Voices
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Music Therapists’ Lived Experience as a Radical Resource:

Moving Beyond Traditional Views on Divergent Bodies and Minds

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Abstract

Within this two-part multimedia publication, music therapists from Australia and Aotearoa, New Zealand present and consider a composite character’s experiences of ableism in music therapy study and practice, drawing from current literature and their lived experiences of disability, neurodivergence, and chronic health conditions. Mainstream healthcare approaches have traditionally prioritised amending perceived deficits. Many contemporary approaches shift focus to supporting individuals to access their full potential by utilising personal strengths and resources. Despite this shift, the options considered viable within this “full potential” still seem influenced by ableist assumptions embedded in healthcare literature, professional registration requirements, and wider societal systems and structures. Cumulatively, these assumptions position disabled identities and experiences as inherently incompatible with those of healthcare professionals. Beyond perpetuating disempowering narratives, this compromises the inclusivity and future potential of music therapy as a discipline and profession. Disabled clinicians are uniquely positioned to identify the aspects of clinical practice and study that disproportionately disadvantage disabled people, as well as options for circumventing or dismantling these barriers. Expertise developed through both receiving and facilitating professional healthcare services as a disabled person can also enhance participant experiences by informing the development and provision of more inclusive and relevant therapeutic frameworks.

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Video: Music therapists' lived experience as a radical resource (Calls to the Please Disturb Hotline). Link: https://www.youtube.com/watch?v=0sFSremGz7s.

Introductory Section

Publication and Video Information

This paper is presented in two parts. Part one, this Introductory Section contains information to contextualise and position this work. This is presented in written text, however screen readers and text-to-speech programs can be used by readers who require an audio format. Part two, titled Calls to the Please Disturb Hotline is presented as a video with accompanying transcript for multi-format accessibility. The content is structured around a hypothetical call centre helpline. As operators for the call centre, the authors respond to a fictional composite character who calls with questions relevant to the intersections of being disabled and being a music therapist (current or aspiring). PowerPoint slides are visible throughout the video. Slides generally feature the character avatar with some accompanying text, or a reflective prompt related to the call's theme. Picture-in-picture videos of the authors are displayed in the top-right corner of the screen whenever they are speaking. Within the transcript, square brackets ("[ ]") are occasionally used to support readability by denoting words which were missed or are inaudible in the video recording

The "Please Disturb" moniker references the theme of the 2022 European Music Therapy Conference ("Music therapy in Progress: Please Disturb"), where an earlier version of this content was first presented. The content has been re-written and re-recorded for publication in Voices with permission from the 2022 conference chairs. "Please Disturb" is also intended as a provocative reference to the experience of many disabled people whose natural human variations are perceived as "disturbing" by others; and our intention as a group of authors to "disturb" the systems that perpetuate this.

In creating an academic work that advocates for the perspectives of people with lived experience of disability in professional spaces, we also wanted to model different ways to share these perspectives and engage with academic content. Although this is ultimately a work which addresses serious themes, we felt it was also important to somewhat diverge from traditions of academic ableism and playfully disturb hierarchical expectations around how content needs to be presented in order to be recognised as legitimate (while still offering a more formal and traditional presentation via the transcript).

Through filming this work, we are shifting our publication from a purely academic written manuscript to a space of performance. Our voices and visible mannerisms are linked with the content for transparency regarding the author's described positionalities; and our use of first-person language further emphasises these links, while also challenging academic linguistic hierarchies (Flores, 2020; Mauranen et al., 2020). Our chosen format of a hypothetical call centre allows content to be shared in a less formal and more conversational style, with moments of humour inserted to alleviate the tension that can be felt when addressing serious content (Anesi, 2018). This format also provides a structure which outlines a specific theme for each call (section of the work) and creates space for moments of reflection in between calls. Our decision to focus on calls from a single character contextualises each call's theme within an overarching narrative, bringing an element of storytelling to this performance.

Humour and performance are radical spaces that have traditionally been among the few platforms for divergent and marginalised identities to publicly share any aspect of their stories (Jones, 2021). Over time, these spaces have been utilised as accessible platforms for advocacy, transforming narratives of "laughing *at* us" to "laughing *with* us" (Lockyer, 2015). Currently, members of marginalised groups frequently utilise these creative outlets for many advocatory purposes, such as to cope with oppression, reclaim and celebrate collective identities, resist and disrupt dominant beliefs, and enact social change (Anesi, 2018; Jones, 2021; Morva, 2016; Shain, 2013).

Engaging with Filmed Content

We invite you to engage with the filmed content in whatever way is most accessible for you. You may prefer to solely engage with the video or the transcript, or you may choose to engage with both at once, or at different times. Although this work conveys a longer-term narrative, the "call centre" format allows content to be broken down into six individual call-themes. You may choose to pause after each call to further reflect on the content or otherwise take a break and come back to it later. Additionally, a timestamped list of contents is provided here to support you in selecting your own starting point:

- Please Disturb Hotline Disclaimer (2:46).
- Call number 1: Models of Disability (4:06).
- Reflective Prompt 1 (12:11).
- Call number 2: Ableism (12:57).
- Reflective Prompt 2 (19:22).
- Call number 3: Crip Time Perspectives (20:10).
- Reflective Prompt 3 (28:45).
- Call number 4: Safety and Disclosure (29:25).
- Reflective Prompt 4 (36:36).
- Call number 5: Accessibility (37:20).
- Reflective Prompt 5 (46:00).
- Call number 6: Advocacy, Questions, and Reflections (46: 54).
- Closing material (54:14).

Within the video, closed captions are enabled for reading the text as it is spoken. You may also choose to have the video open in one tab, and read along with the script in another tab. We have chosen to speak at paces that are accessible for us. If these are not accessible for you, you can increase or decrease the video's playback speed in the "settings" menu below the video. If you require a more consistent vocal pace, or a more familiar accent, you may also choose to input the transcript into a screen reader or text-to-speech generator and adjust the settings as needed.

Between each call, a PowerPoint slide displays a reflective question with "hold music" for the "Please Disturb Hotline" playing in the background. The "hold music" is designed to emulate the feeling of being unpredictably on-hold when contacting a call-centre, and to offer a range of visual and auditory stimuli for those who require this to support their focus. If you require less stimuli to focus, you can pause or mute the video to support your reflections.

Musical Description

The music used in this video was composed and recorded by Zoë Kalenderidis. The music intends to resemble tracks often used while people are "on hold" waiting for someone to answer the phone. It has a groovy jazz feel, performed with a smooth soprano voice and guitar finger-picking accompaniment. The music is played for longer durations at the start and end of the video. Between each phone call, an instrumental version of the music plays for a random duration, then ends abruptly with the sound of a phone ringing to indicate that the call is about to commence. A description of the music with lyrics is provided here:

> *(Jazz-style guitar solo as music fades in)*
> Thank you for calling the please disturb hotline.
> Thank you for calling the please disturb hotline.
> We'll be with you… We'll be with you… Soon….
> *(Jazz-style guitar solo)*
> We'll be with you… We'll be with you…Soon….
> *(Jazz-style guitar solo as music fades out)*

Character Description and Author Positionality

All calls to the "Please Disturb" hotline are made by a single composite character as they transition through different phases of engagement with the music therapy profession: from prospective music therapy student through to experienced music therapist. Throughout these transitions, the character also engages with the less linear process of learning more about disability in relation to their own lived experiences and those of others.

Within the transcript, these phases are conveyed through changes in the language used by the character and the ways they describe their personal experiences and understanding of disability. Visually, the character is shown to age part-way through the presentation, and with each call they are drawn wearing different symbols that reflect their personal understanding of disability. These symbols also contextualise the time period of this publication and the passing of time across the development of this work. In the slides for question 6, the character wears a pin displaying the original Disability Pride Flag, designed in 2016 by Ann Magill (Magill, 2016). On July 28, 2021, after our character avatar's design was finalised, Magill released a visually safer flag design (Magill, 2021). The Visually Safer Disability Pride Flag is featured as the background image for the initial slide of this presentation. The meaning of other symbols displayed by the character are explained across the final slides.

The perspectives expressed by the character are primarily drawn from our collective lived experiences. They are also contextualised by our understanding of the lived experience narratives that have been personally shared with us and that we have encountered through media and literature. Although the experiences of this character reflect more than one author's story, they are not intended to *represent* more than one experience of disability.

The identities and experiences of people who identify as disabled are influenced by innumerable intersectional factors, such as race, gender, class, and religion, among others. These positions influence how the characteristics and expression of an individual's disability will be interpreted by others in their daily life and general society. This extends to influencing the forms of support an individual can (or cannot) access, and forms of discrimination they may be disproportionally exposed to or protected from. In turn, these societal factors shape personal experiences of disability and the resulting daily-life adjustments that they (and/or their loved ones) must make for their safety and quality of life.

Within the "category" of disability, we each have different positions and experiences in terms of: what aspects of our lives are influenced by characteristics of our disability, and how this occurs; the ease or difficulty of perceiving self as disabled; experiences of disclosure as a choice or not; access to healthcare and relevant medical support; whether characteristics of our disabilities are enduring or fluctuating; and whether the influence of our disabilities is more apparent in physical, cognitive, sensory, or other domains.

Our overall positions as disabled people also hold similarities which restrict our collective lived understanding of disability and what it means to "be disabled." For example, within current societal interpretations of race and gender, we are all considered white, and we all identify as, or are socially coded as, women. We have all completed a minimum level of Master's education. We all received access to some form of musical education in childhood or adolescence and are all currently working as music therapists in some capacity. We also live and work in countries with British colonial histories and similar (but not identical) dominant cultural norms.

These circumstances do not reflect those of all disabled people. In particular, due to our racial identities and educational backgrounds, societal power relations offer us privileges that are not extended to all disabled people. While we recognise that our racial and educational positions are overrepresented within the sphere of academic works by authors with lived experience of disability, we also recognise that within broader academic spaces, and within academic research and literature pertaining to disability, *all* lived experiences of disability are underrepresented.

Our intention with this work is to highlight the unique contributions that disabled music therapists can bring to our profession, along with some of the barriers that disabled people can experience in entering or remaining in this field. The combination of these personal and professional identities offers a distinct perspective which is similar to, and different from, that of people who are either "disabled" *or* "music therapists."

More broadly, by acknowledging the existence of disabled music therapists, we are intending to "disturb" enduring beliefs that "Disabled" and "Healthcare Professional" are mutually exclusive identities; and challenge the entrenched ableism that consciously or subconsciously governs healthcare students and professionals to conceal their disabled identities, and practice in ways that conform to non-disabled expectations (Jain, 2020).

Within these intentions, we are mindful of our own positionalities and how these influence the scope of story we can ethically tell. Although all forms of oppression are linked by the overall priorities of hierarchical systems (Berne et al., 2018), there are forms of systemic discrimination which we cannot personally speak to. In particular, we cannot speak to personal experiences of racialisation in relation to our experiences of disability, or intersecting experiences of ableism and racism. We recommend that those seeking to further understand the links between different forms of oppression begin by engaging with the concept of intersectionality, as coined in Crenshaw's seminal 1989 article, and further described in other works. We also highly recommend engaging with content created by disabled, neurodivergent, and chronically ill people whose intersectional identities diverge from our own. Some examples are provided in the Appendix.

Character Avatar: Visual Design

The character avatars presented on slides throughout this video were drawn by Rhyll Hunt (Brede's younger sister). Many aspects of the character's identity and visual design have been left intentionally ambiguous to plausibly encompass a greater range of disabled identities, and to avoid more stereotypical depictions of disability. Some aspects of character design could be left completely ambiguous through restricting the scope of visual cues. For example, rather than showing their whole body, the character is drawn from the shoulders up. This creates more possibilities for imagining the presence (or absence) of physical characteristics associated with particular disabilities, and external indicators like the presence of physical aids. Similarly, the use of a static rather than animated avatar was chosen to limit assumptions that may be made based on the fluidity and range of movements involved in their communication. Although the character's dialogue is spoken by one of the authors, the character's personal method of verbal communication cannot be determined from a static image.

Some aspects of the character's visual design could not remain ambiguous, as the act of creating any visual representation inherently requires decisions to include or exclude certain visible markers of identity. As there is no single way to be disabled, the ambiguity or specificity of some visual markers will be representative of some disabled people and not representative of others. This is further described below, however those who do not wish to be influenced by any visual representation are invited to end this introductory section here and engage with the video's content by reading the transcript or listening to the audio without viewing the visual content.

The character is drawn with ambiguous gender expression to reduce unnecessary gendered assumptions. Similarly, the choice to leave this character unnamed was made to avoid connotations to particular genders or nationalities. The lack of visible facial markers was chosen to reflect majority presentation and avoid visual markers that are overly specific to particular disabilities. We acknowledge that this does not reflect experiences that may or may not be considered disabling, such as: craniofacial conditions like cleft lip and palate or hemifacial microsomia; skin conditions like ichthyosis or vitiligo; or use of external physical devices such as a nasal canula or cochlear implant.

The character's clothing, a button-up shirt and lanyards, reflects "gender-neutral" workplace attire in the author's cultural contexts, but is not intended as a universal representation of workplace attire. Similarly, the absence of symbols or clothing associated with particular religions or spiritualities does not reflect the presentation of all disabled people; however, it allows the character's religious status to be left open. The lack of specific visual markers here could represent: adherence to no religion or to a religion that doesn't display symbols; a personal choice or cultural/political requirement to not display symbols; or that aspects of their disability prevent certain body modifications or the safe adornment of coverings and symbols.

The character is drawn with a fair/light-olive skin tone. This was chosen as a composite reflection of the author's skin tones and cultural heritages as the character's narrative is primarily informed by our personal experiences. We recognise the potential harm of contributing to the overrepresentation of lighter skin tones in medical literature and more general depictions of disability (Aspler et al., 2022; Louie & Wilkes, 2018; Massie et al., 2021). However, we feel a sense of responsibility to not perpetuate harm through the tokenistic representation (Rona, 2023) or "digital blackface" (Sobande, 2021) of appropriating culturally distinctive features and visual markers that do not reflect our lived experiences. From the combination of our lived experiences, there are many stories we can share. There are many more that are not ours to share.

Calls to the Please Disturb Hotline: Video Transcript

Video Link: Music therapists' lived experience as a radical resource (Calls to the Please Disturb Hotline). Link: https://www.youtube.com/watch?v=0sFSremGz7s

Slides 1-3 Description: Slides are titled "Acknowledgements" and contain images of the Aboriginal, Torres Strait Islander, and tino rangatiratanga (national Māori) flags over a white background. Text matching the transcript for this section is progressively revealed across each slide. Picture-in-picture videos of all four authors are laid over the right border of the slides.

> **Grace:** Welcome everyone. This content was developed across Wurundjeri Woi Wurrung and Bunurong lands in Australia, and Aotearoa New Zealand. We acknowledge the Traditional Custodians of these lands, and that their ongoing connections with community, music, and healing precede the formalisation of music therapy as a discipline by millennia.
>
> **Carolyn:** We pay our respects to their Kaumātua**,** Elders, past and present, and extend

this to any First Nations and tangata whenua engaging with this video today. We respect the principles of te tiriti o waitangi.

Zoë: We also acknowledge those in the disability and other marginalised communities who came before us and fought for disabled rights and justice, and those who continue to do so every day. They make it possible for many of us to be included in this conversation today.

Brede: And we acknowledge that we do not speak for all music therapists with lived experience of disability, neurodivergence and chronic physical or mental health conditions. The perspectives and opinions we express here reflect our own experiences as well as our interpretations of the literature and discussions we have encountered up to this point.

Slide 4 Description: Slide contains the following text: "Music therapist's lived experience as a radical resource: Moving beyond traditional views of divergent bodies and minds." The authors names, post-nominals, and geographic regions are listed underneath this. Slide background is an image of the Visually Safer Disability Pride Flag created by Ann Magill (2021). The flag is black with five diagonal stripes in the following colours from top to bottom: green, blue, white, yellow, red. Picture-in-picture videos of all four authors are laid over the right border of the slide.

Brede: This material has been written in the style of a call-centre hotline, accessed by a fictional character at different stages of their music therapy career. During each call, a slideshow will be visible with an illustrated image of this character, as well as the title of the question. At the end of each call, the slide changes to a reflective prompt for further consideration.

My name is Brede and I'll be voicing our character, so I'll introduce myself now. Our other speakers, Carolyn, Grace, and Zoë will introduce themselves as they take calls during the video. So, I'm a white queer person who fluctuates between "she" and "they" pronouns. In earlier versions of this work, I introduced myself as being in my mid or late 20's, but with the passing of time, I've recently turned 30. I live and work in Narrm, also known as Melbourne, Australia; and I currently have access to financial stability, healthcare, and disability supports. I worked as a disability support worker for about five years, and since graduating at the end of 2020, I've worked as a music therapist in a specialist school and through private work in individual, family, and group settings. Depending on the context, I typically identify as disabled or neurodivergent, but I haven't always been so comfortable with these terms.

Question One: Models of Disability

Slide 5 Description: A white slide with an image of the character avatar next to a cartoon phone. Slide is titled with the following text: "Call number 1: Models of Disability." Picture-in-picture videos of Zoë and Brede are laid over the right border of the slide.

Generic phone-ring sound.

Operator (Zoë): Thank you for calling the *Please Disturb* hotline. For the health and safety of our volunteers, we are unable to accept calls that debate their lived experiences of disability; so if you would like to file a complaint, please ensure this is directed toward the relevant system of oppression. Please hold for the next available operator.

"Hold" music plays while waiting for an operator.

Slide 6 Description: As above, with the addition of audio description text for the "please disturb hold music" and lyrics displayed on the right side of the slide (as written under "Musical Description" within the Introductory Section). Picture-in-picture video of Brede is laid over the right border of the slide.

Slide 7 Description: A white slide with an image of the character avatar as presented in previous two slides. Picture-in-picture videos of Zoë and Brede are laid over the right border of the slide.

Operator: (Zoë): This is Zoë speaking. How may I disturb you today?

Caller (Brede): Hi there, I'm in the process of applying to study music therapy, but I've got some health stuff that can make it harder for me to work and study. I've always loved the idea of being a music therapist, but I went to the open day recently and no one else there had a disability or anything.

Operator (Zoë): Hmm… Thank you for calling in about this. I hope you'll feel more confident after our call, but before we go on, it might be useful for me to position myself so you know where this information is coming from. Feel free to ask other operators for their positioning in future too—some of our experiences may reflect yours, and others may not. As with any resource, please approach the information we provide you with curiosity and critique, and consider how it may apply in your personal circumstances.

So, my name is Zoë, I use she/her pronouns. I'm a white woman in my 40's and I am hard of hearing and disabled. I live in Naarm, or Melbourne, Australia, and I'm a second-generation Greek-Australian. Prior to training as a music therapist I worked in the disability community as a support worker for 12 years, and now [I have been working] as a music therapist for the last 6 years.

Alright, with that out of the way, let me assure you that I personally know many music therapists who identify as disabled. Professionals with lived experience of disability and health diversity have also made significant contributions to their chosen health fields. That said, due to institutional barriers, we are still underrepresented in education and healthcare professions. Maybe you can help change that! Can you tell me how you know there were no other disabled people at your open day?

Caller (Brede): Well, no one mentioned having a disability or being sick, and I didn't see any wheelchairs or guide dogs, or any of that other disability stuff…

Operator (Zoë): Hmm, yes… it's common to assume someone isn't disabled until we are shown some sort of "evidence" to prove otherwise (Olkin et al., 2019). These assumptions are also supported through the way disability is represented in media and daily life across many cultures (Burns & Haller, 2015; Goethals et al., 2022; Rees et al., 2019). In healthcare, the medical model of disability is a dominant framework (Radulski, 2022; Shaw, 2019). Here, disability is conflated with disease and seen as something to be treated and perhaps even cured (Goering, 2015; Mankoff et al., 2010; Retief & Letšosa, 2018). Disability is identified by perceived deficits and observable symptoms, and the goal is typically to minimise the way a disability presents (Retief & Letšosa, 2018). The medical model has its place, but it also perpetuates hierarchical power imbalances, stigma, and discrimination against disabled people (Retief & Letšosa, 2018). Training disabled people to conform to non-disabled ideals is often damaging and even dehumanising (Goering, 2015). Focusing on individual treatment positions disability as a personal problem, without acknowledging the wider context.

Caller (Brede): True. I suppose people wouldn't be able to guess a lot of *my* issues just by looking at me either. But… I can't rely on my body or my brain in the same way that other people seem to be able to. Sometimes I end up in hospital when I try to do "normal" things that other people think are easy…

Operator (Zoë): Ahh, it sounds like your personal lived experiences align with the social model of disability. The social model was developed and led by self-identified disabled people (Retief & Letšosa, 2018), so they have an embodied understanding of the barriers we face on a daily basis. This model of disability considers the role of broader society in creating or dismantling disabling conditions (Andrews et al., 2019; Goering, 2015; Retief & Letšosa, 2018). In other words, the social model acknowledges that people experience impairments and differences, but proposes that we are not disabled by these, but by the barriers placed by society (Carter et al., 2022; Goering, 2015; Mankoff et al, 2010; Retief & Letšosa, 2018).

For example, under the medical model, if someone is Hard of Hearing or d/Deaf and wants to attend a concert, it may be assumed that this person can't enjoy music, or that they have to utilise hearing devices or bring an interpreter to experience the music, often at their own expense. The social model firstly acknowledges that many Hard of Hearing or d/Deaf people enjoy music and are musicians, and that music extends beyond audio, and celebrates other sensory experiences, such as visual performance and physical vibrations.

Beyond this, more widespread use of signed languages and alternative communication systems in general society could increase the accessibility of events by default, rather than positioning accessibility as the responsibility of individual attendees or event promoters. With greater accessibility and respect for different ways of being, what we may consider disabling could instead be understood as natural human variations. This isn't to say that someone's difficulties would magically disappear… But in a more accessible society, instead of centring medical interventions and professional expertise; perhaps some of our support needs could be addressed through less invasive measures that centre lived experience expertise and support day-to-day accessibility.

Caller (Brede): Wow, I guess I've always seen my health stuff as a "me" problem. Like I'm just not as good as other people, or when bad things happen it's because I didn't try hard enough. I hadn't thought about that big picture context of those experiences and beliefs… I still don't know about calling myself "disabled" though. When I talk to people, I want them to see me, not a disability.

Slide 8 Description: An updated version of the previous slide, where the cartoon phone has been replaced by the following text: "Person-first language: 'Person with a disability' Identity-first language: 'Disabled person.'"

Operator (Zoë): That's understandable. For a long time, language around disability has been shaped by non-disabled people (Andrews et al., 2019). There has been an assumption that it is kinder to view people as "having a disability," rather than "being disabled" (Illes & Lou, 2019; Sharif et al., 2022). This line of thinking views a person and their disability as separate entities in efforts to acknowledge the person before the disability. Many members of the disability communities argue that this ends up having the opposite effect (Andrews et al., 2019; Sharif et al., 2022). They argue that person-first language dehumanises disability and perpetuates negative attitudes (Illes & Lou, 2019).

As with identifiers like race, gender, and class, lived experience of disability shapes the way people experience the world (Berne et al., 2018; Illes & Lou, 2019). As their disabilities are intrinsically linked with their life experiences and identity, it would be impossible to remove someone's disability and be left with the same person. For some, using identity-first language like "I am disabled" can foster a sense of pride (Andrews et al., 2019) and symbolise reclaiming power that has been historically seized from disabled people. That said, people with lived experience of disability will differ in their preferences for person-first or identity-first language (Andrews et al., 2019; Sharif et al., 2022), so it's always best to ask someone how they prefer to be identified.

Slide 9 Description: A white slide with the heading "A moment of reflection…" in black text. Underneath this, there is a green text-box on the left side of the slide, containing the following reflective prompts: "How was disability framed in your training? What language was used? How has your understanding of disability changed over time?" Audio description text for the "please disturb hold music" is displayed on the right side of the slide.

Operator (Zoë): For a reflective prompt, consider… How was disability framed in your training, and what language was used? How has your understanding of disability changed over time?

Hold music plays between questions, ending with a generic phone-ring sound.

Question Two: Ableism

Slide 10 Description: A white slide with an image of the character avatar next to a cartoon phone. Slide is titled with the following text: "Call number 2: Ableism." Picture-in-picture videos of Carolyn and Brede are laid over the right border of the slide.

Operator (Carolyn): Carolyn speaking. How may I disturb you today?

Caller (Brede): Hello, well, I am full swing into my studies now. While I'm loving learning new things, I also have a growing discomfort that's hard to pinpoint… I know people have good intentions, which makes it even harder that I feel this way. But so many of these "good intentions" end up being backhandedly offensive, disrespectful, or degrading. It's shaking me up, and I am scared that I will eventually break down and just stop my studies.

I'll give some examples… One of the other students in my class shared a meme that showed a Paralympian running with a caption that stated: "the only disability in life is a bad attitude." Other students found it inspiring, and one remarked that it's exciting to become a music therapist because we get to *help* people with disabilities and empower them to *overcome* their disabilities and be their best. But… Regardless of my attitude, my disability exists. And these "inspirational" quotes make me feel like it's all my fault if I struggle with aspects of life that are harder for me.

Then, in the same week, we had a role play assessment where we were instructed to act like we experienced particular disabilities so that other students could pretend to be our therapists. I wanted to leave the room… the entire assessment relied on these stereotypical myths of disability, and the ways that some of my peers portrayed disability made me question whether they'd ever spent time with a disabled person. On top of that, our reading this week talks about one of my disabilities in terms of deficits and how music therapy can reduce those—even though those things are part of who I am. I wouldn't be *me* without them. I don't want to go to class on Monday. What should I do?

Operator (Carolyn): Thanks so much for calling. Before I respond, I just want to introduce myself. I am Carolyn, I'm a pakeha woman living in Aotearoa, New Zealand. I use the pronouns she and her and I live with my husband and two children. I am in my 40s and I have been a music therapist for 17 years. I live with a dynamic disability.

Now that I have introduced myself, first, can I say, how sorry I am that you have had to experience all of those microaggressions. You are not alone and I can relate. Microaggressions are subtle, everyday interactions and behaviours that communicate some sort of bias against marginalised groups like disabled people (Eisenmenger, 2019; Olkin et al., 2019; Qi et al., 2023). The term was first coined in relation to racial microaggressions, and over time has been expanded to apply to socially marginalised groups more generally (Sue, 2010). These are oftentimes unintentional, and people might not even be aware that they are committing microaggressions (Olkin et al., 2019)—even when it seems so obvious to you. No matter how good their intentions were, the microaggressions you described perpetuate ableism.

Slide 11 Description: An updated version of the previous slide, where the cartoon phone has been replaced by the following text: "Ableism: A set of practices or beliefs that discriminate against and devalue people with physical, intellectual, sensory, neurological or psychiatric disabilities. Assumption that disabled people need to be 'fixed' in one form or the other."

Operator (Carolyn): Ableism is a set of practices or beliefs that discriminate against and devalue people with physical, intellectual, sensory, neurological or psychiatric disabilities (Eisenmenger, 2019); and often rests on the assumption that disabled people need to be "fixed" in one form or the other (Eisenmenger, 2019). Sometimes we learn ableism through jokes that make fun of disabled people or aspects of disability… Sometimes through being scolded with: "are you crazy?" when someone disagrees with us… Sometimes we learn ableism through being told that an illness is not serious because it is only dangerous for the people who have existing health conditions… And sometimes we learn ableism during university assignments [(assessments)] alongside a group of well-meaning peers.

The discomfort of experiencing or witnessing ableism is bigger than the people involved. Although it may feel like we're calling out individual people when we draw attention to microaggressions, we are actually calling out the pervasive embedding of ableism in dominant narratives, cultural understandings, and the systems that we all exist in. This can be complex, especially as unlearning ableism is an ongoing process that we all experience differently. The guideline I recommend is to approach the lived experience of individuals with curiosity, and to approach dominant narratives with critique. So, when you feel this discomfort, either through witnessing ableism or feeling called out, question how your own experiences have informed your internal reaction, and consider whose voices you are amplifying in your external reaction.

In our training, role playing assessments can be presented as necessary exercises for developing the ability to take on different perspectives. It would be great if a competency for music therapists was instead to develop this ability through reading lived experience narratives, learning more about ableism, taking time to reflect internally before reacting externally. Maybe someday that will be the case in your university, but until then, call out ableism when it is safe for you to do so, and call your classmates into considering what we have discussed here today. If you feel comfortable talking to university staff, ask them to provide content warnings for articles or assessments that may lean towards deficit discourses or use disempowering language. Above all, just be gentle with yourself on Monday. If possible, schedule a preferred activity or time with a trusted friend after class, just to help ease any built-up tension.

Slide 12 Description: A white slide with the heading "A moment of reflection…" in black text. Underneath this, there is a yellow textbox on the left side of the slide, containing the following reflective prompts: "How were you taught ableism through your life experiences? Were 'role plays' in your music therapy training helpful or unhelpful to your learning and understanding about disability?" Audio description text for the "please disturb hold music" is displayed on the right side of the slide.

Operator (Carolyn): And as for a reflective prompt, consider… How were you taught ableism through your life experiences? Were role plays in your music therapy training helpful or unhelpful to your learning and understanding about disability?

Hold music plays between questions, ending with a generic phone-ring sound.

Question Three: Crip Time Perspectives

Slide 13 Description: A white slide with an image of the character avatar next to a cartoon phone. The character is now wearing a circle-shaped badge with an image of the Disability Flag. Slide is titled with the following text: "Call number 3: Crip time perspectives." Picture-in-picture videos of Zoë and Brede are laid over the right border of the slide.

Operator (Zoë): Zoë speaking. How may I disturb you today?

Caller (Brede): Hi there, I graduated a while ago, and I'm now officially working as a music therapist! I'm really enjoying musiking with people and learning more about what we can experience together. But I'm noticing a sort of disconnect in the way I want to practice and the way things actually turn out.

I'm currently working at a disability organisation where people are offered programs such as art, cooking, music therapy and community-based activities. I have observed that many of the people I work with often need extra time in their day to engage with these and participate more equitably… But everything follows a strict timetable, and it seems to me that because of this timetable, we're not always respecting each person's individual pace.

The staff sometimes seem like they're in such a rush to get everything done and facilitate transitions between different spaces and activities—it's chaotic! Don't get me wrong, the support staff are skilled, and they're dedicated to their jobs, but [they are] short staffed and not to mention underpaid. It feels bigger than something a single person can change…

Anyway, in *my* sessions, I sometimes feel pressured to keep up with this fast-paced environment, rather than matching the pace of whoever I'm working with… and I go between sessions so quickly that I've barely got time to set up the room, let alone plan anything or reflect on the previous session. Rushing about like this is impacting me physically and emotionally, and it makes me question the purpose of my work as a music therapist, and whether I am doing enough to advocate for people with disability. How can I adjust to the unique pace of each person in this busy space and practice in a way that honours that?

Operator (Zoë): Yeah… Thanks for calling and nice to speak with you again. Firstly, I want to let you know that I might need to take some time in answering your question today, and I might even stumble over my words, because, well, I'm feeling quite tired and need to go slowly. I am operating in something called "crip time!" But I'll talk more about crip time later. Firstly, I want to break down what you've said here, because you've made such an important point! Our systems and spaces, even in disability organisations, aren't always set up for disabled people. We encounter many ableist barriers in our daily life, such as inaccessible buildings, or waiting for accessible transport. So things take longer, but also, the way we individually experience time and space might be different from non-disabled people. What this means is that for some people the world feels too fast, or too slow, or both at different times. Yet society somehow believes that disabled folks need to operate in a normative time frame, which actually limits what we can do.

Now, let's talk about the term "Crip." Crip has been used historically as an insult to disabled folks (McCruer, 2006). More recently though, this word has been reclaimed by many in the disability community (Andrews et al., 2019; Dunn & Andrews, 2015; Kafer, 2013), where we seek to invert the othering and oppressive narrative of the crip, to a framing that celebrates who we are. The word crip can feel provocative and even offensive and it's kind of meant to. Acknowledging ableism in our society is unsettling and uncomfortable.

For a parallel, you might be familiar with the term "queer" or "queering" which is also a reclamation of the word "queer" which was historically used to oppress people in the LGBTQIA+ communities (Andrews et al., 2019; McRuer & Wilkerson, 2003).

Slide 14 Description: An updated version of the previous slide, where the cartoon phone has been replaced by the following text: "'rather than bend disabled bodies and minds to meet the clock, crip time bends the clock to meet disabled bodies and minds' Alison Kafer."

Operator (Zoë): So, crip time is a concept derived by Alison Kafer, from her book *Feminist, Queer, Crip*. She writes: "rather than bend disabled bodies and minds to meet the clock, crip time bends the clock to meet disabled bodies and minds" (Kafer, 2013). Crip time benefits disabled people but also those around them. For example, if the timetable of the centre you work in had flexibility, there would be more time to eat at the pace someone needs, with more time to digest and rest together before the next activity; or time to extend the duration of a song or improvisation based on individual engagement styles. With thought and planning, our broader systems of care can operate in crip time.

Caller (Brede): Wow, so what you're saying is that there *are* bigger systemic issues at play here…But zooming in to what I can do on an individual scale at work, how do I apply this in the music space?

Operator (Zoë): Ah, well it is an ongoing endeavour! And I will briefly touch on a few points here. So firstly, getting insight into each participant's unique pace that they move [to] throughout their life. Maybe you've been able to get some of this insight from how they play or listen to music, or what they are feeling or showing you when they come into the space. It is important to note that someone's pace doesn't have to rely on information about their diagnosis. What self-knowledge is this person sharing with you? What barriers are they experiencing? This self-knowledge can be shared through whatever means of communication they use. For example, if someone comes to a session feeling tired, some folks might show you they prefer to go slow or rest and listen to music or play slower music, whereas others might seek energy from faster

> paced songs or jamming. Both of these styles of pacing can be restorative.
>
> Secondly, cripping music moves us away from normative structures of time and normative structures of music so we can let go of ideas regarding "what" needs to be included in a music therapy session and "how" we do it. Many of us are taught to understand music through western styles of music and music theory. And although our understanding of music, as music therapists, may be broader than it is for many people, the structure of our original learning can still prevent us from picturing certain possibilities. Can we allow the boundaries of standard musical structures to be bent and fractured in order to re-conceptualise new ways of music-making? What other ways can an instrument be played, perhaps with a different body part, or co-actively without the focus being on "independence" but on "interdependence." Can we celebrate musical bodies as they are rather than shaping them to fit normative ideas of music?
>
> Thirdly, and perhaps the most challenging, is changing our attitudes. Part of cripping might be how we, as music therapists, interpret the time spent with the participant. Under capitalism, and here in Australia, we're bound by time frames to deliver outcomes efficiently and we value productivity, right? We don't want crip time to act as just another way to perform capitalism and promote capitalist values. So, what if we can shift our thinking and the hierarchy of our values, so that we prioritise being interconnected and having pride in who we are through music? Through this shift we can value connection to ourselves and to others: prioritising interdependence; valuing self-advocacy; celebrating our personal identities; and valuing disabled joy, creativity, rest.

Slide 15 Description: A white slide with the heading "A moment of reflection…" in black text. Underneath this, there is a blue textbox on the left side of the slide, containing the following reflective prompt: "How could crip time perspectives inform changes in the systems you work in?" Audio description text for the "please disturb hold music" is displayed on the right side of the slide.

> **Operator (Zoë):** And for a reflective prompt, consider, how could crip time perspectives inform changes in the systems you work in? *Hold music plays between questions, ending with a generic phone-ring sound.*

Question Four: Safety and Disclosure

Slide 16 Description: A white slide with an image of the character avatar next to a cartoon phone. The character now appears slightly older, and their disability flag badge has been replaced by a green lanyard with a sunflower print. Slide is titled with the following text: "Call number 4: Safety and Disclosure." Picture-in-picture videos of Grace and Brede are laid over the right border of the slide.

> **Operator (Grace):** Hello, this is Grace speaking. How may I disturb you today?
>
> **Caller (Brede):** Hi, umm… Something happened at work today, and I need to process it with someone. It's left me feeling really vulnerable though, so can I learn a bit more about you before I share this?
>
> **Operator (Grace):** Oh, of course, no problem. My name is Grace, my pronouns are she and her, and I've been a music therapist since 1994. I'm a white woman and I was born with a physical disability that was very apparent to other people. I have experienced multiple surgeries and chronic pain, and I'm now an amputee**.** On a good day, my disability is less obvious. And there are some aspects of my music therapy practice that

I've really needed to adapt over the years. I've had many ups and downs in the workplace. And I also have two adult children, and I live and work in Narrm, Melbourne, Australia. I hope that helps.

Caller (Brede): Thanks for that. Yeah, I'm ready to talk about it now. So, we were at a professional development workshop, and the presenter was talking about a condition that I have in a very medical and deficit-focussed way. It made me feel really uncomfortable. And then there was a big discussion with the group about how difficult people with this condition are to work with. I know that they weren't talking about me, specifically. But they were talking about my disability, and, essentially, that's me!

I didn't know whether I should speak up and give them an alternate narrative, or stay quiet so that they didn't project those pathologised qualities onto me. I haven't disclosed much at work yet, but I've talked with a few colleagues about disability and my lived experiences. And during this workshop, one of them leant over to me and said "gosh, I didn't realise you had so many issues." I just froze and I didn't know what to say.

Operator (Grace): Oh wow, yeah, I'm really sorry to hear that happened to you—that sounds really distressing. It's really confronting when highly medical and very deficit-focused information is presented in such an authoritative way, especially without acknowledging people with lived experience who might be in the room. And then it's doubly upsetting when this puts you in a situation where you question previous disclosures, and then your overall safety at work. Our workplaces have often assumed that only the people that we work *with* are disabled, and sadly, I'm aware that very few music therapists feel safe to disclose that they have a health condition or are disabled in their workplace (Warren, 2020). I've felt this way too.

We might be worried that others will assume we can't do our job well (Jain, 2020; Nolan et al., 2015; Tomas et al., 2022), or that we are going to have poor boundaries with the people we work with (Abbott, 2018). There seems to be a lack of open dialogue about the resources disabled music therapists actually bring to their work, and few opportunities to celebrate and value health and ability diversity in our professional teams. Even now, after many years of disclosure, I can still feel quite lonely in some professional spaces.

Slide 17 Description: An updated version of the previous slide, where the cartoon phone has been replaced by the following text: "'Double Empathy' theory: Empathy is a two-way street. We need to reframe perspectives that problematise disabled people, to problems with a society that lacks a concern for reciprocity and mutuality in care towards each other' Damien Milton."

Operator (Grace): So, I'm wondering if you have read about Damien Milton's (2012) "Double Empathy theory"? Damien explains that society often problematises disabled people, and pathologises differences. And, in response to these positions, Damien highlights that empathy is actually a two-way street. He advocates for reframing perspectives that problematise disabled people, to be problems with a society that lacks a concern for reciprocity and mutuality in our care towards each other. Damien's early work continues to inspire deep reflection, and other researchers have expanded on this concept. For example, an interview study with autistic adults reflecting on their access to healthcare suggests there is a "triple empathy problem" (Shaw et al., 2024), and that medical professionals need to have a deeper understanding of the varied experiences of their autistic clients to ensure they can access health services.

While having awareness of the double or triple empathy problem can help to explain the issue, it actually doesn't take away from the fact that many of us have also experienced ableist macro or micro aggressions. And that we can lack positive role models within the music therapy profession of other disabled people who are "out and proud." So, I think it's natural to want to avoid risking that—risking being ignored, excluded, or otherwise harmed by others following disclosure, and to try to protect ourselves from these traumatic interactions.

I guess, I'm hoping to convey to you that you're not alone in feeling unsettled by what happened to you. And as disabled people, we often want to disclose to colleagues to self-advocate, to support open communication, or just to feel more authentic (Jain, 2020; Tomas et al., 2022). We might even be ready to challenge stigma and ableist norms, or we want to work towards improving conditions for others, and society more broadly (Jain, 2020). However, sometimes disclosure isn't a choice, right? Sometimes we need to disclose for access to necessary accommodations; sometimes the way a disability manifests can't be concealed; and sometimes others disclose our information without our consent. So, regardless of the circumstances, we also need our colleagues to respect the intimate and personal nature of disclosure, and to think about how they too can make the workplace a safer space for everyone.

Caller (Brede): Thank you, it's been so helpful to hear that other people have experienced similar situations. One of my colleagues also identifies as disabled, so I'll invite them to meet up for coffee and learn how *they* felt about the professional development session. Maybe we can find a way to express how we felt to the team. And, if we don't feel safe being that direct, maybe there are other ways we can guide our workplace toward developing a safer culture. We could think about future speakers and workshops that present more diverse and affirming information, and use more inclusive language. And next time we book something in, I'm going to ask whether any disabled people are involved in presenting or developing the content.

Slide 18 Description: A white slide with the heading "A moment of reflection…" in black text. Underneath this, there is an orange textbox on the left side of the slide, containing the following reflective prompts: "How do you consider safety and disclosure in your work as a music therapist?" Audio description text for the "please disturb hold music" is displayed on the right side of the slide.

Operator (Grace): So here's a reflective prompt: How do you consider safety and disclosure in your work as a music therapist?

Hold music plays between questions, ending with a generic phone-ring sound.

Question Five: Accessibility and Unlearning Internalised Ableism

Slide 19 Description: A white slide with an image of the character avatar next to a cartoon phone. The character is now wearing a circle-shaped badge next to their sunflower lanyard. The badge contains a white speech bubble over a red background, with the text "low on spoons." Slide is titled with the following text: "Call number 5: Accessibility." Picture-in-picture videos of Grace and Brede are laid over the right border of the slide.

Operator (Grace): Hello there, Grace speaking. How may I disturb you today?

Caller (Brede): Hi there Grace, nice to speak to you again. I started a new job recently and the intake paperwork asked if I had any access needs that required particular workplace accommodations. I'm sure that accommodations could make my work life more sustainable, but I'm not sure how to approach this.

Operator (Grace): It's great to hear from you, and congratulations on the new job! I think there are a few ways that we could approach this. One way to develop relevant accommodations is to consider your personal access needs and the barriers within the workplace setting. So, from there, we could brainstorm how to feasibly address these.

Caller (Brede): I think that's my issue though—I'm not even sure what my access needs are! And the barriers are… complex. Since our discussion on verbal disclosure, I've realised that disabilities can be concealed and revealed in so many other ways (Cureton, 2018; Radulski, 2022). I've been reading about the concepts of masking and camouflaging to describe the ways that some of us can alter how apparent our disabilities are (Lawson, 2020; Miller et al., 2021). Masking and camouflaging behaviours can occur consciously and unconsciously, and they often serve a survival function (Lawson, 2020; Miller et al., 2021)… By appearing "less" disabled, we can be protected against certain forms of discrimination as well as general exclusion from public life (Cureton, 2018; Radulski, 2022; Tomas et al., 2022). In other cases, complying with stereotypical understandings of disability may be the only way that we can qualify for access to essential services and supports (Cureton, 2018; Tomas et al., 2022).

I'm *also* learning that these everyday survival tactics are often detrimental to people's health in other ways (Lawson, 2020; Miller et al., 2021; Radulski, 2022). They can exacerbate existing health conditions, create circumstances in which we develop additional health conditions, and create barriers for people to access support (Lawson, 2020; Miller et al., 2021, Radulski, 2022). As I've been trying to identify and unlearn my own internalised ableism, I'm realising that a lot of my daily thoughts and actions could be interpreted as masking or camouflaging. I've been considering how ableism has influenced my understanding of myself and my place in the world, and I've been reflecting on how this could have developed over time.

Growing up, when I didn't fit the ableist norm of what a disabled person "should" look like, the characteristics of my disability were often misinterpreted by other people as "inappropriate behaviours" or "intentional defiance." So, I learnt to understand these parts of myself as things I should be ashamed of and things I should be able to control. When my disability *was* acknowledged, it was typically interpreted through the "tragedy model of disability," where people were seemingly unable to accept or acknowledge that I was disabled without also totally infantilising me—pitying me for my struggles, and projecting qualities of helplessness and ineptitude. So, since accessing the support I needed often involved accepting that collateral damage to my self-respect and dignity, I learnt to suppress my needs and other aspects of myself wherever possible.

So, I guess what I'm saying is… regardless of whether people perceived *me* as being disabled, our interactions still encouraged me to internalise and identify with the negative qualities that broader society associates with disability and disabled people. The ableist values and assumptions communicated were that I needed to *act* "less disabled" and *be* "less disabled." And that makes me wonder: how much of my personality has developed to accommodate or expunge the ableist assumptions that I absorbed? How has ableism shaped my understanding of myself and my place in the world?

Anyway, now I'm at this new job where I'm actively being invited to advocate for myself and I don't know… How can I communicate my access needs when I've camouflaged them so convincingly that I've even hidden them from myself? I've needed to ignore and invalidate my body's distress signals for so long that it's hard to imagine how those signals could inform changes that *reduce* distress instead. And it's even

> harder to imagine having this validated by other people. Besides... If I've made it this far without accommodations, do I really need them? Maybe this sort of stuff would have helped when I was younger, but I can cope with things well enough now, so I'd probably feel guilty accepting anything… If I cause a fuss about myself, will that take resources away from someone who needs them more? Or what if I ask for something and it's too much? I don't want them to regret hiring me…
>
> **Operator (Grace):** My goodness, you've been on quite a journey. Thank you so much for sharing this with me. You know, it makes sense that you're feeling unsure of how to answer these questions. They are really big questions, and for so long disabled people have faced discrimination in the workplace. You know, from my experience, and from the perspectives I've heard from other disabled music therapists, this pressure that you feel to continue without accommodations might really reflect the pervasive societal pressure to accept working conditions that aren't conducive to your health and safety. Although I don't doubt that more accessible working conditions would improve *your* personal quality of life, actually we can *all* benefit when inclusion and access are genuinely prioritised (Crenshaw, 1989). Of course, there is no "one size fits all" solution for creating workplace inclusion and accessibility; but often, the changes made to make spaces more inclusive and accessible have positive impacts far beyond the sphere of whoever they were initially implemented for.
>
> So, ultimately, you will be the best person to identify your access needs and to imagine these relevant accommodations. Until that's possible for you, you could try taking inspiration from the access needs that you already account for in your music therapy sessions, perhaps. Like: allocating time for movement or other physical regulation; adjusting noise levels through use of headphones or access to a quieter space; the delivery of information through multi-modal communication; and taking individual preferences into account when you're setting up the space. You already know how to do all of that.
>
> And then, some other workplace examples I've encountered can include: negotiating flexible working hours; capacity to work from home where it's possible; negotiating workload and tasks with your team members; and delegating based on individual strengths; maybe even being allocated a workspace that's closer to the things you need, like bathrooms, or a carpark, or emergency exits; personalised ergonomic workstations; providing trolleys to carry instruments around; adjustable lighting and temperature control; receiving information about planning and projects well in advance of deadlines; and accounting for crip time when determining how your day might be structured.
>
> The feasibility and relevance of these accommodations are going to differ depending on your personal circumstances, and the style of work you do, and your workplace. And the way that you are comfortable to approach this will likely evolve over time, so it's also OK to start with the things that you feel are easier or the most essential, and to take it from there!

Slide 20 Description: A white slide with the heading "A moment of reflection…" in black text. Underneath this, there is a yellow textbox on the left side of the slide, containing the following reflective prompts: "What is one action your workplace could take to support disabled employees? What is one barrier that you could dismantle for disabled participants in your therapy space?" Audio description text for the "please disturb hold music" is displayed on the right side of the slide.

> **Operator (Grace):** And a reflective prompt now: what is one action your workplace could take to support disabled employees? What is one barrier in your therapy space that you could dismantle for disabled participants and colleagues?

Hold music plays between questions, ending with a generic phone-ring sound.

Question Six: Advocacy

Slide 21 Description: A white slide with an image of the character avatar next to a cartoon phone. Their “low on spoons” badge has been replaced by a badge containing an image of the Disability Pride Flag. Slide is titled with the following text: “Call number 6: Advocacy, questions, and reflections.” Picture-in-picture videos of Brede and Carolyn are laid over the right border of the slide.

Operator (Carolyn): Carolyn speaking. How may I disturb you today?

Caller (Brede): Hi, well, it’s been a while since I last called. I guess I have found a bit of a groove. I have a supportive workplace, with a lovely team; and after I shared my access needs with my supervisor, we were able to adapt my role a bit!

I’m really thankful that my colleagues are generally open to taking in other perspectives. It means I feel more comfortable telling people when I notice ableism. I even called in a colleague who said, “but I don’t think of you as disabled,” by exclaiming, “but I am disabled!” and then listing lots of the barriers that I have to work around every day! Since this conversation, they have become so interested in learning more, and discussing how they can change some of their practices. And I’ve been finding similar enthusiasm in my broader professional networks as well as in my personal social circles.

At first, I was really excited about this, but I now face a new challenge that is becoming overwhelming. It seems I have become the tokenistic default authority on all things “disability.” I have received emails asking me to advise on how to make spaces more inclusive, I have been asked to review the accessibility of random documents, not to mention the countless conversations where people have asked me what I would do in certain situations from a “disability perspective.” The problem is, I don’t know about the experiences of other disabled people. We’re not a homogenous group, and there are many things I can’t speak to or represent! This unpaid extra workload is also becoming more time consuming and emotionally draining than my day job. So, I’m feeling exhausted, but… I *do* want change and I understand that these conversations are important. I just can’t do it all and I’m struggling. I am also still learning, and I’m not the perfect advocate. One person even pulled me up for using the phrase “blind spots.” I know that I shouldn’t have used it, but I am not immune to accidental ableism… Does that mean that I shouldn’t advocate?

I also find myself only discussing the “positive” aspects of disability—like the strengths and insights I draw from my disabled identity. I feel afraid to share when things are hard, because I worry that it will just prove people’s assumptions that being disabled is a burden, and I don’t want people to think I am not fit for practice! Please help! I have become an unwilling spokesperson stuck in this position of needing to be the perfect “good disabled person” and filtering my disabled self. I’m a muddle of a mess trying [to advocate] for change.

Operator (Carolyn): Ah, thanks for your call. A couple of things came to mind as you spoke. So first, let’s talk about [the] perfectionism in advocacy that you raised. Perfectionism is an impossibility. We can only know what we have come across so far, so our identities and understandings are fragmented, fluid, and changeable. Unlearning is a practice and a process. Presenting imperfect points does not invalidate the entire story. Expecting perfection amplifies the voices of those who fare better in power

> dynamics—people with teams around them to curate their public image, [and] people with influence to escape the consequences of imperfection. Also, our idea of perfection is culturally informed. So we're more likely to see people as "perfect" if they resemble normative ideals, as we assess perfection according to cultural values (Garland-Thomson, 2013; 1997). Expectations of perfection are common across so many areas of advocacy. It's especially tricky in a disability context, and I have more questions than answers. For example, are we only allowed to advocate if our style of cognition aligns closely enough with that of our audience? Does expecting perfection in disability advocacy contribute to a hierarchy that places those who can self-advocate in desired ways above those who can't? We are so often expected to function as if we are not disabled; then face negative consequences when we continue to be disabled. This all feeds the pressure you referred to of needing to be the "good disabled person"—being expected to perform a sanitised representation of disability, and to disclose and educate on command, without consideration of the toll it takes on you (Berenstain, 2016). You could consider what forms of advocacy you can take on at different times, and what is beyond the scope of what you are personally willing and able to do? I often wonder why it is that people in marginalised positions are expected to perform the labour of advocacy to assert their humanity. What roles and responsibilities can people [with] strong systemic power relations and influence take on to enact necessary changes?
>
> Secondly, I just want to say that you are not alone in these struggles. They are all so intertwined, aren't they? One way to feel more supported in your advocacy is to find a community of like-minded people. Join advocacy groups, follow social media pages that can assist in learning more about ableism and more affirming approaches to your practice. You can refer others to these as well, so that it doesn't have to all come from you. Find your community where you can be your whole disabled self and feel the weight of other voices that add to your own.

Slide 22 Description: An updated version of the previous slide, where the character's facial expression has changed to appear less concerned and more hopeful.

> **Caller (Brede):** Yeah, I think that releasing myself from the pressure of needing to be perfect in my efforts will help. And I'll be more able to sustainably contribute to change if I go at my own pace, [and] take breaks from more overt or traditional forms of advocacy, or change the ways that I advocate when I need to rest or prioritise different things. Feeling community support and solidarity will also help ease the burdens of advocacy. And, on that note, it feels important to share that the support I've received through calling this hotline has prompted significant change in the ways that I think about disability and my own identity. As I learn more, I'm building a seemingly endless list of things that I need to learn more about; but I'm also feeling more confident asserting my needs and advocating for myself and others. I'm proud to be a disabled therapist and to openly draw from my lived experiences of disability when connecting with others and considering different perspectives. Thank you so much.

Slides 23-26 Description: White slides with a black text box across the top of the slide, containing the following text: "Thanks to the amazing Rhyll Hunt for the illustrations!" Below this heading, each slide contains an image of the character avatars used in previous slides, along with text that contextualises the symbols displayed on each iteration of the character, as read by Carolyn. Text containing the artist's Instagram handle "@rhylla_arts" is presented below each image.

> **Operator (Carolyn):** You're so welcome. So, these final slides display the character avatars drawn by Rhyll Hunt, accompanied by the following text that contextualises the symbols displayed on the character avatars throughout this video:

- Disability Flag. Colours represent the diverse categories of disability. Gold, silver and bronze evoke Olympic medals to celebrate achievement and ability (Disability Flag, 2023).
- Sunflower lanyard. This is a symbol for “hidden” or “non-visible” disabilities (Hidden Disabilities, n.d.)
- Low on spoons. A reference to spoon theory, which is a metaphor to describe the amount of mental or physical energy a person has available for daily activities and tasks (Miserandino, 2003).
- Disability Pride Flag. The black background represents mourning of, and solidarity against, ableist violence. The colours of the stripes represent five categories of experience: Mental Illness, Neurodivergence, Sensory Disability, Physical Disability, and Invisible or Undiagnosed Disability (Magill, 2017). The flag’s design has now been updated for accessibility by the original artist, swapping bright zigzags for parallel stripes in muted colours.

Thank you so much for watching. We will leave you with this wonderful song.

Slide 27 Description: A white slide with a black text box across the top of the slide, containing the following text: “Thank you for listening!” Audio description text for the “please disturb hold music” and lyrics is displayed on the right side of the slide, and picture-in-picture videos of all four authors swaying to the music are laid over the right border of the slide.

Hold music plays and then fades out as the video ends.

About the Authors

Brede Davis (she/they), RMT, is an early career Registered Music Therapist, working predominantly in disability contexts with young people. Brede’s lived/living experiences of multiple health conditions informs their therapeutic work, volunteering, and broader social advocacy. Brede has presented at national and international conferences, and was recognised as a finalist in two categories at the 2023 Allied Health Awards (Australia). Published works include a co-authored article in *Music Therapy Perspectives* and a reflective case study in “Working Relationally with Young People.” Brede intends for her work to contribute to the ongoing development of collaborative and creative approaches that expand the boundaries of healthcare and accessibility.

Zoë Kalenderidis (she/her), RMT, is a disabled and hard of hearing musician and Registered Music Therapist whose work focuses on promoting wellbeing and equitable access to music within the disability community. She performs with the all-disabled band Bearbrass Asylum Orchestra and leads the Foundation groups in the Melbourne Youth Orchestra’s Adaptive Music Bridging Program, for children with disability who face barriers to music participation.

Grace Thompson, PhD, RMT, is a registered music therapist and Associate Professor in Music Therapy at the University of Melbourne. Grace has lived experience of disability, and has worked with disabled children and young people, and their families, for over 20 years within the early childhood and special education sectors. Her research focuses on understanding how accessible music making can foster relationships and social connection. She is currently Editor-in-Chief of the *Nordic Journal of Music Therapy*.
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Carolyn Shaw (she/her), PhD, NZ-RMTh, is a New Zealand Registered Music Therapist, supervisor, disability advocate, and lecturer at Te Kōkī – the New Zealand School of Music, Victoria University of Wellington. Since graduating in 2007, she has worked predominantly with children, adolescence, and their families across multiple areas of practice. Carolyn is passionate about disability advocacy and in addressing ableism through her writing, research and practice. Her PhD study developed "Post Ableist Music Therapy" to help make this a central focus in her work. Carolyn has been involved in Music Therapy New Zealand council, and the standards of practice working party NZ.

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Appendix

Book formats

Ben-Moshe, L. (2020). *Decarcerating Disability: Deinstitutionalization and Prison Abolition.* University of Minnesota Press. https://doi.org/10.5749/j.ctv10vm2vw

Ndopu, E. (2023). *Sipping Dom Pérignon Through a Straw*. John Murray Press.

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Edited Collections of Lived-Experience Vignettes

Findlay, C. (2012). *Growing up Disabled in Australia.* Black Inc Books.

Wong, A. (2020). *Disability Visibility: First-Person Stories from the Twenty-First Century.* Vintage.

Short Form Video Content

Barbarin, I. [@crutches_and_spice]. (n.d.). [TikTok profile]. TikTok. Retrieved November 11, 2024, from https://www.tiktok.com/@crutches_and_spice. Alternate access via Instagram https://www.instagram.com/crutches_and_spice/?hl=en or personal website https://crutchesandspice.com/

Lima-Roope, T. [@tylerlimaroope]. (n.d.). [TikTok profile]. TikTok. Retrieved November 11, 2024, from https://www.tiktok.com/@tylerlimaroope. Alternate access via Instagram https://www.instagram.com/tylerlimaroope/?hl=en or personal website https://www.tylerlimaroope.com/

Independent Searches for Additional Resources

Those seeking additional resources may choose to combine search terms like “lived experience” and “disability” along with other relevant identifiers. The scope and specificity of results may be adjusted through use of boolean search operators (“AND,” “OR,” and “NOT”) in combination with parentheses or quotations marks as relevant.