

REFLECTIONS ON PRACTICE | PEER REVIEWED

Against Cure and Toward Access in Musical Engagement

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Abstract

In this paper, I reflect on my own experiences undergoing occupational therapy with musical elements in the United States in childhood for impairments related to physical coordination and visual processing. Although therapy involving music was by far the most enjoyable and least painful of the therapies and treatments I underwent as a multiply-disabled child, it was still anchored in the language of removing my impairments and/or aligning me better with nondisabled norms. I build on the work of Robert Gross (incorporating the social model of disability into music therapy) and Emily Elaine Williams (the participatory model of accommodation enabling music for pleasure, not for therapy). I also draw on works in the autistic and cross-disability online spheres on the overmedicalization of disabled people's leisure activities to argue that framing music as a possible agent of cure or normalization harmfully obscures the ways in which music can provide access and mitigate impairments when directed and controlled by the listener, rather than by the therapist. My paper will also contrast music as therapy (imposed by others) vs. music as access tool (self-imposed) via a playlist and corresponding analysis. Music is central to my overall engagement with the world, affecting everything from processing and describing emotions, to communicating, to aiding in sensory processing. By introducing music as an access tool, or even as a form of assistive technology, I aim to challenge the dominant framing of normalization in therapy involving music and shift the focus to affirming disabled ways of engaging with music.

Keywords: occupational therapy; normalization; access; agency; social model of disability; reflection

Fiona's perspective:¹ *Stephanie was in a good mood today. She continues to make great progress on her motor control. She's getting better at isolating her wrist movement from her forearm movement, and working with the metronome seems to be a big help with keeping a rhythm going. Next session, we may work more on her handwriting, as I know legibility is a concern at school. After some object manipulation activities to work on her hand strength and coordination, Stephanie asked to swing, so she did several minutes of that while listening to one of the Therapeutic Listening® CDs and doing some of the prone lifts that she's working on in physical therapy. It's such a relief that she and her mom are so good with following the home program for PT (physical therapy) and OT (occupational therapy). That should help a lot with independent self-care down the road.*

My perspective: *I really like working with Fiona. She's so nice and definitely has the best sensory toys. I guess we have to get the less fun part over with first. The metronome is annoying. I had music in my head and the metronome pushed it right out. At least it's getting easier to move my hands and arms separately, which Fiona says is good. I'm glad we didn't do the handwriting metronome activity today. It's hard to remember to time how I speak to how I write, especially while the metronome is ticking away. I can't imagine going through all those steps to write when I'm actually at school. Buttoning these small buttons isn't my favorite, but it's not the worst. I guess if I get good enough, my mom won't have to help me dress, which the school therapists say would be great. Finally it's swing time. Yes! The swing feels like a hug and like flying at the same time, which is the best! It even makes those boring physical therapy exercises more fun and less painful. The music is quiet and happy. It's definitely my favorite kind of homework by far.*

Therapy with Music

I was born with cerebral palsy, which affects my muscles, notably in movement, balance and coordination. I was also born with the vision impairment strabismus, which means my eyes do not work together, which affects my visual tracking and spatial awareness. I've experienced lifelong motion sickness that has worsened with age. I am also autistic, and while the characteristic sensory issues have been present since infancy, I was not identified as autistic until adulthood, well after I finished therapy.

I had occupational therapy (OT) with musical elements from March 28, 2006 to July 18, 2008 from ages 9 to 12.² This was not formal music therapy, as Fiona is not a music therapist. However, it combined music with therapy and explicitly centered amelioration, if not cure, of various impairments. I feel that my experience of music-assisted OT shares enough, practically and ideologically, with music therapy for my insights to be useful to readers of *Voices*.

In writing this article, I reached out to my former therapist, Fiona Powers. She was able to remember aspects of therapy that I did not, and she generously explained more about the rationale behind the methodology she was using with me, Therapeutic Listening®, and her general process as a therapist. Fiona's primary background is as an occupational therapist, and she integrates Therapeutic Listening® into her OT practice as part of the treatment plan for patients presenting with issues related to sensory processing, motor skills, coordination, attention, and more.³ According to Fiona, I started occupational therapy after my mom was "concerned about visual perceptual/visual motor skills issues." My mom's concern also likely coincided with an increased workload at school requiring more handwriting. In addition to visual perception, Fiona also used Therapeutic Listening® with me on coordinating the muscles in both sides of my body, alleviating motion sickness, strengthening my hands, improving my handwriting, and a bit on independently doing self-care tasks, like fastening buttons.

The Therapeutic Listening® website describes the program thus:

The music in Therapeutic Listening® gives the listener unique and precisely controlled sensory information. The music is electronically modified to highlight the parts of the sound spectrum that naturally capture attention and activate body movement, synchronizing it with the environment. Therapeutic Listening® uses electronic modifications, along with the organized, rhythmical sound patterns inherent in music, to trigger the self-organizing capacities of the nervous system. (VitalLinks, 2022, What is Therapeutic Listening®? section)

I listened through a special set of over-ear headphones that allowed for experiencing what Therapeutic Listening® refers to as modulated music. Fiona explained that modulated music was meant to help me orient myself in space and distinguish noises in the foreground from those in the background. The music would appear to “move” in the course of a song, with sound coming from my right ear and moving to my left, or vice versa. Sometimes it would start from behind me and go in front of me. My program consisted of listening to a selection of Therapeutic Listening® songs for 30 minutes at a time every day, preferably while doing other activities like homework or physical therapy exercises. According to the Therapeutic Listening® website, listening for more than 30 minutes at a time can lead to “disorganization” of the nervous system (Vital Links, 2019). On days when I went to occupational therapy (about once a week), Fiona would have me listen to the music while swinging back and forth in a Lycra swing. She would often add other activities: physical therapy exercises, picking up small objects with both hands, or playing a game that involved maneuvering toy cars through a maze, for example.

The Therapeutic Listening® album I remember most clearly is called *Apricot Jamz* (VitalSounds, 2003), although I listened to other Jamz CDs as well. The Jamz music was completely instrumental and often featured soft instrumentation like woodwinds, guitar, piano, and harmonica. As I remember it, all the songs were covers of popular music, whether from media or children’s songs. Fiona explained that the music is meant to be easily recognizable, to make patients want to move, and to facilitate release of “feel-good” chemicals. I always listened to the music at a fairly low volume. At times, the songs were a bit repetitive, but the modulation effects offset any boredom, and I have always enjoyed and sought out repetitive music as a form of stimming. Autistic activist Amythest Schaber (2014a) explains that stimming (a shortened form of self-stimulating or stereotyped behavior) is often done “to self-regulate, to seek sensory input...and expression.” Stimming often involves repetitive movement. It is worth noting also that autistic and other neurodivergent people’s stimming is often pathologized and singled out for suppression or extinction. People who stim widely report that stimming can aid in focus, anxiety relief, or expressing pure joy.⁴ I did often move to the music as part of therapy, but I don’t recall feeling an internal need to move to it. It was a bit too relaxing and the melodies too improvisational to be dance music.

In addition to Therapeutic Listening®, Fiona also started me on a program called NeuroNet, hoping to improve the ease and legibility of my handwriting. NeuroNet is described as “a research-based learning readiness program designed to help students develop fluency in essential reading, math, and handwriting skills” (NeuroNet, n.d.). The exercises I did involved attempting to coordinate movements in my hands and arms by tapping a certain rhythm on the table, and writing letters in a certain way while speak-singing what I was writing and trying to match the tempo of a metronome. I did the NeuroNet activities in therapy and at home every day. Fiona said that the NeuroNet activities were meant to make my handwriting more “automatic” and improve my ability to isolate certain muscles (F. Powers, Personal communication, October 5, 2021). Fiona considers Therapeutic Listening® and NeuroNet to be separate programs with separate goals, but I experienced them collectively as music-assisted therapy, since the metronome provided a beat, and I sang-spoke the letters of the alphabet to a kind of melody as I wrote them. Therapeutic Listening® and NeuroNet were not related sonically to each other

except for my internal sense of them as music.

Therapy, Music, Pleasure, and Power

While what was going on in my bodymind while I was going to therapy did not truly match what Fiona might have thought,⁵ I consistently had a lot of fun. I have always loved listening to music, so having a type of therapy in which comparatively little was asked of me physically while I got to listen to music was a welcome relief. The swing was the highlight of every session, as I loved the sensation and feeling of weightlessness. Fiona was always very kind and gentle in her approach, stopping any activity that I was distressed by and checking in with me and my mother about how I was feeling. The music was enjoyable to listen to, and neither Fiona nor I can recall any of the music triggering my auditory sensitivity. Fiona did not even know I had auditory sensitivity until I brought it up in our interview, which is a testament both to the humanity of her therapeutic approach and how quiet and uncluttered the sonic environment of therapy was. Even the “worst” therapy exercises, like the metronome writing I mention above, were only annoying and never distressing.

My critique, then, is not aimed at therapy’s methods (as I experienced them) but rather at its underlying aims. The Therapeutic Listening® music was pleasant and fun to listen to, but I was always conscious that its main purpose was therapeutic, not solely for pleasure. The existence of “homework,” the directive to only listen 30 minutes a day lest the music lose its effectiveness, and the pairing of music with exercises aimed at mitigating my impairments make it clear, especially reflecting as an adult, what the focus of therapy was meant to be. Interestingly, in most non-therapeutic contexts I have experienced, music’s power increases the more I listen, whether I am listening for pure enjoyment or to understand the function of particular sonic elements. When I find a particular song I love, I can listen on repeat for hours. In this, Therapeutic Listening® dictates that I engage with music in not only a way opposite to how I normally would, but in a way opposite to how most people understand music. Although my motion sickness was the only one of my impairments Fiona explicitly meant to cure (and is probably the only one of my impairments that is theoretically curable), my impairments were always judged against nondisabled norms of vision, processing, and mobility. Getting closer to those nondisabled norms was the goal, and music, beautiful and gentle as it was, was still a means to that end. In this respect, my critique of music within occupational therapy can also be applied to music therapy since, as Joseph Straus (2014) points out, “Music therapy has positioned itself squarely within the medical model of disability, arguing that many sorts of human variability should be understood as illnesses, diseases, or other sorts of pathological medical conditions, and offering music as a source of normalization, remediation, and therapy toward a possible cure” (*Abstract*, para. 1). Even when outright cure was not possible, music in a therapeutic context was meant to change me, rather than changing my environment.

There was also a power dynamic between Fiona and me, inherent not only to the therapist-patient relationship, but also in the relationship between an adult imparter of knowledge and a child receiver of knowledge.⁶ Fiona set the agenda for each session and decided what responses to sound were effective or not effective. She never used her power negatively, but we were not participating in musicking as equals.⁷ She (and the programs she used) dictated what music I could listen to in sessions, for how long, and, importantly, why I was listening to it. She did not know until our present communications that even before I began working with her, I had a firm idea of what sonic elements I did and did not enjoy, and what internal effects and associations I could create in my bodymind with various types of music. I’m sure she would have been receptive to me sharing this in therapy, but she never asked, which is reflective of the structural power imbalance

between us. Neither she nor I thought of me as someone with music knowledge worth sharing.

I wonder what it might have looked like to engage with music either as an end in and of itself, or as a means to help me access concepts that I wanted, like pleasure, self-expression, or community. The participatory model articulated by ethnographer and musician Emily Elaine Williams (who has a hearing impairment) in the context of bluegrass jam sessions offers an explicitly non-therapeutic model where shared music is the end goal and equal relationships between peers are the means (Williams, 2020). She foregrounds accommodation, a practice for which all musicians are responsible, as a way to affirm the humanity and value of participants. Williams writes of the immense value of peer-based rather than therapeutic relationships, what she calls “the critical state of having a system of relationships able and willing to provide accommodations without holding that provision as power over the disabled body” (p. 58). Unlike Williams’s equal-peers model, or even a model in which I would be learning from an expert musician alongside less expert peers, the model that I encountered with Fiona did not affirm me as I was or honor the knowledge and skills with which I came. Had I been introduced to a model of musical engagement where I could autonomously create music not as a way to approach a concept of normative ability but as a way to create something in a coequal community, that is what I would have wanted. I would have loved to play an instrument as a hobby, the same way that many of my abled classmates did, without having certain modes of engagement predefined for me, or certain responses to sound deemed “good” or “bad.”

Medicalizing Pleasure

The overmedicalization of disabled people’s leisure is not a phenomenon unique to me or unique to having a particular diagnosis. The Facebook page *NeuroDefiant*, whose author describes themselves as “actually autistic, multiply disabled and chronically ill” (NeuroDefiant, n.d) calls attention to this in a post. They deride the “fixing lens” often applied to the leisure activities of disabled people (NeuroDefiant, 2017). Giving some examples of this lens (art becomes art therapy, horseback riding becomes equine therapy, listening to music becomes music therapy, and so on), NeuroDefiant ends by saying, “We can swim, paint, play music and a million other things without a therapy spin to it. When NT [neurotypical] people do these things, it’s just art/ horseback riding / swimming/ making dinner. Stop pathologizing our lives and let us have hobbies and do things without using them in a therapy aspect.” This pathologization of pleasurable activities resonates with my childhood experience with multiple therapies, not just therapy with musical elements. My parents were delighted to see me walking in the pool, or kicking with both legs when I swam, not only because I was enjoying myself, but because it might signal an increase in my balance or muscle strength that brought me closer to unassisted walking. Physical therapy, occupational therapy, and vision therapy were full of games, but all had motives additional to fun. Of course, incorporating fun made therapy better and easier, and I am not arguing for a strict binary.

The fact that I engaged with music in both a therapeutic context and a leisure context is not a problem in itself; where I take issue is first that because of structural ableism, I did not have many substantial opportunities for communal engagement with music outside of therapy, and second that in therapy, music was a means to the end of aligning my bodymind more with abled ideals. I do not expect therapists to be able to address the first issue directly, but I do invite them to be mindful that their patients may have limited or no access to certain leisure-adjacent activities outside of therapy. I understand and sympathize with the need to center therapeutic goals rather than the means of achieving them, but there are participatory, neurodiversity-affirming, social justice informed, and client-centered approaches that both feature goals (often selected with patient direction

or input) and attend to the means of achieving them, without necessarily defaulting to normalization.⁸

Carolyn Shivers, in the panel "Autism Tech and Autistic Experiences" at the forum *Choices & Challenges Technology & Disability: Counternarratives* hosted by Virginia Tech on November 9, 2020, critiqued the use of autistic people's interests as leverage to normalize them in therapy: "We're not using these interests as a way to get to know people, as a way to respectfully enter into their spaces. We are co-opting it as a way to make them less autistic because that's what we are comfortable with. We have our set rules of what we think socialization should look like" (Awni et al., 2020). Particularly when therapy is given to autistic people, therapists often focus on normalizing patients according to nonautistic standards or on the comfort of nonautistics. As Rua Williams noted in the same panel, how the children feel is rarely taken into account. It is worth noting here that my therapist Fiona did not leverage my interest in music to compel me to act a certain way, the way a behavioral therapist might. She did, however, enter into the therapeutic relationship with ideas (no doubt in dialogue with ideas held by my other therapists, parents, teachers, and wider society) about how I ought to process visual and auditory input, how I ought to navigate my environment, how I ought to care for myself, and how I ought to write. None of these goals were presented maliciously, and our relationship was warm, but we did not have equal power and agency. In a therapeutic lens, relationships for their own sake are decentered as the therapist shifts the focus onto "rehabilitating" the patient. It is worth interrogating who therapy as currently practiced is for: whose comfort, whose idea of appropriateness or normality does it center, and whose perspectives does it center? Who needs the adjustment: the patient or society?

Participatory Therapy with Music

What might a participatory, patient-centered therapy involving music look like? Music therapist Robert Gross (2018) articulates something parallel to Williams's participatory model in his discussion of music-centered music therapy, a term coined by Kenneth Aigen. Music-centered music therapy rejects the idea that the patient or client is sick, abnormal, or in need of fixing, and sees the creation of music as a reciprocal activity between therapist and client in which the music is the goal (Aigen, 2005). Gross's model challenges the hierarchy present in music therapy, in which the therapist with superior knowledge directs the activities of the inferior client toward a goal the therapist decides. In my own experience with therapy, Fiona was very conscientious in frequently checking in with me and my parents, but in the end my parents and she (and to a lesser extent my physical therapist and my school therapists) still set the goals for me. I could comfortably opt out of a given activity, but I did not have the power to direct my goals. The goals were decided for me, often accompanied by some concern from school about how I wouldn't be able to "keep up" with my abled classmates if I could not handwrite, use both hands, or navigate the hallways and classrooms in a particular way. My goals were explained to me, and I was happy to go along, but the music only ever flowed from Fiona to me, and on her terms (or, more accurately, on the terms of Therapeutic Listening® and NeuroNet.) Although Fiona selects different combinations of music for different clients, and Therapeutic Listening® does not have a predetermined listening order, the program itself runs on the assumption that people with a certain neurotype will respond to the music in certain ways and then be able to be guided to respond in different and more "appropriate" ways. In a particularly ironic twist, in their *General FAQ* (Vital Links, 2019), the founders of Therapeutic Listening® give advice on decreasing "self-stimulatory behaviors" and discourage patients listening to the music while stimming. I was not labeled autistic at the time of therapy, so my stims were not discouraged. In fact, I was explicitly encouraged to stim by swinging (even if it was not framed that way) while listening to the Therapeutic

Listening® CDs. Had I not been allowed to stim, Fiona would have had a more difficult time working with me to meet treatment goals related to integrating movement and processing simultaneously. As activist Radical Neurodivergence Speaking (2017) points out, “EVERYBODY stims. Recreational pen clicking is a stim. Flapping is a stim. Whistling is a stim. Spinning in circles is a stim... it is not just Those People Over There. It is a human trait.”

Music, Pleasure, Affirmation, and Joy

What would music as affirmation of disabled joy and expression sound like? Allow me to invite the reader to share an experience I have gifted to many friends and loved ones: I made you a playlist. This playlist and commentary outlines some of the ways I have reclaimed my relationship with music in a way that affirms and/or works alongside my impairments. This would allow me to move away from the idea that my bodymind is a “problem” that needs to be fixed – a concept firmly grounded in the medical model of disability that attributes disability to the individual. Music-assisted occupational therapy was meant to use music to change the way my body responded to certain sounds so that I could be, if not cured, then treated. When I use music to facilitate access, there are no right or wrong ways to engage; there is only music I like and music I don’t like, or music I find helpful for a specific purpose and music I don’t. My goal is not to change my bodymind, but rather to work with my bodymind and change my environment so that I am happier and/or less distressed – an approach informed by the social model of disability, which attributes disabling effects to social and environmental circumstances that are hostile to the ostensibly non-typical bodymind.⁹ Rather than using music in a mode where others dictate what steps I need to put my bodymind through to engage “correctly,” I am making the sonic equivalent of ramps to facilitate sensory regulation, enjoyment, and expression without the expectation that I change.

1. For sensory regulation, “[Sleep Now in the Fire](#)” by Rage Against the Machine (Morello et al., 1999): This is perhaps as far as one could get from the soft woodwinds of the Therapeutic Listening® CDs, but it’s my version of foregrounding particular noise so that the music drowns out more unpleasant and distressing sounds, like a running vacuum cleaner or fireworks. Both Tom Morello’s resonant guitar tone and Brad Wilk’s crashing drums are very intense and heavy, which grabs my attention. Something I find amusing about this song in particular is how much the vibration, pitch, and grinding timbre of the guitar solo reminds me of a dental drill, something I can’t tolerate at the dentist but find useful for musicking. I have listened to the song enough to know what to expect, and I can control the volume. Both qualities are vital when I engage with music, especially since other sounds I come across are unexpected and uncontrollable. It is important for therapists to keep in mind that sensory regulation is not always synonymous with being soothed.
2. For movement, “[Prickly Thorn, But Sweetly Worn](#)” by the White Stripes (White, 2007): The White Stripes have been one of my primary musical “special interests,” or, as I reframe it without pathology, deep loves, for several years. Musically, the melody and instrumentation (bagpipes, mandolin, drums) draws from Scottish folk, and Meg White’s prominent steady drumming provides an easy rhythm to tap to. I tap along to it not to improve my rhythm, but because expressing the sensation with my body makes me happy. In the YouTube comments of one live performance of the song, White is described as “the human metronome” (Radio Raven, 2012), which makes an interesting parallel with NeuroNet’s metronome. Rather than disrupting my mental musicking, I am enhancing it. I experienced the

NeuroNet metronome as disruptive both because of the sharp, clicking timbre and because there was no other sound to pull my attention and balance it between different sounds. White's bass drum is softer here, so less overwhelming than a metronome's click, and the variety of instruments means that one sound texture doesn't dominate my attention.

3. For flow of work, "[Haul Away Joe](#)" by The Longest Johns (Traditional, 2018): Sea shanties are another of my longtime musical deep loves, mostly because I find the steady rhythm and repetition satisfying. I have noticed that listening to shanties helps me work at a steadier pace (as they're meant to do). When my executive dysfunction or inertia is making it difficult to start a task, sometimes speak-singing about the task with the cadence of a shanty will help. I am not "fixing" my inertia, as I do not control it or seek to banish it, merely to make it less powerful. When the inertia interferes with something I value (work), the music helps to foreground continued creative flow. It's my self-directed take on what NeuroNet calls automaticity. I am following my internal sense of rhythm, which does not have sharp, mechanical clicks like an external metronome. Depending on the shanty, the musicians can keep time using a drum or by stomping, which are often more smoothly integrated into the sonic mix (and thus less invasive) than a metronome. It's also easier for me to work with music that does not feel sharp.
4. For emotional expression, "[Vienna](#)" by Billy Joel (1977): As I wrote in a previous Facebook post, "Once every so often it hits me that music is a tool for identifying emotions as well, something that I and many other autistics have a hard time with. It was not until I started singing Billy Joel's "Vienna" the other day, out of seemingly nowhere, that it hit me how much I was missing a friend who I associate with that song. This also served to remind me to contact her, which is a struggle [for me]" (S. Ban, private Facebook post, October 26, 2021). Beyond the sonic elements of music, lyrics are often emotionally powerful for me, and a big factor in my constant "mental soundtrack." It's very common for me to be only somewhat conscious of what song is playing in my head at a given time, only to realize upon reflection that it relates to what I'm thinking, feeling, or experiencing in that moment. Melodies or points of rhythmic emphasis can aid in remembering a song and recognizing it when it comes to mind.
5. For communication about ideas, "[Links on the Chain](#)" by Phil Ochs (1965): Phil Ochs is another of my musical deep loves, and I find the timbre of his voice particularly pleasing, especially in the higher parts of his range. I love the repetition of the lyrics "on the chain" and how the guitar accentuates it. Here, Ochs is calling attention to the deep systemic racism within the labor movement and predicting that white labor leaders' failure to extend solidarity to Black civil rights activists will be labor's downfall. I think a similar parallel can be made to the way that prominent independent living movement leaders today fail to fight for people with cognitive disabilities, people of color, and other multiply-marginalized disabled people.
6. For communication about emotions and relationships, "[One of Us](#)" by Heather Dale (2015) : Sonically, this is well within the folk tradition I find comforting, and I enjoy the expressiveness of Heather Dale's voice. Lyrically, it captures the deep feeling of gratitude that I have for those who have shown me what is possible, whether as a scholar, an activist, or a person. A particular friend feels inadequate sometimes, and rather than tell her with my voice or my own words, "I admire you deeply, and I appreciate the path that you're paving for me and other younger disabled people. You have more of an impact than you know," I played her the song instead. One core function of music for me is as communicative echolalia, or a repetition of words or phrases originally from another context, with the intent

of communicating something about a current situation.¹⁰

7. For humor and play, “[I Don’t Want Your Millions, Mister \(All I Want\)](#)” by The Almanac Singers (Traditional & Seeger, 1955): Labor union and 20th century U.S. folk music is not only one of my deep loves, but something I can share with some of my friends. One of my favorite ways of musicking for happiness is to rewrite the lyrics to songs I like. This is a fun solo activity, but even more fun when friends join in. This song as Pete Seeger and the Almanac Singers perform it is not intended to be funny. With simple banjo and guitar and a vocal delivery between plaintive and angry, this is meant to be a song to radicalize people. However, my friend Cal, another disability rights activist and folk enthusiast, encouraged me to rewrite it with humorous lyrics after hearing another activist respond to ableist patronization with “I don’t want your fucking cookies.” (I forget which of us pointed out the scansion of the phrase.) Cal and I will often co-write or exchange humorous lyrics to folk music. Humor and play are not (and shouldn’t be) therapeutic goals, but they are vital to how I use and enjoy music.

For interested parties, here are the lyrics to “I Don’t Want Your Fucking Cookies”:

I don’t want your fucking cookies
 I don’t want pats on the head
 All I want’s my independence
 And for you not to want me dead

Now I don’t want paternalism
 I don’t want your empty words
 All I want is a home to live in
 And freedom to do what I choose

We’ve rejected your fucking cookies
 We won’t let you do what you please
 You want us to sit down and shut up
 While all our people still aren’t free

So I don’t want your fucking cookies
 I don’t want pats on the head
 All I want’s my independence
 And for you not to want me dead

It’s not our lot to be compliant
 We won’t be silent just for you
 Cause we can make our own decisions
 If you object, we’ll say fuck you

Now we’re all finished with your pity
 Our lives have meaning just like yours
 And if you won’t learn then we will show you
 How we’ll set all our people free

So I don’t want your fucking cookies
 I don’t want pats on the head
 All I want’s my independence
 And for you not to want me dead

Conclusion: Centering and Cultivating Creativity

Most people, disabled or not, use music for a variety of purposes: to evoke or express emotions, for social interaction, for communication, or just for fun. Music is inherently valuable, and that value is highly individual. Therapy that is not anti-oppressive and grounded in the patient's wishes mars this intrinsic value by giving the therapist the power to determine what is or should be valuable to another person. Therapeutic goals often involve changing the patient, so that even if therapy is "successful," it is the patient that has the responsibility to change or conform. In fact, the "success" of therapy is often measured by how much the patient now conforms to an abled ideal. If a client does not change or conform, they may be labeled stagnant or noncompliant (recall Fiona's earlier praise of me and my mom for being so diligent with the home program). Fiona told me in our interview that she is moving toward a less time-consuming therapeutic practice, one that gives children time to play and have fun like their abled peers. This growth is laudable, but it does not erase the power resting primarily with the therapist or the end goal being changing the patient. A social model-centered approach would center the music, be fully collaborative, not make value judgments on sounds or responses to them and see the patient as having knowledge and agency.

It is important to note that I am not saying therapy should not exist or that music should never be a part of therapy. Rather, as much as possible, therapists should endeavor to support patients in ways that center patient goals and honor patients' experiences and ways of knowing. In the context of therapy involving music, a therapist could still assist in choosing the music or explaining possible effects of it. They could even participate in musicking with the patient if the patient desires.

Connecting with the collaborative models proposed by Gross (2018) and Williams (2020), the therapy-informed playlist-listening that I propose here would be one possible approach that truly empowers an individual to decide their own goals and areas of focus. By choosing music that they enjoy, a person can use their own power with a therapist as they wish – an approach to musicking that honors and cultivates creativity as well as well-being.

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Stephanie (Steph) Ban is an independent scholar and disability rights activist. Her work explores disability in both the 20th century United States and, more recently, the 18th century French Enlightenment. Steph's scholarly interests include the history of disability activism, the place of disability in historical memory, and histories of neurodivergence (broadly conceptualized). She has presented at conferences in several disciplines, including history, disability studies, and musicology. Her work can be found in *The Activist History Review* and *Disability Studies Quarterly*.

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¹ At her request, I am using the pseudonym Fiona Powers for my former therapist. I have her permission to share her perspectives in this piece. Fiona's perspective and mine are not based exactly on a particular session, but they are based on a plausible session structure, constructed from my memory and a combination of our phone interview and emails we exchanged (see full citations in subsequent footnotes).

² Fiona is not a music therapist and said that she considered our sessions not as music therapy, but as "therapy using musical programs" (F. Powers (pseudonym), Personal communication with the author, November 24, 2021).

³ F. Powers (pseudonym), Telephone conversation with the author, November 6, 2021. All subsequent references to Fiona's goals and methods come from this interview unless otherwise indicated.

⁴ A recent systematic study of autistic perspectives on stimming is Kapp et al., (2019).

⁵ For a discussion of the concept of bodymind, see Price (2014).

⁶ It is important to note that even the hierarchy that places adults above children in a therapeutic context is rightfully being called into question. See Liegghio (2020). In fact, adultism runs parallel to and reinforces ableism. Even if the power dynamic in therapy is based on the adult/child binary and not the abled/disabled binary, there is no reason children shouldn't be active and coequal partners in therapy.

⁷ Musicking, coined by Christopher Small (1999), is an intentionally broad term that centers the

experience of listening and the relationship-building that happens in all musical contexts, not just performance. Everyone can take part in musicking regardless of normative “ability.”

⁸ For an overview of some anti-oppressive approaches, see Rickson (2014) and Pickard et al. (2020).

⁹ For more on the social vs. medical models of disability, see Shakespeare (2006).

¹⁰ Autistic activist Amythest Schaber explains various types of echolalia here. What I describe above as communicative echolalia, they term echolalial scripting used for communication (Schaber, 2014b).