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# Becoming “Unknowing” and “Inexpert”:

## Exploring the Impact of Language on Perception and Power in Music Therapy with Kirsty

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## Abstract

This article explores how the language of disability affects music therapists’ perceptions of the people they work with. A review of the literature examines how music therapy discourse and practice has been influenced by models of disability, specifically in the use of person-first and identity-first language. This is summarised by considering the power of language to affect the unconscious perceptions, choices, and actions of music therapists, leading to collusion between music therapists and inherently ableist social structures. The second half of this article presents the author’s introspective journey of consciously changing language, shifting perceptions, and subverting power imbalances in music therapy sessions with Kirsty, a young woman with autism attending sessions for her mental health. The case study incorporates Kirsty’s own written reflections to demonstrate the potential for collaboration and learning as part of this journey. The article concludes that music therapists might seek opportunities to become “unknowing” and “inexpert” in relation to the people they work with, in a bid to create holistic learning spaces that manifest and embody empowering language. The language of this article reflects the author’s preference for identity-first language. Person-first language is used in reference to Kirsty, at her request.

**Keywords:** music therapy; language; power dynamics; perception; disability models; case study

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## Models of Disability in Healthcare

British stand-up comedian Rosie Jones is known for using the way in which cerebral palsy influences her speech to great comedic effect, by allowing her slower dialogue to lull audiences into a false sense of expectation. Just when it seems clear how a sentence might end, she subverts the obvious punchline: "As you can tell from my voice… I suffer from… being… northern!" (BBC, 2020). Jones (2021, December 3) recently authored the following social media post in recognition of International Day for Persons with Disabilities:

> Today is 'International Day for Persons with Disabilities' – a day for everybody to promote an understanding of disability issues. My disability has never affected me negatively, but people's archaic views impact me on a daily basis. Disability isn't bad, prejudice is.

Jones' words encapsulate a perspective of disability which grew from the disability rights movement and is now widely understood as the "social model of disability," a term coined by disability rights activist and author Mike Oliver (Oliver, 1990). The social model makes clear the distinction between *disability* and *impairment*: "An inability to walk is an impairment, whereas an inability to enter a building because the entrance is up a flight of steps is a disability" (Morris, as cited in Barnes & Mercer, 2003, p. 12). Consequently, social model proponents argue that only when an impaired person experiences exclusion and oppression in a systemically prejudiced social environment, do they become *dis-abled* (Garbutt & Saltiel, 2020; Oliver, 1990; Samaha, 2007; Shakespeare, 2010).

To help illustrate the importance of environmental prejudice in the social model, Samaha (2007) draws on an ethnographic example from an island community in Massachusetts which, due to a hereditary condition, had a significant percentage of d/Deaf inhabitants for a period of two-hundred years. Bilingualism in spoken English and sign language became commonplace among hearing inhabitants, and the community was further able to utilise the functional advantages of signing to communicate in loud settings (such as out at sea) or privately (out of others' sight lines). This example demonstrates that when a community accommodates for diversity, there are fewer disabled individuals. Scholar and educator Nick Walker (2021) articulates this concept succinctly in reference to autism: "If you ask me whether autism is a disability, I'll say no, but if you ask me whether autistic people are disabled, I'll say yes" (p. 68).

The social model of disability traditionally sits in opposition to the older and more dominant medical model of disability. Whilst the social model defines disability as a social creation, the medical model understands impairment to be an "individual deficit" which inherently lessens quality of life and causes disability (Shakespeare, 2010). The medical model receives heavy criticism for placing responsibility on individuals to use medical intervention to eradicate (for example, through prenatal testing) or diminish the effects of impairment to work towards an idealised health type, especially as this reinforces the notion that impairment is undesirable (Shakespeare, 2010). Walker (2021) argues that diversity is "biological fact," and that the concept of impairment verses healthy, or as Walker calls it, "the pathology paradigm," is dependent on the powerful "fictive concept of 'normal people'."

> The most insidious sort of social inequality, the most difficult sort of privilege to challenge, occurs when a dominant group is so deeply established as the "normal" or "default" group that it has no specific name, no label. The members of such a group are simply thought of as "normal people," "healthy people," or just "people" – with the implication that those who aren't members of that group represent deviations from that which is normal and natural, rather than equally natural and legitimate manifestations of human diversity (p. 34).

Goering (2015), however, warns against hasty vilification of the medical model, stating that:

> People with impairments that involve, for example, fatigue, pain, depression, or chronic illness may want both to overcome social barriers and discrimination that oppress all people with disabilities, and to voice their desire to remove or address the troubling accompaniments of their impairments, through medical or other means (p. 135).

This perspective also recognises that for many people, medical intervention is necessary to provide lifesaving treatments, and that they should not receive criticism for attempting to access this. Evans (2004) similarly states that whilst the social and medical model are generally seen in opposition as “soft” and “hard” sciences, each offers something of value to the other.

> The primary challenge for Disability Studies is to resist temptation to fuel an "us versus them" standoff with the medical model. Despite its limitations, the medical model is a pragmatic and efficient means for addressing afflictions of the body, but it also needs assistance from the broad view of Disability Studies to enhance understanding of the disabled population.

Whilst these two models of disability are not the only models, by way of their history and opposing stances, they are the most dominant and influential. However, conciliatory statements such as Goering’s and Evans’ question this binarism and recognise that, when applied to the letter, neither model caters for variance in individual circumstances (Autistictic, 2020; Kim & Fox, 2006). Increasingly there are calls to work towards a “holistic model of disability,” in which an individual’s unique experiences and needs form the basis of a bespoke healthcare journey (Autistictic, 2020). The holistic model is pragmatic in bringing together the affordances of both the medical and social models to address the complex interrelatedness of physical, mental, social, and emotional health. Kim and Fox (2006) state that “the holistic view of health for people with disabilities takes into account both the personal and physical experiences of disability, as well as their social dimensions,” adding that “even in the face of accepted medical wisdom and practice, individuals with disabilities have expertise based on their own life experience and in many respects may be the best managers of their own health” (pp. 484-485).

The phenomenon of contrasting definitions of the word “disability” has led to differing approaches within the healthcare of disabled people. Healthcare professionals’ allyship with a particular model can be indicative of the type of care they offer, sometimes with serious consequences for how this might reinforce systemic prejudice (Bricher, 2010). For this reason, it is crucial for healthcare practitioners to engage with the models of disability and to consider the implications for how associated language, perspectives, and interventions might contribute to the disempowerment or empowerment of disabled people within their practice.

## The Language of Disability and its Power Dynamics

It is within living memory that stigmatising labels such as “moron,” “retarded,” and “handicapped” were accepted medical terminologies for disabled people (Ziegler, 2020). It is unsurprising that, despite progress, there remains ongoing debate as to the correct language to use when describing disability (Botha et al., 2021; Ziegler, 2020). This debate is heavily focused on the use of person-first and identity-first language (Shakespeare, 2010; Walker, 2021).

Person-first language developed in the 1970s as a response to stigmatisation and violence towards the disabled community in earlier decades (Botha et al., 2021), with the intention of dispensing with de-humanising collective terms such as “the disabled” or “a wheelchair guest" (Kenny et al., 2015). Person-first language aims to emphasise respect for a person by referring to people first as individuals before mentioning any disabilities (Dunn & Andrews 2015; Gernsbacher, 2017). This often takes a set structural form, such as "man with autism," "adults with dyslexia," "individual with a learning disability," which is often expanded to emphasise the ability of disabled people to lead full lives, for example "a woman living with cerebral palsy" or "Gordon is living with a diagnosis of ADHD" (Blaska, 1993; Gernsbacher, 2017). Despite its activist origins, person-first language has become synonymous with the medical model of disability due its grammatical emphasis on the person as separate to their impairment, meaning that person-first language has become the dominant language in healthcare settings (Shakespeare, 2010; Ziegler, 2020).

Despite its prevalence, many scholars and activists now argue that person-first language problematically enforces the semantic separation of people from their disabilities, framing impairment as an undesirable characteristic that cannot be conflated with being a person (Botha et al., 2021; Dunn & Andrews, 2015). Nicolaidis (2012) suggests that such language tempts us to imagine disabled people without their impairment, forgetting the integrated, whole identity of the person before us. Consequently, the use of person-first language in healthcare settings has fuelled concerns about institutionalised stigmatisation of disabled people (Bricher, 2010). Jim Sinclair (2013) provides a strong case against person-first language from their own lived experience of being an autistic person, arguing that person-first language implicitly takes away any pride in identifying as disabled on a purely grammatical basis:

> Saying "person with autism" suggests that autism is something bad–so bad that [it] isn't even consistent with being a person…We talk about left-handed people, not "people with left-handedness," and about athletic or musical people, not about "people with athleticism" or "people with musicality."…It is only when someone has decided that the characteristic being referred to is negative that suddenly people want to separate it from the person.

Sinclair instead promotes identity-first language, for example: "disabled man," "Jane is a blind woman," and "autistic children" (Gernsbacher, 2017). Advocates of identity-first language argue that referencing disability first as a key part of identity removes shame and destigmatises impairment, allowing people to take ownership of and imbue previously negative terminology with positive connotations of empowerment and autonomy (Vivanti, 2020; Ziegler, 2020). Parallels can be drawn here with other social movements such as body positivity, gay pride, and anti-racism, all of which reclaim previously negative words such as "fat," "gay," and "Black" as celebratory identity-first adjectives (Garbutt & Saltiel, 2020). Identity-first language is widely considered synonymous with the social model of disability, as it is seen to encourage people to take pride in their identities, promoting the "value and validity of life as a person with an impairment" (Swain & French, 2010, p. 578).

For advocates of the holistic model, the opposing stances of person-first and identity-first language is as problematic as the binarism of the medical and social models, with calls instead for greater individual choice through person-led or person-centred language (Autistictic, 2020; Kapitan, 2017). The argument here is that allowing people to choose the language which describes them is an empowering, enabling process that disrupts the oppression, infantilisation, and mistreatment of disabled people (Autistictic, 2020; Kaptian, 2017; Lister et al., 2020). Kapitan (2017) suggests that "There is no one "correct" answer. The invitation of person-centered language is to value a caring and complicated approach rather than searching for a pat solution." Lister et al. (2020) argue that more effort could be made to consult individuals on language preferences, arguing that the existing blanket enforcements of either person-first and identity-first language "have not included the perceptions and preferences of the audiences they are describing in any systematic way" (p. 622). They present research which shows a range of language preferences within the disabled population, indicating the redundancy of a "top-down, one-size-fits all approach" and the need for multiplicity in language to accommodate for different identities. This research highlights the nascency of the debate on the language of disability, particularly with regards to ensuring that disabled people (both who can and cannot express themselves in the prevailing methods of communication) can access platforms to relate their language preferences not just as subjects of research, but as experts in their lived experience and active participants in their own healthcare journey.

## What is the Relevance to Music Therapy?

### *Tokenism versus Semantics*

Although it might seem obvious, it is worth emphasising here the huge influence of the models and language of disability on music therapy practice. Music therapists spend a large portion of their time in sessions working with disabled people, and outside of sessions are regularly describing disabled people, be it for clinical notes, case studies, service evaluations, or conference presentations. Despite this, and I speak from my own experiences of the profession, there is a lack of centralised guidance and/or training for music therapists on the language of disability and its role in their work. This implies that the onus is on music therapists to take responsibility for researching changes to terminology as influenced by ongoing social movements, activism, and changes to the law.

Music therapists are familiar with this expectation. For example, registration with the United Kingdom regulating body, the Health and Care Professionals Council (HCPC), requires that practitioners undertake self-regulated continued professional development (CPD), including active research and development of key skills. The HCPC's website states that CPD is "how you learn and develop throughout your career, ensuring your skills and knowledge are up to date so that you can practise safely" (HCPC, 2018), yet despite the clear importance of this, only 2.5% of HCPC registrants are audited for CPD evidence each year, meaning that the CPD of individual practitioners goes largely unmonitored. I can recall several examples of music therapists who have been practising for more than ten years without having experienced a CPD audit.

Whilst I am not suggesting that individual music therapists are incapable of meeting the requirements for CPD, my personal observations of professionals using person-first and identity-first language are that self-regulation leads to inconsistencies and, in a worst-case scenario, that a music therapist unintentionally using out-dated terminology (which additionally may not reflect their therapeutic approach) might be seen to be embarrassingly uninformed and in need of refreshing their practice. This implies that music therapists might only seek to update their vocabulary to maintain a politically correct and professional image. Such tokenistic usage of the language of disability encourages us to ask, as Honisch (2014) does: for whom is music therapy?

I have a clear memory of an early seminar from my music therapy training, in which a tutor handed out photocopies of a chapter from *Therapy in Music for Handicapped Children* by Paul Nordoff and Clive Robbins (1971). The group of trainees and tutors collectively expressed discomfort with the word "handicapped," and in the discussion that followed it was agreed that this term was out-dated and no longer suitable for professional use. We were encouraged to look beyond this word (and the similarly antiquated terms that followed) and to focus on the body of the text, which is generally regarded to be radical for its time and widely applicable fifty years later. Reflecting on this experience, I wonder how easily we can "update" a text by substituting such a term. Hadley (2013) argues that music therapists must be aware that, despite best intentions, their perceptions will always be shaped by the narratives of the societies they inhabit. So, when Nordoff and Robbins used the term "handicapped" in 1971, we should expect that contemporary attitudes towards disability might permeate their therapy work due to unconscious bias, regardless of their clear commitment to challenge the status quo. I wonder, what is the effect of presenting this chapter to impressionable music therapy trainees fifty years later?

To complicate matters, the global community of music therapy practitioners collectively straddle the full spectrum of disability models for a variety of reasons, whether it be for professional status, to accrue service funding, to fit in with an institutional setting, or because of differences in approach between various disciplines (Register, 2013). This has resulted in significant disparity in language usage, and I have often been surprised to hear social model-aligned colleagues using person-first language, and vice versa (Register, 2013). The problem of unconsidered language goes beyond simply spotlighting a practitioner's inconsistencies or lack of research; it can have unintended but serious consequences for disabled people participating in music therapy. Ziegler (2020) makes the important yet harrowing point that when respected institutions, such as the legal system and healthcare professions, use and teach inherently discriminatory language in reference to disabled people, stigmatisation becomes coded into our society and sanctioned as normative. This raises questions about the power music therapists have in normalising the discrimination of disabled people through unconsidered language usage (Cameron, 2014).

### *Alignment with the Medical Model and Person-First Language*

Historically, the music therapy profession has sought close alignment, even inclusion, with the medical field. This is due in large part to music therapy struggling to establish itself as a serious healthcare profession (Register, 2013). Music as a medium defies traditional scientific methods of quantification and evaluation, and sessions are often hard to relay in written or spoken format, making it challenging to measure and describe the effectiveness of music therapy (Procter, 2001). Seeking scientific validation by employing the results-driven models of the older, more respected medical establishment has been important for the funding, growth, and recognition of music therapy as an effective healthcare intervention (Cameron, 2014; Register, 2013). Nevertheless, this has led to concerns over the cost to music therapy's integrity as a social, artistic, and community-based therapeutic experience, and there are calls for music therapy to stand complementary to but distinct from the medical model (Cameron, 2014; Procter, 2001).

Alignment with the medical model has also affected the language of music therapy. The medical model's prevailing use of person-first language has permeated music therapy discourse and invited hierarchical "cure narratives" into the field (Bassler, 2014). This is exemplified by such terms as "clinical intervention," "client," and "patient," all of which cast the music therapist as the "do-er" or the agent of change in the therapeutic process (Bassler, 2014; Bunt & Stige, 2014; Honisch, 2014). Bassler (2014) states that "a music therapist who employs the medical model would view a person with psychological, cognitive, or bodily difference as in need of remediating." Such narratives place the music therapist in a remarkable position of power and control, yet Rizkallah (2022) argues that "this cannot be avoided. The therapist in their professional role would also always have more knowledge and expertise than their patient in terms of knowledge of theory, technique and, often, musical ability – it is the definition of each role" (p. 4). Rizkallah (2022) states that "the therapist has more power in the therapeutic situation, and this should be worked with" (p. 7), further suggesting that the word "patient" best embodies the semantics of this relationship and that music therapists should not shy away from using it.

Cameron (2014) however takes issue with music therapy's allegiance to the medical model, surmising that:

> …the keenness of music therapists for acceptance, recognition, and respect from the medical profession…is intensely problematic…it is not that I believe music therapists are not good or well-intentioned people but that, in supporting a medicalising, individualising, normalising ideology, I believe they are complicit in the oppression of the very people they intend to help.

Honisch (2014) agrees by criticising the notion of the music therapist as a healer who should be expected to change someone, asking: "are the aims of music therapy antithetical to those of disability studies?" Walker (2021) also advises healthcare practitioners against using person-first language, stating, "if you use the language of the pathology paradigm, you are reinforcing a social paradigm that harms your clients, and thus you are working against your clients' interests" (p. 140). In addition, arguments for music therapy providing a unique space within medical settings have led to a renewed effort to disassociate from the medical model in favour of the social model, with a strong emphasis on disrupting the inherent power dynamics of the medical model (Cameron, 2004; Honisch, 2014; Metell, 2014; Procter, 2001; Rolvsjord, 2006).

### Alignment with the Social Model and Identity-First Language

A consequence of breaking away from the medical model is a diminishing focus on *change* as proof of efficacy and a renewed effort to provide disabled people with greater social capital (Procter, 2011). Procter (2001) posits an approach to music therapy which seeks to nurture and empower people by "building on people's experiences of who they are and what they can do," suggesting that music therapy spaces should be "enabling." This approach has led to greater introspection with regards to the roles and power dynamics within the therapeutic relationship. Tsiris (2013) claims "the expert-patient dichotomy between therapist and client has no place [in music therapy]" (p. 339), and Rolvsjord (2006) likewise emphasises that mutuality within the therapeutic relationship is key to empowering people. Honisch (2014) provides a picture of what an enabling environment might look like, suggesting that the "therapist and client…take part in a reciprocal encounter in which diagnoses and intervention are replaced by a spirit of collaborative learning." Tsiris (2013) similarly calls for "an emphasis on collaborative approaches where therapist and client are equal and active participants in a musical therapeutic relationship" (p. 339).

Naturally, these attitudes are affected by, and have an effect on, music therapy discourse. In aligning with the social model, music therapists are likely to employ identity-first language and non-medicalised terminology in a bid to demonstrate more obvious mutuality in the therapeutic relationship. For instance, Metell (2014) points out that the term "therapy" is challenging within the context of the social model, as it has the potential to reaffirm disability as an individualised issue. Personally, I have navigated this issue, as have many others, by dropping the word completely and entering spaces as "the musician," "the music lady," or a "facilitator," but this then gives rise to similar concerns about using the term "client" to describe people participating in music therapy, and so terms such as "participant," "person," "player," or "collaborator" are often favoured (Bunt & Stige, 2014; Leonard, 2020). Leonard (2020) suggests that these terms "reflect the consideration of a renegotiated power dynamic" and lead to "self-advocacy of the client…[being] considered as central to the therapeutic process" (p. 106).

The language and philosophy of the social model has not only affected the description of people who participate in music therapy; it has changed the language of the profession itself. Procter (2011) argues that music therapy should be seen as a "craft," shameless in promoting its roots in art and community. This highlights the unique worth of musical-therapeutic skills such as listening, responding, accompanying, and facilitating a "transcendent experience of being remarkably attuned with others within musicing"

(Procter, 2011, p. 253). Establishing this type of language as the discourse of music therapy pushes against the scientific terminology of the medical model and gives music therapists permission to operate outside of "cure narratives" (Bassler, 2014).

### *Alignment with the Holistic Model and Person-Led Language*

It is interesting that despite music therapy's widely acknowledged rootedness within holistic models and practices, there is little to no mention of person-led or person-centred language in the literature. I can only suggest three possible reasons for this. Firstly, there is an implicit understanding in healthcare systems that the trained practitioner "knows best," meaning that they are likely to confidently apply a favoured model or theory without much consultation. Secondly, music therapists often advertise themselves as adhering to a particular principle or approach, implying that prospective attendees should not expect compromises. Thirdly, historically, the bread-and-butter work of music therapists has been with people who by way of their impairment are unable to indicate their language preferences in the prevailing methods of communication, leaving music therapists free to assume responsibility for the decision. Regardless of the reasons, there is a certain hypocrisy to be found in a profession which makes little effort to confer with the population it describes whilst espousing its holistic roots.

### *The Power of Language to Affect Perception*

It is evident from the discussion above that music therapy has a complex history with the models of disability which continues to influence the discourse. Regardless of one's affiliations, the implications for music therapists might initially seem relatively superficial. Language is *around* the work, surely? Does language not become irrelevant once the music starts? How important is it really that music therapists use the "right" language? In their 2018 TED talk, cognitive scientist Lera Boroditsky asks the question, "Does the language we speak shape the way we think?" (Boroditsky, 2018, May 2). Boroditsky goes on to explain that language is bound to culture, and that through the examination of vocabulary and grammar, we can learn an enormous amount about how speakers of a language perceive the world:

> If you ask German and Spanish speakers to, say, describe a bridge, like the one here -- "bridge" happens to be grammatically feminine in German, grammatically masculine in Spanish -- German speakers are more likely to say bridges are "beautiful," "elegant" and stereotypically feminine words. Whereas Spanish speakers will be more likely to say they're "strong" or "long," these masculine words.

Music therapy spaces are not immune to this phenomenon, and so we might understand that when music therapists align their practice to a particular model of disability and subscribe to corresponding language, this reflects and impacts their perception of people and how they work with them. Indeed, this idea is increasingly addressed in music therapy literature. For example, Devlin (2018) states that "the way we think about and work with our music therapy clients reflects something about the way(s) we see them" (p. 236), whilst Metell (2014) makes the important link between language and therapeutic approach, stating that "the discourse of music therapy informs practice and thinking. It is therefore important to be conscious about the use of language and labels." Additionally, in a critique of disabling language used in the HCPC's Standards of Proficiency (SoPs), Pickard (2020) gives the example that the requirement for professionals to "know about…normal and abnormal psychology" not only "enforces an artificial, ableist separation between different ways of being and communicating" but influences those for whom meeting the SoPs is a legal requirement:

> If a Music Therapist perceives a participant with a learning disability as having communication and language development that is ‘abnormal’, this may shape and colour their approach to practice, communication, and forging relationships. This language results in participants with learning disabilities being Othered…and marked as different and potentially deficient through these language choices (pp. 5-6).

So, what does it feel like to identify and challenge this in practice? What does unconsciously prejudiced music therapy look like? How can music therapists recognise and critically engage with their own language-influenced unconscious biases? How can they be changed? In a bid to offer some answers to these questions, I will now present a case study from my own music therapy work with Kirsty, which shares my experience of consciously recognising and changing the language of my work and charts the impact on my perceptions and music-therapeutic choices.

## Case Study: Kirsty

*Kirsty has given consent for this work to be shared. All names and identifying information have been changed to preserve anonymity.*

### *Introduction*

I met Kirsty during a six-month training placement at a mental health support day centre in the north of England, where I facilitated music therapy sessions with adults who were on the path of recovery from a range of mental health conditions including depression, anxiety, trauma, and addiction. Kirsty attended individual sessions for five months, and because of starting delivery during the United Kingdom COVID-19 lockdown, sessions initially took place online for six weeks before moving on-site.

When I first met her, Kirsty was nineteen years old and completing her penultimate year of school qualifications. Kirsty had been diagnosed with autism at a young age and was attending a local college which supported her learning needs with smaller class sizes and one-to-one provision. Whilst she was excelling in her academic work and enjoying the social life of her college, Kirsty was experiencing debilitating anxiety which manifested as insomnia, severe stomach pains, toileting difficulties, breathlessness, and panic attacks almost every day. Her mother, Leah, with whom Kirsty had a close and loving relationship, registered Kirsty at the day centre in the hope that their various holistic wellbeing courses and activities might provide her daughter with respite. Kirsty was actively engaged in the process of her recovery from anxiety and came to music therapy sessions with an optimism for how music might be beneficial to her wellbeing.

Retrospectively, my overall impression of Kirsty was one of a vivacious, chatty, and caring young woman with a curiosity for people and their life stories. She wanted to know about me: Why was I training as a music therapist? What was my training like? Where did I live, and did I like the area? She had a slapstick sense of humour, laughing at my occasional incompetence with technology or my forgetfulness. Kirsty also had a strong connection with her Chinese heritage and culture, having been born in China to Chinese parents, and she retained strong family links in the country. She enjoyed artistic hobbies, favouring Chinese films and music, and was of intermediate level on the flute and the piano. Kirsty was, in her words, “obsessed” with Mandopop music and pop stars Jay Chou and JJ Lin, following their social media accounts with huge enthusiasm. She enjoyed watching live performances of their concerts on YouTube and had installed a karaoke application on her phone so that she could sing along to the accompaniments of her favourite songs.

Kirsty had a limited, yet strong network around her. Whilst her mother was the most prominent supportive figure, Kirsty's piano teacher, Andy, was a huge source of comfort and friendship in her life, to the extent that Andy was a necessary presence at our first few sessions. Leah and Andy's dedication to Kirsty's wellbeing meant that they were keen to convey their knowledge of Kirsty to me. They felt that Kirsty's anxiety was a consequence of having autism, linking her difficulty in interpreting both her own and others' emotions to her problems at school, and her fast-paced, breathless speech to the physical symptoms of panic. Leah explained that last-minute routine changes and being given incorrect information also acted as triggers for Kirsty's anxiety.

It felt important to respect Leah and Andy's knowledge of Kirsty and contemplate the potential relationship between Kirsty's autism and her anxiety, but hearing their assessment made me pause for thought. Kirsty was coming to a music therapy service in a *mental health recovery centre* with the express wish to focus on her *anxiety*, not autism, yet it seemed that if she were better able to manage her responses to environmental stimuli, this would allow her respite from panic attacks. So, if having autism was likely to predispose Kirsty to severe anxiety, did I not have a responsibility as a healthcare practitioner to create therapeutic aims that addressed how Kirsty processed routine changes, incorrect information, and interpersonal relations? Crucially, did I have the ability, or even the right, to change this about her? These were questions that I held in my mind as we embarked on our first online session.

## Session One

Kirsty and I started our first session conversationally, which allowed us to circumvent the challenge of online music-making whilst taking the opportunity to get to know each other's musical backgrounds and tastes. Kirsty was anxious about meeting me, and her body language mirrored this as she periodically buried her face in her mother's arm and whispered to her in Mandarin. Leah successfully encouraged Kirsty to play her favourite music to me using the karaoke app on her phone, and I witnessed a surprising transformation in Kirsty. As the introduction to the song played, she turned her body towards me, closing her eyes and furrowing her brow in concentration. She took a deep breath before launching into the song, her voice soulful and delicate. She had an ear for the pitches of the melody and the shape of the phrases, and, in keeping with Leah and Andy's description, I noticed a breathlessness to her singing as if she was constantly catching up with the pulse of the music. She sang three songs by various Mandopop artists, all of them unfamiliar to me.

Kirsty seemed to be in her element here. She obviously enjoyed singing these songs and seemed to have a real sense of pride in the music as she shared it with me. I started to ask her questions between songs: What was her favourite part of the song? How did she discover the song? Could she translate some of the Mandarin lyrics for me? Kirsty showed more uncertainty with me in these moments by averting her eyes and looking to her mother, though made efforts to answer by conferring with Leah in a hushed voice before replying or asking Leah to speak for her. We finished this session by creating an online collaborative playlist of music and within a few days, Kirsty had already added over fifty songs. I hoped to achieve three objectives with this playlist: to learn more about Kirsty's favourite music, to provide future talking points, and to allow me to learn the accompaniments of the songs in the hope of replacing the karaoke app in sessions.

## Session Two

The playlist gave me a sense of purpose going into our second session. I had prepared by learning a few of the songs Kirsty had selected and I was ready to *make music*. However, the first twenty minutes of our second session were largely the same as the first session, and I noticed that my suggestions to use the piano instead of the karaoke app were ignored in favour of selecting a new song. Eventually Kirsty was persuaded (a joint effort from Leah, Andy, and myself) to allow me to play the piano accompaniment to a song by Jay Chou. Kirsty sang the song in its entirety and there was a feeling, despite the internet lag, that we were connected by the joint musical enterprise. Additionally, in this session I decided to ask questions with more emotive language than last time: How does that song make you *feel*? Is it a happy song or a sad song? Though I noticed that this seemed to push Kirsty too far and she appeared confused.

Whilst I felt some achievement over our rendition of the Jay Chou song, I was left feeling completely unsatisfied as the session ended. It felt like such hard work to be part of Kirsty's musical world, with its unfamiliar language, genre, and culture. Kirsty was already so happy in this world too, without me elbowing my way in and trying to be part of it. Running through these thoughts was a thread of disappointment in myself and my efficacy as a music therapist. I wanted more from Kirsty. I wanted to see her *working* and *changing* in the process of therapy. I wanted to invite her to express her feelings about the music, to sing the music in different ways with me, to share her musical experience, to do the things she did not normally do. Otherwise, what was the point of me being there? I was also fearful that rather than replacing and building on the benefits of the karaoke app, I had *become* the karaoke app. I knew that deep down I was growing frustrated with simply going through new song after new song, mostly as I felt overwhelmingly disadvantaged by my own ignorance of the genre. As I reflected on these feelings, I wondered how to create a feeling of forward momentum in our next session. I came to the conclusion that moving away from known repertoire to song writing might offer Kirsty the opportunity to express and articulate her thoughts and feelings, as well as allow for greater collaboration between us.

### Session Three

The first half of this session followed a similar format to the first two sessions. Once I felt that Kirsty was settled into the session, I asked her if she would like to write a song with me. Kirsty was apprehensive and somewhat resistive, so I tried to introduce some helpful parameters for her, first suggesting that we borrow a chord structure from one of her favourite songs. She seemed enlivened by this idea, and as I looped the chord structure on the piano, she was able to contribute suggestions as to the speed and rhythms, asking for a moderate speed with a marching rhythm pattern. It felt as if everything was going well; Kirsty was engaged and contributing, and there was a sense of shared creativity. It was when I suggested adding lyrics, however, that the activity fell apart. Kirsty was unsure of what to use for lyrics, and despite her trepidation, I went in heavy-handed, suggesting that she might want to sing about her day at school (she had had a difficult morning) or how her anxiety was making her feel that day. Kirsty grew panicked, calling for her mother (who had left the room momentarily), and asked to end the session, which we did.

In this abrupt ending, I felt as though I had found a barrier within Kirsty; a barrier that needed breaking through, a barrier that could become a clinical aim for me. I interpreted her resistance as proof that she was unable to share and express her emotions about anxiety in lyric form, and furthermore I believed it would be *good for her* to do so. We also now had an activity that Kirsty could really *work* on getting *better* at. However, a few days later, I received a follow-up email from Kirsty:

> I was wondering if we could add these lyrics onto our song?
>
> My anxiety is heighten[ed] because of Covid.
> I can't move when I [notice] that someone walks towards me or close to me.
> I [become] very sensitive. I notice the room is cold, dark and can't breath[e].
> I can hear TV noise and feel there are something sticking out of my bed when I lay down to sleep, and can't sleep.
> I feel my body dying when I can't fall asleep.
> I can't face my timetable change at college.
> It is hard to express myself and communicate with others.
> I am often stuck on my memories or thoughts and [cannot switch] off easily.
> I can't wait [until] the pandemic is gone. I can go out to play and swim.
> So I feel better.

## *A Shift in Language, Perception, and Power*

The rawness of Kirsty's words stunned me, and I suddenly felt embarrassed by my narrow-mindedness as I realised Kirsty was telling me that she felt anxious because of the pandemic. I had been so confident in identifying autistic traits as the cause of Kirsty's anxiety that I had formed therapeutic aims that focused on trying to address or even change these traits. In doing so, I had imposed on Kirsty my own prejudiced notions of autism as a problem, a fault - something to be treated in isolation and "dealt with." Her words were the kindest invitation I could have hoped for to challenge me to shift from this oppressive viewpoint to a more holistic understanding of her as a complete identity actively engaging with life and society.

In a bid to make this shift, I reflected on my language, emotions, and actions over the last three weeks of sessions with Kirsty. The language in my session notes was largely person-first in nature, driven by a medical model understanding of disability. Words such as "change," "barrier," and "manage" reflected the way in which I had compartmentalised autism as an obstacle to Kirsty behaving in a way that fitted with my preconceived expectations of a healthy nineteen-year-old woman. I was so focused on discovering what Kirsty was "unable" to do because of autism, so that I could "fix" it. This language not only revealed how medicalised my perception of Kirsty was, but seemed to grant me blind authority to act inappropriately as a diagnostician and healer.

I also cast my mind back to the way I had felt during our sessions. I recalled an overwhelming yearning for greater agency and musical contribution, as well as frustration that my unfamiliarity with the repertoire was preventing me from having greater control over the direction of the session. I wanted to make things *happen*. This feeling of being rather spare in the interaction seemed to surface whenever Kirsty was truly excelling in the musical activity, singing through songs with flow and joy, or demonstrating her extensive knowledge of the repertoire in conversation. Even more alarmingly, I noticed that when Kirsty showed discomfort (for example, in the face of emotive questioning) or extreme vulnerability (in the song-writing process), I experienced feelings of progression, control, and self-satisfaction in my work. I seemed to view myself with the same medicalised perspective: when I was not the expert in the interaction, I felt powerless and ineffective. This had motivated me to make decisions that consistently shifted power away from Kirsty and towards me, making me another factor of disablement in Kirsty's life.

Our third session had seen this in action. When I asked Kirsty if she would like to write lyrics about her experience of anxiety at school, this suggestion was coming from *me*, not Kirsty. I was simultaneously taking away her creative agency, narrowing her range of choice (perhaps she wanted to sing about something else entirely) and imposing my perception of her behaviour as problematic, something that needed to be scrutinised in a therapy session. This had created a power imbalance so tangible and disabling that Kirsty was motivated to end the session early.

Moving forward, I wanted to change my perception of both myself and Kirsty, and I wanted to find the language to help me do this. In thinking of Kirsty "with autism," I was wrestling with two separate entities, pitting them against one another. I started to think about making music with "autistic Kirsty," a complex and complete identity that wanted to use music as relief from anxiety. I also needed to dispense my desire for control, and so I decided to find alternative language for "therapist" and "client." I wondered if I could instead become as "unknowing" and "inexpert" as possible, to encourage Kirsty to lead the way. Perhaps Kirsty might become my "teacher," and I her "pupil." Would using this language in sessions help us to redefine our roles, perceive each other differently, and lead to a more mutual, empowering dynamic?

In planning our fourth session, I decided to offer Kirsty the opportunity to teach me, Leah, and Andy a song from her repertoire in the original Mandarin. Of the three of us, only Leah was able to speak Mandarin, but this would give her a limited advantage as she was unfamiliar with the music. I was optimistic that actively celebrating Kirsty's expertise in this way would reframe the group's perception of her strengths and needs, and I was excited to see where this would take us next.

### Session Four

Initially, Kirsty did not believe me when I asked her to teach us a song. She was confused and surprised that I would want to learn Mandarin lyrics. When she realised my suggestion was genuine, she became excited, now delighted by the idea, and eagerly began to search for a song to teach us. Once she had found one, Kirsty sat up straight and put on a comical teacher voice, gesturing with her hands to get us all ordered and settled: "Right, everybody, shhh!"

As she started teaching us, her naturally fast-paced way of being presented a challenge to her aims, as she would reel off a full phrase of the melody with several words of lyrics, which we simply could not repeat. We needed word-by-word, note-by-note assistance, and once Kirsty realised this, she adapted her pace to suit us. She started to think carefully about how to teach us, tailoring her instruction to each person and considering what help they might need (Leah found the melody most challenging, whilst I struggled most with pronunciation). Kirsty suggested that we split the lines up between us based on who might find a certain phrase easier, and at one point she sourced the pinyin text to aid our learning. Kirsty also began to describe the melody lines in detail: "On this word you go up, then you stay up for all of this bit, hold it here, and then you go down on this word."

Within just ten minutes of the session there was a huge shift in the feel of the group. Previously, Kirsty had been relatively powerless as the focus of three older adults, fully aware of our roles as "helpers" and her role as the "helpee." The environment had been serious and uncomfortable for her, and her unsure and distressed demeanour had matched this. Now, she was thriving and leading the group with energy and confidence. It was also the first time I had seen Kirsty smile. At one point, she was laughing so hard at Andy's pronunciation that she grasped her mother's arm and exclaimed, "I can't sing, I'm laughing too much!" After half an hour of hard work and patience, Kirsty had successfully taught us two verses to a song by Li Ronghao, which we performed to ourselves at the end of the session. Kirsty was disappointed to end the session, though she left with tears of laughter in her eyes and an appetite for continuing the activity next week.

What was different in this session compared to previous weeks that both Kirsty and I came away feeling so nourished and contented? The same Kirsty came to this session, but she was presented with a different environment, one that contrasted not only with previous sessions, but with much of her day-to-day life. I had been approaching our sessions with unfounded assumptions about the role of autism in Kirsty's anxiety, thinking, *well, she's autistic, that must be the problem here,* and this had informed my decision-making and responses to shifts in power. Now, by encouraging myself to describe Kirsty holistically, and to think of her as my teacher and myself as a learner, I was facilitating a space in which someone was not seeking to problematise or change her but offering a platform for her to confidently express her identity, take pride in her heritage and abilities, and discover new strengths. To this end, I wanted to continue finding ways to be unknowing and inexpert on every level of our interaction. Later that evening, Kirsty emailed me a message which in its self-assured tone contrasted with our previous correspondence.

> You might've noticed that I added a new song onto our Spotify playlist. I wanted to share the inspiration of why I like the song with you. It's because of this video here. I love this video so much!....Also here are the lyrics in Simplified Chinese in a video just in case we want to use this in one of our sessions.

Kirsty and I built up a meaningful relationship over six months of therapy sessions. Kirsty became invested in teaching me and sharing her culture, and I became invested in learning. The more she felt me listening, the more she drew on her existing knowledge and skills to engage with new collaborative experiences. As we moved to on-site sessions, Kirsty began to improvise on instruments she had previously refused to play, recorded herself singing covers of songs to send to her aunt in China, and danced with me to new music. Our last session together felt momentous and emotional. To celebrate the occasion, we projected one of her favourite music videos onto the wall of the therapy room and sang along whilst enjoying a sugary dose of bubble tea.

## *A Culture of Asking*

> Music therapists have come to understand…that client self-definition and self-advocacy cannot be an add-on or an afterthought. The very frame of music "therapy," including how goals are conceived and constructed must not occur without the understanding of how individuals see themselves. (Leonard, 2020, p. 106).

For months after our last session, I found myself continuing to reflect on my work with Kirsty. I charted my active process of developing a more identity-first and holistic understanding of Kirsty, which involved introspection, research, supervision, and conversations with colleagues, Kirsty's friends, and family. Then one day I suddenly realised that at no point had I asked Kirsty how *she* perceived herself. This oversight seemed too significant to ignore, and so I got in touch with Kirsty to ask her the questions I should have asked months before. In the spirit of person-led language, I asked her about her sense of identity, her experience of disability, and what language she preferred to describe herself. Kirsty knew that her answers would be shared, and she had this to say:

> Autism does affect me in many ways because I find certain things hard to do and sometimes, I feel I like I don't know how to deal with my emotions. I think the biggest misunderstanding other people have of me is that it is really about the sensory and how much people give you to do, and about how people tell you information. I would maybe prefer to be referred to as a person/woman with autism because I feel like I am a woman with autism. I don't know to be honest with you…The best thing about having a learning disability is that you get to try and learn how to understand yourself slowly. You also get to try and understand how other autistic people think and feel as well as other people without it. I remember the times [in music therapy] where we tried to write our own songs, make covers of songs or just generally make up a tune with the instruments…and just generally jamming whilst doing it. I was able to look at Jay Chou and have a bit of fun with him, that maybe made me feel good…I found a lot of new songs from him. I felt quite happy in the music therapy.

By inviting Kirsty to contribute to my holistic understanding of her, I hope to contribute to a person-led culture of drawing upon the expertise and learning from the lived experience of disabled people. For example, I found it interesting that Kirsty identified with person-first language, especially as this conflicted with my perception of her. Perhaps after serious introspection, she felt that this phraseology was empowering and representative of her experience, or perhaps it reflects her unwitting adoption of the dominant language of the healthcare systems with which she was so familiar. Had she learnt to view her autism as a separate, problematic entity? Had I played a part in re-enforcing this? How would my work with her have been different if I had had this information sooner? Walker (2021) addresses this dilemma:

> Remember that your client may have completely bought into the pathology paradigm and may be ignorant of and even resistant to the neurodiversity paradigm. In which case, in order to support your client's psychological well-being and liberation, it may be your duty as a therapist to introduce your client to the neurodiversity paradigm, and to educate your client (p. 141).

I have not yet felt ready to, as Walker says, "educate" Kirsty on how to think and talk about herself. I had worked hard to shift power away from myself and towards Kirsty, and so how would re-assuming the role of expert once again and telling Kirsty how to think about herself affect my perception of her and myself in relation to her? And how would *she* experience this power dynamic? These unanswered questions only serve to highlight the ongoing nature of this journey.

## Reflections

In this article and case study, I have explored the power of language to represent and reaffirm models of disability, and considered what the implications might be for the discourse and practice of music therapy. Consequently, I conclude that as music therapy becomes increasingly established as an effective and valid form of healthcare, it has the strength to stand confidently alongside the medical profession as a complementary but distinct "craft" with its own approaches, models, and language (Cameron, 2014; Procter, 2001; Register, 2013). Music therapists continuing to use the language of disability without great consideration might pause to contemplate how their perceptions and actions may perpetuate ableist spaces. Similarly, music therapists seeking to develop a more holistic understanding of the people they work with might allow their language to be informed by unique, individual circumstances rather than implementing one-size-fits-all models. As such, I invite music therapists to question their language, critique their perceptions, reflect on feelings of power, and explore the learning language of becoming "unknowing" and "inexpert."

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