that academic environments work and think (Mahipaul, personal communication, June 26, 2023). In addition, legitimacy is challenged when experiential knowledge is interpreted through existing models that leave the intended message silenced or misunderstood (LeBlanc-Omstead & Mahipaul, 2022). As authors, we resonate with these experiences.

The pursuit of professional belonging in occupational therapy is gatekept at learning institutions and workplaces by professional norms, rooted in ableism, that assume inclusivity undermines the core competencies (Easterbrook et al., 2015). Messages that are embedded in individual and institutional interactions in this environment emphasize the feeling that service users are not the intended recipients of professional designation in occupational therapy (Beagan et al., 2022). However, guiding occupational therapy documents suggest that the profession is being challenged to disrupt this status quo. For example, the *Joint Position Statement on Inclusive Occupational Therapy Education for Persons with Disabilities*, published by the Canadian Association of Occupational Therapists (CAOT; 2018), recommends building awareness of “ableist assumptions within the design of competency documents and assessment of competency” (p.1). Similarly, the revised *Competencies for Occupational Therapists in Canada* (ACOTRO, ACOTUP, & CAOT, 2021) promote equity in practice through the analysis of biases and collaboration with stakeholders.

SUOT: STUDENT PERSPECTIVES

Clinicians and students with disabilities and/or disabling health conditions can deepen our understanding of equity in health professional education and practice. Yet, it can be challenging for SUOT students to incorporate the benefits of our dual lens while seeking legitimacy, in both classrooms and during fieldwork. Students, including ourselves, must balance the benefits of bringing our whole selves to occupational therapy with the potential consequences of self-disclosure. Easterbrook et al. (2015) found that “Students felt a conflict between acknowledging the disability and being treated as a whole person” (p.1510).

Much of the landscape of occupational therapy education programs is built on paradigms that assume the service user as the “other” (Sibbald & Beagan, 2022).

As students living with health conditions who are learning in health professions, we often feel unseen because it is not explicitly recognized that we can be both. By failing to explicitly recognize that service users are our colleagues, this “othering” perpetuates stigmatization and exclusion, and limits opportunities for service-using individuals to contribute their expertise and lived experience. In addition, visibility can be experienced as an internal tug-of-war because the requisite of disclosure to ensure a more equitable experience in academia and workplaces for service users incurs the risk of discriminatory and exclusionary consequences (Easterbrook et al., 2015; Sibbald & Beagan, 2022).

Research evidence suggests ableist discrimination by student colleagues, faculty, and university policies (Davis, 2020; Lindsay et al., 2022), though it is rarely acknowledged within the occupational therapy profession (Jung et al., 2014). Fieldwork placement experiences are implicated specifically, noting resistance and concern from preceptors questioning service-using students’ fitness to practice (Davis, 2020; Easterbrook et al., 2015). As Davis (2020), observed, “. . . what is missing from these and all other studies is actual evidence to support this belief” (p.33). The literature reveals a paucity of evidence that SUOT and students are more of a potential client safety risk than any other student or occupational therapist (Davis, 2020). Therefore, the perception of incompetence may arise from unchecked assumptions and biases perpetuated by occupational therapy professionals.

MOVING FORWARD

Given that professional norms in occupational therapy can result in discriminatory exclusion of occupational therapists with disabilities, and given the value of the perspectives of SUOT, occupational therapy is missing out on needed expertise under the guise of concern for client care. Instead, the profession needs to recognize the value of SUOT and to

promote critical reflexivity regarding the false binary of service user and occupational therapist. So, what is the way forward?

To broaden the profession’s access to this dual lens, and meet the expectations within our national documents, occupational therapists need to challenge the binary thinking that leads to doubts about the professional legitimacy of their service-using colleagues, and meaningfully include these colleagues within all aspects of the profession.

INCLUDE US, MEANINGFULLY

SUOT and students should be in positions of influence to improve policies, systems, and curricula. By centring this group of clinicians and students as legitimate, competent members of the field, it is possible to “resist the equation of disability with inability” (Sibbald & Beagan, 2022, p.14). Care must be taken to avoid the exploitation of SUOT and students as free resources to legitimize claims to advancement in equity. Crediting, compensating, and appreciating the complexities of our experience are key toward meaningful inclusion.

PRACTICE ALLYSHIP

Allyship can challenge the “us and them” dichotomy by advocating for SUOT as capable colleagues and leaders in the field. Chacala et al. (2014) point to the importance of practicing allyship for service-using colleagues, since “The responsibility for bridging the disabled/non-disabled cultural divide rested with the disabled therapists, exacerbating inequity.” (p.107).

EXPAND THE LENSES THROUGH WHICH THE PROFESSION VIEWS LEGITIMACY

Part of dismantling ableism in health care and health care education is the recognition that being consumers of health care services and being clinicians/students in health care professions are not mutually exclusive. To make this change possible, there must be recognition of this

binary lens through which the construct of professionalism is applied to the occupational therapy field. Easterbrook et al. (2015) found that “Students felt a conflict between acknowledging the disability and being treated as a whole person” (p.1510). Therefore, learning institutions that train occupational therapists should actively pursue an evolving understanding of the complex dimensions of disability experiences.

TOWARD A MORE INCLUSIVE FUTURE

The narrow lens through which occupational therapists often conceptualize legitimacy within the profession must be broadened to include an expansive appreciation of the ways of knowing and being that occupational therapists profess to enable. Instead of questioning the legitimacy of colleagues who possess a dual lens, occupational therapists would be better served by appreciating the potential added value to client care. The ablest foundations of occupational therapy must be viewed critically to invite reflection not only where we’ve been and why, but what is the way forward, and how can we get there? As the profession works to imagine a more inclusive future, will the status-quo continue to be perpetuated, or

will rhetoric turn into reality and lead the way toward making occupational therapy a more inclusive health care profession?

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Natalie MacLeod Schroeder and CAOT CEO Hélène Sabourin following the presentation of the Helen P. LeVesconte award.

THE 2023 HELEN P. LEVESCONTE ADDRESS: **AN ANTI-SANIST ANTI-ABLEIST IMPERATIVE FOR OCCUPATIONAL THERAPY EDUCATION**

Natalie MacLeod Schroeder

Receiving this award provided me the opportunity to address you, my colleagues and peers, on a national level. That honour comes with a responsibility to use my voice to raise up issues of justice I see occurring on a daily basis. For this reason, I am choosing to share my own personal experiences in the profession, in the hopes of creating a more welcoming space for those who enter today and in future.

DISCLOSURE

I am neurodivergent — a natural, neurological variation that means I receive, process, interpret, and respond to sensory and emotional stimuli differently than someone who is neurotypical. This neurodivergence generated an overflow of words and ideas in my head, at the same time creating a lack of coherence and clarity in trying to pull this address together. It created the need to not have just words and ideas to share with you, but also the *right* words and ideas — the *perfect* words and ideas. And that produced paralysis of thought and action; the fear of rejection from you, my esteemed colleagues, who might find my words lacking in some way. “*Maybe it would be better to not try than to risk saying the wrong thing, in the wrong words.*” What could look like procrastination and lack of preparation was the result of my brain processing the experience of receiving this award and preparing this presentation.

I also identify as a mad therapist, experiencing mental illness throughout my life. Part of this is a result of my neurodivergence — living through periods of burnout and

exhaustion and significant anxiety — and part of this is just a genetic lottery; either way, neurodivergent and mad is who I am.

MY EXPERIENCE

From the time I entered occupational therapy school, I felt at the periphery. I had friends in my program. I have friends at my work. But somehow, I always felt out of place, that I did not completely belong. I identified strongly as part of this profession and as an occupational therapist, but I didn't always feel that sense of belonging *with* my colleagues and peers. As a direct result of my own neurodivergence and madness, I have received feedback throughout my career: on my professionalism; on my professional behaviors; on my awareness of social cues; and social norms; on how and when I respond; on my regulation of my emotions, tone of voice, rate of speech, and volume. These have been forever challenges and often points of shame. *How can I be an OT, and not have learned how to do those things?*

On many occasions I found it difficult and exhausting. Meeting social expectations that are not part of my experience and are not always in conscious awareness creates an additional layer of cognitive effort. This frequently requires attempts at mirroring or masking to look and feel like I belong. My experience, and working with students having similar experiences, has brought me to this brief address today.

STUDENT EXPECTATIONS

Occupational therapy is a profession concerned with accessibility: access to desired and meaningful occupations, and occupational participation. Students often choose occupational therapy because of our many core ideas outside the medical model, and concerns with issues of access and participation. Prospective occupational therapists are attracted to the values and ideals associated with this way of thinking. Many of our students enter

our programs expecting to find these values to apply to the individuals and collectives with whom we work, but also to our educational frameworks, our way of engaging with them, and our ways of educating. Once admitted however, students find our programs are rooted in the colonial, white, racist, ableist, sanist, neoliberal structures of the Academy. They often experience us as educators reproducing oppressive systems and demanding performance within a narrow range of acceptability that fits within these structures and systems. Their experiences need to be examined and addressed as a priority in our profession.

STUDENT EXPERIENCE

While disabled, mad, and/or neurodivergent students today have more connections to resources such as accessibility services for individual accommodations, these themselves are problematic. Long before mad, disabled, and neurodivergent students attend their first classes, they must gather the documentation to legitimize their need for accommodations. If they are lucky, this is a form from a physician — one who is willing to attest to their condition, their needs, and their required supports. However, in some accessibility departments, they must seek expensive, difficult to access services and assessments, at their own expense, to *prove* their claim of disabled status. Imagine an adult who has been living as neurodivergent, mad, or disabled their entire life having to seek a psychoeducational evaluation to determine a diagnosis and academic needs, simply to prove who they are and what they need, to learn.

Once a student's identity has been *validated by others*, they then have the additional labour of managing those accommodations: further meetings with advisors and counselors, the requirement of additional scheduling deadlines for their tests and exams, the challenges of disclosure for obtaining

extensions to which they are entitled, recognizing that each-and-every extension further adds to their burden in tightly packed schedules. The added work of disclosing (or not disclosing) to fieldwork educators and sites, is loaded with risk of rejection if a site is unable or unwilling to work with accommodations. Students also face the added work of disclosing (or not disclosing) to fieldwork educators and sites. They are asked to name accommodations for clinical and community settings that they have not yet experienced. When these accommodations, which may not be needed or may be insufficient, are documented, this process is loaded with risk of rejection. This "disability tax" is applied on top of intense academic programs that are often a struggle for students without disabilities.

Within our courses, when student behaviour does not match expectations, students receive feedback in ways that often challenge their social and communication skills, their emotional regulation, and sometimes their very identities. When the feedback is not received or processed in the way that is expected, it is seen as a deficit in a student, not in our processes. Our methods of teaching and evaluation often have specific expectations of presentation, firm and inflexible deadlines, group work that requires additional labour, many of which may be challenging for neurodivergent, mad, or disabled students.

As a result, these students may choose to leave before they finish their program. Others remain, often struggling to find success. In persisting, they often face further challenges, experiencing the very real and very detrimental effects of burnout. These students are exhausted. They are stressed, and they are struggling.

AN IMPERATIVE FOR OUR PROGRAMS

In a profession that should be welcome, which provides a supportive space for students to learn from and with each other, individual accommodations are not sufficient to meet the needs of neurodivergent, disabled, and mad occupational therapy students. Accommodations should be for individualized support, not a means of providing access. They should be for exceptional circumstances and not the default manner of managing difference in our classrooms. We cannot rely on those services to meet the needs of our students and fulfill our responsibilities to them. *We* must be accessible.

Our programs, and our educators, including myself, need to embrace different ways of knowing and being in our profession. We need to reflect on whether what we require of our students truly reflects what and how they need to be able to do, or whether it is simply one way of doing something among a myriad of acceptable ways. We need flexible programs, teaching methods, and evaluation methods, that focus on the strengths of our learners. When there are genuine requirements

to learn a specific way of being or doing, we need to provide explicit and transparent rationale, instructions, and rubrics that reflect our expectations and minimize or eliminate those requirements created around assumed understandings based in a narrative that is the presumed correct way *to do*.

Within occupational therapy educational programs, it is not enough to **offer spaces** to neurodivergent, mad, and disabled students. We must **make space** in our programs and our profession. We need a better understanding of the strengths and challenges of neurodivergent, mad, and disabled students to better support their sense of belonging. Many programs maintain data on the numbers of Indigenous students, students of colour, and disabled students to support and defend a commitment to diversity. We need to recognize that diversity is not just an objective to be addressed by ticking the correct number of boxes, but is the way our profession lives, grows, and thrives to meet the needs of the ever-diverse individuals and collectives that we serve.

I believe that decolonizing our curricula and our profession addresses not only the long-overlooked needs of

our Indigenous students, colleagues, individuals, and collectives with whom we work, but it further addresses the needs of other racialized, disabled, neurodivergent, mad, 2SLGBTQIA+ students and colleagues, individuals, and collectives, by embracing, honouring, and making space for diverse ways of knowing and being.

This imperative is long overdue.

Dr. Natalie MacLeod Schroeder received the Canadian Association of Occupational Therapists' (CAOT) Helen P. LeVesconte Award for Volunteerism in recognition of her extensive and career-long volunteer contributions. She has held clinical, research, health leadership, and academic roles throughout her career, including as the president of the Canadian Occupational Therapy Foundation and a board director for CAOT. Occupational Therapy Now is pleased to share this abridged version of her address.

ABOUT THE AUTHOR

Natalie MacLeod Schroeder has been an occupational therapist for more than 30 years, working clinically, in leadership, and in education. Dr. MacLeod Schroeder can be reached at: Natalie.MacLeodSchroeder@umanitoba.ca.

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ADVOCATING FOR NEURODIVERGENT-AFFIRMING SPACES WITH LIVED EXPERIENCE

Kayla Warren

When I first learned about occupational therapy four years ago, I couldn't have imagined myself as an occupational therapy student advocating for neurodivergent-affirming practices. Instead, I was simply hoping to reduce my anxiety. My occupational therapist helped me understand that most of my anxiety was triggered by too much sensory input and helped me develop sensory modulation skills and tools to use in overstimulating environments. This positive experience prompted me to learn more, which led to my graduate school application. Now, I use my knowledge and experiences to promote access to accommodations, advocate for neurodivergence acceptance, and suggest neurodivergent-affirming practices.

ACCESS TO REGIONAL PLATFORMS GRANTED THROUGH ADVOCACY

I have faced multiple barriers during my education. Each experience has reinforced my desire to increase accessibility for future students. Like others (Bulk et al., 2017), I want to raise awareness about the deeply rooted societal stigma around neurodivergence, mental illness, disability, and the inherent ableism in our society, while simultaneously challenging it. Much like my female role models in science, technology, engineering, and math (STEM) who felt alone in male-dominated fields, I entered the rehabilitation field without knowing neurodivergent academics who could be role models for me. I admire how women in STEM tell others about their journeys, and so I feel it is essential for me to speak up about how neurodivergent people can work as health care providers.

I have been open on social media and Newfoundland news platforms about my university experience and the invisible labour required to address disability-related barriers. These advocacy efforts led to an opportunity to speak on a panel created by Autism Society of Newfoundland and Labrador (ASNL) about my experiences with autism and what towns and schools can do to support Autistic people. This panel included the president of Memorial University of



Newfoundland, a pediatrician from the Janeway Children's Health and Rehabilitation Centre, and a community leader.

I was nervous about potential pushback for speaking out about the barriers I encountered in the occupational therapy program. Instead, speaking out led to an invitation to join an adult autism spectrum disorder working group with other occupational therapists in Newfoundland and Labrador, as a consultant with lived experience navigating the health care system.

KEY MESSAGES WITHIN MY ADVOCACY WORK

Accommodations don't make an environment accessible or equitable

Accommodations are both difficult to access and an insufficient measure to ensure equity. Medical documentation is generally the first step for accessing services, which can be time-consuming and costly. And even with documentation, I still needed to advocate to get the supports I needed for class and fieldwork. In the occupational therapy program, with its focus on equity and justice, I was surprised by the difficulties I encountered. Some of my experiences are similar to experiences described by the "professional misfits" who participated in Beagan et al.'s study (2022), who state that "while those who fit may experience professions as open and committed to diversity, those who constantly come up against the institution may feel the abrasiveness of institutionalized whiteness, upper-class-ness, able-body-mind-ness, and heteronormativity" (p. 3).

Accommodations also don't address the underlying inaccessibility in environments historically designed to oppress people who did not fit into the dominant culture (Pooley & Beagan, 2021). Occupational therapists often advocate for accommodations on an individual level so clients will have their needs met and can be themselves at their school or workplace. The fact that some occupational therapists hide aspects of their own identities suggests that accommodations are not enough to lead to equity

(Beagan et al., 2022; Bulk et al., 2017). Programs must consider options other than accommodations to promote equity, such as part-time study options. While education programs emphasize the need to function in a full-time occupational therapy role across practice sectors, this model offers much less flexibility than the real world (Zafran & Hazlett, 2022). Following graduation, therapists can work part-time or full-time, in an area of practice aligned with their skills and abilities, and in environments that can accommodate fluctuating needs.

Greater acceptance of neurodivergence needed in multiple areas of society

Neurodivergent-affirming practices in towns and businesses

During my ASNL panel presentation, I highlighted benefits of having neurodivergent people as employees and active members of the community (Krzeminska, et al., 2019). I also discussed neurodivergent-friendly ways of communication, such as not forcing eye-contact or suppressing stimming, providing options to email rather than call, and using of alternative forms of communication. There are many other measures that the broader community can implement to increase accessibility for neurodivergent people. Most suggestions will benefit everyone. More accessible environments are both reflective of greater acceptance and

offer greater likelihood of interactions between neurodivergent and neurotypical people, which also leads to acceptance.

Personally, embracing neurodivergence means moving away from the notion of neurodivergent people as broken neurotypicals that need fixing, and instead focusing on how society's practices disable individuals (Bottema-Beutel et al., 2020). I — as do those in my peer community — view neurodivergence as an identity rather than a disorder. What makes neurodivergence disabling is when we are expected to act neurotypical around others and face bullying or heavy criticism when we do not.

EXAMPLES OF COMMUNITY LEVEL ACCOMMODATIONS

SETTING SUGGESTIONS

| SETTING | SUGGESTIONS |
|-----------------------------|---|
| PLACES OF EMPLOYMENT | <ul style="list-style-type: none"> • Where possible, offer flexible work hours and options for both in-person and remote work for all employees. • Allow reasonable accommodations without requiring documentation or disclosure of disability. • If documentation is essential for an employee to receive accommodations, allow for time off, and pay for their assessment. |
| ADVISORY COMMITTEES | <ul style="list-style-type: none"> • Hold committee meetings in accessible locations and provide multiple options to attend. • Advertise meetings in multiple manners (e.g., bulletin boards, radio or TV advertisements, social media). • Offer honorariums when possible: If you designate a neurodivergent person as a regular member on a committee, consider them an expert on accessibility, and offer an honorarium for their time. • Deliver material in multiple formats (e.g., written, large print, verbal, closed captions, digital so can be viewed later). • Provide access to fidget objects, alternative seating, and regular movement breaks. |
| BUSINESSES | <ul style="list-style-type: none"> • Offer sensory-friendly hours where there is no background music, reduced lighting, decreased scanner volume, and fewer people in the store or office. • Train employees about alternative communication forms. • Don't treat stimming as a suspicious behaviour. |
| TOWNS | <ul style="list-style-type: none"> • Provide educational opportunities for businesses and community groups. • Offer incentives for businesses offering sensory-friendly times. • Insist that developers follow universal design principles when designing new buildings. • Retrofit older buildings to meet universal design principles. |

Neurodivergent-affirming practices in education

When asked about neurodivergent practices within education on the panel, I suggested universal design for learning, which encourages a strengths-based approach and supports multiple learning styles (Dalton et al., 2019). Educators should focus more on what a student can do as opposed

to what they can not. In elementary and secondary schools, measures can include allowing fidgeting (e.g., rather than encouraging quiet hands), incorporating movement breaks into lessons, providing alternative seating or standing desks, and allowing sensory breaks without earning them. For post-secondary students, programs can increase flexibility, such as offering

online or in person synchronous and asynchronous classes and options to take programs with part or full-time schedules. To make this option more financially possible, the National Student Loans Service Centre allows students registered with a permanent or prolonged and persistent disability to be classed as full time with a 40% course load and allows a maximum

of 520 weeks instead of the typical 340 weeks (Government of Canada, 2022). However, flexibility is still program dependent. Certainly, I am not the first person to struggle with the occupational therapy program's courseload and there are multiple reasons that qualified students need part-time options to access a program.

I am pleased to use my expertise to highlight areas where there is room for improvement. I hope that awareness about these issues will lead to change, even if it's a slow process and there's still a long battle ahead.

Health care settings benefit from neurodivergent-affirming practices

I'm glad I faced my fear of pushback and spoke on the panel. After the conference, a few occupational therapists approached me with positive feedback. On my next fieldwork placement, my preceptor remembered me, and asked to draw upon my expertise of navigating the health care system as an Autistic adult and join a regional adult autism spectrum disorder working group. She drew upon my strengths to adapt a pre-existing sensory modulation program designed for a mental health setting to be more inclusive for neurodivergent clients. There has been an increase in the number of neurodivergent-identifying adults seeking support for mental health concerns. As occupational therapists, we can respect our clients' identities, even without formal diagnosis, and use evidence-based skills, such as those used for co-occurring mental illness, sensory processing differences, and environmental adaptations (Kirby et al., 2023).

My role in the working group is now permanent. As a service user representative and community consultant, I identify current gaps and ideal solutions, and suggest services that are both beneficial and realistic

within the public health care system's constraints. I have drawn attention to the lack of services for people aging out of the pediatric system, the unclear pathway for an adult diagnosis, and the requirement of a diagnosis to access autism services. Solutions I suggested included: a program for continuing care into adulthood, neurodivergent-informed education for other health care professions, not gatekeeping services to only people with formal diagnosis, and assisting clients navigate the system if they decide to pursue an autism diagnosis.

In a recent initiative, therapists in the working group gathered feedback from clients about their assessment and intervention tools. They are now searching for evidence-based, neurodivergent-affirming alternatives, as well as beginning to modify their communication style as needed so clients can unmask.

Through my attention to advocacy, I found confidence to unmask more often, and neurodivergent clients tell me that my openness took the pressure off them to mask as well. I still feel pressure to mask neurodivergence with clients and co-workers to maintain the status quo. I make my decisions to unmask within the context of my professional responsibilities: to be client-centred and focus on equity and justice when advocating for allocation of resources (ACOTRO, ACOTUP, & CAOT, 2021). I also want to be an example that, even if it's a slow process, speaking up can make a difference in the long term.

My experiences of encountering barriers in post-secondary and health care settings taught me the distinction between the tokenistic use of the words diversity, inclusion, equity, and justice, and living these ideals: making systemic changes and going against the grain to remove structural barriers designed to

exclude those who are different. This knowledge will follow me for the rest of my career, and I will continue to apply the skills I have developed in future practice.

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AD-HOC EDITOR: PAULETTE GUITARD

DEVELOPMENT OF NEW TOOLS IN OCCUPATIONAL THERAPY: **THE ADDED VALUE OF SERVICE USERS' EXPERTISE**

Alexandra Lecours

Given that occupational therapy focuses on collaborative relationships to promote individuals' and communities' occupational participation (Egan & Restall, 2022), it is important to include service users in the development of new tools used in occupational therapists' practice. This article describes our experiences and the benefits of consulting workers in the process of validating a new conceptual model to equip practitioners working in occupational health.

Experts in a given field traditionally develop and update the currently available tools for guiding professional practice through a scientific research process. For example, a new tool to assess a person's driving abilities could be developed and validated by researchers with expertise in cognitive science or visual perception. Good practices in the development of such tools also involve professionals, such as occupational therapists. This enables access to a wealth of practical experience (Jorm, 2015). However, few studies account for the knowledge and perspectives of service users, e.g., the individuals or communities for whom these tools are intended.

MODEL OF PREVENTIVE BEHAVIOURS AT WORK: ILLUSTRATION OF A VALIDATION PROCESS WHICH INCLUDES SERVICE USERS

The Model of Preventive Behaviours at Work was developed to support occupational therapists in understanding the different variables that influence healthy participation in work (Lecours, 2020). Specifically, it presents individual (e.g., education and experience), organizational (e.g., values and priorities), and societal (e.g., laws and rules) factors that influence individuals' ability to engage in behaviours conducive to their health, safety, and well-being at work. This model can help occupational therapists support people and organizations in their efforts to prevent workplace injuries and disability. This model, during its development process, has been the subject of validation studies with experts in organizational health research (Lecours, 2021) and professionals, including occupational therapists (Lecours, 2023). We subsequently conducted a consultation with workers to enrich the validation process. Indeed, Arblaster and colleagues (2018) suggest that obtaining a diversity of experiences, including data based on subjective life experiences, adds value to a validation process' quality. Among other approaches, triangulating opinions from people with varied expertise on a topic (e.g., scientific, professional, experiential) provides more realistic validation (Carter et al., 2014).



Given these benefits, we attempted the experiment of validating the Model of Preventive Behaviours at Work with nine workers of varying genders, ages, fields of work, and experiences. Discussions supported by open-ended questions allowed us to document the worker's views on the model's clarity, relevance, representativeness, completeness, and practical applicability (Lecours, 2023).

KNOWLEDGE AND EXPERIENCES OF SERVICE USERS: ENHANCING THE PROJECT

The ideas the group shared allowed us to improve the model to make it more usable in the field. For example, some people made concrete remarks to clarify terms used in the model: *"I don't understand what the word 'request' means. I am not sure what that applies to."* Others raised issues related to the model's applicability: *"The second preventive behaviour, I understand it, but I don't see it in my job. I have a hard time seeing how it can be applied, how it can be possible in the restoration."* These discussions with workers also allowed us to note the model's strengths, particularly regarding its relevance for practice, as this worker says: *"I think it would be good for everyone to use this model; this would promote communication within the team regarding occupational health."* The group also found the model to be comprehensive and applicable to the various realities of people at work: *"I think the model is very well done, it is global and touches on many factors. It is exhaustive and can be applied to several trades."*

This consultation process helped to build on the model's strengths and identified changes to improve elements identified as less clear or relevant. These changes, based on service users' opinions, reinforced the model's applicability to their work environments. This validation exercise also contributed to the model's usability in a collaborative relationship between the occupational therapist and individuals or communities. Including the service user community adds a more human component to the research process for developing or validating tools for professional practice (Lakeman, 2010), and allows for a better approach to practical issues and sustainable changes in practice (Green et al., 2009).

In conclusion, the experience with the Model of Preventive Behaviours at Work's development and validation has been positive and has enhanced our tool. We hope this information will inspire other occupational therapy teams to include service users in their work given the many benefits encountered, particularly in facilitating the application of occupational therapy knowledge. This avenue also represents a way to apply collaborative relationships in occupational therapy research.

ADDED VALUE OF CONSULTING SERVICE USERS AS PART OF THE VALIDATION OF THE MODEL OF PREVENTIVE BEHAVIOURS AT WORK

Provides access to experiential knowledge in tandem with scientific and professional knowledge

Improves the tool's apparent validity, acceptability, and applicability

Ensures a level of literacy adapted to the user population

Promotes the power of service users in the research process

Promotes collaboration between research teams and the community

Enables a first step in translating knowledge from research to practice

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EMPOWERING OUR HEALERS: OCCUPATIONAL THERAPY'S IMPACT ON PHYSICIAN HEALTH

Ashley Warnock & Adam Ly

When I, Dr. Ashley Warnock, connected with my co-author, Adam Ly — an occupational therapist — I was partway through my residency and struggling with my work-life balance. I had assumed physicians didn't use occupational therapy services themselves, but I have since come to appreciate the value that occupational therapy adds to the health care system. Adam and I wish to identify common mental health challenges physicians experience, provide a case example, and highlight the skills occupational therapists can use in supporting physician health.

According to the National Physician Health Survey, among more than 3,800 Canadian physicians, 53% reported symptoms of burnout, 25% reported experiencing moderate to severe levels of anxiety, 48% screened positive for depression, and 36% reported thoughts of suicide at some point in their lives (Ipsos, 2022). Approximately half of the respondents are either likely or very likely to reduce their clinical work hours in the next 24 months. Major barriers for physicians in maintaining a healthy lifestyle include a lack of time, heavy workloads, stressful work environments, and long hours. Only 33% indicated that they had access to psychosocial support in their current workplace. Overall, the report showed that doctors' mental health has declined since the 2017 survey (Ipsos, 2022).

THE ROLE OF OCCUPATIONAL THERAPY IN SUPPORTING PHYSICIAN HEALTH

Occupational therapists can collaborate with physicians to address factors that impact their health. The occupational science or therapy lens enables a comprehensive approach to challenges that physicians encounter within their work contexts and reveal how doctors' cognitive, physical, emotional, and environment-related skills support or create barriers. Physician health issues can include burnout, perfectionism, and coping with ableism/sanism in medicine. Burnout is an occupational hazard, which may make an occupational therapy lens particularly relevant in identifying and addressing the causes of physician burnout (World Health Organization, 2019). Physicians may also internalize high standards from their social and work contexts, which can enable unhealthy perfectionism (Gerada, 2019; Peters & King, 2012). Occupational therapists can help people identify ableist/sanist policies and advocate for safer work environments (Neilson, 2020). With their focus on occupational participation and understanding of the biopsychosocial model and health care systems, occupational therapists have a broad skillset that can improve physicians' mental health, occupational participation, and wellbeing (see Figure 1).

Figure 1

EXAMPLES OF OCCUPATIONAL THERAPY ROLES WITH PHYSICIANS



DR. WARNOCK: ILLUSTRATING THE OCCUPATIONAL THERAPY ROLE

Residency at the University of Toronto's Department of Psychiatry is an enriching experience. Students and staff have the privilege of learning from psychiatric experts and an exceptionally diverse group of people with lived experience. Every day, I attend to meaningful clinical duties and listen to patient concerns, provide care in Canada's busiest emergency department on-call (after hours), perform routine administrative duties, such as documentation and medication prescription, and participate in extracurricular leadership activities. When I met Adam, I struggled to find balance in my work and personal life as someone with an identity other than that of a doctor. I occupied many life roles that I was not fulfilling at the time, such as a friend and partner. I knew that to be the best doctor I could be, I needed to fulfill all my life roles that were important to me.

By tailoring treatment to my individual needs, occupational therapy assisted me to develop a framework for completing goals and managing demands. For example, Adam and I spent time talking about my values and ways to complete high-quality work without sacrificing them. We determined opportunities to implement personal and professional boundaries that helped create meaning in my life at work and home. Fortunately, my health care provider understood the role of occupational therapy and made a referral to make this happen!

THE EFFECTS OF OCCUPATIONAL THERAPY ON MY HEALTH AND WELLNESS

In addition to clinical knowledge, a physician's role necessitates cognitive flexibility and advanced management skills. This is not easy. Occupational therapists can assist physicians to manage workload and workplace issues and learn strategies and skills for overall wellbeing. They can also advocate for better working conditions for physicians, such as accommodations or policy changes.

My residency experience has been greatly influenced by occupational therapy.

Because I am only halfway through my training program, I am grateful that I still have time to implement the strategies Adam taught me. I've evolved into a more efficient learner who enjoys her work, and I believe this has influenced the quality of care that I provide. Working with an occupational therapist taught me how to better understand myself and how I best perform my work, set realistic expectations of myself and others, implement boundaries, navigate workplace resources and supports, educate myself about healthy living, use skills that I learned in context, and improve my work efficiency. I am also more confident in expressing my needs.

THE MISCONCEPTION OF OCCUPATIONAL THERAPY

I believe that physicians as a whole underuse occupational therapy services. In retrospect, I feel this is due to physicians' lack of awareness of, and exposure to, occupational therapy for health care professionals. There is also a stigma associated with mental health and disability which can prevent physicians from seeking help. Many physicians perceive a societal expectation that we should be infallible and possess unwavering cognitive, emotional, and psychological strength. But, like our patients, physicians are human beings who will struggle from time to time. Physicians can have disabilities, both visible and invisible (Church, 2017).

ADAM LY: SUPPORTING PHYSICIANS AS AN OCCUPATIONAL THERAPIST

I have worked with many physicians over the years to return to work, stay at work, and to participate in occupations that are important to them. I have also advocated for physicians in institutions with ableist policies and procedures, who are now thriving after changes happened. In one case, the institution's accessibility department hired an occupational therapist!

As Dr. Warnock's experience demonstrates, occupational therapists can support physicians to develop and refine skills, advocate for their needs, and promote institutional change. Physicians have unique needs, environmental demands, and contexts that can impact their functioning and wellbeing. Occupational

therapists can assess environmental issues and help physicians to live more meaningful and healthy lives both personally and professionally. I encourage physicians to learn about occupational therapy's scope by either visiting occupational therapy associations' webpages or talking to occupational therapists and physicians who have used them either for themselves or their patients.

We encourage physicians to promote occupational therapy to other physicians and stakeholders to increase awareness, access, and care. Occupational therapists can be one piece of the puzzle to help physicians resolve worsening systemic and individual health challenges. Physicians need support — occupational therapists can listen, empower, guide, advocate, and collaborate!

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HOW OCCUPATIONAL THERAPY IS THE UNSUNG HERO IN MY ARTHRITIS CARE TEAM

Eileen Davidson



Arthritis is so much more than joint pain.

It also takes an integrative team to treat many forms of arthritis.

I live with rheumatoid arthritis (RA), which I was diagnosed with at the young age of 29. It's hard to think of an aspect in my life unaffected by arthritis.

As a single mother, the unrelenting fatigue can make caring for myself and my child seem like a mountain to climb each day.

Arthritis is the most common cause of long-term disability in Canada. One in five Canadians live with a form of the more than 200 forms of arthritis musculoskeletal conditions (Arthritis Society Canada, 2023), and a lot of people need an occupational therapist's guidance.

Rheumatologists can give advice on medications to combat our diseases and describe what they are, but they don't really explain how to adapt and live well with arthritis. They are also an important part of our health care team when it comes to sending us to the right care we need outside of their scope. Fortunately, my rheumatologist referred me to occupational therapy.

ARTHRITIS IMPACTS ALMOST EVERYTHING WE DO

Arthritis can make simple daily tasks painful, such as washing my face or vacuuming. A shower can leave me in need of a nap. Medications and inflammation can cause me to be foggy and forgetful. Every day I walk a fine line between doing too much or too little, both of which can aggravate my arthritis symptoms.

The struggles that I experience daily are incredibly common. Initially, I felt incredibly alone in how arthritis was affecting me each day, but that is far from the truth.

Occupational therapy can help us better participate in activities of daily living, maintain independence, and achieve a better overall quality of life while helping protect inflamed and painful joints and other debilitating arthritis symptoms.

MY EXPERIENCE WITH OCCUPATIONAL THERAPY HAS CHANGED OVER THE YEARS

I went from being devastated to a patient leader. Eight years into my diagnosis, I am now a well-known RA patient advocate, writer, speaker, support group host, and patient partner in health research and steering committees. For all I do now as a patient advocate, I can thank occupational therapy. My therapist helped me understand, navigate, and thrive while doing what I love to do as an advocate, mother, and person living with arthritis.

OCCUPATIONAL THERAPISTS GO BEYOND HELPING US WITH WORK

I knew what a physiotherapist was, but I had no clue what an occupational therapist was. By the time I was diagnosed, I was ready to be placed on long-term disability, so I wondered why I needed to see one if I didn't have an occupation anymore. Little did I know occupational therapists could help me with so many aspects of my life that I was struggling with due to my arthritis diagnosis and the comorbidities that come with it.

Occupational therapists aren't there for only work advice. "Occupation" means

the things we need, like, and want to do — from parenting, socializing, house chores, our sex lives, and of course work life balance. The occupational therapists I have met through my own treatment and advocacy work use easy-to-understand language, so I actually get what they are saying. The role of an occupational therapist is endless, much like our journey with arthritis.

OCCUPATIONAL THERAPISTS HELP WITH THE LITTLE THINGS THAT BECOME A BIG DEAL

Help with joint protection

One of the simplest, yet most efficient, pieces of advice from an occupational therapist was simply to put my most used items at arm's length to reduce joint pain and overuse. These modifications around my environment help me avoid overusing my joints, reduce fatigue triggers, and prevent further injury.

Now I have shelves placed around my house with my most-used items easy to reach and ready for use, which surprisingly reduces a lot of pain for myself. Arthritis also causes cognitive dysfunction, so this simplifies my daily routine even when I am feeling forgetful, foggy, and confused from my disease or medications.

Help with self-management

Occupational therapists introduced me to prioritizing, pacing, positioning, and planning (Gilmour, 2021). Without these, RA can be extremely overwhelming.

Prioritizing - When living with chronic pain and limited energy, prioritizing what really matters to us is key.

Pacing - Breaking down the activities that worsen symptoms into smaller tasks can make a significant difference in our productivity levels while navigating difficult-to-manage symptoms, such as fatigue.

Positioning - As a writer with RA, I spend hours at the computer, which is one of my biggest pain and fatigue triggers. Proper posture and body ergonomics is a game changer for me.

Planning - I always have to plan my day to balance my symptoms. It was an occupational therapist who asked me what time of day I feel my best and pointed out that is when I should be doing my most strenuous tasks.

HELP WITH UNDERSTANDING THE MECHANISM OF OUR PAIN

Occupational therapy can help us understand the “mechanism” of the pain and equip us with tools, techniques, and exercises to help alleviate it. For example, an occupational therapist mentioned I was adding too much heat to my inflamed joints. Instead, I should have been adding ice because heat increases inflammation.

HELP WITH THE OVERWHELMING CHOICES WHEN SELECTING ASSISTIVE DEVICES

When searching for the right assistive devices to aid with arthritis, it can be incredibly overwhelming to consider what we need for specific joint issues and what is good quality or cost effective.

My first device was less than successful. My pre-diagnosis pain was brushed off as discomfort caused by carpal tunnel. The suggested wrist brace from the drug store always felt too tight as there was not enough space for my joint swelling. Eventually, I did find a physician who listened and agreed to test for RA; I then began to get more support.

There is no doubt that using equipment that can help place less stress on joints is really useful in managing

RA, but which is best for us? How do we properly use them? What do we actually need? Electric can opener, jar openers and extended tap turners, a raised toilet seat, a tool to wipe ourselves? A little help to narrow down the options goes a long way.

THE PROBLEM IS...

There is, however, a huge problem. Not everyone with arthritis is being sent to see an occupational therapist in a timely manner or has access to occupational therapy, especially if they live in a rural environment, or have financial or language barriers. Some rheumatologists omit to inform patients they can be referred to an occupational therapist.

Unfortunately, I did not get to see an occupational therapist when my son was a baby, but I now know that an occupational therapist could have been really helpful for me as I struggled so much with childproof locks or carrying items. I missed out on this pivotal help in my role as a mother with RA. Early and effective treatment is crucial in the outcome of someone’s journey with RA and I wish I had benefited from an occupational therapist’s advice as activities became more difficult.

As someone living with arthritis, I believe it is incredibly important to send patients — either newly diagnosed or throughout their progressive arthritis journey — to an occupational therapist. The lack of referral and knowledge about their roles leads to a lot of people relying on what they read online when they should have access to efficient, customized, comprehensive support.

MY CONCLUSION AS SOMEONE LIVING WITH ARTHRITIS

Occupational therapists play a crucial role in my health care team. Not only do I now understand occupational therapy’s importance in my own chronic illness journey, but also in the health care system in general. Occupational therapists can provide

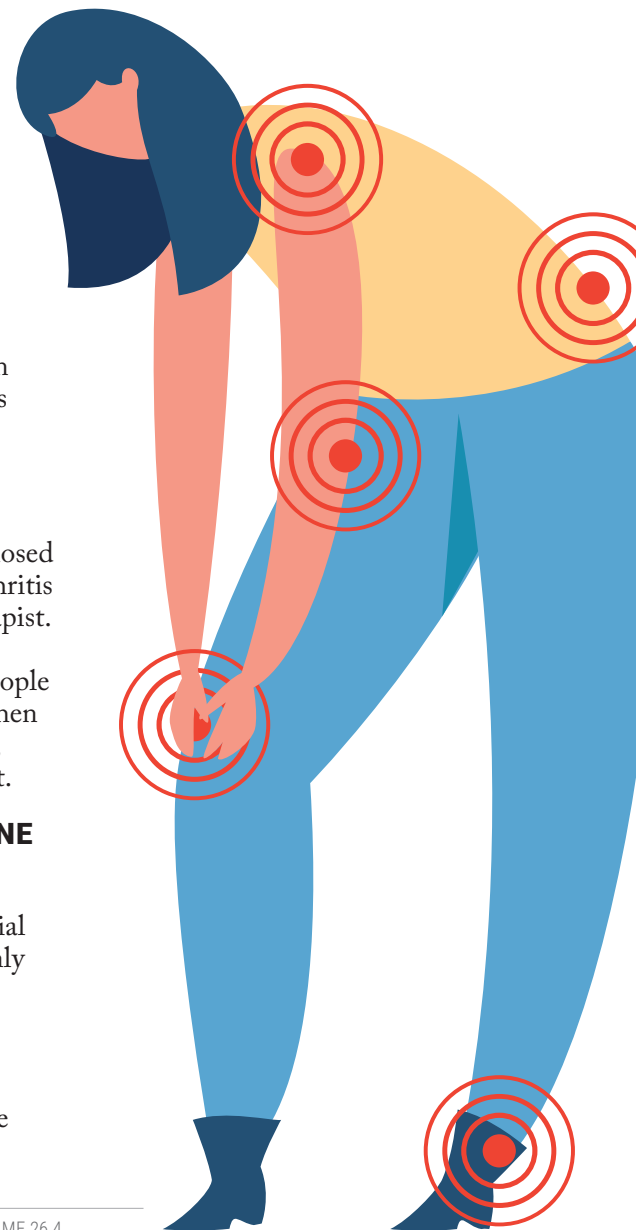
many answers to help understand, adapt, or navigate the complex issues that come with RA and other forms of arthritis. They provide a unique type of care and expertise that has been valuable throughout my journey.

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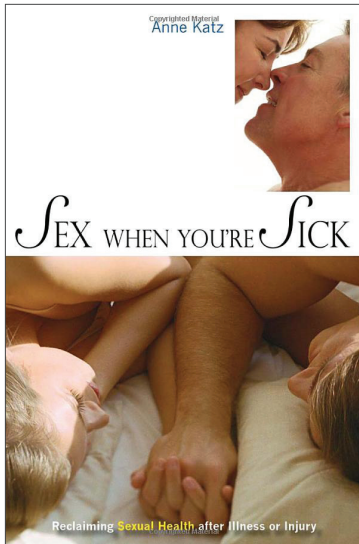


BOOK REVIEW

SEX WHEN YOU'RE SICK: RECLAIMING SEXUAL HEALTH AFTER ILLNESS OR INJURY.

Anne Katz, 2014. Hygeia Media.

Review by Naomi Hazlett, MScOT, BSc, erg.



Injury or illness requires adjustments in life . . . but does not equal the end of loving. (p. ix)

WHO IS THIS BOOK FOR?

People looking for information to apply in their own lives and to begin conversations with their care providers.

Occupational therapists who are looking for specific information on sex, injury, and illness.

It is difficult to bring up sex with your therapist. It's hard to know what to ask, and it's hard to know what you need. *Sex When You're Sick* helps begin that conversation.

While more technical than some self-help books, it is grounded in anecdotes and examples to help the reader apply the strategies inside. These accounts can help people seeking information find the right words to describe their challenges and feel less alone in their own journey. The technical knowledge also arms readers with an idea of what to expect when

adjusting their sex life to align with their changing abilities.

Occupational therapists will find information to help them understand the impact of specific illnesses and diagnoses on sexual health.

Sex When You're Sick is a good first resource since it lays a foundation for those looking to learn more about sex and illness or injury. It is a great complement to more contemporary books that focus on specific diagnoses and other aspects of sexuality. 🍷

IN THE NEXT ISSUE SEPTEMBER/OCTOBER 2023



The next issue of *OT Now* shines a spotlight on *CAOT 2023 Conference: Hybrid*. Read or skim the pages for summaries of take-home conference messages (both everyday practice ideas and policy initiatives) and discover how "A Year of Yes" led Moira Peña to become the closing ceremony's featured speaker. You'll also be inspired to reignite your passion and embrace neurodiversity-affirming practices, learn about issues impacting occupational therapy in Saskatchewan, reflect on curiosity as a life-long practice, and even find out how Phillip Wendt's dedication as CAOT president led him to be locked in a conference room! If you missed this year's conference, or would like to recapture the energy, we hope you will take a stroll through this issue while imagining breathtaking Saskatchewan skies.





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Don't overspend on your insurance. Make the switch today for better savings, preferred service and coverage that's tailored to you.



1. On average, clients save 20%. Savings are based on each client's individual profile.

2. Parking tickets are not taken into account. Discounts may vary per province.

3. Discounts may vary per province.