# Troubling Disability:

# Experiences of Disability In, Through, and Around Music

by

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A Dissertation Presented in Partial Fulfillment
of the Requirements for the Degree
Doctor of Philosophy

Approved November 2018 by the
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May 2019

# ABSTRACT

The purpose of this study was to trouble existing conceptions of disability that ground music education literature and practice. I sought plausible insights into how disability is experienced in, through, and/or around music by participants who are disabled persons/persons with disabilities (DP/PwD). Insights gained might allow readers to complexify and trouble taken-for-granted assumptions about disability. Questions included: (a) How do participants experience disability in, through, and around music? (b) What plausible insights related to disability can be gained by attending to participants' experiences of disability in, through, and around music? (c) What plausible insights related to inclusion can be gained by attending to participants' experiences of disability in, through, and around music? The inquiry approach was grounded in Buberian relational ontology, phenomenology, interactional theories of disability, and narrative.

Seven DP/PwD participated in this study: (a) Erica, a 14-year-old diagnosed with a developmental disability of unknown etiology; (b) Duke, a drummer diagnosed with Williams syndrome; (c) Birdie, an abstract visual artist with epilepsy who used music to inform her art; (d) Daren, a b-boy/breakdancer diagnosed with Tourette syndrome, (e) Sienna, a legally blind social work college student who played banjo in a music therapy-based bluegrass band and participated in musical theatre; (f) Ice Queen, an undergraduate flute player recently diagnosed with Attention deficit/hyperactivity disorder (ADHD); and (g) Culann, an adult counselor and music listener with ADHD and mood disorders. Data generation included conversational interviews, observations, artmaking, and serendipitous data.

Data co-generated with participants were crafted into narratives of their lifeworlds, including description of their experiences with disability in, through, and around music and in other aspects of their lives. An envisioned conversation among all participants demonstrates the shifts and complexities in the meanings of disability and unpacks different ways participants describe and understand disability and the myriad roles that music plays in their lifeworlds. The final chapter of the study offers discussions and suggestions regarding thinking about and approaching disability (i.e., interactional theories, intersectionality, and identity), inclusion (i.e., belonging, suggestions by participants, and anti-ableist pedagogy), and research/writing.

# DEDICATION

This document is dedicated to all disabled persons/persons with disabilities. Your experiences matter. Your stories matter. Your musics matter. Your voices matter. You matter.

# ACKNOWLEDGMENTS

First, thank you to Erica, Duke, Birdie, Daren, Sienna, Ice Queen, and Culann who opened up their lives, their identities, and themselves to me. It was an honor to be with you all, to come to know you all, and to embrace the world with you all. I hope that your stories and ideas might help other music teachers create more open and meaningful spaces for all people; I know that what I have learned from you all has greatly shaped my own practice.

I also want to acknowledge all of the students/participants, faculty, and staff in places where I have worked as a music teacher/facilitator: Lee School (Springfield, IL); DeLand-Weldon CUSD 57; Country Meadows, Willow Grove Kindergarten and Early Childhood Center, and everyone at Killdeer Countryside School District 96; Arizona State University; Higher Octave Healing (Tempe, AZ); and James Madison University. I love/loved learning with and from you. I would also like to thank some very special teachers whose ways of being are all over this document, including: Loretta Campbell, Kelly Donahue Dimidik, Sam Reese, Greg DeNardo, Joe Grant, Maud Hickey, Janet Barrett, Peter Webster, Carlos Abril, Jill Sullivan, Evan Tobias, Marg Schmidt, Roger Mantie, and Ted Solís. Sandy Stauffer, I would not have come out West to study and surely would not have stuck through the degree or this project without you. Thank you for constantly challenging me, for listening to me, for reminding me to listen, for talking with me, and for encouraging me to be brave and try new things. Kim McCord, thank you for opening up so much about disability scholarship to me through your class, our chats, and our projects together. Alice Hammel, I know you have never been my teacher of record for a class, but your work and your continued friendship teaches me so much. Also, thank you to those whose scholarship taught me, including but not limited to: Adam Patrick Bell, Tuulikki Laes, Joe Abramo, Warren Churchill, Juliet Hess, Judith Jellison, Alex Lubet, Petra Kuppers, Neil Marcus, and Martin Buber.

So many friends have supported me through my work on this document. Shayne Hamm, you may have passed away long ago but your spirit still moves through me every day and I know there is some of you in this document. Emmett O’Leary, thank you for being the big research

brother that I did not know I needed and for starting me down the road of phenomenology. Ryan Bledsoe, I so appreciate your playfulness and how you encourage me to play as a writer, researcher, educator, and human. Isaac Bickmore, thanks for being a constant collaborator and friend. Austin Showen, I owe you so much for challenging me and constantly being ready to jam and chat. Tim Nowak and Jared O'Leary, thank you for pushing me to think about different things and also for calling me out when I get too pretentious. Also, a big thank you to all of the ASU doctoral student community with whom I interacted during my time on campus, including, but not limited to: Soyeon Kang, Joyce McCall, Nathan Johnston, Sarah Minette, Tavious Peterkin, Corrie Box, Elizabeth Bucura, Vinny Brancato, Emily Schwartz, Yousef Alsayegh, Nathan Botts, and Hyung Seok Kim. Outside of ASU, Dave Stringham, you deserve a special thank you. You have supported me, been an informal mentor and co-provocateur, and cooked up new ways of opening up music and art education to underserved communities with me: thank you for all you have done and continue to do.

Thank you to all of the Rathgebers, Sheppards, Rykaczewski, and Bylinas. Mom and Dad, you will never know how grateful I am to have such loving and supportive parents who nurtured my musical life, my curiosity, and my empathy for others. I love you and thank you for all you have sacrificed to help me explore my own path. To Jon, Susan, and Molly Kanner, thank you for being my "logical family," people I can always turn to for artistic and personal inspiration. Thank you to our pets, current and past, even though none of them can read: Simone de Beauvdog and Judith Barkler (dogs); Ravi, Lola, and Suni (chinchillas); and Martin Bubler (beta fish), thank you for the love you give; know that I owe you my life. Finally, Kasia Rathgeber, my loving wife and best friend, this is as much your document as it is mine. I could not have started, sustained, or completed this journey without you and all that you have done. You support me in ways that I cannot fathom, in ways that I might never fully understand. Your empathy and care for all people is endlessly inspiring and endlessly educative. I am in awe of you for so many reasons. Thank you and know that I love you

TABLE OF CONTENTS

CHAPTER Page

CHAPTER Page

APPENDIX

# LIST OF TABLES

TABLE Page

# LIST OF FIGURES

FIGURE Page

# CHAPTER ONE: AN INTRODUCTION

**Disabled Country**
If there was a country called disabled,
I would be from there.
I live disabled culture, eat disabled food,
make disabled love, cry disabled tears,
climb disabled mountains and tell disabled stories.

If there was a country called disabled
I would say she has immigrants that come
to her from as far back as time remembers.

If there was a country called disabled,
then I am one of its citizens.
I came there at age eight. I tried to leave.
Was encouraged by doctors to leave.
I tried to surgically remove myself from disabled country
But found myself, in the end, staying and living there.

If there was a country called disabled,
I would always have to remind myself that I came from there.
I often want to forget.
I would have to remember...to remember.

In my life's journey
I am making myself
at home in my country.
(Marcus, 1996)

What does it mean to experience disability, to be disabled, or to live as a person with a disability? In his poem “Disabled Country,” Disability Arts Movement pioneer Neil Marcus shares his perspectives as a disabled artist living in “a country called disabled.” In this country, disability is, verse by verse, (a) a culture, identity, and landscape that shapes one’s being-in-the-world and being-with-others; (b) a near universal human condition; (c) a subject position constructed and operationalized through medical discourses and the edicts of medical experts who seek to remediate or end disability; (d) a social construct, emerging out of organizations, “place, time, activity, and encounter” (Lubet, 2011, p. 21), that forces humans to be identified or to identify themselves as disabled based on hegemonic ableism; and (e) a way of *living*. In a different work, Marcus (1983) also frames disability as a way of living that requires a certain kind of artful creativity to be within a world filled with physical, legislative, and social structures that may be inaccessible or hostile toward disabled persons/persons with disability (DP/PwD).[1]

> Disability is not a brave struggle or courage in the face of adversity.
> Disability is an art. It's an ingenious way to live. (Marcus, 1993)

Through these words, his theatrical works such as *Storm Reading*, and poetry written with disability artist and scholar Petra Kuppers in *Cripple Poetics: A Love Story* (Kuppers & Marcus, 2008), Marcus invites readers and audience members to come to know what disability is like and what disability means for him, thereby opening his lifeworld[2] and experiences to be given[3] to others. Marcus does little to clarify disability or to suggest a grand theory of disability. Rather, he exposes the myriad ways that disability *is* and is experienced by DP/PwD as socially imposed, as medicalized, as pride, as pity, and, above all, as an “ingenious way” of living in the physical and social milieu in which DP/PwD are embedded.

### Purpose Statement and Research Questions

In this study, I embrace Marcus’s efforts to complexify disability. I do so in order to challenge and problematize essentializing and totalizing conceptions of disability that inform research about and facilitation of music making and music learning for and with DP/PwD (e.g., “inclusion”). I focus on the personal phenomenological accounts of specific DP/PwD and their experiences of disability in, through, and around music as a means of offering counter-narratives of disability and inclusion. While existing narratives of disability, such as disability as a personal tragedy, inform current inclusive pedagogies, I suggest that new types of inclusive-practices may grow from counternarratives of disability that challenge existing grand narratives.

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[1] I explain my use of this dual formation (e.g., DP/PwD) in the next section of this chapter.

[2] I explain the concepts of “lifeworld” in depth in Chapter Three. In brief, a “lifeworld” is one’s reality as subjectively experienced and understood (Husserl, 1936/1970; Merleau-Ponty, 1945/2005; van Manen, 1990).

[3] In Chapter Three, I discuss Stein’s (1989) understanding that empathy occurs when one is able to be “given” the experiences of others, in which one is allowed to access, even partially, the lifeworld of an other.

In brief, the purpose of this study was to trouble existing conceptions of disability that ground music education literature and practice by exploring the personal experiences of disability in, through, and around music with specific DP/PwD. I sought to uncover and share “plausible insights” (van Manen, 1990, p. 9) into how disability is experienced in, through, and around music experiences of participants. These insights might, then, allow readers to complexify and trouble taken-for-granted assumptions of what disability can mean and be “like” in, through, and around music, and these troublings and complexities might then ground inclusive practices different than those prevalent in music education historically. The central phenomenon in this study is experiences of disability in, through, and around music. Questions guiding this inquiry are:

(1) How do participants experience disability in, through, and around music?
    (a) What manifests through experiences with disability in, through, and around music?
    (b) How do participants perceive, interpret, and describe their experience of disability in, through, and around music?
(2) What plausible insights related to disability can be gained by attending to participants’ experiences of disability in, through, and around music?
(3) What plausible insights related to inclusion can be gained by attending to participants’ experiences of disability in, through, and around music?

## Clarification of Vocabulary

**DP/PwD**. In this document, I use the dual formation of disabled persons/persons with disabilities purposefully to place both identity-first (i.e., “disabled people”) and person-first (i.e., “person with a disability”) labels in tension, unless a specific label/formation is preferred by a specific author or participant. This usage of DP/PwD may be clunky, but it allows me to forward the in-between positionality of disability and to highlight the inherent tension that arises when discussing experiences of disability and disability identity. Also, I intentionally embrace the power and art that exists within the word “disability,” regardless of the discomfort this may pose to some non-disabled readers, rather than use euphemisms such as “exceptional” and “special needs.” Yet, I also wish to respect the naming rights of persons who identify as a “disabled person” and/or “person with disabilities,” and, as such, used the dual formation to center disability while respecting the agency of people who experience disability deeply. I use the term “nondisabled” in accordance with Linton’s (1998) encouragement that scholars center disability, with regard to identity, and the experiences of disabled persons in their work. In illustrating her point, Linton makes use of identity-first formations (e.g., disabled person) and positions those usually deemed “normal” or “typical” as “nondisabled.” I use “nondisabled” in this document with similar intent—to center disability, though I opt for a more interactional approach to naming (i.e., DP/PwD), as discussed above.

**In, through, and around music.** I use “in, through, and around music” in this document to highlight the manner in which participants’ experiences of disability impact and are impacted by their participation *in* purposeful musical interactions (i.e., voluntary participation in a bluegrass band), exploration of self and connection to others *through* music (i.e., expressing oneself through lyrics or finding new friends through shared musical interests), and participants’ presences *around* music at events or in circumstances where music is ancillary or not the focus (i.e., riding around with friends while music plays). Participants’ experiences of disability often changed from being *in* music to being *around* music rather quickly and, as such, the lines between how music impact their experience with disability frequently blurred. Using “in, through, and around” allowed for flexibility to follow participants’ experiences of disability in a confluence of individual and social contexts grounded by music.

### Outlining a Rationale

Why is this study important? Why am I doing this study? Question such as these allow researchers to grapple with what grounds their research. Vagle (2014) suggests that researchers answer these questions by laying bare their personal motivations and the problems to which they would attend in a study. This laying bare can be done by exposing the personal, research-based, and/or theoretical problems that ground a researcher's interest in a specific topic. Below, I present the interlocking personal, research-based, and theoretical problems related to disability and inclusion that ground this study.

**My experiences of disability - trigger warning.**[4] Two types of personal experiences motivate this study. I have experienced disability in at least two different ways that shape how I understand this study, myself, participants, and life in general. First, I experience disability first-hand as someone with a mental illness and my way of experiencing and understanding disability does not resonate well with existing literature on disability. Second, I have experienced disability professionally as a music teacher. Through my experiences working with DP/PwD and nondisabled persons in and outside of schools, I have sought to foster inclusive practice and have observed other music education professionals essentialize DP/PwD even while trying to "include" them. From these experiences sprouted problems that I have observed and felt. In the next two sections, I identify problems that have manifested for me through experiences of disability in, through, and around music. Sharing this information not only provides a personal rationale for this study but also allows me to identify myself and my positionality related to the central phenomenon of this study.

***Experiences as a disabled person/person with a disability.*** I could be identified as a "disabled person" or "person with a disability." As such, I have a vested interest in how researchers and teachers understand disability and relate with other DP/PwD. I was diagnosed as being bipolar/having bipolar disorder at the time of writing this document, although I have been treated for clinical depression since I was at least 18 years old. I have experienced disability on a number of fronts, from the rush and eventual crash of maniac episodes, to interacting with my family members as they live through bouts of severe depression, and even to joining family and friends in sorrow as suicide took another life. In general, I have thrived, perhaps owing a great

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[4] In this section I provide highly personal commentary on depression, mention suicidal ideation, and address multiple disability microaggressions (e.g., languages and practices). This commentary may be shocking to some readers and/or many induce memories of trauma for others.

deal to my support network and my privilege as a white, middle class, cisgender male, heterosexual, able-passing person from the Midwest of the United States.

My experiences of disability are complex and involve both individual facets (e.g., insomnia, hypomanic episodes, major depressive episodes, suicidal ideation, and feelings of intense anxiety) and social facets (e.g., constantly worrying that my openness about my experiences of disability will be read as problematic by peers, seeing others with similar identities and diagnoses implicated as major threats in the wake of the nearly daily mass shootings occurring in the United States at the time of this writing, and inadequate healthcare with regard to mental health services). I experience disability in profound ways as well as in mundane ways. There are days when I can barely get out of bed because of desperately empty feelings and times when I am hyper-productive but grapple with overinclusive thinking.[5] Sometimes I experience disability in ways that are easy to identity, such as when I have a hypomanic episode and notice that I am speaking far too fast and wanting to do "all of the things." I sometimes experience disability as something that fades into the background, such as when I am hiking with my wife and dogs during days of mental stability. Sometimes, I want to identify overtly as bipolar and share communion and/or to belong with others "like me," such as when I read Ellen Forney's (2012) wonderful *Marbles: Mania, Depression, Michelangelo, and Me: A Graphic Memoir*. Some days I hide this identity either because I do not want to talk about it or because I fear that others will judge me as somehow "messed up." Other days I would like to let another identity shine, as when I am "a teacher" and am helping students facilitate participatory ukulele jam sessions. Sometimes I notice the intersection of being "bipolar" and "teacher," such as when a bout with insomnia slows my thinking and breaks the flow of my work teaching instrumental methods. I

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[5] Overinclusive thinking or conceptual overinclusion is a "failure to preserve conceptual boundaries, such that irrelevant ideas are considered essential conceptual elements" (Ottemiller, Elliot, & Giovannetti, 2014, p. 289) and is highly connected to divergent thinking. Overinclusion is a common "symptom" of Schizophrenia as well as Bipolar Disorder. Greenwood (2016) suggests that it is one of the positive traits of Bipolar Disorder.

experience disability when I meet with my psychologist to check in on my medication, when I work on avoiding mind traps with my counselor, when writing feverishly, when I cry along to the music of the Decemberist, when facilitating songwriting with formerly-incarcerated men, and when I learn with and alongside students during general music methods classes. Regardless of the day, the identity, or the facets of life, disability is always there, and it is always something that is part of my experiences, if not always *the* thing I experience.

The point of sharing these details is to show that my experiences of disability are inherently complex and cannot be reduced to a simple matter of identifying and treating some internal difference in mind-body function. My experiences of disability cannot be understood only as social stigmatization. My experiences with disability are not a given, fixed, solitary identity that defines all of who I am. My experiences of disability are always fluid; my experiences of disability may involve stigma at times but not as much in other times; and my experience with disability is not entirely knowable or predictable. As someone who could be identified or who self-identifies as a member of the disability community, I feel there is a need for more nuanced approaches to disability in music education research in order to avoid producing knowledge and practices built upon essentialized stereotypes and rigid conceptions of disability rather than on the real and complex experiences of disability of DP/PwD.

***Experiences with teaching DP/PwD.*** I have spent the majority of my professional life focused on working with DP/PwD and creating inclusive and adaptive music making and music learning practices. From a young age, I was concerned with issues of equity and inclusivity or “fairness” to the young me. I asked a lot of questions when friends were moved from the “regular classes” to a “special class” located next to the boiler room in our small school. I asked questions about family members who never seemed to have chances to be in school or to go out in the community. Later in my first teaching experience in college, I gravitated toward working with learners who were DP/PwD and found a general sense of a calling, for lack of a better word, to make all of my teaching and facilitation as “inclusive” as possible for all learners. Yet, this calling did not remove me from experiencing ableist practices as an participant or observer.[6]

As a teacher, I have heard and sometimes used disability labels (e.g., retarded, crazy/insane, psycho/psychotic, and lame) in pejorative manners, and used other words and phrases as adjectives to describe minor personal happenstances (e.g., Oh, that’s my OCD; I’m totally ADD right now; Ugh, I’ll have PTSD because of that disgusting pizza; I totally spazzed out; Sorry to be all autistic right now). I have heard these words and phrases spoken loudly and cavalierly by passionately inclusive and progressive teachers in teachers’ lounges and in hushed tones in the hallway after school. I have spoken some of these words and still catch myself relying on some of them, such as “crazy,” even as I write this document. In these ways, we have reduced the complexity of disability, equated disability to general annoyances, totalized disability as a negative state of being or doing, and erased the meaning of the words and people implicated. I have worked with colleagues designing curriculum and noticed the way we often do not worry about inclusion until faced with a singularly DP/PwD whose presence disrupts the flow of our “engaging lessons.”

I have read countless threads on music teacher social media groups asking for help with how to teach “x student” with “y diagnosis” “z skill” and I have read the replies that suggest that physical presence of the student is often enough, lest by doing anything teachers negatively impact the rest of the learners. In these ways, music educators have engaged in constructing and reifying ableism, developed only case-by-case adaptations rather than robust curricular and relational change, and worked to marginalize “x students.” In addition, we have spoken about disability *to* largely nondisabled groups without regularly speaking *with* DP/PwD about disability. Through speaking and acting in these ways, we demonstrate a need for outside expert support in order to “include” (i.e. work with) DP/PwD. I suggest that the many professional development

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[6] I discuss “ableism” in depth during CHAPTER TWO in the first section, within Socially-Focused Conceptions of Disability, under the heading “Ableism.”

sessions, magazine articles, trainings, and books that deal with so called inclusive practices may illustrate and perpetuate a large-scale mystification of disability and DP/PwD that grounds existing ableist discourses concerning music learning and music making.

Other the years, as I came to present and write about disability, I found that my go-to advice for inclusion became: “Have you talked and/or worked with this specific learner? I wonder what ideas they have.” As a researcher, I found that I needed to give this question more attention, because as a teacher I often forgot my own advice. I began to wonder if I needed to approach my calling differently, to remember my go-to advice, and, to paraphrase Husserl (1900/2002, p. 168), to get “back to disability and DP/PwD themselves.” Powerful understandings and new practices, and a new, relational attention to disability and DP/PwD themselves might flow from a troubling of existing conceptions of disability and practices aimed at including DP/PwD.

**Problematizing disability in music education research.** In music learning and music making literature, disability and DP/PwD are essentialized, totalized, and framed as a problem. Jellison (2015a) notes how the “special” in “special needs students” is a euphemism for “problem.” Euphemisms such as “special needs students” and “learners with special needs” (e.g., Gerrity, Hourigan, & Horton, 2013; Hagedorn, 2002; Hammel & Hourigan, 2017), “exceptional learners” and “children with exceptionalities” (e.g., Atterbury, 1990; Blair & McCord, 2016), “differently-abled” (e.g., Gould, 2005; Jorgensen, 2007), and “handicapped students” (e.g., Gfeller, Darrow, & Hedden, 1990; Jellison, Brooks, & Huck, 1984) provide linguistic structures, often guided by policy and legislation, that avoid the word “disability.” These writers follow naming trends that replace “disability” with positive-sounding terminology that may inadvertently essentialize or re-essentialize DP/PwD as (a) “different” and “not normal” in a “normal” center, (b) “atypical” or “atypically developing” in a center comprised of “typical” or “typically developing” people, and (c) “outsiders” in need of “inclusion.” The proliferation of these rhetorical moves suggests that music education, as a field, is concerned primarily with finding ways to include those conceived of as “other” and also concerned with remediating disabilities or fixing impairment in order to fit learners conceived of as being outside of the nondisabled center into existing practices (Dobbs, 2012; Bell, 2017; Laes & Churchill, 2018). Overarching conceptions of DP/PwD as a subaltern position is illustrated in literature that focuses on: (a) assessing the abilities and differences of specific learners in order to create adaptive tools and approaches to music teaching,[7] (b) attitudes toward and perspectives on DP/PwD from the standpoint of nondisabled educators and peers,[8] and (c) inclusive pedagogies designed to help nondisabled music educators find ways to interact with and support DP/PwD.[9] Yet, these literatures are primarily about *nondisabled* persons, *their* practices, *their* conceptions of disability, and *their* views, which centers "nondisability" and reaffirms ableism in an unconscious and unproblematized manner.

In much of the existing literature, authors encourage a broadening of the center in music education and greater attention toward issues of diversity in general, suggesting that such moves can lead to equitable music making and music learning practices for DP/PwD both in and outside of school. And, authors of the studies in listed Appendices A through C and shared elsewhere in this document have made great strides in expanding inclusivity. Yet, the extent to which the voices of DP/PwD rarely drive suggestions for practice, typically focus on how DP/PwD behave rather than how DP/PwD experience disability in, through, and around music. Laes and Churchill (2018) state that "in spite of the liberating progress that has been made on this front, we contend that those with disabilities have yet to receive the same kind of recognition afforded to the able-bodied/minded Others" (p. 2).

What is so dangerous about existing research *about* disability that it warrants the current study? I suggest that the very fact that so much of existing literature speaks *about* disability

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[7] See Appendix A for a bibliographic overview of diagnosis-centric literature.

[8] See Appendix B for a bibliographic overview of perceptions and attitude literature.

[9] See Appendix C for a bibliographic overview of literature focused on mainstreaming.

indirectly from the perspective of the nondisabled for the purpose of including DP/PwD in nondisabled-centric spaces points to dangers. First, there is danger of omission of first-hand perspectives *of* DP/PwD; in much of the literature, authors speak *about* disability without speaking *with* DP/PwD or giving space for DP/PwD to speak for themselves[10] to the extent they may wish or want to do so.[11] There is danger of omission in that research and practice rely upon grand narratives of disability constructed primarily by nondisabled authors. A second danger exists when researchers base their work on these grand narratives. Grand narratives of disability built upon (intentional or unintentional) omission of DP/PwD inform further research and practice and reify rigid conceptions of disability as either an individual problem or a form of social oppression.[12] When operating from either individually- or socially-focused conceptions of disability, researchers may miss the complexity of disability which arises at the intersection of individual and social experiences (Shakespeare, 2014); they may miss how disability is constructed and de/reconstructed by time, space, activity, and relationality (Kuppers, 2014; Lubet, 2011). Research and practice that flow from rigid conceptions of disability are doubly in danger of omission, then, and may work to reinscribe otherness and essentialize DP/PwD. Missing the complexity of an issue such as disability and omitting the direct voices of DP/PwD may lead to narrow research and limited practice, which does little to positively impact the lives of DP/PwD in, through, and around music.

**Problematizing inclusion in music education.** As noted above, music education literature and practices related to disability and inclusion frequently operate within medicalized

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[10] While many of such authors might, indeed, speak to DP/PwD, the author's voice and ideas are certainly privileged in publications. Perhaps this is somewhat inevitable when using specific research methodological frameworks (see "On Research and Writing" in CHAPTER SIX for additional commentary).

[11] Spivak (1985) might wonder if participants can "speak for themselves" or, if they can, if what they speak is legible to those to whom they are speaking. I address this in CHAPTER THREE.

[12] I refer here to Individual-Focused Conceptions of Disability and Social-Focused Conceptions of Disability. See CHAPTER TWO, "Disability in Disability Studies Literature" for more commentary on these conceptions of disability.

frames that center disability as an individual problem in need of fixing (Dobbs, 2012; Bell, 2017; Laes & Churchill, 2018). This frame, called the "medical model" or "individual model" (Oliver, 1983; Oliver, Sapey, & Thomas, 2012),[13] has been critiqued in Disability Studies literature and in Disability Rights Activism in favor of socially-focused and interactional conceptions of disability. Socially-focused and interactional models allow for critical analysis of barriers to equity, access, and inclusion (in the case of social-focused conceptions and models) and/or provide means of embracing the diversity of disability experience and considering how disability is constructed at the confluences of time, space, activity, and relationality (in the case of interactional conceptions of disability).[14] Yet, given this shift in activism and disability scholarship—including a growing body of literature in Disability Studies-informed musicology (e.g., Howe, Lerner, & Straus, 2016; Lerner & Straus, 2006; Lubet, 2011; Straus, 2011), there is little evidence of a similar theoretical shift in music education literature and practices.[15] Without a Disability Studies-informed critical shift in research and practice, music educators reify older frames and practices and cement what is presently understood and practiced as *the* natural or right way of practicing and researching with little need for problematization. Under-theorization and under-theoretically-informed research around disability and the lived experiences of disability of DP/PwD in, through, and around music can be addressed through embracing and problematizing theories of disability. Doing so may allow researchers and teachers to consider disability as "a topic that is useful, important or interesting" (Laes & Churchill, p. 9) in and of itself.

In this study, I embrace theoretical frameworks and related concepts culled from Disability Studies literature in order to approach disability with frameworks different from

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[13] In Chapter Two, I discuss these types of conceptions of disability under "Individual-Focused Conceptions of Disability."

[14] I discuss both "Social-Focused Conceptions of Disability" and "Interactional Conceptions of Disability" in Chapter Two.

[15] Notable users of Disability Studies and Disability Rights theoretical constructs in music education literature include, but are not limited to: Abramo (2012), Bell (2014, 2017), Churchill (2015), Dobbs (2012), Laes (2017), Laes and Churchill (2018), and Rathgeber (2017).

medicalized and individual-focused perspectives common in music education literature (Dobbs, 2012). Specifically, I embrace interactional conceptions of disability through which one might attend to how disability is constructed and experienced as constantly shifting interactions of social and individual facets of experience. Perspectives such as Lubet’s (2011) social confluence theory, Shakespeare's (2014, 2015; Corker & Shakespeare, 2002) critical realist approach, Kuppers’ (2009, 2011) rhizomatic model of disability, and McRuer’s (2006b) performative-based Crip theory encourage researchers to consider the interplay between individual and social aspects of disability as they flow and shift in relation to time, space, activity, identity, and social interaction. Using these interactional frameworks of disability in this study allowed me to consider complex understandings of what disability is and how it is experienced by participants and to attend to details of their lifeworlds otherwise hidden from my perspective. My use of frameworks developed in Disability Studies discourse intentionally seeks to draw in theoretical literature outside of the common special education and rehabilitative literature, and to encourage a new kind of praxis shaped by the scholarly and advocacy work of authors who experience disability directly and/or who work to challenge and trouble accepted understandings of disability and practices built upon understandings grounded in a critical attention to disability and the experiences of DP/PwD themselves.

In music education, disability is framed within discourses of inclusion, and authors of music education literature and practice forward numerous approaches to inclusion. These approaches are rooted primarily within special education and disability policy derived notions of mainstreaming, which situates inclusion in relation to placement, support, and participation of DP/PwD in spaces and in activities alongside nondisabled persons. Mainstreaming encourages educators to think of equitability and accessibility in the placement and interaction of DP/PwD in relation to their “regular peers” (National Study of Inclusive Education, 1994). Numerous approaches that have sprung from the implementation of mainstreaming and/or mainstreaming-based literature address efficacy of facilitation, economic efficiency, community, and issues related to power and identity (Osgood, 2005). I acknowledge the positive uses and potentials of the mainstreaming approaches. My intention in this section of the document, however, is to suggest while these approaches have been and continue to be positive, they may be, as with all things, dangerous, as Foucault (1994) explained,

> My point is not that everything is bad, but that *everything is dangerous*, which is not exactly the same as bad. If everything is dangerous, then we always have something to do. So my position leads not to apathy but to a hyper- and pessimistic activism. I think that the ethico-political choice we have to make every day is to determine which is the main danger. (p. 256)

In the next section, I address four specific approaches to mainstreaming, which might be considered inclusive technologies, that have grown out of past research and practice: differentiated instruction, normalization, assistive technology, and universal design. I problematize these approaches to mainstreaming in order to identify how these inclusive practices may be limiting for DP/PwD and, therefore dangerous with regard to fostering inclusion.

***Differentiated instruction.*** Differentiated instruction is a mainstreaming framework common in music education literature (e.g., Adamek & Darrow, 2010; Bernstorf, 2016; Cane 2009; Darrow, 2014; Hammel, Hickox, & Hourigan, 2016; Hammel & Hourigan, 2017). Tomlinson (1999) defined differentiated instruction as a practice in which

> teachers begin where students are, not the front of a curriculum guide. They accept and build upon the premise that learners differ in important ways. Thus, they also accept and act on the premise that teachers must be ready to engage students in instruction through different learning modalities, by appealing to different interests, and by using varied rates of instruction along with varied degrees of complexity. (p. 2)

Differentiation occurs through individual adaptations to content, pedagogical process, and learner product, all of which are varied in complexity based on the unique needs of specific students (Darrow, 2014; Hammel, 2008; Tomlinson 1999). Differentiated instruction may be catalyzed in classes by (a) creating specific learning experiences and goals for each student who needs accommodations and (b) developing multiple tiers or tracks in which students are placed with the expectations of upward mobility. While differentiated instruction attempts to level socially-imposed barriers to learning and achievement by creating unique curricula for individual students, in practice a teacher might make differentiated instruction decisions based on diagnostic and medical information—such as information in Individual Education Programs and 504 Plans.[16] Also, differentiated instruction may be problematic in that not all learners identified for differentiation may actually need it or want it. Likewise, not all parents of learners identified for differentiation may see the need for their children to have differentiated options, and similarly, parents might not want differentiation that could cause social marginalization for their children. Also, differentiated instruction can become a tracking system if not conceptualized from the individual learner perspective, thus defeating the creation of inclusive and/or mainstreamed learning contexts.

***Normalization.*** Normalization, as envisioned by Nirje (1969) and expanded by Wolfensberger et al. (1972), has been a key approach to inclusion in music education, particularly in the work of Judith Jellison (Jellison 2012; 2015a; 2015b; Jellison, Brookes, & Huck, 1984). Normalization ensures that DP/PwD have access to "Culturally normative music experiences and participation in socially valued roles and socially valued activities" (Jellison, 2012, p. 67). As such, normalization as a mechanism of mainstreaming includes: "(1) creating a quality music program and a culture of inclusion; (2) gathering information; (3) planning and implementing strategies; and (4) thinking ahead" (Jellison, 2015a; p. 104). Yet, normalization reifies "being in the norm" as the ideal state of being and assumes that DP/PwD desire or need "socially normative

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[16] Both Individual Education Programs or IEPs and 504 plans are legislatively mandated means of supporting students with diagnosed impairments/disabilities. IEPs are stipulated in the Individuals with Disabilities Education Act (1990; IDEIA, 2004) which has federal funding and supports leaners with: specified learning disability, other heath impairments, autism spectrum disorder, emotional disturbance, speech or language impairment, visual impairment including blindness, deafness, hearing impairment, deaf-blindness, orthopedic impairment, intellectual disability, traumatic brain injury, and multiple disabilities. 504 plans are outlined in Section 504 of the Rehabilitation Act of 1973, a civil rights law, and these plans are generally used to support learners not eligible for support under IDEA/IDEIA, such as some learners diagnosed with ADHD. Unlike with IEPs, 504 plans do not have specific federal funding. Both IEPs and 504 plans are developed by a team of teacher, staff, parent, and sometimes, student who meet to identity goals and accommodations.

experiences” and “socially valued roles.” As hooks (1989) reminds us, there might be much of value in the margins, far away from the socially normative.

***Assistive technology.*** Assistive technology (AT), also referred to as “adaptive technology” in some literature, includes

> any item, piece of equipment, or product system, whether acquired commercially off the shelf, modified, or customized, that is used to increase, maintain, or improve functional capabilities of a child with a disability . . . [excluding] a medical device that is surgically implanted, or the replacement of such devices. (Individuals with Disabilities Education Improvement Act/IDEIA, 2004, § 602)

Assistive technologies include any devices that assist DP/PwD in communicating, in perceiving and understanding information, in negotiating barriers, and in accessing professional, therapeutic, and leisure activities (Watts & McCord, 2010; Thompson, Watts, Wokcik, & McCord, 2003). Due to the increasing presence of assistive technology in music learning and music making spaces (Scott et al., 2007), a great deal of recent literature focuses on identifying and discussing the use of assistive technology (e.g., Adkins et al., 2012; Bell, 2014; Bugaj, 2016; McCord, 1999; 2002; McCord & Fitzgerald, 2006; McCord, Gruben, & Rathgeber, 2014; McCord & Watts, 2010; McHale, 2016; Nelson, 2013; Watts & McCord, 2016; Randles, 2015). Assistive technologies are used either to help remediate individual impairments in order to make certain activities more doable (i.e., hearing aids and listening devices to make sounds audible for hard of hearing learners) or to level barriers to participation by creating alternative entry points (i.e., using Braille notation for a blind learner who is literate in Braille).

While assistive technologies may address a variety of individual and/or social barriers to learning and participation, the use of devices and adaptations also suggests that there are prerequisites for inclusion and that the systems that require these adaptations are stable and not in need of change. As such, music teachers who use assistive technologies with DP/PwD may neither identify nor challenge the problematic assumptions and ideologies that appear to make AT seem necessary in the first place. In addition, music teachers who choose AT might do so based on medicalized information or personal assumptions about learners, thereby imposing certain kinds of assistive devices without consulting the learners directly. Assistive technology can become a diagnosis-based “cure” that a teacher selects off-the-shelf based on a learner’s medical diagnosis alone. Assistive technology can also be conflated with adaptive pedagogy in that using AT implies that the tool/technology is all that is needed, not a change in thinking or practice itself.

***Universal design in education.*** The approach to mainstreaming-based inclusion called Universal Design originated in architecture and the theoretical work of Robe Mace (1997; 1998; Story, Mueller, & Mace, 1998). Mace sought to develop building practices that encourage equitable, flexible, and intuitive use of designed materials, clear and multi-modal presentation of information, and designs that require low effort to use and to adapt to one’s needs (Mace, 1997). Mace’s universal design has been integrated into education as Universal Design for Education (Bowe, 2000), Human-Centered Design (Cooley, 2000; Greenhouse, 2010), Universal Design for Instruction (UDI) (Burgstahler, 2007; 2008), and Universal Design for Learning (UDL) (Rose & Meyer, 2000; 2002; Rose, Meyer, & Hitchcock, 2006; Meyer & Rose, 2000).

Universal design-based thinking overlaps with socially-focused conceptions of disability, similarly to assistive technology, in that it directs designers to consider carefully what physical, attitudinal, and ideological barriers may exclude certain people from certain ways of being in the world and being with others. Universal Design as integrated into educational settings may be a useful heuristic and is growing in its use in music education literature (e.g., Darrow, 2010; 2016; McCord, 2013; McCord, Gruben, & Rathgeber, 2014). Universal design does, however, operate on the assumption that all needs and barriers can be knowable and/or accounted for prior to meeting individual learners. Music teachers using universal design principles may proactively develop differentiated materials that broadly meet the needs of students with different kinds of processing and expressive capacities rather than meeting learners and constructing structures and practices *with* the learners that meet learners’ needs and desires. Universal Design practices may be powerful and yet may also give educators problematic confidence in a proactive planning process that may negate the possibility of negotiating learning structures with learners.

The inclusive technologies addressed above (i.e., differentiated instruction, normalization, assistive technology, and universal design) are theoretically-informed approaches to mainstreaming common in music education literature and practice. Each of these approaches draws on different kinds of individually-focused and/or socially-focused conceptions of disability and inclusion. Each approach has affordances and constraints with regard to mainstreaming, and the authors who have championed these approaches to inclusion have directly impacted the field and the lives of students and participants who are DP/PwD by encouraging more welcoming and equitable music making and music learning experiences. Yet, these approaches to mainstreaming may be limited with regard to creating inclusive, diverse, engaging, and meaningful music making and music learning practices with DP/PwD—and with all participants—because they grow from medicalized and rehabilitative discourses of disability rooted primarily in individually-focused concepts of disability that emphasize teacher expertise over the autonomy of DP/PwD. Mainstreaming *for* DP/PwD situates music teachers in the position of remediators, assuming the need for a specific kind of medicalized and diagnostic-specific body of knowledge in order to treat students and participants who are seem as essentially other. In addition, mainstreaming-based approaches to inclusion often fail to address deeper structures of disability oppression from which barriers to participation and exclusion may grow and, as such, these approaches to inclusion may be defeatist at best.

**A different way to understand disability and DP/PwD, and to foster inclusion.** My personal experiences of disability and my reading of existing music education research and practice suggest that specific voices and theoretical conceptions related to disability are missing, and current conceptions and practices, including research practices, are problematic. Inclusion, as practiced in music education has relied upon a notion that inclusion is a practice of mainstreaming that can be facilitated through the use of inclusive technologies, broadly conceived as both pedagogy and device. In this study, I attempt to trouble disability and inclusion in existing music education research and practice by focusing on the individual experiences of disability in, through, and around music with participants who are DP/PwD. By engaging in this inquiry, I aim to point toward new ways of considering disability and fostering inclusion in music learning and music teaching spaces. To work toward the aims of this study and the possibility of disrupting hegemonic practices, I draw heavily on the philosophical work of Martin Buber and his approaches to relational ontology and inclusive pedagogy.

Martin Buber was an Austrian-born Hasidic Jewish scholar, interpreter, translator, and philosopher who drew on and critiqued the work of Kierkegaard, Nietzsche, and Heidegger (Friedman, 1996). Buber's central interest in much of his philosophical work was relational ontology, also known as his philosophy of dialogue. Buber, in his text *I and Thou* (1958), argued that being is not just *Dasein* or being-in-the-world as an individual, as Heidegger (1927/1998) asserted, but, rather, being is *Mitsein*, being-with-others (Friedman, 1965). Buber encouraged humans to come to realize how their existence was relational through experiences of true meeting and unity afforded by open dialogue. Buber called all people to realize that "All real living is meeting" (1958, p. 11).

At the heart of Buber's philosophical work is a challenging of the subject-object binary rooted in Western European philosophical traditions since Descartes (1644/2012). Rather than an ontology of separation between the subject and another object, Buber envisioned an ontology of relation in which subjects and objects are only considered separate through the relationships in which they meet (Buber, 1958). Humans, Buber contended, have a two-fold nature based upon how they relate to "others" within their world. A human is both separated from objects and also one-and-the-same with the objects, based upon their relationships. To this end, Buber articulated two attitudes—ways of being—in the world: I-it and I-Thou.

An I-it attitude is one in which an observer (i.e., I) considers herself separated, a distinct entity, from an object (i.e., it)[17] within her world. This attitude grounds what Buber and phenomenologists such as van Manen (1990) observe in the so-called “hard sciences,” in which scientists detachedly inspect objects (e.g., plants, animals, other humans, biological systems, etc.) within their world from aesthetic, biological, typological, or mathematical perspectives. Within an I-it relationship, the “I” can observe, measure, and describe the “it” of her consciousness, constructing a relationship of difference and of otherness. The “I” experiences the “it” in its temporal and separate existence.

On the other hand, an I-Thou attitude is one of which one  (i.e., I) meets an other (i.e., Thou) within her world openly through genuine dialogue.[18] This attitude grounds a true knowing of the full existential nature of life, an attitude that allows for the realization of one’s interconnectedness. The “I” can meet the “Thou” in a state of mutual respect and full presence to come to know their existential mutuality. The “I” does not experience the “Thou,” but rather both come to know each other, themselves, and their combined being in a new light.[19]

Though Buber did not specifically address issues of education in *I and Thou* (1958), it is clear from his collected essays in *Between Man and Man* (1965) that he acknowledged the implications that “I-it” and “I-Thou” attitudes might have for critiquing and developing educational practices. In his essay on education, Buber calls for openness between teachers and students, specifically urging teachers to acknowledge the full humanness of the students with whom they work. Buber notes the inherently non-mutual teacher-student relationship constructed by

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[17] Buber (1958) suggested that one might replace “it” with the pronouns of “he” or “she” in order to situate the “it” as a relation of distance and of objectification.

[18] Friedman (1965) defines Buber’s notion of “genuine dialogue” as: “not merely the interchange of words . . . rather, the response of one’s whole being to the otherness of the other, that otherness that is comprehended only when I open myself to him in the present and in the concrete situation and respond to his need even when he himself is not aware that he is addressing me.” (p. xvi)

[19] Buber makes clear that humans need experience built upon “I-it” attitudes in order to exist and to biologically and psychologically function within material reality. “I-Thou” relationships, to Buber, constitute the meaningful and spiritual dimension of being that makes it worth living within material reality.

educational mores of teacher authority and expertise. Buber suggests two streams in which an "I-Thou" attitude might occur in educational practices: "empathy" and "inclusion."

Of empathy, Buber states:

> Empathy means, if anything, to glide with one's own feeling into the dynamic structure of an object . . . it means to "transpose" oneself over there and in there. Thus, it means the exclusion of one's own concreteness, the extinguishing of the actual situation of life, the absorption in pure æstheticism of the reality in which one participates. (p. 97)

Empathy is then a complete realization of the relationship that an "I-Thou" attitude can allow: one in which the teacher becomes lost in the being of the student, the student becomes lost in the being of the teacher, and both lose their concrete existence to transcend the particularities of the temporal and spatial contexts which they inhabit. Buber suggests that such a relationship is impractical and possibly unethical because it might disrupt a teacher's ability to guide students toward new ideas, chart the academic growth of students, and continue to challenge students.

In place of empathy, Buber (1965) suggests a relationship of inclusion that accepts the possible need for separation between teachers and students, while also opening the teacher to the perspective and being of an "other." Buber further defines inclusion as

> the extension of one's own concreteness, the fulfilment of the actual situation of life, the complete presence of the reality in which one participates. Its elements are, first, a relation, of no matter what kind, between two persons, second, an event experienced by them in common, in which at least one of them actively participates, and, third, the fact that this one person, without forfeiting anything of the felt reality of his activity, at the same time lives through the common event from the standpoint of the other. (p. 97)

Educationists Shady and Larson (2010) interpret Buber's position, asserting:

> Genuine education requires genuine dialogue, although the possibility for inclusion between teacher and student is somewhat limited. When an instructor considers both his or her own position as educator and the position of a student as a person being educated, inclusion is present . . . The work of the educator therefore involves bringing the student into the relation of genuine dialogue by seeking to understand the student. Similarly, the educator can foster genuine dialogue among students and between students and texts, so that the students experience others in an inclusive manner. (p. 86)

Buber's (1965) conception of inclusion encouraged the teacher to have each student's existential being inhabiting their consciousness, creating a foundation for praxis built upon knowing and caring about students first and foremost rather than considering content, curricula, or other educational issues from the start.

Educationist Woo (2012) addressed common misconceptions related to Buber's inclusion. Woo suggests that Buber's inclusion is neither simply empathetic imagination on the part of teachers toward students nor is it a teacher's ability to build and sustain relationship with students. Rather, Woo suggests that Buber's inclusion involves embracing an existential in-betweenness on the part of the teacher. Living and acting in-between a teacher's subjectivity and the subjectivities of learners positions them toward a certain kind of openness. Woo situates a Buberian inclusive teacher as one who enacts a way of being similar to that of a Freirean liberatory pedagogue (Freire, 2000; Shor, 1987), one who seeks to learn from and with students while also purposefully leading students toward new understandings. Taking a decidedly Freirean tone reminiscent of the notion of teacher-student and student-teachers (Freire, 1968/2000):

> The teacher and student are commonly participating in an education, not just for the student, but also the teacher. They are performing institutionally defined roles of teaching and learning, where both agents are in fact the teacher and learner at the same time. (Woo, 2012, p. 842)

Acknowledging the mutuality of teaching and learning in contemporary classrooms, Woo (2012) suggests, may allow both teachers and students to engage in a dialogue-based form of education that does not merely reproduce cultural systems and norms, but paves the way for critical and emergent knowledge construction for both parties.

Veck (2013) identified Buber's conception of inclusion as a potentially essential philosophical principle for fostering "inclusive schooling" and critiquing the general/special education dual system. Veck worried that special education policies force educators into taking on only "I-it" attitudes toward students, specifically those students who may be DP/PwD. Veck drew upon another educational writing by Buber, his 1948 (1997) *Israel and the world: Essays in a time of crisis*, in which Buber uses the metaphor of sculptor for teachers with an "I-it" attitude and the metaphor of gardener as teachers with an "I-Thou" attitude. Buber (1948/1997) identified sculptor teachers as those who believe that "education means shaping the child into a form which the educator must first visualize, so that it may serve as the directive for his work" (p. 149) This perspective all but forces an educator to take up an "I-it" attitude in order to measure, assess, and plan for their treatment of the student to make the student into a correct sculpture or embodiment of educational dictates for "right" learning. A sculptor teacher relies upon objective measurement tools and assertions of expertise from professionals who label and codify educational treatment, a position that relies upon an individual-focused conception of disability. Sculptor teachers use specific remediation plans to fix students and shape them into more independent learners, Veck (2013) asserts. On the other hand, as gardener, a teacher meets a student, elevates the student's present becoming, and nurtures the existential being and potentiality of the student (pp. 621-622). To Veck, being a gardener positions a teacher as engaged in constructing educational experience in collaboration *with* students, encouraging emergent and creative learning on the part of all, and celebrating and relying upon the presence of bodies/minds with different abilities and perspectives within learning contexts. In many ways, the gardener-teacher embodies the in-betweenness Woo (2012) identified as central to Buberian inclusion.

Buber's (1965) conceptions provide a different perspective of inclusion focused on how people might act and be *with*—a relational ontology of all people within a specific context (Shady & Larson, 2010; Veck, 2013; Woo, 2012). Buber's (1965) inclusion and his conception of I-it/I-Thou attitudes (Buber, 1958) can act as a useful heuristic by which to examine and critique contemporary educational practices, specifically those which situate teachers in the role of objective assessor and shaper of students. One might draw on Buberian inclusion and the underlying notions of mutual care and open meeting in order to consider the roles and attitudes embodied by different actors in educational ventures.

Buber's relational ontology (1957, 1958) and conceptions of inclusion (1965) inform much of the work that went into constructing this document. I drew on Buber's philosophy of dialogue in the research and writing of this document in order to meet participants and to explore our combined world together and, through this, embrace them and their experiences. Buber's conception of inclusion informed my approach to inquiry, research writing, and contemplation with participants and their experiences in this study.

### Overview of the Document

Below I provide an overview of the contents of the chapters that comprise this document. In "Chapter One: An Introduction," I have called attention to the ways music making and music learning research has narrowly considered disability and the lives of DP/PwD. I have also troubled different approaches to mainstreaming-based inclusion prior to discussing Buber's (1965) conception of inclusion and its connection to education. In “Chapter Two: Dialogues with Literature,” I provide essays that open up dialogue with literature about (a) conceptions of disability, (b) disability labels and identities, (c) how music education scholars have addressed disability and DP/PwD, and (d) how researchers have attended to the lived experience of disability through phenomenological or phenomenologically-related approaches. In “Chapter Three: A Process of Inquiry,” I outline a process of inquiry that draws primarily on phenomenology, and, in the spirit and practice of bricolage, on narrative inquiry to ground my work in describing participants' experiences of disability in, through, and around music. I articulate data generation, describe issues of researcher reflexivity and ethics, and note my analytical process.

Chapter Four and Chapter Five comprise the majority of this document. “Chapter Four: Lifeworld Narratives” includes individual storied accounts of each participant's experiences of disability in, through, and around music. These narratives highlight the individualities of each participant and their experiences. The narratives include drawings created by participants, co-constructed playlists, and co-written song lyrics. In “Chapter Five: An Envisioned Conversation,” I present an imagined conversation among all participants and make connections with literature and theories addressed in prior chapters in order to demonstrate the shifts and complexities in meanings of participants' experiences with disability in, through, around, and beyond music. I also unpack the different ways participants describe and understand disability and music in their lifeworlds. In this chapter, I model a kind research presence informed by Buber's (1957; 1958; 1958; 1958; 1965) relational ontology that I discuss more directly in the final chapter. Finally, in "Chapter Six: Openings," I offer discussions and suggestions related to thinking about and approaching disability (i.e., interactional theories, intersectionality, and identity), inclusions (i.e., belonging, suggestions by participants, and anti-ableist pedagogy), and research/writing.

# CHAPTER TWO: DIALOGUE WITH LITERATURE

The purpose of this study was to trouble existing conceptions of disability that ground music education literature and practice by exploring the personal experiences of disability in, through, and around music with specific DP/PwD. I sought to uncover and share "plausible insights" (van Manen, 1990, p. 9) into how disability is experienced in, through, and around music experiences of participants. These insights might, then, allow readers to complexify and trouble taken-for-granted assumptions of what disability can mean and be "like" in, through, and around music, and these troublings and complexities might then ground inclusive practices different than those prevalent in music education historically. In this study, I focus on the lived experiences of disability in, through, and around music from the perspective of persons diagnosed with disabilities/impairments. Although I am concerned with the first-person accounts of participants in this study, participants and their experiences do not exist in a vacuum. Rather, people and their experiences, in general, "are embedded in a complex network of social relations. Those relations in turn determine [what/who] can appear, where and in what capacity" (Shakespeare & Corker, 2002, p. 3). In other words, people are embedded, view, viewable, and viewed through different discourses of disability. Discourses of disability construct different subject positions, shaping how disabled subjects and nondisabled subjects relate with one another, subtly shaping their actions, utterances, and interactions (Barnes & Mercer, 2010; Kuppers, 2014; Lubet, 2011; Siebers, 2008). Disability is a highly-contested and taken-for-granted nature of disability (Brantlinger, 1997; Siebers, 2008, Winance, 2007) and, as such, any inquiry that touches disability and focused on the lived experiences of DP/PwD ought to explore the contested terrains in which DP/PwD and nondisabled persons exist and interact.

Below, I map some of the contested terrains of literature related to disability. More specifically, I seek to open a dialogue between existing literature and the central phenomenon of this study (e.g., experiences of disability in, through, and around music).[20] First, I map the ways in which disability is constructed and understood within Disability Studies literature and articulate three prevalent conceptions of disability. Second, I discuss some of the ways music teachers and researchers have addressed disability and the lives of DP/PwD. Third, I address issues of labeling and identity pertinent to discussions of disability. Finally, I review a series of studies of lived experience of disability, many with connections to music and art, that attended critically and/or phenomenologically to disability. These four sections are presented as loosely connect essays. I suggest beginning with the first “section,” however, the last three sections can be read in any order.

## Disability in Disability Studies Literature

Three types of conceptions of disability arise within Disability Studies discourse. Individual-focused conceptions of disability construct disability as residing solely within an individual DP/PwD. Socially-focused conceptions of disability construct disability as the outcome of social arrangements and material barriers that impinge upon equal access to resources and relations. Interactional conceptions of disability position disability as a constantly changing outcome of the interaction of individual and social factors within the complex confluences of time, space, activity, and relationality (Lubet, 2011). The ideas outlined in this section highlights the complexity of discourses and lived experiences that touch upon and intersect with disability. Before beginning, however, it is important to provide some clarity regarding terms Disability Studies authors use when discussing how disability may be constructed.

**Impairment, disability, and disablement.** Impairment, disability, and disablement are three interactive terms used by Disability Studies scholars to trace the contours of different conceptions of disability. Oliver, Sapey, and Thomas (2012) defined *impairment* as “a

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[20] Vagle (2014) encouraged phenomenologically-informed researchers to engage in a “partial review of literature.” Although any review of literature may be “partial,” Vagle has suggested that many common forms of literature reviews in research “can put at risk the phenomenologist’s philosophical and methodological commitment to remain as open as possible to the phenomenon” as a firm orientation toward existing literature may “end up settling matters before the study [is] even conducted” (p. 72)

characteristic of the mind, body or senses within an individual which is long term and may, or may not, be the result of disease, genetics, or injury" (p. 16). Impairment is an individual's physiological or psychological make-up that may be seen as "different" from the norm in appearance or function. *Disability*, on the other hand, is the detrimental impact of one's impairment upon their lived experiences. A disability may be the cause of social exclusion (Oliver, Sapey, & Thomas, 2012) or a limitation to performing a "major life activity" such as caring for oneself (Americans with Disabilities Act of 1990, as Amended, 2008, § 12102) because of one's impairment.

To illustrate the differences between impairment and disability, consider a person who is deemed to have a visual impairment via medical assessment of her visual acuity, which is 20/70 or lower in comparison to the expected norm of 20/20. This person's characteristics of sightedness is her impairment. Because of this impairment to sight, this person's disability may include:

- limitations in reading printed text,
- an inability to see obstacles in her physical environment,
- unemployment or under employment due to a high proportion of jobs that require sightedness,
- constraints upon the kinds of social activities (i.e. certain types of sports, playing music in music groups that use music notation, watching movies in theatres, taking part in a dissertation committee, etc.) she may take part in and the social groups to which she can belong (i.e. sports teams, music groups, friend groups that regularly go to see movies, being a "reader" on of a dissertation presented only visually, etc.), or
- issues of self-esteem related the experiences listed above.

*Disablement* equates to the pathology of disability, a term that accounts for the cause of disability in relation to impairment. Returning to the example above, disablement for this person occurs when her visual acuity does not fit with the sighted requirements of the activities: her impairment may be seen as the direct cause of her disability. Her disablement may, in another way, be seen as a result of social structures informed by social assumptions of the primacy of vision, since she might well be able to perform required activities through the use of Braille, text-to-speech adaptations, screen readers, and magnification devices. In other words, problematic social structures related to her impairment are the cause of her social disablement. Disablement may also be a mixture of individual and social structures in the example above.

**Individual-focused conceptions of disability.** Individual-focused conceptions of disability (IFCD) are the most prevalent and persistent ways of addressing disability. IFCD call attention to body abnormality, disorders, differences, or assumed deficiencies as the cause of one's personal experiences of disability (Barnes & Mercer, 2010, p. 18). Impairment is a deficit of body/mind construction, and disability is the lived impact of impairment. From this perspective, the individual is the site of disability; one's impairment results directly in her disability. Disablement is the direct cause and effect relationship between one's impairment and disability (see Figure 1). Put simply, people are disabled by their bodies/minds. IFCD consider the individual as at a deficit, as weak, or as abnormal to an extent that their bodies/minds require treatment of fixing.

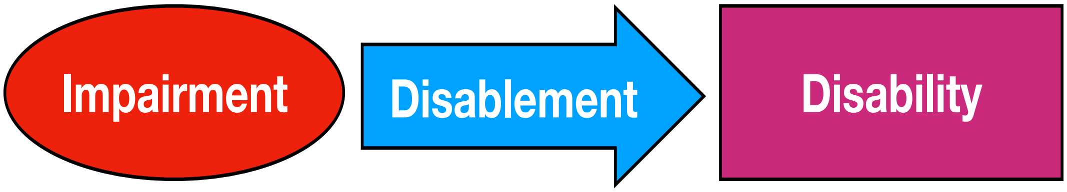

Figure 1: Individual-focused conceptions of disability

The direct cause-effect nature of disablement in IFCD inform and is informed by medical identification and legal subjectification of persons identified as having a disability (Barnes & Mercer, 2010; Oliver, 1998; Oliver, Sapey, & Thomas, 2012). For example, medical authorities develop diagnostic criteria, assessments, and labels to categorize impairment types. This information is codified and shared through medical diagnostic manuals such as the World Health

Organization's *International Statistical Classification of Diseases and Related Health Problems* (2016), the *American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders* (2013), and *The Merck Manual of Diagnosis and Therapy* (Porter, 2011). In the U.S., diagnostic manuals, in turn, inform federal policies that govern who is considered. Federal legislation such as the Section 504 of the Rehabilitation Act (1973), the Americans with Disabilities Act (1990), and the Individuals with Disabilities Education Act (1990) dictate the rights that persons with disabilities are ensured and, in doing so, create a specific image of the disabled subject: the individual with a disability.

Disabled subjectification within IFCD creates performative social roles for the person with a disability, for medical authorities, and for others within a cultural milieu (Kuppers, 2014), roles which continually reinforce the legitimacy of the structure of society and reify disability as an individual problem. Disability scholars have proposed theoretical models of disability which, I suggest, are rooted within individually-focused conceptions of disability. Rioux and Valentine (2009) identified two models I categorize as primary approaches to disability that are informed by IFCD: "biomedical" and "functional" (p. 48).

***Biomedical approaches.*** Biomedical approaches to disability consider psychological and psychological impairments as the singular cause of disability (Rioux & Valentine, 2009; Scambler, 2012). Impairments can be treated through biotechnology, such as pacemakers for persons with heart irregularities, and medicine, such as the use of selective serotonin reuptake inhibitors for people with depression. Biomedical approaches position an individual's impairment as the primary object of expert actions to fix, cure, reduce the effects of, or eradicate the impairment by removing the disability from the person's experiences. An outgrowth of this type of IFCD thinking is the so-called "medical model a model identified by Michael Oliver in the first edition of *Social Work with Disabled People* (1983).[21] The medical model is, to quote the second edition of *Social Work with Disabled People* (Oliver, Sapey, & Thomas, 2012):

> presupposes that the problems disabled people experience are a direct consequence of their impairment which leads professionals to attempt to adjust the individual to their particular disabling condition. There is likely to be a programme of re-ablement designed to return the individual to as near a normal state as possible. (p. 12)

Linton (1998) critiqued the medical model, insisting that

> the medicalization of disability casts human variation as deviance from the norm, as pathological condition, as deficit, and, significantly, as an individual burden and personal tragedy. Society, in agreeing to assign medical meaning to disability, colludes to keep the issues within the purview of the medical establishment, to keep it a personal matter and "treat" the condition and the person with the condition. (p. 11)

Oliver (1983) as well as Barnes and Mercer (2010) identified the World Health Organization's [WHO] International Classification of Impairments, Disabilities and Handicaps (1980) as a direct manifestation of medical model thinking. The WHO (1980) defined impairment as "any loss or abnormality of psychological, physiological or anatomical structure or function" (p. 28) and disability as "any restriction or lack resulting from an impairment of ability to perform an activity in the manner or within the range considered normal for a human being" (p. 29).

***Functional approaches.*** Functional approaches to disability allow one to consider the impact of disability with regard to functional abilities and capacities of the individual caused by an impairment (Scambler, 2012). Although medical expertise informs functional approaches of disability, policy makers can also be the gatekeepers of disability by deeming what functions and abilities count as worthwhile to have and which are deviant (Rioux & Valentine, 2009). Policy makers construct norms of what it means to be a functional being, to be able, by considering the types of individual and social roles and tasks a person with a diagnosed disability can and cannot do (Campbell, 2005; Nagi, 1991). From a functional approach perspective, disabilities can be rehabilitated through early diagnosis and work with experts whose aims is to assist those who

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[21] Oliver (1990) has since distanced himself from referring to a "medical model," favoring the phrase "individual model." Based upon Oliver's initial work, Disability Studies scholars use the phrase "medical model" as a way of referencing Oliver's notions of medicalized notions of disability. The phrase does not appear in the current edition of *Social Work with Disabled People* (Oliver, Sapey, & Thomas, 2012).

have disabilities to find alternative ways of negotiating “major life activities” (ADA, 2008) through occupational or other therapies, and through the use of adaptive technologies such as prosthetics for amputees or alternative communication systems for people with speech or language impairments.

The Americans with Disabilities Act or ADA (2008) is grounded within a functional approach; it defines disability as “A physical or mental impairment that substantially limits one or more major life activities of such individual,” with major life activities including “caring for oneself, performing manual tasks, seeing, hearing, eating, sleeping, walking, standing, lifting, bending, speaking, breathing, learning, reading, concentrating, thinking, communicating, and working” (§ 12102). The Individuals with Disabilities Education Improvement Act or IDEIA (2004) is also rooted in a functional approach to disability as it defines a “child with a disability” as a child diagnosed with an impairment “who, by reason thereof, needs special education and related services” due to the impact of the impairment upon their academic functioning (§ 602). The IDEIA impacts educational policy and practice and profoundly shapes music education practices and conceptions of inclusion, particularly those which frame inclusion as ameliorating functional differences in relation to existing structures.

***The disabled subject and IFCD.*** Individual-focused conceptions of disability inform medical approaches, policy decisions, and subject experiences of “individuals with disabilities.” Swain and French (2000) illustrated the negative aspect of IFCD subject experiences, noting that,

> Disabled people are subjected to many disabling expectations, for example to be ‘independent’, ‘normal’, to ‘adjust’ and ‘accept’ their situation. It is these expectations that can cause unhappiness, rather than the impairment itself. (p. 573)

Sullivan et al. (2010) studied paraplegic persons’ rehabilitation experiences at New Zealand's Otara Spinal Unit (OSU), and this study can be read as an example of IFCD subjectification. Sullivan et al. identified aspects of the participants’ subjugation, including: dispossession and alienation of one’s body, a totalization of one’s identity and being through their labeled impairment, and, from these, the creation of docile bodies through bodily maintenance regimes.

Sullivan et al. found that newly-labeled paraplegics come to experience and embody a feeling that "they have not only lost the power to move and feel their bodies; they have, in addition, lost possession of disability" (p. 31). A paraplegic may come to see her body as not truly their own, becoming alienated from herself, seeing her body and its functioning as belonging to experts. Sullivan et al. found that residents of the OSU felt that their labels of impairment were seen as the totality of their being by OSU staff and, because of this, their personal identities as humans were taken from them by the staff. One participant noted:

> Instead of treating you like an adult, an individual person, you are just Number 6, Room 10. OK, it is his [Number 6's] time to shit, it is his time to piss, put him in his chair . . . [But] everyone is different, every person is different . . . (p. 35)

In this example, not only did the participant suggest the loss of his unique "individuality," he also alluded to the regimes of bodily maintenance that he and other participants experienced. Sullivan et al. noted, "The imposition of a universal bowel and bladder program was one of the most deeply personal ways . . . participants . . . felt the impetus of the unit was to turn them into totalized, paraplegic bodies" (p. 35). Technologically- and surgically-imposed universal schedules and training regimes that attempt to teach paraplegic persons a correct ways of using and feeling their bodies have the impact of shaping participants' understandings of themselves and their senses of agency and humanity.

Campbell (2008) identified a kind of functional subjectification in her discussion of internalization of ableism. Campbell identified the means by which disabled bodies—along with everyone within a culture—internalize norms of ability. The embodied norms rely on negative assumptions related to and a tragedy mindset about disability and disabled persons, creating disabled subjects that embody inferiority. Campbell stated:

> Internalised ableism[22] means that to assimilate into the norm the referentially disabled individual is required to embrace, indeed to assume an 'identity' other than one's own – and this subject is repeatedly reminded by epistemological formations and individuals with hegemonic subjectifications of their provisional and (real) identity. I am not implying that subjects have a true or real essence. Indeed, the subjects' formation is in a constant

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[22] I address ableism more fully below. In general, ableism is used as a term for prejudice based on ability grounded within "the devaluation of disability" (Hehir, 2002, p. 1) and the oppression of DP/PwD.

> state of fluidity, multiplicity and (re)formation. However, disabled people often feel compelled to fabricate 'who' they are – to adopt postures and comportments that are additional to self. (p. 10)

Postures and comportments along with identities, roles, and subject positions for people with disabilities can be formed through public policy, such as legislation, that reinforces and is reinforced by cultural assumptions regarding normalcy and abnormality (Campbell, 2008; Hehir, 2002).

Additionally, IFCD impact the subjectification of others—creating normate positions—in relation to people with disabilities. Swain and French (2000) suggest that discourses of disability as personal tragedy tend to impact the subjectification both nondisabled and disabled persons. For example, a nondisabled person may look at a person with a disability and consider how sad the person's life is, consider themselves lucky to not have such a disability, and see the only action they have is to help the person with a disability through charity and funding preventative measures. "Better dead than disabled" (p. 573) is a phrase that Swain and French categorized as a core narrative in a personal tragedy approach to disability. The core narrative not only frames how a nondisabled person may approach persons with disabilities but also how the nondisabled person thinks about disability and the disability-related language they use. IFCD tend to place persons with a disability in a low status social position and, as such, terms of disability become common metaphors to use in describing negative aspects of life. Terms such as "lame," "idiot," or "gimp" as well as phrases such as "being a blind in the dark," "feeling schizo," or "you're so OCD" become acceptable for use in social settings and in popular media. In this way, the personal tragedy of disability becomes a general metaphor to describe any tragic or negative event, such as referring to a "crippled economy."

Media uses of disability terminology and stereotypes demonstrates subjectification of both "typical" persons and persons with disabilities. For example, common disability stereotypes impact how persons with disabilities act within the world and how "typical" people interact with persons with disabilities. Stereotypes found in mass media include:

> the disabled person as pitiable and pathetic, as an object of curiosity or violence, as sinister or evil, as the super cripple, as atmosphere, as laughable, as her/his own worst enemy, as a burden, as non-sexual, and as being unable to participate in daily life. (Barnes, 1991, pp. 45-46)

Other disability scholars have also investigated mass media and offer compelling data related to how IFCD may impact the subjectification of both disabled and “typical” persons. For example, Garland-Thomson (2002) examined popular photography and visual data and identified subject positions such as “the wondrous” (i.e., monsters and prodigies), “the sentimental” (i.e., the poster child or Tiny Tim-types), “the exotic” (i.e., the disabled athlete or model), and “the realistic” (i.e., the office worker with a disability). Garland-Thomson’s subject positions inform the roles performable by persons with disabilities and the relational distance a “typical” person may take on when meeting or viewing a disabled other. Mitchell and Snyder’s (2000) interrogation of popular literature yielded the concept of “narrative prosthesis.” A “narrative prosthesis” is the use of a disabled person in a story to prop up the development of a plot. Common use of a narrative prosthesis usually comes about by positioning persons with disabilities and disability as things to be battled, to be ameliorated, to be dealt with as punishment, or to be overcome.

**Social-focused conceptions of disability.** Social-focused conceptions of disability (SFCD) are outgrowths of disability civil rights movements in North America and Europe in the 1970s (Cameron, 2014). SFCD center one’s attention on how social structures are ill-fit for bodies/minds deemed to be impaired. Rather than seeing disability as directly caused by the biological makeup of an individual’s body/mind or the functions of which her body/mind is capable, SFCD identify disability as an outcome of social arrangements that make one’s body/mind stand out and be labeled as incapable of functioning to its fullest existent. In other words, “it is society which disables . . . impaired people” (UPIAS, 1975, p. 3). SFCD minimize the importance of impairment in individual lived experience of disabled people in order to highlight issues of social marginalization and othering (Rioux & Valentine, 2006; Shakespeare, 2014). SFCD focus upon social practices rather than individual attributes (Finkelstein, 2001, p. 2).

SFCD construct impairment as individual difference in biological or functional aspects of one’s mind/body. Disability arises from the ways society and social spaces respond to, omit, and create barriers to social participation for people who have impairments (Cameron, 2014, p. 136; Oliver, Sapey, & Thomas, 2012). From SFCD perspectives, disability is an outcome of a mismatch between social structures and impaired bodies/minds (see Figure 2). First, nondisabled bodies/minds create social structures that directly or indirectly impose barriers upon bodies/minds that are different. Second, the organization of social structures informs a general conception of who is in—able—and who is out—disabled. The formation of what it means to be disabled further marginalizes, oppresses, and disables those considered to be too different from the idealized normate for/by which the social structures were constructed. Thus, disability and being disabled is misrecognized as natural deviation rather than ideologically informed, which, in turn, gives rise to stigmatization of disability (Barnes & Mercer, 2010)

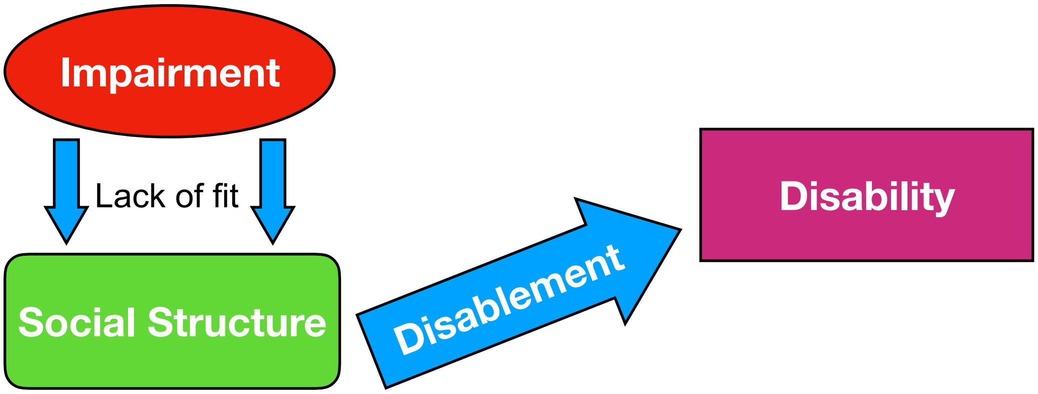

Figure 2: Socially-focused conceptions of disability

Scholars use SFCD to investigate how “The philosophical and cultural bias upon which the individualistic negative response to impairment rests is rooted firmly in the foundations of western culture” (Barnes, 2012, p. 12). IFCD are also uncovered and inspected through the use of SFCD. Authors informed by SFCD make use of theoretical approaches rooted in neo-Marxist critical theory, structuralism, and social constructionism (Goodley, 2011; Oliver, 1998; Shakespeare, 2014). These theoretical approaches are catalyzed in SFCD literature to outline and problematize barriers to participation, which are characterized as mechanisms of social exclusion for those who have impairments. Oliver (1998) articulated how critical theory is used in barrier finding, stating:

> [Critical theory] sees disabled people's problems explicitly as the product of an unequal society . . . Notions of disability as social oppression mean that prejudice and discrimination disable and restrict people's lives much more than impairments do. So, for example, the problem with public transport is not the inability of some people to walk but that buses are not designed to take wheelchairs. Such a problem can be "cured" by spending money, not by surgical intervention, assistive computer technology, or rehabilitation.
>
> Ideologies perpetuate practical barriers and exclusions. As long as disability is assumed to be an individual matter of personal tragedy or heroic triumph over difficulty, disabled people are excluded from society. Ordinary education, employment, buildings, public transport, and other things which most people can take for granted remain largely closed to disabled people, or at least they present obstacles which each person has to tackle individually. By emphasising "deficiency and dependency," doctors tend to reinforce these ideologies. (p. 1148)

Kuppers (2014) states this another way: "Barriers like [sic] inaccessible architecture, historically shaped attitudes, and the resulting institutional discrimination are now the disabling factor, not the individual body or a person" (p. 27). Barriers come in many forms, including, most notably: (a) environmental or organizational structures (Adamek & Darrow, 2010; Goodley, 2011; Oliver, 1990; UPIAS, 1975), such as classrooms that may have too much sensory information and, thus, are unwelcoming of a person with sensory processing impairments, and (b) relational structures, such as stigmatization that limits social interactions between nondisabled and disabled persons (Adamek & Darrow, 2010; Goffman, 1963; Goodley, 2011; Kuppers, 2014; Oliver, 1990). The types of barriers one seeks to address allows consideration of disability from different perspectives. I focus below on critiques of environmental/organizational and relational structures as the types of barriers most regularly addressed by authors in literature drawing on SFCD.

***Environmental or organizational structures.*** By focusing to environmental or organizational structures, researchers and activists attend to how material organization and construction of society act as disabling factors. A classic example is that of stairs. Stairs are barriers for people with differences in ambulation, such as persons who have impairments and who use wheelchairs, crutches, walkers, etc.  SFCD-based critiques of stairs, specifically stairs used in public spaces, address the problematic nature of stairs for physical access to a space. Such critiques might inspect the assumptions of an ideal human "walker" who uses stairs in order to uncover how stairs create performative roles of disabled and nondisabled. Disability rights advocates in the 1990s brought attention to problematic environmental conditions related to social oppression of disabled persons through events such as the "Capitol Crawl," where persons who usually used mobility devices left those devices at the bottom of the U.S. Capitol steps and crawled up to the entrance (Nielsen, 2012). The "Capitol Crawl" is a profound example of disability rights advocates attempting to illustrate how environmental barriers act as means of disablement (see Figure 3).

Figure 3: "Capitol Crawl" photograph by Tom Olin (1990)

Critiques of environmental or organizational structures provide concrete data by which to identify and illustrate abstract issues, such as the social construction of disability. Oliver (1990) used analyses of environmental and organizational structures to challenge IFCD-informed ideologies. Oliver questioned dominant ideologies and suggested material changes that might remediate socially disabling factors, stating: “as material forces change, so will ideology” (p. 81). Taylor and Butler (in Taylor, Mann, & Basmajian, 2008) reiterate Oliver’s (1990) assertion as they discuss the ideological power of constructing curb cuts and other public barrier-reducing techniques to create a more open and welcoming community. By identifying environmental barriers as social exclusion factors, disability rights advocates encouraged the drafting and passage of legislations such as Section 504 of the Rehabilitation Act of 1973 and the Americans with Disabilities Act of 1990 (ADA).

One outcome of an environmental approach to disability and the legislation described above was an emergent concern over creating “barrier-free” designs for buildings and commercial products. The “barrier-free” approach to public design inspired what is now known as Universal Design. Based on the work of Ron Mace (1997, 1998), Universal Design is a proactive attempt by architects and designers to use design as a medium through which to forward inclusion by constructing more inclusive spaces. Mace (1998) envisioned that the design of products and environments that “broadly define the user” (no page number) might foster more inclusive social spaces.

***Relational structures.*** Kuppers (2014) stated, “Disability is relational, it speaks to relations between people” (p. 21). By focusing on barriers in relational structures, authors articulate how the social construction of disability impacts relationships among and between disabled and nondisabled persons. Major concerns addressed by authors who focus on relational structures are: issues of stigmatization (Goffman, 1963), personal identification and disability pride (Kuppers, 2014; Linton, 1998), and discourse and representation of disabled persons (Garland-Thomson, 1997, 2001, Mitchell & Snyder, 2000; Tremain, 2005). By identifying and analyzing relational structures as social barriers, authors address how disabled and nondisabled subjects are constructed and the performative roles that such subjectification stipulates for both subject positions. Rather than affirming IFCD subject positions, SFCD-informed scholars use relational structures to investigate how roles of (dis)ability create relational distance among and between disabled and nondisabled persons.

Erving Goffman's (1963) *Stigma: Notes on the Management of Spoiled Identity* is an early example of a relational approach to disability. In this text, Goffman considered the ways in which a disabled person, specifically one with a visually identifiable impairment such as differently-formed limbs or facial tics, is met and conceptualized by nondisabled persons. Goffman speculates that, when meeting, persons not marked with stigma signs read the stigma of others and attribute a "virtual social identity" (p. 2) to them. A virtual social identity may conflict with the disabled person's actual or personal identity. Goffman explains:

> While [a] stranger is present before us, evidence can arise of his possessing an attribute that makes him different from others in the category of persons available for him to be, and of a less able kind—in the extreme, a person who is quite thoroughly bad, or dangerous, or weak. He is thus reduced in our minds from a whole and usual person to a tainted, discounted one. Such an attribute is a stigma, especially when its discrediting effect is very extensive. (p. 3)

Goffman asserted that the stigma shapes the experiences, roles, and relationships afforded to those who possess the stigma symbol. Goffman posited that when someone without a stigma symbol identifies a person who possesses a stigma symbol, the person without a stigma might "believe the person with a stigma is not quite human" (p. 5). Stigmas manifest in language through "terms such as cripple, bastard, moron [used] in daily discourse as a source of metaphor and imagery [which] tend to impute a wide range of imperfections on the basis of the original one" (p. 5). Stigmatization shapes perception and frames how nondisabled people understand and interact with disabled persons. Stigmatization also shapes how disabled persons consider themselves and interact with nondisabled people through processes of passing and/or positive self-identification.

Disability Studies scholars have inspected disability representation in relation to stigma and subjectification. For example, Shelley Tremain (2005) drew on the work of Michel Foucault to interrogate how contemporary relationships and conditions of disability have come to be and how they might otherwise be reframed to foster positive social change (p. 1). Tremain critiqued how disability is constructed and disseminated through medical and human sciences (e.g., psychology and psychiatry) because of the problematic way disability shapes the self-perceptions of those labeled as disabled or nondisabled. Tremain examined disability language and positionality, asserting that “if one speaks, signs, or writes, one always speaks, signs, or writes from somewhere, some social position, and does so with some set of political, social, and ethical values and beliefs” (p. 13).

Language constructs new kinds of persons, such as “a person with a learning disability,” and, consequently, constructs other kinds of people, such as those “without a learning disability” (Tremain, 2005). Taking account of disabling relational structures allows one to see disability as a fiber within the culture of a specific group, a fiber that, along with other areas of difference (e.g., gender, race, ethnicity, sex, class, etc.), dictates who can participate in particular social roles and relationships and who cannot (McDermott & Varenne, 1995). The fiber of disability within the textile that is social life also impacts how those within the society define what it means to be an independent, autonomous being and a dependent other (Reindal, 1999).

***Ableism.*** The twin terms of “ableism” and “disableism” arose from SFCD, due in part to different disability civil rights movements. Wolbring (2008) defined ableism as:

> a set of beliefs, processes and practices that produce – based on abilities one exhibits or values – a particular understanding of oneself, one's body and one's relationship with others of humanity, other species and the environment, and includes how one is judged by others. (pp. 252-258).

Disableism is a related construct and refers “to the oppressive practices of contemporary society that threaten to exclude, eradicate and neutralise those individuals, bodies, minds and community practices that fail to fit the capitalist imperative” (Goodley, 2014, p. xi). Ableism has been used to refer to both ableism—the valuing of certain abilities over others—and disablism—the social oppression of DP/PwD based upon ableist assumptions, values, and practices. Hehir's (2002) definition of ableism as "devaluation of disability" (p. 1) may be more in line with disablism whereas Linton's (1998) definition combines both: "ableism . . . includes the idea that a person's abilities or characteristics are determined by disability or that people with disabilities as a group are inferior to nondisabled persons" (p. 9). I follow Linton and Campbell (2005, 2008) in using "ableism" to encompass and build upon both concepts.

Researchers such as Wolbring (2008), Campbell (2008), and Hehir (2002) have suggested that ableism may be one of the most socially accepted forms of oppression in contemporary society. Campbell (2008) noted the prevalence of ableism within the contemporary milieu, stating:

> From the moment a child is born, she emerges into a world where she receives messages that to be disabled is to be *less than...,* a world where disability may be *tolerated* but in the *final instance*, is *inherently negative*. We are all, regardless of our subject positions, shaped and formed by the politics of ableism. (italics in original, p. 151)

As a prejudice based on ability, ableism is tacitly enacted through many existing cultural practices that separate people based on ableist categories: (a) architectural design that favors certain abilities over others (e.g., the use of stairs rather than ramps) separate people in physical space, and (b) educational practices that organize learners into categories for instruction and access to opportunities based on ability measures (e.g., using literacy measures to sort students into groupings in which some students lose access to other learning opportunities because of extended literacy instruction, or using physical measurements or characteristics to decide which musical instrument a learner is allowed to pursue).

Ableism grounds deeply-rooted privileges that oppress both DP/PwD and nondisabled persons alike (Kattari, 2015). Ableism is legislated through law and policies on an institutional level, perpetuated through problematic disability representation (e.g., inspiration porn),[23] and

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[23] Grue (2016) defines Inspiration porn as "(a) an image of a person with visible signs of impairment who is (b) performing a physical activity, preferably displaying signs of physical prowess, and is (c) accompanied by

enacted in daily interactions which subtly demean disability and devalue DP/PwD (e.g., microaggressions).[24] Ableism constructs disability stereotypes and subject positions as well as stereotypical ways for nondisabled persons to respond to DP/PwD (e.g., infantilization, paternalism, and subjugation).

***The disabled subject and SFCD.*** Scholars drawing from SFCD regularly inspect issues of subjectification, specifically addressing subject positions constructed upon IFCD ideology. By drawing attention to sociocultural issues such as environmental and relational barriers, the use of SFCD allow people to consider disabled persons as a collective minority group and SFCD-informed critiques empower disabled persons to view disability as a positive if problematic identity position (Hughes & Patterson, 1997). Though it is problematic to be disabled due to social oppression, disability and diagnosis categories can afford DP/PwD specific social groupings that can be empowering for them through unity of identity or similarity of experience.

SFCD-based theorizing by primarily disabled authors affords disabled persons narratives and heuristics by which they may come to know themselves more fully (Shakespeare, 1996). For example, the narrative that disabled persons are members of an oppressed minority in the work of scholars writing from SFCD flips the oppression framework by rejecting “personal tragedy” conceptions of disability and forwarding an “affirmation approach” (Swain & French, 2000). The accounts of disability bloggers such as Brown (2011), Ladau (2015), Monje (2012), and Sinclair (2013/1999), the actions of disability rights protesters such as those in the aforementioned “Capitol Crawl” or the 1990 ADAPT protest (see Figure 4), and the expressions of unity by DP/PwD at disability pride events such as New York’s disability pride parade (see Figure 5) affirm disability as both a basis for minority identity as well as a positive, individual facet of identity.

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a caption that directs the viewer to be inspired by the image in question” (p. 2).

[24] Keller and Galgay (2010) note that disability microaggressions can impact persons with disabilities by 1) denying their personal identities and experiences, 2) denying them of their privacy, 3) treating them as if they were helpless, 4) helping or otherwise using them for personal gain, 5) ascribing specific abilities or impairments “due to the presences of a disability” (p. 254) and 6) patronization.

Figure 4: “I can’t even get to the back of the bus” photograph by Tom Olin (1990)

Figure 5: Picture from NY Disability Pride Parade by Seth Wenig (2015)

Swain and French (2000) took an affirmative stance to disability identity by suggesting that one might take on

> a non-tragic view of disability and impairment which encompasses positive social identities, both individual and collective, for disabled people grounded in the benefits of life style and life experience of being impaired and disabled . . . succinctly expressed [as] . . . proud, angry and strong. (p. 569)

An affirmative stance to disability empowers disabled persons to find themselves in union with other disabled persons and allows for recognition of shared culture that includes ways of being-in-the-world, common languages or linguistic formations, and a burgeoning arts movement (Kuppers & Marcus, 2008).

**Interactional conceptions of disability.** In light of postmodern and poststructural theorizing in Disability Studies, scholars have articulated interactional conceptions of disability (ICD). Authors suggest that impairment and/or individual facets impact one's experience with disability as do social facets (Shakespeare, 2014). Disablement is an outcome of both individual facets including impairment and social structures. Disablement is not a direct or singular cause-effect as in IFCD or SFCD, rather, disablement circulates among individual and social facets (see Figure 6, where disablement is represented by the blue lines). Disablement in ICD is recursive and complexly entangled within individual and social experiences of everyone within a particular community.

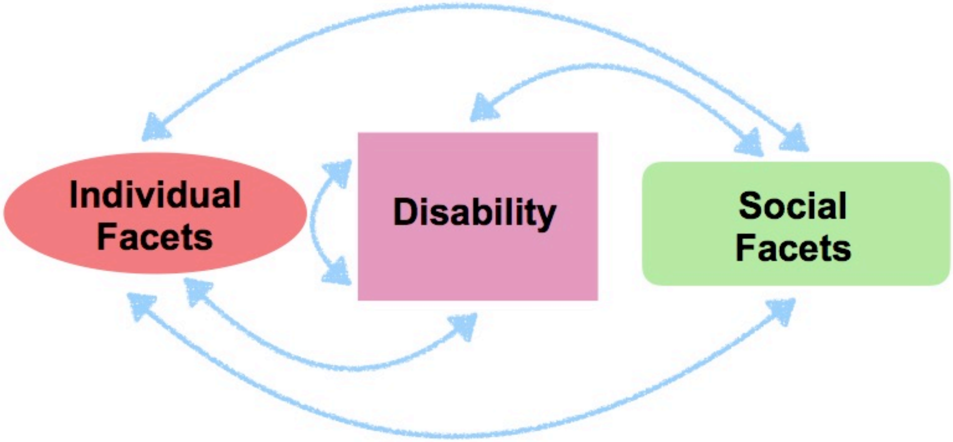

Figure 6: Interactional conceptions of disability

ICD ground diverse approaches to disability scholarship and these approaches often have little in common other than a general consideration of the interplay between individual and social aspects of disability. I classify ICD-informed approaches to disability scholarship as:

- the cultural analysis of disability (McDermott & Varenne, 1995), which examines how individuals, practices, and institutions interactively press upon one another. Disability can be used as a lens for inspecting culture;
- the capability approach (Mitra, 2006; Nussbaum, 2003, 2006; Sen, 1992), which considers disability as “deprivation in terms of capabilities or functioning that results from the interaction of an individual’s (a) personal characteristics (e.g., age, impairment) and (b) access to available goods (assets, income) and (c) environment (social, economic, political, cultural)” (Mitra, 2006, p. 237);
- the interface model (Smeltzer, 2007), which “is based on the premise that disability exists at the meeting point or interface between a person’s medical diagnosis and the environmental factors that affect disability” (p. 193);
- the social confluence theory (Lubet, 2011, 2014), which explores disability and identity changing at the confluence of “place, time, activity, and encounter” (Lubet, 2011, p. 21);
- the critical realist approach (Corker & Shakespeare, 2002; Shakespeare, 2014, 2015), which encourages scholars to attend to the lived experiences of DP/PwD, account for the individual and social factors that construct disability in a person’s life, and develop emergent theories of disability and impairment.
- the rhizomatic model of disability (Kuppers, 2009, 2011), which draws on the work of Deleuze and Guattari (1987) in order to allow “for thoughts to be pried open, form familiar things to be disassociated, and unfamiliar things brought into contact with one another” in relation to disability and disability as lived. (Kuppers, 2011, p. 93); and

- Crip theory (e.g. McRuer, 2006a; 2006b; Sandahl 2003), which draws on theories of performativity by Goffman (1959) and Butler (1990, 2010, 2011) to inspect how disability is performed at the intersection of different discourses.

Each of the approaches outlined above leans slightly more toward either IFCD or SFCD. Below, I discuss the final four approaches outlined above because they appear to be the most flexible and, as theoretical lenses, afford broad ways for considering disability in the lives of participants in this study.

***Theory of social confluence.*** In Lubet's (2011) theory of social confluence, disabilities are seen as identity positions that are changeable based upon a person's environment, practices, and social relationships. Lubet clarified, stating:

> the fundamental unity of identity is social confluence—that is, the role in which an individual finds herself at any time. The role is subject to redefinition at a moment's notice, as soon as one proceeds to the next encounter. (p. 2)

Lubet, a musician and musicology professor, expanded upon Disability Studies discourses informed by SFCD to construct his social confluence theory upon returning to work at the University of Minnesota after neurosurgery to mediate pain and gain use of his right arm and hand. Lubet explains:

> During this return to work, I learned that my disability status was defined in radically different ways depending on the social, cultural, and institutional context of the moment. The social confluence theory was thus born on a day when my disability identity morphed several times over, depending on with whom I was interacting. What made this seem all the more remarkable was how little I actually had to travel to undergo these identity transformations. (p. 2)

For Lubet, disability and impairment are not transcendent of cultural context or particular intersections of time, environment, social interactions, and cultural practices. Rather, disability and impairment are constantly defined and redefined, constructed and reconstructed as a person moves from place to place, engages with people here and there, and acts in relation to this or that set of norms.

Lubet (2011) developed his theory of social confluence as a means of placing Disability Studies discourse in dialogue with literature on music making and learning practices. Lubet suggests that musical pedagogies and practices, specifically those often found in Western classical conservatory settings, may be disabling and impairing on a scope not yet adequately addressed in either music or Disability Studies literature. From Lubet's perspective, the fetishization of technique and the disciplining technologies used to "teach" technique work together to construct broader notions of what it means to be impaired and, thus, disabled (Lubet, 2009b). Lubet's (2011) theory is useful in any field as it allows one to consider how "definitions of disability and impairment can vary drastically, sometimes surprisingly, according to cultural practices" (p. 20). Keeping social confluence in mind requires one to consider how interactions of "place, time, activity, and encounter" (p. 21) constantly construct and reconstruct disability, oppression, subjectivity, and, specifically, identity from one moment to the next.

***Critical realist approach.*** The central assumption of a critical realist approach to disability is that "people are disabled by society *and* by their bodies" (Shakespeare, 2014, p. 75, emphasis in original). A critical realist approach to disability asserts that

> disability is always an interaction between individual and structural factors. Rather than getting fixated on defining disability as a deficit or a structural disadvantage or alternatively a product of cultural discourse, a holistic understanding is required. Put simply, the experience of a disabled person results from the relationship between factors intrinsic to the individual, and extrinsic factors arising from the wider context in which she finds herself . . . I do not explain disability as impairment, and I do not see impairment as determining. My approach is non-reductionist, because I accept that limitations are always experienced as an inter-play of impairment with particular context and environments. Impairment is a necessary but not sufficient factor in the complex interplay of issues that result in disability. (pp. 74-75)

Intrinsic factors might include motivation, personality, and attitude toward impairment. Extrinsic factors may include the physical environment in which one finds oneself, oppressive or supportive institutional practices, social relations, and economic realities.

A critical realist approach to disability sees impairment as individual embodied differences. Based on this, Shakespeare (2014) defined "disability as the outcome of the interaction between individual and contextual factors" (p. 77). Disablement, then, is the flow of individual and social interactions. Additionally, Shakespeare suggested that the theoretical division of impairment and disability may be hard to maintain empirically, stating: "impairment and disability are not dichotomous. It is difficult to determine where impairment ends and disability starts" (p. 25).

Shakespeare developed the "critical realist approach" because of his concern over the reductive nature of IFCD and SFCD.[25] Rejecting a strong approach to SFCD, Shakespeare (2014) suggests that

> the distinction between biological/individual impairment and social/structural disability is conceptually and empirically very difficult to sustain. For example, learning difficulties may be associated with stigma and discrimination, but the individual deficits and the social responses shade into each other, and it is hard to extricate the contributions of each factor. (pp. 21-22).

Shakespeare has criticized SFCD-based scholars for their inadequate accounting of the experiences of disabled people with degenerative chronic illnesses. Specifically, Shakespeare was concerned that SFCD causes scholars to reject explorations into the very real and limiting manner in which impairments may impact one's lived experience. Impairment from a critical realist perspective is a matter of life for all humans due to disease and ageing. In this way, impairment is a uniquely human predicament, a predicament that could become a meeting point to inspect the commonality of human experiences. At its heart, a critical realist approach to disability allows scholars to resist or bridle ideological leanings in order to better study impairment and disability as lived rather than as assumed. Shakespeare (2015) made his intentions along these lines obvious, stating:

> I would rather start by trying to figure out things about the lives of disabled people and the disabling barriers that they face, and then draw on theory, where required, to explain the patterns and relationships which are uncovered. (p. 3)

Toward these ends, Corker and Shakespeare (2002) advocate for drawing as needed on theoretical approaches as diverse as individual and social notions of disability as well as poststructuralism, psychoanalysis, feminism, queer theory, representation, performativity,

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[25] Shakespeare uses the terms "medical model" and "social model" in his discussion, though, in content, his descriptions of these models can be seen to fold well into my use of IFCD and SFCD, respectively, in this document.

embodiment, biopower, and deconstruction, among others, in order to investigate the complexities of the lived experiences of disabled persons.

A critical realist approach centers first and foremost upon the actual lives of disabled persons. Actual lives are comprised of a range of positive and negative experiences as well as shades of grey between that binary. The work of Neil Marcus (e.g., 1993, 1996; Marcus, Lathim, Marcus, & Access Theater, 1993; Kuppers & Marcus, 2008) implies a critical realist-related position through his rejection of binary understandings of disability, seeing disability as neither only trying or only empowering. One of Marcus's most pointed articulations of his interactionalist-leaning position comes from *Storm Reading* in which he stated: "Disability is not a brave struggle or 'courage in the face of adversity.' Disability is an art. It's an ingenious way to live" (n.p.).

***Rhizomatic model of disability.*** Kuppers's (2009, 2011) model of disability holds many similarities with those posited by Shakespeare (2014) and Lubet (2011). First, Kuppers identified both social and individual facets of disability in a fashion similar to Shakespeare (2014). Kuppers critiqued views of disability as an essence, a transcendental concept or state a priori of actual lived experience. She suggested that the lived experience of disability is far more different from theoretical or abstract conceptions of disability and that, as such, the focus of disability scholars should be on lived experience. The lived experience of disability is more flexible, diverse, and unwieldy than existing theories can capture, Kuppers asserts. Kuppers (2011) also acknowledged that disability ought to be conceived of as a plural rather than a singular construction, contingent upon the complex confluences of time, space, activity, and relationality. In this way, Kuppers's approach is similar to Lubet's (2011) social confluence theory. Yet, Kuppers (2009, 2011) moved further by imploring us to consider disability rhizomatically.

Kuppers (2009) drew heavily upon Deleuze and Guattari's (1987) notion of rhizome in order to articulate the plurality of both disability and the lived experiences of being disabled. Deleuze and Guattari offered the rhizome as a model for understanding the existential nature of human life as one of connections and heterophony: "any point of a rhizome can be connected to anything other, and must be. This is very different from the tree or root, which plots a point, fixes an order" (p. 7). Taking on a rhizomatic ontological perspective requires one to accept multiplicity and interdependence as perhaps the only human universals. All human beings are both utterly similar to and utterly different from one another, each person having a unique way of being-in-the-world. Yet, one's being and the beings of others do not exist in isolation, but, rather, in complex networks of interdependence. Human life is individual as much as it is social.

Kuppers (2011) envisioned a model of disability that embraces the rhizome as a map and in doing so attempted to focus upon the interdependent and multiplicitous nature of human life. Lived experience of disability is interdependent intrinsically and extrinsically at the same time. Disability is intrinsically interdependent through the confluence and interrelation of emotions and self-images known through one's physiological and psychological states. Disability is extrinsically interdependent in the play of social experiences and relations that are the sites of inclusion/exclusion and empowerment/oppression. Kuppers illustrated:

> [A rhizomatic model of disability] is a model in which the extrinsic and intrinsic mix and merge, as they do in my own physical and psychical being when I am in pain, and cannot walk up the stairs, and wish for a painkiller, and take pride in my difference (what other choice do I have?), and feel unable to speak of the nature of my discomfort, cannot find words, but find comfort in the company of others whose pain might be difference, but who somehow feel simpatico . . . The rhizomatic model of disability produces an abundance of meanings that do not juxtapose pain and pleasure or pride and shame, but allow for an immanent transformation, a coming into being of a state of life in this world, one that is constantly shifting and productive of new subject/individual positions. (p. 95)

A rhizomatic model of disability resists any stable approach to disability and to the lives of disabled persons, requiring one to accept a multiplicity of meanings, experiences, and practices that may be a person's lived experience of disability.

***Crip theory.*** Authors such as McRuer (2006a, 2006b) and Sandahl (2004) have explored how disabled identity and subjectivity is performed. Drawing on performative discourses in fields such as gender studies, critical race studies, and queer studies, these researchers have articulated "Crip theory." Crip theorists suggest that rather being "disabled" and possessing a potentially totalizing identity, being "Crip" is one of many intersectional identities performed by persons who might otherwise be categorized as “persons with disabilities” or “disabled persons.” Instead of conceptualizing disability as arising out of disablement, Crip theorists discuss disability as performative and intersectionally situated, meaning that one is not disabled, as such, but is Crip when doing Crip things, or things that call attention, either intentionally or not, to difference in ways that arouse the specter of disability in other social actors.

Sandahl (2004) provided a precursor to Crip theory in her research on solo autobiographical performances by gay and disabled artists. Placing Disability Studies into dialogue with queer studies, Sandahl suggested, encourages researchers to reject any “tendency to absorb and flatten internal differences” (p. 27) and embrace intersectional perspectives and pluralist accounts of life as lived. Through dialogue, one can experience the convergences between “being queer” and being “Crip” and thereby “[expose] sites for activism and [clarify] significant issues for [a specific identity] group” (p. 28).

The use of the term “Crip,” from “cripple,” is significant as it represents a reclaiming of a historically pejorative term for purposes of community-building and community pride, similar to the reclamation of “queer.” Originally used to refer to persons with physical impairments, Sandahl (2004) clarified that in contemporary use by those in the disability community, “the term *cripple* . . . is fluid and ever-changing, claimed by those whom it did not originally define . . . the term Crip has expanded to include not only those with physical impairments but those with sensory or mental impairments as well” (p. 27). Sandahl implicated the practice of “cripping” as an analytic approach that “spins mainstream representation or practice to reveal able-bodied assumptions and exclusionary effect . . . [to] expose the arbitrary delineation between normal and defective and the negative social ramifications of attempts to homogenize humanity” (p. 37). One approach to cripping might be through flipping the ableist script or applying common disability tropes to seemingly nondisability-related situations, such as positioning an attractive person, often seen as an “erotic object” as an “object of pity.” Another approach is to call attention, even hyperbolically, to one’s Crip performance. One might flaunt bodily difference or do other things that may run counter to stigma management (e.g., Goffman, 1963; Garland-Thomson, 1997).[26] As such, cripping can be “deployed to challenge oppressive norms, build community, and maintain [one’s] self-worth” (p. 38).

Although Sandahl (2004) did not reference “Crip theory” in her work, her implication of the potential for “cripping” as a theoretical tool was further developed by McRuer (2006b) and others. McRuer, drawing on cultural and queer studies, considered how and why able-bodiedness and heterosexuality were constructed, potentially in tandem, producing what he calls “compulsory able-bodiedness” (p. 2), or the assumption that being nondisabled is the natural and right situation for humans. Crip theory allows one to explore the repetitive performance of able-bodied identity, a performance that cannot be fully embraced or completely repeated by living humans due to the inherent inconsistencies of the socially constructed and dictated “performance guidelines” of discourse and the uniqueness of the human performer. Drawing on Butler’s (1990) work, McRuer (2006b) suggested that there might be “ability trouble” that should be addressed, “not the so-called problem of disability but the inevitability, even as it is made compulsory, of an able-bodied identity” (p. 10). McRuer intended to take a more activist-centered perspective through his invocation of “Crip” in Crip theory, making strong allegiances with disabled arts performers and “self-identified Crips in the street” (p. 33) who act, rather than to take a purely academic posture with its assumptions of objective distance.

Central to McRuer’s (2006b) “Crip theory” are five “tentative principles” (p. 71). The first principle can be summarized as taking a position that supports disability-based identity politics while also contesting such politics, seeing disability as a unifying identity group while also seeing the way disability falls apart as a unifying category. The second principle involves “coming out” as disabled and embracing historical threads of disability and queerness while also talking back to those histories in order to discover new ways of being Crip. The third principle suggests that Crip

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[26] Some DP/PwD act as to “pass” as not-disabled. Passing “refers to the way people conceal social markers of impairment to avoid the stigma of disability and pass as ‘normal’” (Brune & Wilson, 2013, p. 1).

theorists demand a more just and accessible world through their actions, rather than distance through scholarly analysis. The fourth principle grows out of the third by urging people to insist on the possibility of a disabled world—a world not haunted by the oppressive strains of compulsory able-bodiedness. Finally, McRuer's fifth tentative principle for Crip theory encourages all to interrogate and work to transform all sites—physical, social, economic, etc.—where disability identities emerge, calling out what one is not or cannot be now due to oppressive constraints.

Building on McRuer's (2006b) work, Cosenza (2010) suggested that Crip theory can allow one to carve out a borderland between ablebodiedness and disability, a liminal space that is open to those with "invisible disabilities," like herself, who may not be afforded such a welcome through other disability discourses that she sees as created by and for physically disabled persons. Beyond the IFCD- and SFCD-informed frames, Crip theory provided Cosenza, a person diagnosed with dyslexia, with a framework to inspect the ideological production of ablebodiedness. The Crip, rather than the disabled person, might then "emerge as a more fluid term critiquing and claiming the contradiction and ambiguity of the borderlands" (p. 3). Through an analysis of her own Crip performance of her piece "SLOW," Cosenza articulates how her dyslexia presents in her life, making her Crip-ness evident at certain times while not all the time. Identity, then, is in the *performance* of identity.

Viewed performatively through Crip Theory, disability becomes an even more difficult "thing" to define and describe with any sense of precision because it is performed in so many different ways and because each performance offers a new way of *being* disabled and *being* human. Disability and disabled being are, then, as fluid and ambiguous (Cosenza, 2010) as ablebodiedness. By attending to disability as performance, one may be able to "Crip" ability (e.g., Sandahl, 2004) and open spaces for difference in the ever-shifting liminal spaces between disability and ability (Cosenza, 2010). At the same time, attending to Crip Theory provides one a theoretical frame that may potentially open up the intersectionality of disabled performance.

**Summary.** Each conception of disability described above—individual focused, social focused, and interactional—not only constructs specific disabled and nondisabled subject positions, but also has a different type of use in relation to research and practice. I provide a summary table below (Table 1) that explains (say something about the headings).

| Conception | Impairment | Disability | Disablement | Approaches | Uses |
|---|---|---|---|---|---|
| Individual-Focused | Abnormality or deficit of an individual's body/mind construction or function | The lived impact of having an impairment<br>Bodies/minds disabled an individual | Impairment directly causes disability. | Biomedical<br>Functional | Identifying and providing medical treatment and/or governmental services |
| Socially-Focused | Individual body/mind differences (natural human diversity) | Exclusion and oppression of those with impairments through barriers to participation<br>Society disables persons | The ill fit of society to individuals with impairments create disabling conditions<br>Ableism | Environmental<br>Relational | Identifying, challenging, and attempting to remove environmental or relational barriers. |
| Interactional | Individual body/mind difference in construction or function | Individual and social experiences of having an impairment<br>Society and bodies/minds disable | Recursive | Cultural analysis<br>Capability approach<br>Interface model<br>Social confluence<br>Critical realist<br>Rhizomatic<br>Crip Theory | Considering the individual person's lived experience of impairment and disability<br>A systems approach |

Table 1: Summary of three primary discourses of disability.

## Labels and Identities

Issues related to labels, labeling, and terms of identity are complex, interwoven, and easily misunderstood, specifically in relation to disability. Diagnostic labels such as "Williams syndrome," "Tourette syndrome," and "Attention-deficit/hyperactivity disorder" are used by physicians, psychologists, and therapists to identify a specific constellation of symptoms and/or differences in mind/body construction and/or functioning. These labels allow medical practitioners to select research-based treatments for those whose mind/body composition and functioning or behavior deems them outside of a medically-defined norm. Government labels such as those articulated in IDEIA (2004) (e.g., “mental impairment,” “speech and language impairment,” and “emotional disturbances”) and other legal labels such as “legally blind” and “on disability” are bestowed to specific persons by medical practitioners, teachers, and governmental authorities after a series of examinations, paperwork completion, and case meetings. These labels may act as keys to access specific governmental resources, such as Individualized Educational Programs, 504 plans, Social Security disability benefits, and ADA civil rights protections. Diagnostic labels and governmental labels have their roles in assisting persons with finding treatments, therapies, supports, and resources that may add considerably to their quality of life.[27]

The act of labeling is built upon a network of power relationships which deem certain ways of being and doing as being “outside of the norm” (Baglieri & Shapiro, 2017). Disability Studies authors assert that any notion of *normalcy* is contextual and culturally-embedded. In this way, they reject normalcy as a transcendental essence, a “Vitruvian Man,”[28] by which all minds/bodies are to be measured. Barnes and Mercer (2010) illustrated this point when they state that there is a

> considerable variation historically and cross-culturally in both patterns in perceptions of impairment and disability and appropriate local policy responses. Hence, it is important to locate attitudes and practices within a specific social context and examine the interaction of diverse economic-material, cultural and political factors. (p. 15)

Although *normalcy* may be culturally-specific, a Vitruvian Man constructed of Western-European bodily, mental, and behavioral norms has become a default image of what it means to be normal. Garland-Thomson (1997) identified this Vitruvian Man as a *normate*, a term that refers to “the constructed identity of those who, by way of the bodily configurations and cultural capital they

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[27] As someone diagnosed with a mood disorder, I benefit from my diagnosis in order to secure medications and therapies that improve my mental state.

[28] Leonardo Da Vinci’s famed anatomical drawing *Le proporzioni del corpo umano secondo Vitruvio,”* more popularly referred to as the “Vitruvian Man” displays an idealized male body, with proportions culled from the architectural writing of Vitruvius (Le Floch-Prigent, 2008).

assume, can step into a position of authority and wield the power it grants them" (p. 8). The "normate" might be seen as an ideal form, an essence, of what we conceptualize as *the* human subject. Yet, the normate is an ideological outcome rather than an ontological position.

**Music education and labels.** A recurring theme in music research relating to disabled persons are comparative studies on the musical abilities of "typically developing" learners (i.e., nondisabled learners) and those of DP/PwD, often using diagnosis-based grouping (see Appendix A). Yet, many of these studies find few differences between the binary-situated groups. For example, Jellison and Flowers (1991) found strong similarities between disabled students (n = 73) and nondisabled students (n = 155) in their musical preferences related to playing musical instruments, kinds of music to listen to, and musical activities in which to take part. Of their findings, the researchers state:

> Perhaps the most notable outcome of this study is the similarity of responses between students with disabilities and their nondisabled peers. Although the music teacher must consider individual differences that are important for the development of meaningful music curricula and effective teaching strategies, the label "disabled" or "handicapped" may connote more differences or even a variety of differences that are simply unimportant for day-to-day music classroom instruction and classroom routines. (pp. 328-329)

Jellison and Flowers noted the potentially meaningless or problematic nature of attending to labels to inform specific pedagogical approaches for students with specific labels. Jellison and Flowers' study, and the work of others below, exist primarily to debunk the false binary of ability/disability in music and to "normalize" DP/PwD. Yet, examples of music educators seeking specific tips, strategies, and approaches to be used when working with students with specific diagnostic labels abound on social media music teachers' groups and forums.[29]

Hammel and Hourigan (2017) feared that diagnostic labels may be used by music educators in ways that block communication and empathy between teacher and learners. They

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[29] Many of these groups, such as those on Facebook, are "closed" and are, therefore, not publicly available. I avoid sharing specific examples here to avoid unethical lurking (i.e. Bruckman, 2002), although the search feature on social media groups or forms may allow one to find illustrative discussions by searching for dialogue around specific labels (e.g., Autism, blind, ADHD, etc.).

stated, “Knowing your students and their needs can be far more important than the specific labels included in their paperwork” (p. 203). Labels can impact one’s conceptions of a learner, as Cassidy (1991) found in her study of the impact of labels and visual cues of disability on how undergraduate and graduate music students rated disabled and nondisabled six- and seventh-graders’ choral singing. Cassidy found that raters tended “to be sensitive and generous of their evaluations” (p. 32) of DP/PwD when they knew via labels or visual cues (e.g., presences of a wheelchair and facial features characteristic of persons diagnosed with Down syndrome) about disability. This response may be an indication of sensitivity, as Cassidy suggested, or it may indicate a difference in expectations and/or in willingness to provide critique when faced with a disabled learner. Perhaps Cassidy identified one way that labels create notions of problematic difference in music education practice.

Labels may be seen as an essential characteristic of the learner, one that requires a different means of engaging with, supporting, and treating the learner/person. Because of this, some music educators, researchers, and governmental policy makers avoid using labels directly. Strike (in Strike & McConnell, 2002) noted:

> Labels are for jars not for people. People look on the disability and they put a label on that person and they use that label for the rest of their life and I think that is disgusting. Labels are for jars. They are not treating us like a person. I am not an object like a jar or a statistic. That is what I believe in. It puts people down. Like they classed me as mental retardation and treated me like a child, not an adult. I don’t like that label. Why should I use it, I am a person first. The label comes second. You shouldn’t label a person unless you know the person. You should recognize them as a person first. If you can get away from the label and concentrate on the individual, you will find the individual will help you, then you can help them. (p. 58)

Such sentiments lead to the proliferation of “person-first language.”

**Person-first language.** Person-first language came into prominent usage in educational literature and was legitimated as the correct phraseology to use when writing or speaking about DP/PwD through Bailey’s (1991) heavily cited “Guideline for Authors” for the *Journal of Early Intervention*, a highly influential journal on disability and inclusive education. Bailey offered person-first language as a means of challenging demoralizing discourse regarding disabled persons. Two years later, Blaska (1993) passionately advocated for writers to consider the power embedded within the words they use, suggesting that a change in terminology when speaking about "people with disability" may help alter problematic public discourse that places people in this population into oppressive positions. Blaska stated:

> The philosophy of using person first language demonstrates respect for people with disabilities by referring to them first as individuals, and then referring to their disability when it is needed. This philosophy demonstrates respect by emphasizing what people can do by focusing on their ability rather than their disability and by distinguishing the person from the disability. (p. 27)

Persons with diagnosed disability using person-first language may do so in a positive manner in order to suggest that disability is not a prominent part of their personal identity.

Person-first or people-first language (i.e., an "individual with disabilities," "people with disabilities," or "students with special needs")[30] dates back to late the 1960s and by the 2000s was considered *en vogue* or politically correct labeling practice related to disability (Titchkosky, 2001). Language guidelines were also written into public policy (e.g., IDEIA, 2004). Prior to the 1980's, terms that labeled people according to their disability, such as "retarded," "handicapped," "cripple," and "an autistic" were common parlance. Since then, person-first formations that emphasize the person rather than the disability have become socially-acceptable parlance in education (Friend, 2014). This is specifically true in music education literature from North America where, in the words of Adamek and Darrow (2010),

> Educators are encouraged to use "person-first" language, which is just as it sounds, putting the person first before the disability. Rather than seeing the person as the disability first, person-first language demonstrates that the person has many characteristics and qualities of which a disability might be one . . . The purpose of this approach is not to minimize or deny disability, but to affirm that the student is more than the disability and that the disability does not supersede all of the other human attributes that the child possesses. (p. 8)

A dedication to person first languages was reiterated in practitioner publications such as Jellison (2015a), Abramo (2012), and Darrow and Armstrong (1999). More recently, the phrase "children

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[30] "Typical" or "typically developing" are often preferred terms to refer to nondisabled persons when using person-first language.

with exceptionalities" has begun to be more common in music education literature as another variant of the person-first formation (e.g., Blair & McCord, 2015). For music educators, the use of person-first language is intended to encourage teachers and "typical" peers to see a "student with a disability" as a unique individual rather than focusing on their disability in a totalizing manner (Adamek & Darrow, 2010; Hammel & Hourigan, 2017; Jellison, 2015a). Yet, as I will discuss below, some disability rights advocates feel that person-first language does little more than foreclose any conception that one's disability or label may be an integral and/or positive aspect of their life in order to manage the unease of nondisabled persons.

**Identity-first language.** "Nothing about us without us," a common disabilities rights slogan (Charlton, 1998; Nielsen, 2012; Rembis, 2017; Yeo & Moore, 2003), grounds an ethic of self-determinism that extends to "disabled persons" the right to self-identity and name how they conceptualize disability in their lives. Bickford (2004) noted,

> Most of the literature referring to language and disability reflects the opinions of professionals. Ironically, we have failed to ask the stakeholders about their own preferences. Those preferences should be recognized and respected by people without disabilities. We need continued research to determine not only preferences of people with disabilities but also the perceptions of those without disabilities toward those with disabilities. (p. 125)

Self-identifying and naming one's world can lead disabled persons to use or to avoid person-first language. When eschewed, person-first might give way to "identity-first" language through which people claim themselves to be "disabled," "autistic," "dwarves," or "blind," drawing attention to the ways that disability or specific disability labels impacts the personal and cultural identities of persons who have impairments. Disability Studies scholars and disabled persons (e.g., Bickford, 2004) may even reject person-first language as being socially-imposed rather than individually situated. As Cameron (2014) noted:

> disability ceases to be something that people 'have' and is understood instead as an oppressive relationship, as something 'done to' people with impairments. People have impairments but are not 'people with disabilities.' They are disabled by poor or non-existent access to the public places where ordinary life happens and by the condescending and unwelcoming responses of those who occupy these spaces. (p. 137)

“Identity-first” language, then, may allow DP/PwD to assert disability as a minority status, as such, a form of social cohesion.

Titchkosky (2001) criticized person-first language used by governments in North America specifically due to the negativity person-first language places upon feeling one’s disabled status as an aspect of one’s identity. Titchkosky affirmed the potential positive benefit of using “identity-first” formations. Common reasons for “identify-first” language voiced by disabled persons and disability rights groups include:

- countering the diminishment of the important role disability and labels may play in the formation of a person’s identity (Ladau, 2015);[31]
- rejecting the negative manner in which labels of disability are read and by which disability is totalized as disease and deficit (Sinclair, 2013/1999). From this perspective, person-first language minimizes one’s personhood suggesting that one is a person “despite” one’s disability (Monje, 2012); and

Egan (2012) affirms “identity-first” terminology in a blog post entitled *I’m Not a “Person With a Disability”: I’m a Disabled* Person:

> I am disabled . . . I am disabled by a society that places social, attitudinal and architectural barriers in my way. This world we live in disables me by treating me like a second-class citizen because I have a few impairments. (blog post, no page numbers)

Brown (2011) stated a preference for “disability-first” language, specifically a desire to be “an Autistic” rather than “a person with Autism.” Brown noted that for her “autism is an inherent part of an individual’s identity—the same way one refers to Muslims. African-Americans, Lesbian/Gay/Bisexual/Transgender/Queer, Crip, Chinese, gifted, athletic, army brat, or Jewish. Monje (2012) rejected person-first language:

> The "person-first" construction demands that I be treated as a person *despite* my autism. My preferred identify-first construction demands that I be treated as a person *because of*

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[31] For transparency, I inform the reader that Brown (2011), Ladau (2015), Monje (2012), and Sinclair (2013/1999) are, or were originally, blog posts. In light of Bickford’s (2004) call to involve stakeholders in conversations about disability language, I suggest that blogs such as these offer disabled persons a means of making their ideas about disability language visible accessible in a way that other “credible” means may not as easily afford.

> *my autism*. It shows that my experiences come from a unique way of interacting with the human condition. It's more than just an identity label, it's a way of showing that this is not an add-on to the human condition, it's an active modifier of it that gives it depth and specificity beyond what a simple add-on label, a simple little passively constructed person-first homogenizing modifier, could ever do. (emphasis in original, blog post, no page numbers)

Brown (2011) suggested that person-first language serves nondisabled persons more than DP/PwD by letting them feel better about their language, about disability, and about their potential place in a system of oppression that impacts the lived experiences of DP/PwD.

In order to flip the ableist script, "identity-first" formations allow disabled persons to affirm cultural identities that situation them as belonging to a group(s) with shared cultural practices, such as the Deaf community in which may share the common language of American Sign Language (Ladau, 2015; Padden & Humphries, 1990). In addition, "identify-first" formations may buck the Cartesian split of mind/body inherent in person-first formations, which see the disabled mind/body as a mind with a malfunctioning body.[32] By acknowledging that "the experience of impairment within an ableist context can and does effect formation of self – in other words 'disability is me', but that 'me' does not need to be enfleshed with negative ontologies of subjectivity" (Campbell, 2008, p. 158), one might begin to construct positive disabled subjective positions and ontologies. Through positive identification, DP/PwD might then find cultural unity through meaningful group organization with others who have a similar identity position rather than being forcibly grouped in diagnostic manners by medical, legislative, and educational experts, as is the case with IFCD-based modes of labeling and identification (Winance, 2007).

Yet, some authors wonder to what extent a disability identity can become totalizing for disabled persons as well as nondisabled persons (e.g., Shakespeare, 1996, 2014). What other

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[32] Interestingly, considering person-first from a Cartesian perspective calls into question the usefulness of such language in the face of impairments that may impact cognitive functioning. If the "person" in person-first language is really referring to a "mind," can a mind be separate from something—a body—that impacts the functioning of the mind? Can someone be a person—read "mind"—with cognitive impairments? Rejecting the Cartesian split, can one be "with" something that is an integral aspect of what it means to be them as a "person"? Campbell (2008) suggested that perhaps such formations are not sustainable logically but imply internalized ableism that supports a negative ontology of disability and a negative subject position for those deemed "disabled."

identities might a disabled person hold and to what extent might identifying only as disabled further marginalize a person. Using Crenshaw's (1991) notion of intersectionality, I suggest that identity-first language can be problematic as it may totalize a "disabled person" as only disabled and not as disabled and black, or disabled, black, and cisgender. Kuppers (2014) might add that a totalizing identity such as being "only disabled" may lead to further disablement by missing or misrecognizing the interlocking mechanisms of oppression. Additionally, Shakespeare (1996) identified the possibility that placing too much focus on disability-first language and drawing too much from SFCD-informed social critiques can cause persons who identify as disabled to ignore the reality of their experiences with impairment. By focusing on social structures and disability identities, Shakespeare fears that disabled people may not account for how their embodied experience of impairment impacts their personal and social lives.

**Identity as performance.** Growing out of the ICD-informed investigations of disability as both social constructions and individual experiences, some Disability Studies and Disability Arts researchers have called for identity, and human life, to be considered as performed. Researchers such as McRuer (2006b; in Peers, Brittain, & McRuer, 2012) and Kuppers (2001, 2011, 2014) have considered disability the lens of performativity as developed in the research of Erving Goffman (1959) and Judith Butler (1990). I review the work of these two scholars to explain how identity may be understood as social performance.

***Goffman and performance of identity.*** In *The Presentation of Self in Everyday Life*, Erving Goffman (1959) used the metaphor of theatrical performance to analyze social interactions.[33] For Goffman, what is of interest in social interactions is how social actors manage the flow of information about themselves between and among one another, how one shapes the perception of another person about themselves. Goffman specifically studied the interactions between people at work to see how an individual "presents [oneself] and [one's] activity to others,

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[33] His approach is often called the "dramaturgical approach" in sociological identity studies.

the ways in which [one] guides and controls the impressions [others] form of [one], and the kinds of things [one] may and may not do while sustaining [one's] performance before [others]" (p. i).[34]

Goffman (1959) noted that what is material can be understood, while what resided within "ideas" such as "attitudes, beliefs, and emotions . . . can be ascertained only indirectly, through [one's] avowals or through what appears to be involuntary expressive behaviour" (pp. 1-2). What one presents, or performs, to others is what can be understood directly. From Goffman's perspective, much of one's presentation of oneself is voluntary, with actions and verbiage used purposefully to control the flow of information. The "self" here, perhaps better likened to one's social identity, is malleable to the situation and/or the presence of specific other social actors. However, not all that is presented is done so voluntarily, as some information is given without direct intent; this concept gives rise to Goffman's (1963) notion of stigma.

Goffman (1959) outlined seven elements of performance. First, one must believe in the part one is playing in order to establish sincerity of performance to other social actors. Second, one creates "a front" (p. 13) through repeated performance in a particular situation, and this front provides a form and set of performance guidelines one may use to establish continuity. Third, performances have a "dramatic realization" (p. 19) through which one highlights specific factors of their performance that one wants to ensure the audience observes. Fourth, actors enter social interactions with an "idealization" (p. 22) or idealized or abstract concepts of how one and others should act in a given situation. This provides a loose script to follow, allowing for lower cognitive load. Fifth, performers exhibit "maintenance of expressive control" (p. 33) in which one stays in character by presenting the correct actions and minimizing the impact of incidental or inadvertent actions in order to continue to establish continuity and sincerity in their performance. Sixth, a social actor attends to the possibility of misrepresentation (p. 37), of performing actions that question the validity of their front and may cause others to question their genuineness. Finally, Goffman identifies mystification (p. 44), in which an actor purposefully conceals information from

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[34] I have bracketed to clarify and make gender-neutral Goffman's prose.

other social actors either to mitigate potentially damaging information coming to light or to arouse the attention of other social actors.

The situation in which one is finds oneself and the overriding, hopefully shared, definition of the situation and roles to be taken by all social actors greatly shapes how one acts and presents themselves. For example, in situations with expectations of professionalism, in which one person is in a subordinate role to another actor, the situation defines the ideal roles and performances to be played. In such a situation, roles are implicitly negotiated between actors, often with the superior's role definitions being honored. On occasion, definitional disruptions or mismatches may arise either when actors fail to negotiate or when one person involuntary breaks from the definition. In either case, social actors may or may not note the disruption, depending on how they evaluate the needs of the situation. If there is a need to help one save face, then the other social actors may not note the disruption. If, however, the other social actors deem the disruptive actions as an affront to the norms, then they may call attention to the disruptive actions/actor.

Goffman's concept of performativity may be of use in considering disability identity in settings when disability is framed as deficit or when those identified as being "disabled" or diagnosed with a disability are seen as possessing a "spoiled identity" by other social actors (e.g., Goffman, 1963). For example, those who affirm disability as a positive identity may note that discourses which seek to place the person-first and to "see the person, not the disability" encourage DP/PwD to develop a front or mask, one of either the front/masked person *with* a disability who autonomously works to be overcome impairment (i.e., the super Crip), or the front/mask of the poor person with a disability who is need of care from others (i.e., the poor cripple). Actors in these situations may find themselves pressed by other social actors to keep up appearances in order to tacitly support ableist structures and "compulsory able-bodiedness" (McRuer, 2006a, p. 301) or hegemonic able normativity.

For “maintenance of expressive control” (Goffman, 1959), in the case of “super crips,” DP/PwD may then need to overemphasize their self-autonomy and non-impairment to affirm their personhood first and minimize their stigma through acts such as making able-normative jokes that ease nondisabled persons’ distress in the face of their impairment or by allowing themselves to be inspirations for nondisabled others, as in inspiration porn. For the “poor cripple,” to maintain expressive control may mean that they must happily accept all help offered to them, even if such help is detrimental, and constantly bracket their own agency and any positive aspects of their impairment so as to continue the nondisabled person’s sense of superiority and self-congratulatory zealous charity. Advocates for identity-first formations and disability pride may find themselves taking up a mask as “hyper Crip,” reveling in their difference in the face of able normativity, seeking to shock nondisabled persons as they seek union with other “hyper Crips.”

***Butler and performance of identity.*** While in Goffman’s (1959) perspective much of how one performs may be voluntary, if subconscious, Judith Butler’s notion of performativity, as described in *Gender Trouble* (1990) and *Bodies That Matter* (2011), suggests that the subject, the actor themself, is constituted through performances that are heavily dictated by discursive power. Performances of gender, race, sexuality, disability, etc. are formed through the dual systems of social norming and individual action. Social discourses form the basis of what can be thought and, thus, forward a narrative of means to *be* and to *act* within normal society. These discourses structure the performances of individual actors within a society, informing their thoughts, actions, and relationships.

Butler (1990) suggested that identity is not expressed in *being* but in *acting* through discursive and mainly subconscious linguistic and “theatrical” performances. Repeated identity performances create a sense of stability by reifying dominant norms related to one’s identity position(s). Stereotypes, structural oppression, and the repression of one’s own individuality are continually reinforced through one’s performance of her identity in personal and social spheres. These performances allow persons to construct coherent self-narratives, establishing a sense that her life possess a consistency in way of *being* and *acting.* Self-narratives and performances reproduce, reinscribe, and reify dominant discourses of what it means to be a woman/man, to be black/white, to be transgender/cisgender, and to be disabled/nondisabled. Orderly, organized, and predictable societal action operates upon an assumption of the stability of identify binaries; each position within a binary relationship is co-constructive in that one position (i.e., disabled) is informed as much as by the being and acting of the other position (i.e., nondisabled) as it is informed by its own being and acting (p. 10). Insiders construct who will be seen as *outsiders*; yet the outsiders' performances shape the insiders' performances as much as the performances of the insiders themselves. What separates the insider and outsider are perceived differences, yet only differences that *matter*: performative differences that conform to the stability and precision of binary relationships.

Socially-acceptable identities that are one's notion of *I* are carved out of these binary relationships. Through repetitions of performances, a consistency of the *I* is established in the perceptions and conceptions individual and of social actors. Yet, as Deleuze (1994) would remind us, repetition is not the same as equivalency in that what is repeated is not repeated in the exact same manner—repetitions are not identical: "To repeat is to behave in a certain manner, but in relation to something unique or singular which has no equal or equivalent" (p. 1). An essential concept of repetition excludes any sense that repetition one is different from repetition two. Existential repetition—repetition as actually lived—will always vary subtly through performance.

Through performances of binaries such as disabled/nondisabled, the binary is reestablished but at the cost of exposing for a moment the metaphysical rather than empirical nature of differences, potentially carving out a borderland for DP/PwD. Butler (1990) asserted that performativity exposes the metaphysics of difference and, in doing so, subverts dominance, ruptures norms, and offers new ways of thinking and, thus, new ways of *being*. Butler notes subversive performativity offers pathways towards change as well as opportunities

> to think through the possibility of subverting and displacing those naturalized and reified notions of gender that support masculine hegemony and heterosexist power, to make

> gender trouble, not through the strategies that figure a utopian beyond, but through the mobilization, subversive confusion, and proliferation of precisely those constitutive categories that seek to keep gender in its place by posturing as the foundational illusions of identity. (p. 44)

We might easily rework Butler's point here by inserting disability and ableism, thus suggesting that performativity may help us

> to think through the possibility of subverting and displacing those naturalized and reified notions of [disability] that support [able-bodied/minded] hegemony and [ableist] power, to make [disability] trouble, not through the strategies that figure a utopian beyond, but through the mobilization, subversive confusion, and proliferation of precisely those constitutive categories that seek to keep [disability] in its place by posturing as the foundational illusions of identity.

Considering disability and/or disabled identity as performance may hold disruptive power to challenge able-bodied/minded hegemony and ableist power. In a discussion with Sunara "Sunny" Taylor (in Taylor, Mann, & Basmajian, 2009), Butler addressed disabled performativity in a roundabout manner by exploring how Sunny's adoption of a SFCD changes the ways she enacted her disability in public.[35] Sunny, "who uses a wheelchair because of a congenital physical disability" (p. 186), reframed common actions such as walking, asking for help, accessing social spaces, and her interdependent existence through what can be described as subversive performance of her disability. In this way, Butler opened up her conception of performativity to be one that can be more conscious and purposeful so that one can act to subvert norms and discourse. Indeed, Butler (2010) makes this opening up clear in her discussion about performative agency in which she situates performativity as a framework by which to inspect the complex confluence of factors that create ways of being through a "processes of reiteration, re-establishment, and sedimentation" (p. 149). Performativity, however, does provide a way of seeing who agency is seated, diffused, and disrupted through changes and repetitions.

***Crip performativity.*** McRuer (2006b; in Peers, Brittain, & McRuer, 2012) and Kuppers (2001, 2011, 2014) have stretched Goffman's and Butler's conceptions of performativity within

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[35] Butler (in Taylor 2009) does not specifically address performativity, but this theoretical lens is central in her discussion with Sunny.

their theoretic disability work. McRuer (2006b) asserted that through performing disability in an affirmational manner (i.e., taking up a disability-positive identity and/or acting as a “hyper Crip”), one can be disruptive to “compulsory able-bodiedness” (p. 301). McRuer suggested (in Peers, Brittian, & McRuer, 2012) that DP/PwD may perform disability in unexpected ways, possibly with violent repercussions from nondisabled persons. Yet, in doing so, one may carve out a space for difference that breaks the camouflaged facade of hegemonic able normativity. McRuer shared how Disability Arts performers, such as Leroy Moore Jr. of Krip Hop Nation[36] and Sins Invalid[37] and Riva Lehrer with her painting series “Circle Stories”[38] present disability and DP/PwD in ways that seek to redefine disability in the 21st century, and offer glimpses of beauty, boldness, and being with and through disability.

Another Disability Arts performer, Petra Kuppers, drew on performativity in her theatrical and theoretical work. Of disabled performativity, Kuppers (2001) stated:

> The disabled performer is marginalised and invisible - relegated to borderlands, far outside the central area of cultural activity, into the discourses of medicine, therapy and victimhood. At the same time, people with physical impairments are also hypervisible, instantly defined in their physicality. The physically impaired performer has therefore to negotiate two areas of cultural meaning: invisibility as an active member in the public sphere, and hypervisibility and instant categorization . . . [in order to] attempt to break through stereotypes of passive disability. (p. 25)

Kuppers suggested that being aware of how disability is performed may allow for new types of knowledge that embrace multiple frameworks through which to understand and engage in disability and artmaking. Through the performance of disability,

> the performing body is present, and makes its presence felt, but the body denies insights into its truth. Disability *is*, but isn't clear. Pain and muscular effort *is*, but isn’t read-able, and knowable, and able to be put into pat narratives. Once we have opened up these liabilities of binary identity, we can hopefully move forward to explore the specificities and richness of differences in embodied living. (p. 39)

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[36] http://kriphopnation.com/

[37] https://www.sinsinvalid.org/

[38] https://www.rivalehrerart.com/circle-stories

Kuppers encouraged purposeful acts of performing disability that trouble social certainty regarding what it means to be disabled. She suggests that making art that highlights disability may resist obscuring difference while at the same time forwarding an embrace of unique mind-body differences as unique ways of being-in-the-world and being-through-art. Kuppers (2014) suggested that the dual acts of acknowledging the performative nature of disability while also actively performing disability may be “a productive way of shifting certainties” (p. 46).

**Labels, Identities, and the Act of Naming.** Disabled persons/persons with disabilities are diverse and so are their opinions about the usefulness of labels and identity positions and, as such, there is little agreement about preferred terminology of disability, although policy documentation norms often shape the labels and frames people use. Shakespeare (2014) has questioned the meaningfulness of attending to labels or means of identification, as he feels they may or may not tell a researcher—or anyone else—much about the person’s experience and/or political or cultural inclinations. Shakespeare suggested that disability terminology is more of a fascination/fetishization for those who identify as *nondisabled* or as *not being with disability* and commented, “many people with impairments do not want to identify either as impaired (with a label) or disabled (with a badge): they want to be seen as ordinary members of society, free of limitation or classification” (p. 87). Yet, as Campbell (2005) asked, who has the privilege of naming and identifying, whose naming/identifying counts in the end, and/or what subject positions are constructed and foreclosed through the act of naming/identifying? In what ways might naming reify or challenge ableist scripts? Perhaps best to keep in mind that, as Pullin (2009) noted, “Any language used to describe the issues around disability is understandably—and rightly—politically charged” (p. 1). If so, then attending to labels and language related to disability is not as simple as memorizing a set of specifically field- or legislatively-approved formations and a rigid vocabulary. Rather than misunderstanding expertise as legislated from above—often by nondisabled actors—it is important to consider how individual DP/PwD label and identity themselves in order to understand how they understand themselves, their lives, their disability/ies, and their being-in the world and being-with others in the world.

**Disability in Literature Related to Music Making and Learning**

In this section, I address some of the ways music education literature and authors have addressed disability and the experiences of DP/PwD. First, I provide a general overview of the existing literature and identify three categories into which much of this literature falls. I then address critical disability discourses in music education literature (e.g., Dobbs, 2012; Laes & Churchill, 2018). Finally, I review studies that focus on the experiences of disability for DP/PwD, particularly studies in which authors draw on concepts from Disability Studies theorization.

In general, the majority of music education literature addressing disability can be organized into one of three categories: (a) investigations into music learning and music making characteristics of DP/PwD with specific diagnoses and the development of diagnosis-specific pedagogical practices; (b) explorations of nondisabled perceptions of and attitudes toward DP/PwD in music making and music learning spaces and/or mainstreaming[39] in general; and (c) identifying and developing general approaches for mainstreaming. Music education authors have attended to differences in music making and music learning of DP/PwD as populations of learners with different diagnosis have entered music making and learning spaces after events such as World War II, the passage of legislations such as the 1965 "Federal Direction Needed for Educating Handicapped Children in State Schools" (PL 89-313), and changes in diagnostic criteria.[40] As new types of learners entered the classroom carrying badges of difference (i.e.,

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[39] Kochhar, West, and Taymans (2000) define mainstreaming as a practice in which students who are DP/PwD are "served, to the extent possible, in classrooms with nondisabled peers" (p. 12), an idea which is rooted in PL 94-142's "least restrictive environment" provision. Mainstreaming generally refers to the placement of disabled students in educational settings with nondisabled, similarly-aged peers. This placement practice originally focused upon preparing individual disabled students for their presence in "regular" classrooms and engagement with nondisabled students and teachers (Hick, Kershner, & Farrell, 2009).

[40] See Appendix A for a bibliographic overview of diagnosis-centric literature.

diagnoses or other stigma symbols), music educators sought to understand the learners and meet their needs by focusing on diagnostic-based characteristics. With the rise in mainstreaming after the passage of the Individuals with Disabilities Education Act (1990), music education researchers began to attend to the social aspects of inclusion by focusing on perceptions of and attitudes about DP/PwD and mainstreaming from the perspective of nondisabled learners—often referred to as "typically developing peers"—and both preservice and inservice music teachers.[41] Authors of literature in this category sought to identify and understand what social barriers may exist that negatively impact DP/PwD and their participation in music making and music learning experiences. Literature of both the previous categories have grounded the development of pedagogical practices used primarily for the purposes of mainstreaming DP/PwD into classrooms with nondisabled learners and/or to support DP/PwD in different settings.[42] In literature on mainstreaming/inclusion, authors either address mainstreaming broadly or focus on assistive/adaptive technologies, collaboration with support staff, differentiated instruction, ensemble-specific accommodations, and Universal Design for learning in order to develop practices and competencies for supporting learners who are DP/PwD in music making and music learning spaces.

While literature in the above three categories has profoundly impacted the field and supported music educators in developing their adaptive skills and competencies for working with different kinds of DP/PwD, Laes and Churchill (2018) and Dobbs (2012) have voiced concern that music education authors often focus on medicalized discourses, relegating disability and the lived experiences of DP/PwD to a problem to be solved, and, with this, have focused on pedagogical issues rather than the ideas and concerns of DP/PwD. Dobbs, in her examination of disability-related articles published in the *Journal of Research in Music Education* between 1990 and 2011, found a troubling reliance by authors on medical/functional/deficit models of disability (e.g., IFCD)

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[41] See Appendix B for a bibliographic overview of perceptions and attitude literature.

[42] See Appendix C for a bibliographic overview of literature focused on mainstreaming practices.

rooted in and reifying ableist assumptions and practices. Dobbs found that much of the disability literature she reviewed demonstrated implicit understandings that “to be marked with a disability is to be subjected to deep disclosure, to be compelled to submit particularistic and detailed data, and to be discursively made up” (p. 16). Dobbs found that authors often focused on labels of disability, emphasizing embodied functional deficits and assumed diagnosis-based pedagogical approaches. By relying upon a medial/functional/deficit model (e.g., IFCD), Dobbs noted that researchers “reflect and reinscribe historical attitudes and practices that bind music education with disability, including the design of research paradigms, the treatment of human subjects, and the framing of underlying research assumptions” (p. 23). Dobbs suggested the need for music education researchers to adopt Disability Studies-informed perspectives in order not only to critique and problematize existing discourses and the practices they inform, but also as a means

> to construct all children in all their complex materiality—all else should follow. Given that both teaching and music are socioculturally situated historicized practices that occur in the human here-and-now, scholar-researchers and educators must acknowledge that all participants in the music research/teaching environment work together in constructing each other in myriad ways, which includes their perceptions of ability and disability: their social constructions of each other are directly influenced by the concentric rings of culture within which individuals interact. (p. 23)

A handful of researchers in music education have focused on the lived experiences of DP/PwD in music and/or adopted Disability-Studies-informed perspectives to guide their work.

Abramo and Pierce (2013) engaged in an ethnographic case study of the music learning practices used at a school for the blind. The researchers engaged with 55 students at a school for the blind. Many students had previously been enrolled in public schools considered as being “inclusive” or offering “inclusive music classes,” where students with disabilities were educated alongside nondisabled students. The participants generally noted that their experiences in “inclusive” public school spaces were negative because of a lack of extra help on the part of their teachers and harassment from peers. Additionally, the participants described a dislike of using Braille notation. Caroline, one of the participants, stated:

> I was able to learn one or two easy songs with Braille music with a teacher . . . But after a while, I found it confusing. . . . To this day, if I used it, I'd still be memorizing. . . . So why continue with Braille if I can learn by ear and have to memorize anyway? (p. 18)

Abramo and Piece suggest that Braille or any notation system was "cumbersome and time-consuming" (p. 18). Instead of relying upon sight-based musical notation or performance cues and pedagogical structures informed by sight-normative practices—including Braille, the researchers found that participants used aural strategies such as calling out changes or repeats and altering rhythms to note section changes. Abramo and Pierce suggest that their findings might be used to problematize support structures offered or the lack thereof in "inclusive music classes." Intended supports may act as structural barriers that can negatively impact the music making and music learning of blind students.

In my own work, I examined the practices of a community music therapy rock band, The Smooth Criminals, comprised of young adult members diagnosed with developmental disabilities and adult assistants (Rathgeber, 2017). I drew on SFCD and social capital theory as a framework to discover how the group negotiated physical and social barriers to music learning and music making. The adult members made use of

> Strategies [such as] . . . visual/communicative aids (coloured stickers and numbers) and adaptive instrumental technique (e.g. re-voicing of chords, retuning of instruments and non-traditional uses of instruments/tools) . . . [as] means of confronting possible physical barriers to participation. (p. 379)

Although these adaptive strategies may have assisted DP/PwD in the band, I noted the that the ableist habitus, or ableism, of the adult assistants led to them to infantize DP/PwD members or impose normative practices upon those members. Confronting ableist habitus in music learning and music making practices such the community music therapy rock band, I suggested, requires that all within a group

> critically examining what [music learning facilitators] and learners consider to be popular music, reconceptualizing skills like ear-playing and notions of 'appropriate' musical technique, fostering an inclusive, hospitable environment where each learner collaboratively generates and accumulates symbolic capital, embracing a haphazard approach to learning and adaptation and valuing the overlapping nature of performing, creating and listening. (pp. 379-380)

Both my own work (Rathgeber, 2017) and the study of Abramo and Pierce (2013) demonstrate the need for facilitators to learn from and alongside DP/PwD and to be consistently critical and mindful of their implicit biases and misrecognitions related disability.

In an investigation of composing with Tim, a learner diagnosed with Down Syndrome, Bell (2008) called into question the way that labels, subject position, and relational roles/practices regarding disability might act to disempower specific learners. Bell found that by meeting with Tim as a collaborative artist, rather than placing the participant in the role of disabled and disadvantaged other with himself (Bell) fitting into a position of savior teacher, allowed for an empowering and enabling experience for both Bell and Tim. Based on this positionality, composition occurred through a dialogue-based and supportive relationship that grew from Tim's strengths and interests to shape the approach instead of following a set of diagnosis-specific prescribed pedagogies.

In another study, Bell (2014) discussed his work with Phil, an adolescent diagnosed with Down syndrome and learning guitar. This study extended Bell's interest in developing positive and mutual relationships between learners who are DP/PwD and teachers. Bell investigated adaptive technologies for use in playing guitar with the participant, hoping to find ways to work against disabling barriers embedded within the guitar.[43] Bell offered Phil adaptive devices and approaches such as the EZ Chord, the Davis EZ Chord, the Barre Chorder, and open tuning, and gave him time to explore each. Phil generally rejected the adaptations and enjoyed strumming and palm muting a standard tuned guitar as a percussive instrument in informal jam sessions with Bell. Through his experience working with Phil, Bell began to question whether it was the guitar or his approach to guitar-learning that might be disabling for Phil. Bell had assumed that Phil valued playing chords as a harmonic accompaniment and that that value would shape his progress,

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[43] All instruments are designed for a specific body/mind type. Mass-produced instruments are constructed by designers to meet the mind-body requirements of a wide-array of people and, as such, are often grounded on ableist assumptions about what a mind-body is and how it should function. From this understanding, Bell (2014) suggests that it might be useful to consider instruments as "having disabilities," using a "social model" perspective to inform his work.

interests, and adaptations. Yet, when Bell followed the lead of Phil, they both found new ways to play and learn guitar. Bell noted that “Giving [the participant] agency as a learner and allowing him to dictate the pace and structure of the lessons was critical in making his guitar-playing experiences successful” (p. 12). Bell’s work here, then, brought critical attention toward how disabling ableist help and pedagogy can be.

In another study, Bell (2017) shifted his attention toward following the experiences of DP/PwD in music and athletics by interviewing Patrick Anderson, a wheelchair basketball player and musician, about his experiences, noting similarities and differences between sports and music practices. Bell used Lubet’s (2011) social confluence theory to investigate how Patrick experienced disability in different settings. Patrick shared how medicalized conceptions of disability functioned for gatekeeping purposes in wheelchair basketball, the ways disabled identity could be catalyzed positively by ingroup members, and how the dictates of the social milieu within wheelchair basketball constructed him an able-bodied athlete. Patrick discussed status as a wheelchair using person whose legs had been amputated below the knee gave him access to wheelchair basketball and a disabled identity. Within this context, he is able-bodied because to *not* use a wheelchair, to have “typically-functioning legs,” and to *not* possess a disabled identity would not provide him access to the sport (Bell, 2017). Patrick did not experience disability in a salient way in his music making because he felt that his identity and mind-body difference did not impact his musicking (e.g., singing and playing guitar). Because of that, he was reluctant to join disability-specific musicking groups or activities. As a gigging musician, he felt little need to identity as disabled and described few experiences where he felt disabled, stating that “in music there are a million things that you can do and ways of approaching things, so it doesn’t seem like I hit dead ends, I just hit forks” (p. 121). Bell noted the way that Patrick’s experiences of disability and disabled identity were a fluid aspect of who he was rather than a totalizing component of his entire life. Yet, Bell noted his worries as to how Patrick might be totalized in music education practices that are well enmeshed in medicalized conceptions of disability. Bell concluded:

> One of my foremost fears as a music educator is that my pedagogy causes or contributes to someone's experience of disability in music. To guard against this I must continually examine the culture I foster in the music-learning realm, and ask myself: "How, when, and where do I contribute to a fellow human's experience of disability in music?" . . . the relative dearth of attention to Disability Studies in music education reflects a troubling reality: on the whole, the field has thus far failed to grapple with the construct of disability and its associated effects of marginalization. The primary benefit that Disability Studies offers music educators is how to think about disability, which might influence how researchers examine existing pedagogical approaches and invent and enact new ones. "How-to" inclusive and/or universal strategies outlined in articles aimed at teachers are useful in many music education contexts, but they require a critical and theoretical consideration of the specific scenarios in which they are to be used. Disability Studies provides a framework with which to contemplate the multiple aspects and consequences of these actions. (p. 123)

Outside of music education literature specifically, Strauss (2011) began using Disability Studies in music scholarship to explore the notion of what "hearing" really means in a direct attempt to critique ableist assumptions of a single and accepted type of hearing. Strauss discussed "deaf hearing," commenting on how deaf musicians hear music through feel and suggesting that "[h]earing does not necessarily involve a one-to-one mapping of sense perception onto a single sensory organ; rather, hearing can be a much more multi-sensory experience" (p. 167). Strauss identified a need for more critical conversations about the ableism that grounds accepted practices in music. He suggested that "By deconstructing [the] unreflecting reliance on normal hearing, we can construct a new understanding of the ways people make sense of music as complex, varied, and diverse as people themselves" (p. 160). Echoing Strauss' suggestions, Churchill's (2015) uses autobiographical and narrative data to critique music education and music therapy literature that he sees as being replete with ableist language and assumptions.

Churchill (2015) contemplated the importance that being "hard-of-healing" and being inspired by deaf culture have had on him as a teacher-scholar and on his personal sense of being. Churchill worried that studies that situate deaf persons as in need of treatment or specific remediation such as using music for the development of normalized speech tend to construct deaf subjects who are not worthy of music making or music learning experiences. Churchill (2015) encouraged music education researchers and teachers to pay attention to deaf culture and the musical practices of deaf persons to uncover new modes of being musical. To these ends, Churchill articulated a narrative strategy through which to broaden understanding about deaf and hard-of-hearing musicians in light of the medicalized and rehabilitative discourses (e.g., IFCD) that ground much of deafness research in music education. Churchill suggested the researchers examine autobiographical accounts of deaf and hard-of-hearing musicians; explore metaphors, different writing formats, and creative analytical practices in researching deaf and hard-of-hearing musicians and musical practices; investigate embodiment of characteristics and practices of deaf and hard-of-hearing musicians; explore disruptive means of musicking by deaf and hard-of-hearing musicians; and offer counter-narratives to call into question master narratives that subjugate deaf and hard-of-hearing musicians. Churchill presented the ASL work of Deaf Finish musical artist “Signmark” using these narrative practices to offer a disruptive counter-narrative to the master-narrative of “overcoming deafness” or “deafness as the opposite of being musical” common in music practices and literature (i.e., Beethoven overcoming his deafness to continue composing). In his conclusion, Churchill challenged the common focus of music inquiry related to deafness and being hard-of-hearing—that of “How can we help them?”, and asserted the position of asking, instead, “How might understanding the music making of [deaf and hard-of-hearing] musicians benefit music education?” (p. 34).

**Summary.** In much of music education literature, authors tend to speak *about* DP/PwD for the purpose of assessing musical abilities or behaviors often in order to construct diagnostic-specific or general pedagogical approaches to teaching music *to* DP/PwD. In light of mainstreaming policies instituted through Section 504 of the Rehabilitation Act of 1973 and IDEA, some music education researchers investigated the impact of mainstreaming and barriers to mainstreaming by attending to how nondisabled peers of DP/PwD and teachers (e.g., preservice and inservice music educators) perceive DP/PwD.[44] Through speaking *about* and attending to the

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[44] Jellison and Taylor (2007) reviewed 32 studies published between 1975 and 2005 “related to the study of attitudes, inclusion, and persons with disabilities” (p. 10) found in six research journals in the fields of music education and music therapy. The studies included descriptive survey studies of music teachers’ attitudes toward students diagnosed with disabilities (n = 14) and experimental or quasi-experimental studies of the

perceptions of and attitudes toward DP/PwD from the perspective of nondisabled persons authors of music education literature have adopted individual-focused conceptions of disabilities and unintentionally constructed disabled subjects as essentialized others. Doing so, they may create caricatures in which DP/PwD may be spoken *about* and *for* in hopes of creating more inclusive music teaching practices. Yet, the actual people on whom the caricature are based fade to the background, their first-hand experiences of disability with their complex interactions of individual and social facets disappear, and the meaningful aspects of their identity and/or personhood are left behind in a conversation more concerned with teachers, pedagogies, and policies related to DP/PwD than with the lived realities and meaningful experiences of DP/PwD.

Music education researchers (e.g., Dobbs, 2012; Laes & Churchill, 2018; Abramo & Pierce, 2012; Rathgeber, 2017; Bell, 2008, 2014, 2017; Churchill, 2015) have urged music education researchers and teachers to turn their attention toward the lived experience of disability instead of attempting to destroy or fix disability through remediative and medicalizing practices. Rather than continuing to construct caricatures and pedagogies, even if they appear effective for "inclusion" and prove to be "teaching music" efficiently to DP/PwD, music education researchers and teachers might need to turn to the lived experiences of DP/PwD to see what they might learn about disability, inclusion, and life in, through, and around music from the perspective of DP/PwD. There is reason to believe that music educators may learn a great deal from the perspectives of and experiences of DP/PwD that might trouble essentialized and totalized notions of disability that ground existing inclusive practices. For example, Laes and Westerlund (2018) investigated the impact of face-to-face interactions with DP/PwD who led music workshops on student teachers' understanding of disability. The researchers commented on the power that experiencing disability

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impact of extended contact with students diagnosed with disabilities, videos, and labels on the attitudes of music teachers, undergraduate students, and similarly-aged, nondisabled peers (n = 18). Jellison and Taylor suggest that the only trend notable in findings is that carefully-structured, direct interactions between disabled students and nondisabled persons can positively impact attitudes. I revisit some of the studies reviewed by Jellison and Taylor along with studies published since 2005 to further investigate what can be surmised about how disabled students are constructed and addressed in music education literature. Includes Appendix B includes a summary sample of literature focusing on perception and attitudes of DP/PwD by nondisabled persons, some of which Jellison and Taylor (2007) reviewed.

as performed (e.g., as lived, embodied, and enacted differently by different DP/PwD) had on reframing music student teachers' conceptions of expertise, performance, musicianship, disability, and personhood and how these experiences encourage music student teachers to become reflective and critical of ableism. Laes and Westerlund concluded:

> we have argued that performing disability in music teacher education may provide us a lens through which we may reflect on how we understand the goals of teaching and learning diversity in a broader sense than the mere toleration of difference. We encourage teacher educators to take advantage of the different strengths, perspectives, and types of expertise as opportunities for cooperation that not only complement inclusive music education, but also help to move beyond inclusion and towards a democratic, diverse society. (p. 43)

Based on their arguments and the discussions of other authors identified in this section, music education researchers and teachers may need more chances to see disability performed and to consider the many ways disability is constructed and experiences. Engaging with these types of counter-narratives might help decenter ableism and center DP/PwD in discussions regarding inclusive music making music learning practices. Doing so might problematize music education approaches that speak and teach *of*, *at*, *to,* and *about* DP/PwD shift instead toward speaking and learning *with* and *from* DP/PwD.

### Exploring Lived Experiences of Disability and Developing Practice

Some authors have begun to consider how they might inspect, represent, and discuss disability as a lived experience rather than using and reifying IFCD-based narratives. Below I review a some of the publications in which researchers have examined disability as experienced, felt, constructed, and altered through the course of one's life from the first-hand perspectives of DP/PwD. First, I review two phenomenologies of disability (e.g., Padilla, 2003; Diedrich, 2001) in which the authors "describe in writing . . . everyday experience of being disabled—the meaning of being disabled—in the world; and in doing so, [authors] attempt to communicate about and through [these] experiences to others" (Diedrich, 2001, p. 225). I present these publications in order to map how phenomenology can be used to trouble disability, albeit outside of music education. I then review two articles exploring a project that sought to open up "the meaning of being disabled” through artistic engagement in order to present the “actual lives” of DP/PwD to audiences, allowing the audiences access to the lifeworlds of specific DP/PwD. I share these two articles to demonstrate examples of researchers and teachers who have made use of artistic methods to generate and present data on the lived experience of disability. Both phenomenological and artistic practices/engagements shape the process of inquiry in this document and the ways in which the co-generated data are [re]presented and explored in Chapters 4, 5, and 6.

Padilla (2003) made use of a phenomenological approach to investigate the lived experience of disability of Clara, a woman who had sustained a head injury. Through the investigation, Clara articulated feeling of nostalgia, abandonment, and hope as she had “to embrace a new life that’s so different from the one [she] knew and loved . . . it is a frightening choice . . . one that [she kept] making and unmaking” (p. 413). Regarding feelings of nostalgia, Padilla explained the way that Clara conceptualized the present and future in tandem; conceptions that conflicted with her pre-injury life “kept the past ever-present” (p. 417). Clara shared a longing for her past self, her past activities, and past friends, defining her present life as one of loss. Clara’s experience with disability was shaped by the loss of her control over her own mind/body, abandonment by her friends and her abandonment of her friends after her injury, and her own need to abandon her past and expectations from it that disabled her. This last aspect of abandonment led the participant to feelings of hope. Clara hoped that she could let go of her past and experience disability as an “opportunity to relate to life more meaningful” (p. 419), something which her nostalgic living did not allow. Reflecting upon the research process, Padilla grappled with how his attention to the lived experiences of Clara forced him to come face to face with his ableist assumptions and the inherent ableist prejudices that colored his field’s (i.e., occupational therapy) philosophy and practice. In this way, Padilla moved from being interested in the Clara’s “heroic” living in the face of disability toward considering how his own experiences through phenomenological research called into question his approach to being-with Clara, and others, as an occupational therapist. Padilla asked, “What would happen if we worked with our clients as co-investigators of the meaning of their life experience rather than recipients of our expert knowledge of able-bodied function?” (p. 422). With this, Padilla began to catalyze his research and practice to embrace the notion, as shared by the participant, that “Life is not a problem to be solved but a reality to be experienced” (p. 422). Clara’s commentary presents the complexity of her lived experiences, which venture over terrains of terror, sadness, nostalgia, abandonment, and hope.

Diedrich (2001) used a phenomenological frame to investigate “three autobiographies that deal with the experience of disability caused by neurological damage” (p. 209), including Sacks’s *A Leg to Stand on*, Maris’s *Waist-High in the World*, and Bauby’s *The Diving Bell and the Butterfly*. The purpose of her literature-based phenomenological investigation was to “raise anew the question of the meaning of being *disabled* . . . to describe the ways in which the experience of disability anticipated a philosophy, specifically the philosophy of phenomenology” (p. 209, italics in original). Diedrich implied that experiences of the body “breaking down” were a central characteristic of the texts. Much like Padilla (2003), Diedrich (2001) noted how the authors of the texts forwarded a clear sense of before and after impairment. “Breaking down” manifested in authors’ accounts of their experience of disability in three ways: breakdown and recovery, breakdown as taken for granted, and breakdown as catastrophic. Sacks’s account was replete with feelings of “[b]odily alienation, or dissociation” (p. 213) following neurological impairment and then experiences of finding one’s body or recovering into a new body. From a phenomenological perspective, Diedrich suggested that breakdown causes a shift or change in intentionality, yielding new understandings about one’s body and one’s being. Maris’s account in *Waist-High in the World* demonstrated how her impairments caused her to confront aspects of her lived experiences often taken for granted by nonimpaired persons in the form of changes in life processes and through interacting with what Disability Studies scholars might call physical and social barriers. For Bauby in *The Diving Bell and the Butterfly*, Diedrich (2001) suggested that the author’s bodily breakdown, which involved complete paralysis and inability to speak, was catastrophic in that Bauby's body changed from being a part of him to becoming another object of his consciousness, requiring a complete and unwelcomed shift in his being-in-the-world. His being-in-the-world was one of being-in-his-body, yet he was unable to feel and experience his body as a way of interacting with the world. As Bauby took up writing, he found a new way to interact with and in the world, necessitating a change in subjectivity and lived experiences.

From these accounts, Diedrich positioned breakdown as a key precursor for phenomenological investigation of disability—she positions the texts as somewhat unintentional phenomenologies— in that breakdown naturally calls one's attention to something taken for granted in a manner that may allow one to attend to disability from a bracketed position, "[standing] back from the world in order to view it differently, or perhaps to view it for the first time" (p. 212). Diedrich concluded:

> The radical transformation of [the authors's] beings-in-the-world—their experiences of breaking down—are the condition of the possibility "to seize the meaning of the world." Through their experiences of disability and through their compulsion to communicate those experiences to others . . . [they] reveal not only something about what it means to be disabled but also something about what it means, simply, to be. (p. 228)

Padilla (2003) and Diedrich (2001) were purposefully phenomenological in their work, as the authors drew heavily on the philosophical work of Husserl (1931/1960), Heidegger (1927/1982), and Merleau-Ponty (1945/2005) and also noted their phenomenological leanings. Padilla (2003) and Diedrich (2001) addressed issues of intentionality and meaning structures, using the vocabulary of phenomenology, while they sought to understand how disability is experienced by DP/PwD. Other authors have addressed a similar focus (i.e., understanding how disability is experienced by DP/PwD) without specifically evoking phenomenology. I now turn to the non-phenomenological work of Galloway, Nudd, and Sandahl (2007) and Strickling (2002) and discusses the "Actual Lives" project. This project centered upon examining life as lived, and as such, their work connects to the work of Padilla (2003) and Diedrich (2001). Following my review of the "Actual Lives" project, I articulate how all of the articles reviewed in this section resonate with the study outlined in this document.

Galloway, Nudd, and Sandahl (2007) and Strickling (2002) explored the lived experience of disability from the perspective of DP/PwD through their facilitation work and scholarship related to the “Actual Lives” project. This project used collaborative arts-making as a medium to facilitate dialogue about disability between DP/PwD and nondisabled persons within the same community. The purpose of the project was to develop “simply staged, autobiographically-based solo and ensemble pieces that critique cultural and medical attitudes toward disability, reassert the sexuality of disabled people, trouble the reduction of disability to metaphor, and attempt to engage the imagination of audiences in re-envisioning what it means to live with disability” (Strickling, 2002, p. 143). Strickling worked with Terry Galloway, Celia Hughes, and disabled adults in crafting theatrical works that “[engages] the specific concerns, desires, and needs of disabled people and puts those issues front and center before largely non-disabled audiences (p. 143).

In the initial iteration of the project in 2000, 15 disabled persons worked with the facilitators over the course of one week to construct and perform personal narratives which allowed the participants to present the uniqueness and complexity of their lived experiences of disability and their “actual lives” (Strickling, 2002). The DP/PwD performed their narratives to a standing-room-only audience of mostly nondisabled persons, sharing their experiences as a way to purposefully cause the audience members to call into question their misunderstandings and misassumptions about disability and the lives of DP/PwD. Through their project, the 15 participants were able to define what disability was, what disability meant to them, and the labels by which they named their experiences in order to come to understand “the ways that disability contributed to their experience of daily life” (p. 145). Through the construction of the narratives and performances, participants shared: (a) stories of success at college, (b) moments of feeling included or excluded socially, (c) taking music lessons, and (d) flirting with potential sexual partners. The participants demonstrated how “Disability is a ‘social drama’ in the sense that the appearance of the disabled body in public life interrupts the ‘normal workings of society’” (p. 146).

Engaging in the “Actual Lives” project afforded participants chances to demonstrate how the experiences of disability are both similar and different for each person (Strickling, 2002). Participants also voiced their feelings about the oppressive outcomes of the social construction of disability by highlighting experiences of marginalization, desexualization, medicalization, and stigmatization. In this way, they were able to “talk back” to the oppressors in their past (and present) and to the repressive systems built and rebuilt, often unintentionally, by audience members. Stickling noted that “the ’*Actual Lives’* project offered the *potential* for agency on the stage, but there is no guarantee that the disabled persons, by sheer bodily presence or through the force of autobiography, will necessarily achieve it” (p. 159). Yet, the possibility here was much more than many of the participants had experienced in other realms of their lives. By sharing disability through their experiences, DP/PwD had chances “to complicate the cultural meaning of disability by adding [their] privileged personal narrative to the visible presence of disabled bodies on the stage” (Strickling, 2002, p. 145).

According to Nudd and Sandahl (2077). the “Actual Lives” project grew a great deal after Strickling’s original publication, with multiple locations and groups (DP/PwD) sharing their first-hand accounts of their experiences of disability (e.g., privileged personal narrative). Based on her experiences as facilitator in numerous versions of the project, Galloway worked with researchers Nudd and Sandahl (2007) to consider what broad understandings the “Actual Lives” project might add to theatre through facilitating discussions about accommodations, which the authors suggested were considered “a thorn in the side” for many theatrical organizations” (Galloway, Nudd, & Sandahl, 2007, p. 229). Rather than physical and financial accommodations, the authors suggested that what really was needed was a change in “theatrical structures and performances for maximum participation of both performers and audiences” (p. 229). Such a change would yield a new ethic (e.g., the “Ethic of Accommodation”) comprised of four components:

1. At its core, an Ethic of Accommodation means that the majority does not rule. Instead, accommodation means including everyone wanting to participate, often necessitating that the majority make difficult changes in its practices and environment. These chances are not made begrudgingly, but with goodwill, creativity,

> and a strong dose of humor, elements that often find expression in the performances themselves.
>
> 2. The ethic includes the politics of listening as well as the politics of speaking. Whereas most minority groups maintain they have been "silenced" by the majority and thus place speaking at a premium, disability communities often place listening on the same plane. People with disabilities often feel they have not been listened to or even addressed. In this context, listening does not have to happen with the ears. Listening, here, means being taken into consideration, being attended to.
> 3. The Ethic of Accommodation means making room for difference possible, letting go of preconceived notions of perfectibility, and negotiating complex sets of needs. Often these needs "compete" with one another. Accommodating disability or other forms of difference often does not seem practical or marketable, since doing so often raises costs or necessitates work that seemingly benefits only a few. Marketability is not our concern.
> 4. The Ethic of Accommodation inspires creative aesthetic choices from casting, choreography and costuming, and also the use of space for the creation of new material. Practicing the ethic enhances theatrical practice. (p. 229).

This ethic is directed toward creating equitable meetings for performers, writers, directors, etc. and built upon a foundation of consideration for minority perspectives, validation of differences and diversity, and action toward creating new structures collaboratively without preconceptions that remove possibilities.

The work of Strickling (2001), Galloway, Nudd, and Sandahl (2007), Padilla (2003), and Diedrich (2001) resonates with the study outlined in this document. Three of the publications (i.e., Strickling, 2001; Padilla, 2003; Diedrich, 2001) privilege the perspectives of DP/PwD, centering DP/PwD and their lived experience in research discussions *about* disability. Not only do these authors spotlight the voices of DP/PwD in their work, but they also position the reader into direct contact with different accounts, in different mediums and representations of "what it means to be disabled" and "what it means . . . to be" (Diedrich, 2001, p. 228). Galloway, Nudd, and Sandahl (2007) demonstrated how work *with* DP/PwD, rather than writing *about* them, can allow for inclusive or accommodative strategies to bloom organically. The "Ethic of Accommodation" took shape through relationships and insights developed *with* DP/PwD, rather than through attention toward seemingly "objective" measurements, characteristics, and diagnoses *of* DP/PwD. In other words, they co-generated a means of being inclusive that arose through attention to the concrete experiences of DP/PwD from a relational perspective of working *with* people. In general, the articles reviewed in this section demonstrate how taking seriously the lived experiences of DP/PwD may allow for new understandings of what disability is, what it means to be disabled, and how one might act ethically to engage in being together with others in the world.

# CHAPTER THREE: A PROCESS OF RESEARCH

The purpose of this study was to trouble existing conceptions of disability that ground music education literature and practice by exploring the personal experiences of disability in, through, and around music of specific DP/PwD. I sought to uncover and share “plausible insights” (van Manen, 1990, p. 9) into how disability is experienced, interpreted, and understood in and through music or around music-adjacent experiences of participants. These insights might allow readers to complexify and trouble their taken-for-granted assumptions of what disability can mean and be “like” in, through, and around music and ground new inclusive practices in music education. I worked to embrace actual lives—lives as lived rather than lives as assumed (e.g., Galloway, Nudd, & Sandahl, 2007; Strickling, 2002), in order "to describe in writing . . . everyday experience of being disabled—the meaning of being disabled—in the world; and in doing so . . . attempt to communicate about and through [these] experiences to others" (Diedrich, 2001, p. 225). The following questions guided my inquiry:

(1) How do participants experience disability in, through, and around music?
    (a) What manifests through experiences with disability in, through, and around music?
    (b) How do participants perceive, interpret, and describe their experience of disability in, through and around music?
(2) What plausible insights related to disability can be gained by attending to participants’ experiences of disability in, through, and around music?
(3) What plausible insights related to inclusion can be gained by attending to participants’ experiences of disability in, through, and around music?

## A Phenomenological Frame

Given the purpose of the study and my dedication to embrace actual lives implicates phenomenology as a framework for inquiry focused on uncovering and engaging with lived experiences (Creswell, 2012; Randles, 2012). van Manen (1990) described phenomenology, stating:

> Phenomenology aims at gaining a deeper understanding of the nature or meaning of our everyday experiences. Phenomenology asks, 'What is this or that kind of experience like?' . . . phenomenology does not offer us the possibility of effective theory with which we can now explain and/or control the world, but rather it offers us the possibility of plausible insights that bring us in more direct contact with the world. (p. 9)

The goal of a phenomenological researcher is to consider what a specific experience "was [or is] really like" (p. 99) by "[producing] orientated, strong, rich and deep texts—texts which invite dialogue with those who interact with it" (p. 21).

Merleau-Ponty and Bannan (1956) stated that phenomenology is a philosophical inquiry that focuses on developing

> an account of space, time, and the world 'as lived.' It is an attempt to describe our experience as it is and to describe it directly, without considering its psychological genesis or the causal explanations which the scientist, historian or sociologist may give. (p. 59)

Phenomenology provides researchers a framework to examine consciousness, or, more specifically, to examine what and how one becomes conscious of a specific phenomenon (Husserl, 1931/1960). Researchers specifically attend to the intentional relationships between subject and phenomena (i.e. "intentionality") and the existential reality constructed through the accumulation of intentional relationships (i.e., "lifeworld") through careful attention to participants' subjective experiences. While doing so, researchers aim to avoid pre-understanding and theorizing using external concepts (i.e., bracketing/bridling). Adopting a phenomenological frame in this study provides a means of focusing on participants' subjective experiences of disability related to music (e.g., Abramo & Pierce, 2012; Bell, 2017; Churchill, 2015; Dobbs, 2012; Laes & Churchill, 2018; Rathgeber, 2017) from an interactional perspective (e.g., Kuppers, 2009l Lubet, 2011; Shakespeare, 2014). In the next sections of this chapter, I describe core aspects of phenomenological thought and inquiry: (a) lifeworld, (b) intentionality, and (c) bracketing/bridling.

**Lifeworld.** "Lifeworld" is a central concept in phenomenological discourse. Husserl (1936/1970) introduced the *Lebenswelt*, defining it as "the world of immediate experience" (p.

103). van Manen (1990) clarified Husserl's idea, suggesting that the lifeworld is "the world as experience," or the world as subjectively experienced in a pre-reflective state. The lifeworld is, according to Merleau-Ponty (1945/2005), the world that "precedes knowledge, of which knowledge *always* speaks, and in relation to which every scientific schematization is an abstraction and derivative sign-language" (p. ix).

Bucura (2013), writing from a social phenomenological perspective, stated that "One's lifeworld is comprised of all experiences, understandings, and people one encounters" (p. 16). The lifeworld can be considered to be "the inseparable connectedness between subjects and objects" (Vagle, 2014, p. 27). Attending to the lifeworld of a person requires a researcher to focus on the subjective meaning of an experience of that person as uncovered, interpreted, and continually changing through their experiencing. A person's lifeworld can never be completely known by others, as it is often beyond clear description or interpretation, nor can any account of lifeworld seek to illuminate what is manifest in a person's lifeworld outside of the relationships between and among the person and a phenomenon. An account of a person's lifeworld is always partial (Stein, 1996; Vagle, 2014). As such, researchers of lifeworld often act as cartographers of specific terrains, always uncovering incomplete images of concrete subjective experience.

**Intentionality.** Consciousness and the process of becoming conscious of a phenomenon—or the act of constructing one's lifeworld—is the central concern of phenomenologists (Husserl, 1900/2002; van Manen, 1990), who wish to "uncover and describe the structures, the internal meaning structures, of lived experience" (van Manen, 1990, p. 10). Rather than conceptualizing consciousness as a general openness to the world, phenomenologists contend that "all consciousness is consciousness of something" (Sartre, 1947/1970, p. 6). "Intentionality" is a term used to indicate the relational directedness between subject (e.g., a person) and object (e.g., another person, a physical object, or kind of experience) of consciousness (Husserl, 1931/1960).[45] Vagle (2014) defines "intentionality" as

> the inseparable connectedness between subjects (that is, human beings) and objects (that is, all other things, animate and inanimate, and ideas) in the world. . . . It is used to signify how we are meaningfully connected to the world. (p. 27)

Intentionality may be facilitated by one's sensory or intellectual attentional focus toward something apparently external of oneself or it may be "the meaning[ful] link people have to the world in which they find themselves" (Freeman & Vagle, 2009, p. 3). Attending to how different thinkers and researchers conceptualize intentionality allows one to consider different types of phenomenological inquiry.

Husserl (1931/1960) defined intentionality as "nothing else than [the] property of consciousness: to be consciousness of something" (p. 33). Husserl originally envisioned phenomenology to be a means of bringing philosophy in line with positivist science in the early 1900s in order to "attain absolutely valid knowledge of things" (in Kockelmans, 1967, p. 26). Because of this, Husserl conceived of intentionality in a rather scientific manner: a person's pre-theoretical and pre-intellectual experience *of* an object. Using an "of-ness" conception of intentionality, as Vagle (2014) describes it, positions a researcher toward uncovering characteristics and structuring aspects of experience that are essential for one to become conscious *of* a given phenomenon. In search of "essences," a researcher attempts to describe how a phenomenon is experienced as "this phenomenon" rather than "another phenomenon."

Heidegger (1927/1982), a student of Husserl, and Gadamer (1960/2004), a student of Heidegger, developed a conception of intentionality rooted in how one interprets a phenomenon, leading to the development of hermeneutic phenomenology. Heidegger (1927/1998) considered phenomenology to be the study of states of being in which a person comes to find themselves. Multiple intentional relationships allow for one to find oneself *being-in-the-world, Dasein*, with

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[45] According to Huemer (2017), Husserl was inspired by Franz Clemens Brentano, who developed and introduced the concept of intentionality and who stated, "Every mental phenomenon includes something as object within itself" (Brentano, 1995, p. 88).

certain things, or, stated differently, certain things manifest as one interprets the situation in which one finds themself. Vagle (2014) suggested that it is useful to understand this conception of intentionality as one focused on "in-ness" where, rather than consciousness being *of* something, a researcher considers how one becomes consciousness of the interactive relationships between a person *in* relation to a phenomenon.[46] Conceiving of intentionality as "in-ness," a researcher inspects what manifests when a person has a conscious relationship with a phenomenon, attending to how a person interprets what it means to *be* "in" the phenomenon.

Vagle (2014), drawing on postmodern thought, identified a third way to conceive of intentionality—as "through-ness." Hoping to "re-imagine the matter [of intentionality] outside of a descriptive-interpretive dualism" (p. 40) and disagreements regarding the proper focus of phenomenological inquiry as either "of-ness" or "in-ness," Vagle used "through" to insert movement into the discourse around intentionality, suggesting that intentional "meanings are generative" (p. 41). Vagle casts intentionality as a constantly shifting being through experiences and as not one-sided. The subject and object constantly play with and on one another as "intentionalities of different shapes, sizes, and contours [run] all over the place" (p. 41). For Vagle, conceiving of intentionality as "through-ness" requires that researchers "embrace phenomena as social and not belonging to the individual" (p. 41), because "individuals are not 'experiencing the phenomena' in isolation" (p. 42) but through a matrix of ever-evolving intentional relationships. Because of this, researchers, participants, texts, and readers become part of the intentional experiences and meaning-making process. Vagle states:

> whatever understanding is opened up through an investigation will always move with and through the researcher's intentional relationship with the phenomenon—not simply in the researcher, in the participants, in the text, or in their power positions, but in the dynamic intentional relationships that tie participants, the researcher, the produced text, and their positionalities together. (p. 30)

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[46] Vagle (2014) notes that, whereas a Husserlian perspective of intentionality might seek to study how a person comes to consciousness *of* love or *of* pain, a Heideggerian perspective looks at the things that manifest as one is *in* love or *in* pain (p. 39).

By rejecting any assumption that intentionality can be studied in any transcendental or universal manner—where the researcher finds *the* key to consciousness through description of essences or interpretation—to find some sort of grand meanings, Vagle's (2014) "through-ness" conception of intentionality encourages researchers to attend to both meta-meanings and the particularities of a given person's temporal, spatial, and social positions as they have an experience. In this way, Vagle aligns himself with Sartre's (1947/1970) supposition that intentionality is context specific rather than transcendental in nature. Sartre noted that one cannot become conscious of all phenomenon by studying one manifestation of a specific phenomenon. Rather than studying "trees," one can only inspect "this tree . . . you see it just where it is: at the side of the road, in the midst of the dust, alone and writhing in the heat, eight miles from the Mediterranean coast" (p. 5). Attending to "this tree" or "this phenomenon" from this perspective, Vagle's (2014) conception of "through-ness" requires a researcher to approach meaning in relation to phenomena as myriad and specific rather than singular and universal.

**Bracketing/bridling.** In order to "gain access to the meaning structures of a phenomenon" (van Manen, 2014, pp. 215-216), phenomenologists seek to investigate lived experience from a pre-judgmental perspective. To do so, requires that one bracket or purposefully suspend one's pre-existing understandings and bias regarding a phenomenon in order to experience it as given, a process also known as epoché (Beyers, 2016; Husserl, 1990/2001; van Manen, 2014). van Manen identified different ways phenomenologists can bracket: (a) meeting a phenomenon in a state of wonder and seeking to fully live an experience anew so one can describe from within, (b) setting aside *a priori* interpretations and assumptions, (c) leaving behind one's theoretical or theory-informed understanding of a phenomenon so as to suspend abstraction for the concrete, and/or (d) moving beyond pre-established methods and data generation in order to develop tools better suited to inspect the phenomenon as given in the light of the constantly changing now.

Husserl (1913/1982) explicated that only through “bracketing” could one attain what he considered a “natural attitude,” so as to transcend one’s individual subjectivity as impacted by the contents of one’s already constructed lifeworld. Husserl hoped to find a kind of transcendental subjectivity, a pure consciousness, whereby one might clearly view and describe experiences without contamination of external conceptions. Scholars have critiqued Husserl’s notion of transcendental subjectivity and the very possibility of being able to bracket fully in any manner (e.g., Dahlberg, Drew, & Nyström, 2001; Fontana & Frey, 2008; Heidegger, 1927/1982; Vagle, 2014). These critics noted that one’s ability to understand, make meaning, and even *be* are always already “inextricably and unavoidably historically, politically, and contextually bound” (Fontana & Frey, 2008. p. 115). In light of this, Dahlberg, Drew, and Nyström (2001), Dahlberg (2006) and Vagle, Hughes, and Durbin (2009) suggest that rather than bracketing, phenomenological researchers should approach reflexivity through the practice of bridling. Bridling is a means of restraining pre-understandings that might limit one’s openness in a conscious act. Taking on this approach allows one to value what one brings with them to a study while also attempting to “bridle understandings so that we do not understand too quickly or carelessly or so that we do not attempt to make definite what is indefinite” (Vagle, 2014, p. 67).

My bridling process in this study involved journaling, in which I worked to identify any preconceptions that might be clouding my inquiry. The act of writing down, and sometimes crossing out, these preconceptions often allowed me a chance to place them to the side or at least to be more conscious of their impact on my work. I also found that listening and holding back from asking follow up questions when they came to me during interviews helped me to bridle in the moment, as I would lose myself in the interview at points, following the participant. Another common bridling tactic I used in this study involved sketching out my thoughts and then trying to sketch from a participant’s perspective regarding a topic, which often open up points in which I might assume a specific meaning from the participant that did not arise from their commentary. My final bridling process was perhaps the most painful: drastic rewriting.

Throughout the process of this study, I wrote a great deal only to read what I had written and realize that it was filled with preconceptions, assumptions, or did not resonate with the participants' lived experiences. After discussions with participants and/or revisiting the data, I often found myself deleting large sections, even chapters, of text and feverishly writing in ways that resonated with the participants' lived experiences.

**Phenomenology for qualitative research.** Phenomenology as a philosophical practice encourages thinkers to understand life and reality by going "back to the 'things themselves'" (Husserl 1900/2002, p. 168), thus taking on a natural or phenomenological attitude (Sokolowski, 2000). Taking on a phenomenological attitude requires one "to look beyond the prejudices of common sense realism, and accept things as actually given" (Smith, n.d., n.p.), to attend to phenomena as given rather than as conceptualized through theory and preconceptions (Sokolowski, 2000). Phenomenologists attend to the intentional relationship between subjects and objects to understand what a specific experience of, in, or through a phenomenon is like and means to the person having the experience. Often inward-looking and directed toward a phenomenologist's own experience with a phenomenon, philosophical phenomenologists seek to map their lifeworlds as they consider the existential realities of their own being and becoming.

When integrating phenomenology into qualitative research, the phenomenological attitude becomes turned outward and the researcher directs their attention toward "discovering how human beings understand, experience, interpret, and produce the social world" (Sadowski, 2004, p. 893). A qualitative researcher adopts the phenomenological attitude to understand phenomena as lived by others, tracing the changing relationships with and interpretations of things manifest in their lifeworlds (Vagle, 2014). Rather than conceptualizing one's own phenomenological experience as generalizable to all others, phenomenology can be used as a framework by qualitative researchers to investigate multiple and varied accounts of participants regarding a phenomenon, and to offer "plausible insights that bring us in more direct contact with the world" (Van Manen, 1990, p. 9), the world as lived by the participants.

Stein's (1989) philosophical work provides a strong rationale for adopting the phenomenological attitude for qualitative researchers. Stein, a student of Husserl, examined empathy, characterizing empathetic acts as those in which a person is "given" the consciousnesses, the experiences of others.[47] Through her discussion of the phenomenology of empathy, Stein encouraged readers to attend to the lives and consciousnesses of others, asserting that one cannot understand the complexity of the world, or one's own life, without attempting to know how the world is lived through the lives of others. Doing so, a researcher maps parts of the lifeworlds of others, allowing readers to be given these partial accounts of the experience of others. Through this giving of experiences, a reader might come to know their own world more vibrantly and find the others (i.e., research participants) partially manifest in their own lifeworlds. The notion of "giving of experiences" is crucial in Stein's writings, and I will refer to the idea of "giving of experiences" later in this chapter.

Dahlberg, Drew, and Nyström (2001) and van Manen (1990) avoid calling their qualitative research explicitly "phenomenology," although they overtly employ a phenomenological attitude and draw from phenomenological thought to frame their ontological positions. "Lifeworld Research" as envisioned by Dahlberg, Drew, and Nyström (2001) makes use of phenomenological perspectives so as to help researchers attend to subjective experiences of participants. Dahlberg, Drew, and Nyström affirm the notion that "The picture of those for whom we care or educate (or, of those who care and educate) is always incomplete without taking into account their own understanding of themselves, their lived bodies, and the meaning that their life situations hold for them" (p. 92). Thus, "lifeworld research" may allow researchers to add to or get beyond objective accounts of reality constructed through measurable means (e.g., symptoms and grades) in order "to illuminate the human being and the lifeworld" (p. 91) in their complexity and concreteness. van Manen (1990) suggested that his work was best situated within the larger

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[47] Stein (1989) notes that these "given experiences" are always partial.

sphere of human science research, specifically with a focus on pedagogy. His work is phenomenologically rooted

> because pedagogy requires a phenomenological sensitivity to lived experience (children's realities and lifeworlds). Pedagogy requires a hermeneutic ability to make interpretive sense of the phenomena of the lifeworld in order to see the pedagogic significance of situations and relations of living with children. And pedagogy requires a way with language in order to allow the research process of textual reflection to contribute to one's pedagogic thoughtfulness and tact. (p. 2)

van Manen argued that research is inherently phenomenological in that

> to do research is always to question the way we experience the world, to want to know the world in which we live as human beings. And since to know the world is profoundly to be in the world in a certain way, the act of researching-questioning-theorizing is the intentional act of attaching ourselves to the world, to become more fully part of it, or better, to become the world. (p. 5)

van Manen suggested that a phenomenological perspective to research places the focus on learning and sharing one's very being in order to learn about the world in which we interact with others so as to "come face to face with its mystery" (p. 6). Such research may have import in relation to being-in-the-world, being-in-the-world-with others, and, through this, acting ethically, thoughtfully, and tactfully.

### Design of Study or Becoming a Phenomenological Bricoleur

In this study, I used a phenomenological framework to ground my research. The ideas of phenomenological philosophers and qualitative researchers encouraged me to attend to the lifeworlds of participants who are PD/PwD and to investigate what manifests in their lifeworlds during experiences with disability in, through, and around music. In doing so, I sought to note the intentional relationships that appear, contort, and disappear when touching disability and music as lived in participants' experiences. By bridling my own pre-understandings and external theoretical means of understanding, I felt better equipped to avoid falling into individually-focused or socially-focused conceptions of disability with their neatly defined means of disablement and attention to symptoms and barriers. By investigating the phenomenon of disability in, through, and around music as lived by multiple participants, I sought to uncover and share "plausible insights" (van Manen, 1990, p. 9) into how disability is experienced, interpreted, and understood in and through music or around music-adjacent experiences of participants. These insights might, then, allow readers to complexify and trouble their taken-for-granted assumptions of what disability can mean and be "like" in, through, and around music.

Phenomenology is a disruptive means of engaging with the world (Husserl, 1936/1970; Pate, 2012). Taking up phenomenologically-grounded inquiry requires one to disrupt one's own understanding of a phenomenon in order to "attempt to understand a phenomenon as it is lived, known, and experienced by others, and reveal its 'glimpses' as tentative and fleeting manifestations" (Pate, 2012, p. 32). Taking up phenomenology calls one to disrupt commonly accepted empirical and theoretical means of engaging with research. And taking up phenomenology encourages one to disrupt the very means of researching, implying a need for generative methods. As a disruptive "method," taking up phenomenology might require a researcher to act as a bricoleur who is "empowered to draw upon their conceptual and methodological toolkits depending on the nature of the research context and the phenomenon in question . . . [emancipating them] from the tyranny of pre-specified, intractable research procedures" (Kincheloe & Berry, 2004, p. 13). In this study, therefore, I took on the role of a phenomenological bricoleur; I embraced constantly varied and responsive means of generating and considering data, acknowledged the murkiness between the empirical and the philosophical, and allowed for the production of new forms knowledge. Through brideling, as noted earlier, I often came into contact with new perspectives and tools that resonated best with participants' lived experiences. As such, becoming a bicolor was necessary if I hoped to open up participants' lived experiences in any way that would (re)present them well.

As a phenomenological bricoleur, I was called by the phenomena and the participants with whom I interacted to co-construct approaches to inquiry alongside and in the presences of participants. Yet, I did not set out doing so from the beginning. Initially, I leaned upon phenomenological methodological work of Moustakas (1994), Sokolowski (2000), van Manen (1990), and Vagle (2014), sketching out what was, in reflection, a far too rigid "method" that I had hoped would allow me to act in a less-than-rigid manner. But a rigid plan made for a rigid means of working and thinking. I constructed diagrams and timelines, conceptualized specific processes for writing lifeworld narratives for each participant, and saturated my writing with even more theory than exists in the current document. I did so out of a feeling that I needed to *be* a researcher of a certain kind, as if I could take on an identity whole-hog. This was problematic in that I was trying to be a "researcher" rather than being and becoming Jesse while doing research. As I found myself in the thick of research and as I found myself interacting with others, I realized my need to be/become myself and to reframe research as an action rather than as an identity in order to allow myself to be present *with* participants, their experiences, and my own self. Below, I articulate my process of inquiry in this study. Please note that I present it linearly, yet it was anything but linear as it was lived out in my life and this study. This inquiry process is heavily informed by the approaches outlined by Pate (2012), Vagle (2014), and van Manen (1990; 2014) with the influence of Kincheloe and Berry's (2004) research bricolage and Bruner's (1986) and Polkinghorne's (1995) understanding of narrative inquiry.

**Discovering a phenomenon.** At the outset of this study—and for years before, I had struggled to understand and articulate what the "central" phenomenon of my research is or could be. I had been interested in disability for much of my professional life due, in part, to my own experiences with mood disorders and my wish to enact inclusive pedagogical practices with DP/PwD, who I found were often marginalized in their music learning and making experiences in school. As I engaged in original research, I could not determine if I was focused on disability, the lives of DP/PwD, inclusion, inclusive music education, or any other related central phenomenon. I considered investigating "experiences of inclusion/exclusion in music learning," but found that I was less interested in investigating "inclusion" and more concerned with finding ways to live inclusively. I originally set out to study "the music experiences of PD/PwD," conceiving of "music experiences" as the phenomenon. I did not actually "find" the phenomenon until rather late in the game, until I was asked by a colleague to explain my topic post-proposal. I stuttered a lot as I tried make the “topic” clear and, after many restarts, I blurted out “well, really, I’m interested in what manifests when DP/PwD experience disability in, through, and around music.” Disability was clearly one aspect of the phenomenon, yet, as Vagle (2014) and Pate (2012) might remind me, a phenomenon is shaped by its contexts, which may be myriad. As I make music and teach people about music and music pedagogy, music provides a basic context, as the phenomenon of disability might manifest differently in, through, or around music than in another context, such as at a doctor’s appointment or at the supermarket. As such, the central phenomenon in this study “experiences of disability in, through, and around music.”

**Encountering a problem.** In Chapter One I articulated problems at the center of my motivation to take on the research outlined in this document related to disability and music. In Chapter Two, I reviewed literature that illustrated and complicated these problems and provided means of considering the problems via existent research. Through review of literature, I noted that researchers in music regularly regard disability as a medical and/or individual concern (Dobbs, 2012), adopting and employing individual-focus conceptions of disability. These conceptions create subaltern—or subordinate—subject positions for DP/PwD, and savior subject positions for music educators and therapists as they seek to eradicate disability (Laes & Churchill, 2018) or at least fix malfunctioning mind-bodies for the purpose of efficient and effective music instruction and performance preparation.

Music making, learning, and therapy practitioners are often “products” of schools of music that champion hyperability (Lubet, 2009a) and enact ableist practices that sort out or exclude DP/PwD due to worries over loss in quality of performance if “those” students, who might need accommodations, are admitted. As such, practitioners may have limited experiences engaging with DP/PwD in, through, and around music. Without concrete experiences engaging with DP/PwD and chances to come to know the unique experiences and meanings of disability in, through, and around music for DP/PwD, one might wonder how a practitioner would act when meeting DP/PwD inside or outside of classrooms (e.g., Dahlberg, Drew, & Nyström, 2001).

Without concrete experiences or representations of disability and DP/PwD in music, perhaps such practitioners may attend to features, such as diagnostic labels and/or functional terminologies along with stereotypical media representations, they may construct problematic understandings of what disability is and can be and what it means to be DP/PwD, while never considering the ablest and phantasmagorical ways these understandings impact their practices. Beyond practices, music education research is firmly situated within medicalized IFCD, as Dobbs's (2012) study illustrates and as Bell (2017) and Churchill (2015) note. Such foci on practitioner-centric concerns illustrates that music education research and practice often address disability from an ableist position, using ableist tools, and, as such, "include" disability and DP/PwD only in ways that preserve the ableist center of music education (Laes & Churchill, 2018). Without counternarratives, ableist narratives and problematic conceptions of disability and inclusion may continue to shape music education literature and practice.

**Embracing philosophy and theory.** As phenomenology is rooted in philosophical inquiry, taking on a phenomenologically-informed framework to ground my inquiry requires one to deal with philosophy and to understand how philosophy shapes inquiry and presentation (Sokolowski, 2000; Vagle, 2014). Often, phenomenologists identify philosophical frames that shape how they understand the world and, thus, how they will attend to a given phenomenon.[48] Yet, phenomenological literature is replete with commentary eschewing the use of any philosophy or theory that might veil a researcher from some sort of pure intuition (Kockelmans, 1967) because, as van den Berg (1972) noted, "the phenomenologist is obsessed by the concrete" (p. 76). Kockelmans (1967) explained, "Husserl [did] not want any induction or deduction but sole intuition on the basis of a very exact analysis and description" (p. 29), avoiding presuppositions in order to attend to primordial phenomena. van Manen (2014) shared a general distrust of theory, suggesting a hardline difference between theory and phenomenology:

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[48] Vagle (2014) and van Manen (2016) have suggested that different philosophical frames create different kinds of phenomenology.

> a theorist observes and interprets the world through the optics and the vitreous vocabularies of the theoretical frame by means of which he or she thinks and within which he or she has been captured" . . . [whereas the phenomenologist] aims to question the assumptions and abstractions or theory, push off theoretical frames, shake off the captive constraints of concepts, and penetrate and deflate the suppositions that are wittingly or unwittingly adopted by theory. (pp. 65-66)

The apparent distrust of theory on the part of some phenomenologists is problematic. Phenomenologists and phenomenologically-informed researchers are always already thinking through theory and theorizing because theory, even tacitly identified theory, colors the ways in which all humans attend to their worlds and make sense of their experiences. Making sense out of experiences is particularly outside of the purview of phenomenological inquiry, yet, phenomenologists must still be conscious of the manner in which theories inform their work, what they note, how they describe lifeworlds, and how their work might impact human life. Theories, according to Nealon and Searls Giroux (2012), allow for the taking of different perspectives and attending to different dimensions in intellectual work. Vagle (2014) asserted a crucial need for phenomenologists to ground themselves theoretically, particularly when one's study has social justice implications. Vagle invites phenomenologists to draw on theory, but to be sensitive and critical to the assumptions theories hinge upon and to interrogate how theories may empower as well as hinder a phenomenologist's ability to remain open to the phenomenon. Vagle states:

> Human experience is too complex, too fluid, too ever-changing to be captured in, or . . . constrained by a theory. The point of "coming back to" the data using theories is to acknowledge that the work of a researcher is to contribute to ongoing theorizing. (p. 74)

Vagle suggests that the impacts of theory upon the views and approaches of a researcher "become interesting and important parts of the work because they are always already interesting and important parts of the lifeworld" (p. 75). I describe theories to which I return, and how I return, in the section below.

***Taking up theoretical and philosophical claims.*** In this study, two claims deeply informed my thinking and being. Although I bridled these two claims throughout the inquiry, they are central to how I understand the phenomenon. The first claim is theoretical: disability is individually manifest, socially constructed, and continually shaped by the interaction of time, space, activity, and relationality. In this way, I have taken up an interactional conception of disability consistent with the theoretical work of Kuppers (2011), Lubet (2011), and Shakespeare (2014). Because of the interactive nature of disability, a single theoretical or abstract model of disability cannot explain how disability is lived (Kuppers, 2011). In order to understand disability, one must experience it and/or find ways to be given the experience of others (e.g., Stein, 1989). This leads to my second claim.

The second claim is philosophical. I find resonance in Martin Buber's dialogical philosophy which sees in being-in-the-world, *Dasein*, as being-with-others, *Mitsein* (Buber, 1958; Friedman, 1965). The central thesis of Buber's work is that existence is relational, being becomes between beings. Buber (1958) suggested that "All real life is meeting" (p. 11) and that one meets another in one of two ways. One might meet another with an *I-it* attitude in which one considers oneself separated from an other object/person; separate from an it. Through this attitude, the I can observe, measure, and describe the "it," or the object to which one's intentionality is directed. The "I-it" attitude allows for distanced contemplation but is rooted in separation and difference, which constructs otherness between the I and the it. By contrast, the *I-Thou* attitude allows for openness and connection which constructs communion through genuine dialogue.[49] The *"I-Thou* attitude colors meeting as embrace in which two entities come to know each other in their concreteness while also experiencing a unique type of being that manifests in between them. Buber (1958, 1965) made clear that humans need experience built upon "I-it" attitudes in order to exist and to biologically and psychologically function within material reality. "I-Thou" relationships, to Buber, constitute the meaningful and spiritual dimension of being that makes it worth living within material reality. Additionally, Buber (1957) claimed that one can never fully know the world and being through only an "I-it" attitude, stating, "The world is not comprehensible, but it is

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[49] Friedman (1965) defines Buber's notion of "genuine dialogue" as: "not merely the interchange of words . . . rather, the response of one's whole being to the otherness of the other, that otherness that is comprehended only when I open myself to him in the present and in the concrete situation and respond to his need even when he himself is not aware that he is addressing me" (p. xvi).

embraceable: through the embracing of one of its beings." (p. 27)

In this study, I conceive of being-in-the-world as being-with-others, a stance that requires me to embrace rather than trying to comprehend existence, experience, and reality through reductive "I-it" relationships. As such, I dedicated myself to embrace participants and their experiences, to take their realities seriously, and to try to find the existence that flourished between us. Because of this, I attempted to avoid making use of fixed or rigid research or analytic approaches that would center "I-it" thinking and doing, an attempt that was aided by drawing on Kincheloe and Berry's (2004) concept of research and bricolage.

**Finding participants in varied contexts.** For this study, I sought participants who were DP/PwD and who had shared experiences with the central phenomenon (i.e., experiences of disability in, through, and around music), who were willing to take part in a potentially lengthy data generation process, who would provide thick and rich accounts of their experiences, and who were interested in exploring the meaning and manifestations of the phenomenon with me (Creswell, 2012; Moustakas, 1994; Vagle, 2014). Given that the central phenomenon is "experience with disability in, through, and around music," all participants needed to have some experience with disability in, through, and around music. While it may seem apparent as to who *could* be a participant—someone who has a disability—this presupposes that disability resides within individuals, rather than being an interactive, relational construct (e.g., Kuppers, 2011, 2014; Shakespeare, 2014) through which disabled and nondisabled subjects are constructed based on the specificities of time, space, social interaction, and policy (Lubet, 2011; Tremain, 2005). Disability, as such, is experienced by everyone; however, I limited participation in this study to DP/PwD, those positioned in these specific subject positions through the dictates of policy or medical diagnosis.

I decided to answer the question of articulating a clear description of "who are participants" by determining that the answer needed to be useful for finding participants, and I decided on the following: persons diagnosed with a disability/impairment who have experiences with music that they find personally meaningful and that they wish to share and discuss. I acknowledge that using this terminology presupposes an individual-focused conception of disability and may confuse diagnosis with impairment or disability (e.g., Shakespeare, 2014), yet any means of "identifying" persons is problematic and requires one to presuppose identity frames and subject positions. In order to "remain open to the phenomenon [in its] multiple and varied contexts" (Vagle, 2014, p. 127), I did not specifically dictate what could count as "meaningful musical experiences."

***Recruiting participants.*** I created a recruitment contact script (Appendix D) which I shared via email, social media, physical printouts, and/or verbally with local disability-related groups (e.g., university office of disability services, independent living associations, diagnosis-specific advocacy groups, school districts, religious organizations) and with music venues/organizations (e.g., music stores, community ensembles, private teachers, and community music organizations). Potential participants responded directly to me or were referred to me by caregivers, neighbors, or organization gatekeepers. I sought to engage a group of participants who were diverse with regard to gender identity, sexual orientation, age (13+), race, ethnicity, and socioeconomic status in order to *attempt* to investigate disability intersectionality (e.g., Erevelles & Minear, 2010; Moodley & Graham, 2015).

Recruitment remained open throughout the study, and I eventually came into contact with 14 interested persons who fulfilled the broad criteria, 11 of whom met with me for preliminary discussions about the study. At these pre-interview meetings, potential participants and/or their guardians, for participants in vulnerable populations,[50] had time and space to ask questions they might have had about the study. We also began to get to know each other. We informally chatted about who we were, what we liked to do, favorite musics and musical activities, and the like, all of

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[50] Two participants qualified as being members of a vulnerable populations due to age and/or legal status regarding mental capability. The participant who was a minor was always accompanied by a guardian or personal aid and an older participant with a guardian was accompanied by his guardian during the first interview, after which the guardian requested to only have transcripts of subsequent discussions.

which I documented in a notebook to provide starting points for later potential interviews. These pre-interview meetings also provided opportunities to secure consent/assent (APPENDICES E, F, & G).

Ten participants consented/assented to take part in the study, with one withdrawing after our initial meeting due to worries over scheduling. I met with the remaining nine participants for a first interview/conversation. Following the first interview, one participant withdrew due to medical issues and one participant stopped responding to communication.[51] The remaining seven participants completed the study. These participants included:[52] (a) Erica, a 13-year old diagnosed with a developmental disability of unknown etiology who recently had been non-verbal; (b) Duke, a drummer diagnosed with Williams syndrome; (c) Birdie, an undergraduate abstract visual artist with epilepsy who used music to inform her art; (d) Daren, an undergraduate breakdancer diagnosed with Tourette syndrome, (e) Sienna, a legally blind social work undergraduate who played banjo in a school-based, community music therapy bluegrass band and participated in musical theatre; (f) Ice Queen, an underclass undergraduate flute player recently diagnosed with ADHD; and (g) Culann, a counselling practitioner and avid music listener with ADHD and mood disorders. These participants were mainly white and of Western European descent (six of seven), mostly heterosexual cisgender (six of seven), and had completed some college (five of seven).[53]

**Being "given" the experiences of participants: Data generation.** In this study, I conceptualized "data generation" as a process of positioning myself so that I could be "given" the experiences of participants (e.g., Stein, 1989). Through these givings, I sought to encounter the participants in their concreteness within their lifeworlds. I met participants for a series of three

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[51] This participant eventually responded that he was too busy with school and work to participate any further.

[52] All participants have pseudonyms in this document. Four chose their own pseudonyms. Three participants—Daren, Erica, and Duke—preferred that I create their pseudonyms.

[53] I note the limited diversity of participants with regard to ages, race, ethnicity, and disability/impairment in Chapter Five. This limited diversity made it difficult to investigate disability intersectionality in any robust sense.

conversational interviews, observed or engaged with participants in a musical experience meaningful to them, and, at times, made art with participants. Sometimes, our meetings included a bit of all three of these “data generation” tools. All three data generation tools, along with transcriptions, annotations, researcher memos, and a reflective journal, provided for multiple data streams of data acting in a “nested arrangements” (Yin, 2011, p. 82) in order to have thick and rich data. I provide further detail on the data generation tools below.

***Interviews.*** I sought to engage participants in something akin to a “conversational interview” protocol (e.g., Chase, 2008; Denzin & Lincoln, 2008) to allow for a welcoming and reciprocal relationship between myself and participants and to encourage participants to share stories and not just answers. Chase (2008) notes that “the stories people tell constitute the empirical material that interviewers need if they are to understand how people create meanings out of events in their lives” (p. 70). I generated a series of open-ended questions (Appendix H) to serve as doorways into these stories that might allow participants to “give a direct description of [their] experience as it [was]” (van Manen, 1990, p. 54). In accordance with suggestions regarding interviewing persons diagnosed with cognitive disabilities (e.g., Brewster, 2004; Finlay & Lyons, 2001; Lewis & Porter, 2004; McCarthy, 1998; Sigelman, Budd, Spanhel, & Schoenrock, 1981), I developed questions using guidelines I constructed from other research on interviewing participants in vulnerable populations, including participants diagnosed with cognitive impairments (Appendix I), and brought drawing tools to encourage nonverbal means of communicating. Owing to my ontological position, *being-with*, and my attention to the different contexts and ways disability could be experienced in, through, and around music, I followed participants as they told stories and ventured into contexts that might have seemed ancillary to music at first sight, rather than redirecting participants to ideas or activities that interested me. This allowed for the generation of substantially thicker and richer data, and, in many cases, significantly longer and more personal interviews than expected.

Participants engaged in three interview that took place at times and in locations identified by participants. Participants agreed to take part in interviews for up to one hour each, but nearly all participants wished to continue past the one-hour mark. Participants identified settings for our interviews that would be the most comfortable for them. These settings included coffee shops, concert venues, art museums, studio spaces, university classrooms, restaurants, breweries, houses/garages, cars, as well as my university office.

The first interviews (i.e., the first one following consent/assent) were often more structured due to our unfamiliarity with each other, although making use of notes I took during pre-interview meetings and the comfortable settings in which these meetings took place helped to encourage an open informality by the end of our time for most participants. Afterwards, second and third (or more) interviews were more open and led to participants sharing stories, songs, music, artwork, and more. During all interviews, I limited my note taking so as to be present with participants in their stories and storytelling (e.g., Vagle, 2014).

I recorded all interviews using a ZOOM H1 audio recorder and an iPhone set to airplane mode to record video. After each interview, I transcribed recordings verbatim as soon as I could, using the video data to add any annotations regarding non-verbal communication. These transcripts provided jumping off points for following interviews. All participants and/or guardians had access to transcripts via an encrypted, cloud-based platform.

***Observations and engagements.*** During the first interview, I asked participants to identify and describe a meaningful musical experience in which they were then regularly engaged and sought permission to observe them as they had such an experience. Five participants welcomed me to observe them. Four participants asked me to engage with them in their musical experiences. As such, I was able to observe *and* engage with two participants. Observations included: (a) being an audience member at Erica’s performance in *Pirates of Penzance Jr.*, (b) being a fly-on-the-wall at one of Daren’s breakdancing student organization practice sessions in a large open university hallway at night, (c) spending time with Birdie in a room full of looms as she feverishly worked on a weaving project while listening to music, (d) watching a video with Sienna of them—Sienna's preferred pronoun— performing with their bluegrass band at a community picnic, and (e) attending a concert band performance featuring solos by Ice Queen. Musical engagement included: (a) jamming with Duke in his garage and attending a concert with him, (b) listening to music with Sienna, and (c) going on a road trip with Culann while we listened to a playlist he had made for us.

I made audio-visual recordings of all observations and engagements with the exception of Erica's performance in *Pirates of Penzance Jr.* and Ice Queen's concert band concert due to copyright issues and, instead, took copious notes in these settings. Observations/engagements took place between either the first and second interview or the second and third interview to allow us to discuss the experiences after my observation or participation. During follow-up interviews, we often watched videos of the observations/engagement and discussed what participants were feeling, thinking, and the meaning they made from the experiences related to disability and music.

***Artmaking.*** Vagle (2014) encouraged researchers to investigate art objects and the process of making art objects in addition to other means of data generation, in order to attend to the means in which a phenomenon shifts and circulates through art. Though I initially invited participants to draw or make music with me to help me step inside the phenomenon with them, I found it more productive to ask participants what they would like to do together. Artmaking as suggested by participants included: (a) listening and discussing "Sound of Silence" as covered by Disturbed with Sienna, (b) constructing a new road trip playlist with Culann, (c) writing songs with Duke, (d) drawing and free-writing with Ice Queen, (e) being present with Birdie as she painted and chatted about life to a purposefully-made playlist, (f) singing and drawing with Erica. Daren did not want to take part in artmaking for this study. I made records of all artmaking objects and processes digitally and annotated them via notes in Apple *Preview* for visual data and Haselberger and Weiss' *Transcription* for audio data. Artmaking often took place during interviews, although Culann and I constructed our playlist after his final interview using a collaborative Spotify playlist and Facebook messenger, per his request.

**Finding myself: Ethics, reflexivity, and trustworthiness.** As a "scholar," I am the writer of this document and the "storyteller-medium" entrusted to convey generated data. I am, as Allsup (2017) indicates, "condemned to represent . . . [obliged] to record and re-present the lives of others, to share with readers some discovery or insights that remained hitherto undetected by the author" (pp. 8-9). Through dialogue with participants in this study, we generated data; yet, that "raw" data was not, by itself, the phenomena of participants' experiences of disability in, through, and around music. My job was not just to "capture experience, but render it" (Allsup, 2017, p. 10), to shift through the raw data for meaning related to the central phenomenon, and depict it in a readable and artistic means. As a renderer of lived experiences—as the researcher and writer of this document—I am granted a great deal of power in my privileged position. My privilege here is rooted in how my identities and backgrounds have given me currency to enter spaces of a developed and growing technical and grammatical vocabulary that enables me to speak from and through ideological frames, granting me the position of a political subject who can speak and be heard by other academics in ways that perhaps—and unfortunately so—participants might not be "able" to, or more specifically, might not be afforded the privilege to speak and be heard (e.g., Spivak, 1988).

All across this document, my privilege is showing. But, if that is so, then what is there to do about it? As a renderer of lived experience, as a privileged writer, I am charged with a duty to approach generated data in a way that allows one "to gain access to the meaning structures of a phenomenon" (van Manen, 2016, pp. 215-216). I am charged to naively observe—through bridling—and render lived experience to make it legible to others. I found this way of being as a writer well-suited to help trouble the totalizing conceptions of DP/PwD in, through, and around music. At the same time, I found myself almost repulsed that I might be allowed to unproblematically relish in an ethically problematic power position for researchers. Who am I to observe and report on the lives of the participants in this study? Who am I to “speak for others”?

Alcoff (1991) articulates an important premise relevant for a discussion of the ethics of research and writing, stating: “The ‘ritual of speaking’ . . . in which an utterance is located, always bears on meaning and truth such that there is no possibility of rendering positionality, location, or context irrelevant to content” (p. 14). A writer is “inextricably and unavoidably historically, politically, and contextually bound” (Fontana & Frey, 2008, p. 115). Thus, I expose my own location, the positionality from which I speak as the writer of this document. As a white, cisgender male, middle-class, heterosexual, married, college-educated person from the Midwest of the United States, I carry with me utterances and gestures that form how and what I say and do. I speak from and through this positionality and use utterances purposefuly I to speak to others who share this or related positionalities. The utterances and gestures recognized by the people and institutions to whom and which a dissertation is traditionally structured to speak may not be the utterances and gestures recognized and valued by the people about whom I speak in this document (i.e., the participants). As such, I risk using utterances and gestures to discuss the lived experiences of participants that may be foreign, illegible, or repulsive to them. Because no utterance or gesture is apolitical (Fontana & Frey, 2008; Roman & Apple, 1990) and each gesture carries with it the ideological and problematic remnants of the positionalities and locations in which it was developed and used, it can, through its use, have the impact of supporting structures of oppression (Alcoff, 1991). I did not, and do not, want to speak about and for participants with altruistic intentions only to find that the way I have done so leads to further oppression and marginalization. And yet, I recognize that this may happen.

Alcoff (1991) offered additional insights that, when put into dialogue with phenomenological discussions of researcher reflexivity (e.g., Dahlberg, Drew, & Nyström, 2001; Dahlberg, 2006; van Manen, 1990; Vagle, Hughes, & Durbin, 2009; Vagle, 2014), may assist researchers and writers like myself in grappling with the ethical issues inherent when attempting to “speak for others.” Alcoff (1991) urges researchers to “interrogate the bearing of our location and context on what it is we are saying” as an explicit aspect of our practice (p. 25). In a similar vein, Vagle (2014) implicates the need for a “post-reflexion journal” as central to phenomenologically-framed research. I made use of such a journal to bridle my pre-study understandings and to challenge my own historical and discursive positions, utterances, gestures, and even understandings that I brought to bear on my reading and writing with/through the lived experiences of participants in this study. I made use of Vagle’s (2014) bridling questions to encourage my personal reflection in this journal and noted:

> 1. Moments when [I] instinctively connect[ed] with what [I] observe[ed] and moments in which they/we instinctively disconnect[ed].
> 1. [My] assumptions of normality.
> 2. Our bottom lines, that is those beliefs, perceptions, perspectives, opinions that [I] refuse[d] to shed; and
> 3. Moments in which [I was] shocked by what [I] observe[d]. (p. 132)

These reflections allowed me to grapple with the ethical ends of my positionality and provide a space through which I can consider the possible impacts of this research upon the lives about those of whom I speak/write. Reflective writing, which is far more “I-It” in structure, allowed me to have dialogues with myself prior to returning to the “I-Thou” interviews and interactions with participants.

**Finding the phenomenon: contemplating and writing.** van Manen (1990) famously stated that for phenomenologically-informed researchers, “writing is our method” (p. 124). My “method” emerged though playful, sometimes painful, and embraceful (e.g., Buber, 1957, 1958) engagements with generated data. These data included audio-video recordings of participant interviews, observations/engagements, and artmaking; transcripts filled with highlights, underlined words and phrases, and marginalia including questions and memos; artworks constructed by, with, and/or alongside participants such as paintings, weavings, dances, songs, and playlists; and researcher notebooks that included mind maps or other visuals—such as comic strips and doodles—illustrating preliminary as well as problematic meanings that manifested through engagements with participants, along with reflections, comments, conjectures, and bridling. The "analytical" approach, then, was a recursive exploration (e.g., Vagle, 2014) of these generated data, including reading transcripts, watching/listening to recordings, writing, rejoicing, discussing with participants, re-reading, re-watching/-re-listening, re-writing, re-discussing, agonizing, and re-rejoicing as meanings emerged on the page through keystrokes, pen strokes, brushstrokes, and a fair bit of temple strokes. All of this became a means of rendering lived experiences (Allsup, 2017) into legible living meanings on the pages of this document.

Bruner (1987) famously stated that "We seem to have no other way to account for lived time save through stories" (p. 692). Similarly, Clandinin and Connelly (1990) shared that "people by nature lead storied lives and tell stories of their lives" (p. 2). Bruner's (1987) and Clandinin and Connelly's (1990) comments were true of the participants in this study who were telling/sharing stories, illustrating their experience of disability in, through, and around music through narrative. Through stories, participants shared what manifested in their lifeworlds when they were intentionally directed to their experiences of disability in, through, and around music. While I first worked to write straight-forward phenomenological descriptions for each participant, their stories and storied experiences kept interrupting me. I kept having the nagging feeling that I was creating work that was neither engaging to write nor enjoyable to read and, more troubling, was engaging my researcher voice and privilege in a highly-problematic manner.

Following a conversation with my mentor regarding these feelings, I had a moment of insight and asked myself, "Well, what about stories?" Encouraged by the bricolage of Kincheloe and Berry (2004) as well as the flexibility of appraoch advocated by Vagle (2014), I constructed different ways to (re)present the lifeworlds of the participants. Rather than presenting formal "textual descriptions" that dissect lived experience and display the structures of the lifeworlds of participants with medical-like precision, as advocated by Moustakas (1994), Sokolowski (2000), and, to a lesser extent by van Manen (1990), I generated "lifeworld narratives" through which I describe and re(present) participants' experiences as lived out in their contexts of time, social interaction, and place (e.g., Clandinin & Connelly, 2006, 1990; Lubet, 2010; Polkinghorne, 1995).

Through these lifeworld narratives, I share aspects of the lifeworlds of participants in a way that centers their voices and individualities, and draws heavily on their verbatim utterances during interviews and their artworks.

Crafting lifeworld narratives required that I take on slightly different approaches to render tentative meanings into writing. I took different writing paths and styles for each participant in order to provoke the phenomenological specters, the partial representations of participants, to act and speak on the page as much as possible as they did in person. For example, Culann used expletives, sarcasm, historical references, and song lyrics to share his experiences during interviews and I sought to evoke that on the page. Birdie told interrupting stories, would burst into and out of telling fast-paced and detailed tales, and consistently focused discussions on visual lines and aural frequencies, which were also apparent in her artwork. Making her phenomenological specter act this way in her description required me to use textual, artistic, and visual data in a thoughtful manner. I discuss each method of analyzing and writing participants lifeworld narratives in more depth in Appendix J.

**Contemplating but not pathologizing: A self phenomenology.** As I developed the lifeworld narratives, I began engaging in a "thematic analysis" (e.g., van Manen, 1990) across the accounts of participants in order to see what their collective experiences meant in relation to the phenomenon under investigation (i.e., experience of disability in, through, and around music). "Analysis" seemed far too clinical and pathologizing for my purposes in this study, so I conceptualized this process as "distanced contemplation" in which I entered into a separated *I-It* relationship with participants. In this contemplation, I did not seek to determine essential and universal themes, but, rather, I sought commonalities and diverging points among the intentional relationships between participants and music making (e.g., Vagle, 2014). I noted connections, diversion, and mutations of themes of meaning among and between participants.

Near the end of the distanced contemplation, I began to consider how I might construct a polyphonic composite text for Chapter Five, as advocated by Vagle (2014), while retaining my dedication to forwarding the voices of participants instead of only speaking for them (e.g., Alcoff, 1991). I began to envision a complex text where participants might speak to, with, and alongside each other, illustrating constantly shifting meanings related to their experience of disability in, through, and around music. Yet, I initially wrote what looked like a straight-forward analysis with developed themes and participant comments that seemed to articulate these themes. I was uncomfortable about this structure and the way that it forced me to tidy up and almost sanitize these the themes. So, I took a break to check my email and I had a daydream—or maybe a hallucination—that challenged my thinking and writing. This dream/hallucination provided the impetus for the structure of Chapter Five. Of this dream/hallucination, I wrote the following in my journal:

> It is strange, I've been thinking so much about getting this damn document done—and thinking probably a little too intensely on what the hell phenomenology is, anyway—that things are, for lack of a better term, getting spooky as I sit and write the analysis section. To put it bluntly, I feel the presence of the participants, or at least the traces of them I've created in chapter four.
>
> So, I'm sitting . . .  alone today. I got an email during my writing time and I went to answer it and I started to feel that feeling you get when someone is watching you. No one was (I'm almost in a space where no one could lest they be in front of me or sitting beside me). I finished the email and went back to writing. As I wrote down the pseudonyms of participants under different headings in this section to serve as a reminder of where their stories converge, I pictured each of them in vivid detail. I stopped and almost whispered all their names and it was like they were all there right in front of me. I blinked and I felt them move to behind me. They were talking to each other, pointing at the screen making notes about what I was writing and sharing stories and talking to me:
>
>> Sienna: “That’s not what I really meant …”
>>
>> Me: [erase the sentence, look at the transcript, start again]
>>
>> Sienna: [Nodding, and to Erica] “There, he got it better this time.”
>>
>> Culann: “I just wish he’d cut the shit and get into talking about why 90s music is the best.” [He crosses his arms.]
>>
>> Duke: “Listen, my professor, you’ve got this. I’m stoked. I cant waite” [*sic*]
>
> These people have never, as much as I can tell, been in the same space (well, two of them worked together at one point, before the study), but they were chatting in a very friendly manner.
>
> Listen, I know it may sound strange, but in that moment, I felt as if they were there with

> me, behind me and encouraging me. I'm welling up as I write this because of this intense feeling of strength that this has given me. I cry because I feel like I'm doing this for them as much as for me, again.
>
> Breath, Jesse. Embrace the moment.
>
> So, why did I say "phenomenology" before? Well, I feel like I just experienced phenomenology, or at least felt what this perspective can foster. Well, maybe I’m feeling the kind of inclusion, in the Martin Buber sense (of course), that phenomenology can be a doorway into. I feel that these people, or at least traces of these people, are present in my consciousness, present in my mind, in concrete and vivid detail as I work. I wonder if what I’ve written so far could mean as much to someone reading it as it does to me? . . .
>
> Erica: “Let’s sing”
>
> Wish I could just join Erica and the group, but I need to write this thing. Maybe I could do both . . .

I decided to be present in this dream and stop fighting my urge to join Erica and the group. I constructed an envisioned conversation to present the meanings made during my distanced contemplation. This conversation was a chat in which participants could meet with each other to talk about the shared meanings and manifestations related to their experience of disability in, through, and around music. Taking this approach allowed me to avoid enacting a pathologizing type of analysis relying upon cause/effect types of diagnoses of lived experience that allow a researcher to place lived experience and intentional relationships into tidy boxes. I struggled with how I might present such a polyphonic contemplation that would (re)present the themes and allow the mutations of each theme rise to meet the reader.

To construct in Chapter Five the thematic conversation I imagined among the participants, I continued to “[stay] as close as possible to the original data” (Dahlberg, Drew, & Nyström, 2002, p. 183), I attempted to allow the data, and through it the participants, to speak with one another about their lived experiences. I had to remind myself that the persons I constructed in this conversation are phenomenological specters, partial representations created through interview, observation, transcriptions, deep thought, and, probably, and overactive imagination. They are manifestations in my own lifeworld as I have been intentionally directed toward the central phenomenon in this study. At this point, I was attempting to make meaning of the meanings of others. As I wrote Chapter Five, I encouraged these phenomenological specters to speak with one another and to riff on themes in order to articulate how their experiences, interpretations, and meanings bump up, change, and tangle with each other. For reading ease, I structured the conversation so that one person "spoke" at a time, although in my consciousness, they were and are all speaking in a messy mix of textures and combination. Yet, I found it difficult to "listen" to all the voice at once. So, the conversation evolved as I directed my own intentionality toward one voice at a time as presented in Chapter Five. In many ways, this distanced contemplation developed as a personal phenomenological investigation of my experience as a phenomenological investigator of the lifeworlds of others.

This approach to distanced contemplation resonates with what Polkinghorne (1995) might call "narrative analysis" in which the researcher works

> to configure the data elements into a story that unites and gives meaning to the data as contributing to a goal or purpose. The analytic task requires the researcher to develop or discover a plot that displays the linkage among the data elements as parts of an unfolding temporal development culminating in the denouement. (p. 15)

Narrative analysis may result in the construction of an "emplotted story." The plot was the participants' experiences with the disability in, through, and around music and the linkages were the overlapping meanings and manifestations. The links in Chapter Five are rather fragile as they are changed each time they are addressed by a different participant. While I do agree with Polkinghorne's assertion that narrative analysis should allow "recursive movement from the data to an emerging thematic plot" (p. 16), I worked against his suggestion that narrative analysis needed be focused on explaining "how and why a particular outcome came about" (p. 19). Rather than looking for an essentialized singular "how and why," I presented many voices, many hows and whys.

My approach to this distanced contemplation and writing process reaffirmed my ontological positionality of *being-with* participants in dialogue (e.g., Buber, 1967, 1958, 1965),[54]

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[54] At this point of the study, it might be more apt to say that I was *being-with* their dialogue, as they were not physically present nor active in the analysis and writing process.

my hope to “give” you the experiences of others (e.g., Stein, 1989), my use of an interactional conception of disability-informed theoretical framework, and my dedication to speak with and highlight the voices of participants (e.g., Alcoff, 1991). Also, the format of the distanced contemplation and the imagined conversation among participants allowed me to decenter “normal” or “typical” ways of being in research in order to embrace and center difference. In this document, the envisioned conversational floods over to the final chapter, so that participants also speak to each other, to me, and to readers about what they wish for in the world.

In Chapter Four, I share narratives whereby readers might *be*-with participants and come to understand their experiences with disability in, through, and around music. In Chapter Five and in Chapter Six, I connect participants’ experiences of disability in, through, and around music through the imagined conversation described above and by tying to theory and literature presented primarily in Chapter Two. Chapter Six presents some of my own extrapolation of meaning and suggestions built upon these meanings with regard to understandings of disability, inclusive practices, and ways of being-with others through writing and research. In this final chapter, I make connections to concepts and literature addressed in Chapter One.

***Trustworthiness.*** Trustworthiness is privileged over validity or verisimilitude in phenomenologically-framed research. van Manen (1990) noted: “We are less concerned with the factual accuracy of the account than with . . . whether it is true to our living sense of it” (p. 65). Yet, I feel an ethical need to (re)present the ideas, stories, and meanings of participants as clearly and accurately as possible in order to avoid speaking for them. In order to establish trustworthiness with participants and with you, the reader, I engaged in the following processes, informed by Creswell (2008, pp. 250-252), the suggestions of Alcoff, (1991), and Hess’s (2018) “reciprocal, reflexive, and reflective” (p. 15) writing:

- Multiple data moments[55] (e.g., interviews, observations/engagements, artmaking, recordings and transcriptions)
- Member checks with participants and/or guardians throughout, including the ability to be the editor of their own lifeworld narratives. All participants received a draft of their narratives and had two months to read, comment, and correct. I have included their responses either in footnotes in their narratives or in Appendix K.
- A reflective journal to attend to my researcher bias, bridling, and issues regarding ethics.
- An "audit trail" document in which I noted all "steps" I took during data generation and analytical details.
- Peer review by a research mentor and writing colleagues.

### Timeline

My work on this study took place from March 2014 through October 2017. I wrote and edited the proposal—of which very little still exists in this document—from March 2014 until November 2016 and defended it on December 9, 2016. I began full-time work as Assistant Professor of Music at James Madison University in the Fall of 2016, which took a toll on the speed of completing this document and added challenges to securing IRB approval from both Arizona State University and James Madison University. I was eventually approved by both institutions to begin data generation as of January 4th, 2017. At that time, I began contacting individuals and organization gatekeepers to find potential participants. I meet with potential participants throughout Spring semester of 2017 and conducted interviews, observations and engagements, and artmaking from March of 2017 through October 2017. Distanced contemplation and writing of lifeworld narratives took place from February 2018 until early June of

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[55] I avoid the use of the word "triangulation" here in order to highlight my agreement with Vagle (2014), who argues that that triangulation "has some applicability to phenomenological research, [yet] I am concerned that such a practice might make the distanced contemplation more mechanistic that I prefer . . . in phenomenological research, when we have multiple data moments such as interviews, writing, and observation from a number of participants, over a period of time, I do not think one need to triangulate across these moments in order to say something meaningful" (p. 97).

2018. I continued writing throughout the summer of 2018 and early Fall semester of 2018. I defended this dissertation on November 19, 2018. I worked on final edits from January 2019 until April 2019.

# CHAPTER FOUR: LIFEWORLD NARRATIVES

## Prelude to the Phenomenologies of Others

This chapter includes a series of seven lifeworld narratives of others (i.e., not my own lifeworld, but the lifeworlds of participants). The purpose of these lifeworld narratives, which act as textual descriptions of the lifeworlds of participants, is to bring "the fullness and richness of the experience to the reader . . . allowing [the reader] to go beyond emotion or a mere feeling about the topic and find in oneself the physicality evoked by the words" (Wertz, Nosek, McNiesh, & Marlow, 2011, p. 2). I present the lifeworld narratives in a multi-faceted and arts-inspired manner based on Vagle's (2014) advocacy for the same, Kincheloe and Berry's (2004) call for "bricolage," and drawing tools from narrative analysis (e.g., Bruner, 1986; Polkinghorne, 1995). I do so to create the possibility of encounters between you (i.e., the reader) and others (i.e., the participants). By embracing polyvocality and presenting participants' experience in ways that are congruent with their words, their ways of being, and their musics, I aim to decenter essentializing narratives of disability and afford openings for you to do the same.

In other words, I provide what Stein (1989) might characterize as "foreign experiences" (p. 2), or experiences and understandings that exist in the lifeworlds of someone other than the reader, in order to place you into an intentional relationship with people not physically present and their experiences (p. 8). If, as Buber (1957, 1958, 1965) suggested, inclusion and the very act of living is grounded on chances to become conscious of the consciousness of others, then reading these lifeworld narratives may afford moments in which you might trouble essentialized conceptions of disability and being disabled in, through, and/or around music experiences. Although "themes" are embedded in each lifeworld narrative, I bridle myself purposefully as a writer to allow you to walk with participants and to embrace the world through embracing the experience of these participants.

I have chosen to represent each participant's lifeworld narrative differently on the page via choices of font style, size, and sometimes color, often decided in consultation with the participants. Spacing and justification also vary, as does inclusion of artworks, song texts, and more. These choices are consistent with my approach as bricoleur, phenomenologist, narrativist, and being-in-relationship with participants. A paragraph about choices in representation can be found at the beginning of each lifeworld narrative.

Navigate this chapter in any order you wish. I have ordered the seven phenomenological descriptions so that participants with similar medical diagnoses are paired together (developmental disabilities, neurological disabilities, blindness, and learning disabilities and mood disabilities), but this order, which is problematic because of the medical framing, may not be the most meaningful way for you to read about the participants. To help you choose how you might navigate this chapter, I offer a brief description of each narrative:

- An interaction between **Erica**, a 14-year old diagnosed with a developmental disability of unknown etiology,[56] **her parents**, and me. **Erica** and I also draw together, sing together, and communicate through music (pp. 120-139);
- A screenplay focused on `DUKE`, a 29-year old diagnosed with Williams syndrome, who shares his musical life as the "Duke" of a downtown music scene (pp. 140-153);
- An interrupted narrative of Birdie, a 23-year old diagnosed with generalized epilepsy. Birdie paints and weaves while discussing sincerity, passion, frequencies of life, and her storm-like nature, while also listening to and discussing music (pp. 154-166);
- A first-person depiction of an intense breakdancing session and a dream sequence from the perspective of Daren, a 21-year-old diagnosed with Tourette syndrome (pp. 167-173);
- A depiction of Sienna, a 21-year-old diagnosed legally blind, at a potluck in the mountains as they (Sienna's preferred pronoun) sing, play banjo, and share their ideas on diversity, stereotypes, barriers, and inclusion (pp. 174-229);

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[56] I feel awkward identifying the participants with their diagnoses. My only intention in doing so is to provide information pertinent to their participation and descriptions in this study.

- A first-person trip through the trophy hall of Ice Queen, a 19-year-old diagnosed with Inattentive Attention Deficit Hyperactive Disorder, Generalized Anxiety Disorder, and Emetophobia (i.e., fear of vomit and vomiting). Ice Queen shares stories of pride and social dis/connection through large ensemble performance experiences (pp. 230-241); and
- A road trip with Culann, a 53-year-old diagnosed with Attention Deficit Hyperactivity Disorder, Major Depressive Disorder, and Specific Learning Disability. Culann shares music and experiences that were/are both incongruent and congruent with who he is.

The last section of this chapter, “Epilogue to Phenomenologies of Others” (p. 264), ties together some of the methodological and philosophical issues that arose from crafting this chapter. This section may logically follow Chapter Three as it reiterates the purpose of phenomenology and its connection to the purpose of this study. I have placed it at the end of this chapter for two reasons: (a) to allow the approach to inquiry to flow throughout the entire document and (b) to clearly differentiate the “phenomenology of others” presented in this chapter from the “phenomenology of self” in the next chapter.

### “Sing with Me”: Erica, Who Lives to Make Music

**Pseudonym:** Erica

**Age**: 14

**Diagnosed disability:** Developmental disorder of unknown etiology, of global impact

**Narrative representation:** Erica’s lifeworld narrative is an interaction between her, her parents, and me. Erica often communicated through singing and sharing songs. She would rather sing or listen to a song with someone than “talk” around questions. Erica also appears to think and experience much of the world in song, a point iterated by both Erica and her parents. Erica uses YouTube as her preferred musical medium, and so in preparation for writing this lifeworld narrative, I constructed a playlist of songs that Erica specifically identified during our times together.[57] Some of these songs appear in the description below. I use three text justifications and different fonts to draw attention to the participants in the interaction:

**Erica’s comments and lyrics from songs appear in bolded Comic San font, presented along with artwork generated during interviews. All of her comments are center-justified in order to center her voice in her narrative.**

Comments from her parents are presented in Comic Sans MS, left justified. These comments came about through independent discussion with them conducted via email with Erica’s guidance, as they are not fond of speaking for Erica. Her parents’ responses are

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[57] Erica’s playlist: https://www.youtube.com/playlist?list=PLTQ29jrBRKVwutSYMAgouhr_zqI-N9yXY

situated asynchronously in this lifeworld narrative and are situated throughout to provide additional commentary on the meaning of specific utterances and experiences.

My comments and descriptive notes are presented in Arial, right justified.

---

**"'Pour, oh, pour the pirate sherry,**
**Fill, O fill the pirate glass!**
**And, to make us more than merry,**
**Let the pirate bumper pass!'[58]**
**I liked singing in Pirates,**
**'Pour, oh, pour the pirate sherry.'**
**I like when people sing with me. I live to make music."**

"When Erica was more or less non-verbal, she used a keyboard to type, 'I live to make music.' When the aide who was working with her attempted to correct her, prompting her with, 'Erica did you mean to say, 'I love to make music,' Erica repeated herself (with a kind of non-verbal emphasis), 'I live to make music'."

**"What music do you like?"**

"I like the Beatles a lot. Do you know any Beatles songs?"

**"Yes!"**

---

[58] (Sullivan et al., 1990). https://youtu.be/7iQsVwbvK7U

“What song would you like to sing, Erica?”

**“What song would you like to sing, Jesse?”[59]**

“Any song, really. Do you know ‘Yellow Submarine’?”

**“‘In the town where I was born,’”[60] sing with me,**

**Lived a man** “‘Lived a man

**Who sailed to sea.’”** Who sailed to sea’”

**She points to the screen, “What’s that song?”**

“Yellow Submarine.”

**She continues to point to the screen.**

“Oh, do you want me to play it? I think I have it on iTunes.”

**“Yes, YouTube.”**

“Okay, ‘Yellow Submarine’ coming right up.”

**“What’s that song? Say it again,” she asks in a teacherly voice.**

“Yellow Submarine.”

**“Who sings it?”**

---

[59] Incidentally, this question—with my name included—has become part of Erica’s morning ritual, per her father. Apparently, I asked her this question a lot.

[60] (Lennon & McCartney, 1966). This song is repeated extensively throughout this lifeworld narrative. To decrease footnote clutter, I will not cite it past this one time.

“The Beatles.
Erica, what other music do you like?
What do you like to do with music?”

**“‘When Doves Cry,’ Mom’s song. I like to sing.”**
**She opens up YouTube on the laptop in front of us**
**and**
**finds the music video for Prince’s “When Doves**
**Cry.”[61]**
**“Mom played it with me.”**

We watch the music video together. I realize that I am becoming uncomfortable with some of the overly sexual imagery in the video. I wonder why I feel this way.

**The song ends, and Erica asks, “Let’s sing.”**

“What song?”

**“Yellow Submarine”**

“Socially, Erica connects individuals to songs. This is less true as she gets older, but for many years, she connected a song to an individual and named them from the song. Her connection with people is through music. Her speech is still limited and scripted, but in interactions she often asks some version of ‘What is your favorite song.’ For many years, her social interaction with an individual, even if it had been months, or even longer, was to approach that individual with his or her song.”

“Do you want to sing with the recording?”

---

[61] https://www.youtube.com/watch?v=UG3VcCAlUgE

I begin to search my iTunes for the song. I click play.

**Erica looks disturbed, "No, YouTube."**
**She gestures for my laptop.**

"Is there a different version you know of?"

**"Yes, new tab."**

I offer her the laptop.

**She searches for a specific version.**[62] **She clicks play**
**and points to me, "Sing!"**

"'In the town where I was born, lived a man who sailed to sea. And he told us of his life in the land of submarines. So we sailed up to the sun, till we found a sea of green. And we lived beneath the waves. In our yellow submarine.'

**"'We all live in'**

'a Yellow Submarine, a'

**'Yellow Submarine,**

**Yellow Submarine.'** 'Yellow Submarine.'

We all live in a'

**'Yellow Submarine,"**

'Yellow Submarine,'

---

[62] https://www.youtube.com/watch?v=krIus0i9xn8

**'Yellow Submarine.'"**

Yellow Submarine.'"

We listen and sing together

**The song fades out. Erica scrubs the play head back**
**to the beginning. "Again," she requests,**
**"Let's sing again."**
**She motions to me to click play,**
**offering the laptop.**

I click play.[63]

**Erica smiles and dances in her seat. After the first**
**verse, she motions to me and says, "Sing," with an**
**excited squeak.**

"'And our friends are all aboard, many more of them live
next door.
And the band begins to play.'"

**She pantomimes playing a trumpet during the**
**instrumental break.**

I join along.

**"'We all live in'**

"'a Yellow Submarine, a'

**'Yellow Submarine,**

**Yellow Submarine'."**

'Yellow Submarine'."

---

[63] https://www.youtube.com/watch?v=krIus0i9xn8

### She dances.

I dance.

“My song was ‘The Wheels on the Bus’[64] and I was the driver on the bus. [Her mother’s] song *was* ‘Sweet Love.’[65] One of her Aunts’ was ‘A Horse with No Name.’[66] Yours is ‘Yellow Submarine.’ She has an incredible memory for music, even if she is not a good historian or self-reported regarding other things. She told me that she still remembers her maternal grandparents singing to her, and they died when she was three. I am inclined to believe her. After I asked her, she started singing their songs.

Erica and I regularly drew pictures while listening to music during interviews. After the songs finished, we would explain what we had drawn and why.

Figure 7. Erica’s first drawing for “Yellow Submarine.”

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[64] https://youtu.be/-0icbqvmehs

[65] https://youtu.be/5Y9DYGiDL1o

[66] https://youtu.be/Tm4BrZjY_Sg

During the second interview, after I had observed Erica perform in her middle school's production of *Pirates of Penzance, Jr.*, we started drawing without listening to music. I asked her, "What was your favorite thing about doing *Pirates*?"

**[silence]**

**"I don't know what I did."**

"That's okay. Was there anything you didn't like about doing *Pirates*?"

**[silence]**

"Did you have any friends who were in *Pirates* with you?"

**"Yes!" her eyes light up, "Margarete and Maya and Harrison and Wally and Ashanti and Crissy and Olive."**

"That sounds like most of the cast."

**"Yes! We sang on stage. I liked singing on stage.**
**'Pour, oh, pour the pirate sherry,**
**Fill, O fill the pirate glass!'"[67]**
**She asks me to open my computer and she searches for a song.[68] She pushes play and sings along.**

I listen.
After the song has ended, we go back to drawing. I break the silence and ask, "Erica, what else do you like to do?"

---

[67] https://youtu.be/7iQsVwbvK7U

[68] https://youtu.be/7iQsVwbvK7U

**"Singing with friends,**
**'B-I-NGO, B-I-NGO, B-I-NGO.'"**
**She gently takes over the laptop keyboard and**
**trackpad, opens a new browser tab, searches for a**
**specific version of '"Bingo"[69] that uses background and**
**melodic material form Iggy Azalea's "Fancy,"[70] and**
**clicks on the video.**

**She draws as the music plays.** I draw.

**"B-I-N-G-O, Bingo was his name-o."**

Figure 8. Erica's second drawing of "Yellow Submarine" depicting one person.

**She smiles, points to the picture, and asks, "What's that song?"**

"Yellow Submarine."

**"Say it again."**

---

[69] https://youtu.be/O8Xj5-Wz-hk

[70] (Kelly et. al., 2014)

"Yellow Submarine."

**"And who sings it?"**

"The Beatles."

**She opens another browser tab, searches for her version of "Yellow Submarine,"[71] and says, "Let's sing, you and me."**

And so, we sang and listened again.
I attempted to ask Erica questions about her drawing,
about school, and about music, in general.

**"Sing," she replied as she rocked to the beat, making on and off eye contact.**

"'As we live a life of ease, every one of us has all we need.
Sky of blue and sea of green, in our yellow submarine.''"

"Erica will often withdraw in social settings . . . living in her own soundtrack is one way she withdraws. Much of the social life around her is paced at a speed which makes it difficult for her to participate. It is difficult, but patience and a willingness to slow down are important for inclusion of Erica."

**"Let's play piano. I like playing piano. I'll play 'Fount.'"**

---

[71] https://www.youtube.com/watch?v=krIus0i9xn8

**She plays the melody of "Come, Thou Fount of Every Blessing"[72] multiple times on the piano.**

"Erica just started learning piano. She does not read music—I don't think—but she has an incredible ear and memory for music. She often learns her singing parts and all other parts by the second rehearsal for a musical or concert. She does not read scores but from her memory. I fear that some may underestimate what she is capable of learning by memory and not be willing to work with her in that way."

I begin to play a chord progression along with "Fount."

**She smiles for one round of the melody and says,**
**"I'll play,"**
**scooting over more on the shared piano bench.**

I listen.
"How long have you been playing piano, Erica?"

**"Six weeks," she rocks excitedly, "I like playing piano"**
**and then she sings, to the tune of the Leonard Cohen**
**song, "'They say I have a piano that I play before the**
**Lord, the mighty face, the mighty face, the mighty face is happy . . . Hallelujah!'"**

---

[72] https://youtu.be/g10AJN3KHns

"She taught herself to speak by inserting speech sounds into tunes that she knew. She sang the sound until she could say it. When Erica was basically non-verbal, she was up front in church with youth who were to help lead the congregation in a song. No one had stepped up to the mic. She did, and assumed role as song leader, encouraged the congregation to sing on the chorus, and just listened to them as they did. It was the first time many in the congregation had ever heard Erica make a sound."

"Erica, now that the musical is over and you're almost done with middle school, what music will you do?"

**"I want to sing. Sing with me. 'Low, low, low, low,**
**low, low, low, low, low,'**
**[her smile fades a bit and her eyes dull]**
**'Low, low, low, low, low, low, low, low, low'[73]"**

"Jon Bellion?"

**"All Time Low," she takes over the laptop, opens a new tab, navigates to YouTube, types with one finger the name of the song into the search bar, and selects the exact version she has watched before. She points to the video[74] and looks at me as if asking me to be the one who initiates the music.**

"Sure!" I click the video and we watch and listen.

---

[73] (Bellion, Williams, Cubina, & Mendes, 2016)

[74] https://youtu.be/AXnqkVTFUqY

I am again somewhat stunned by lyrics from this song, one that I had already heard, but that in Erica's presence feels somehow inappropriate *for* her because of discussions of "masturbating" and other sexual imagery. This thought and feeling troubled me, similarly to when we listened to "When Doves Cry." Was I being paternalistic? Infantilizing her?

Figure 9. Erica's drawing for "All Time Low" depicting herself, with a noticeable space

**"I'm at an all time low," she sings quietly with the song each time the line repeats. As the song concludes, she turns and sings, almost in an asking manner, "Hey ho, nobody home. Yet I will be merry. Hey, ho, nobody home."**

**She opens another tab on the computer browser and**

**points, "Morning in America."[75]**

"Who sings that?"

---

[75] https://youtu.be/VHCMAlLNJNc

**“Jon Bellion. It’s good.” She clicks play.**

We listen.

The song has a chipper, anthem-like feel but hides a darker meaning with its commentary on drugs, mental health, and social isolation. Bellion (in Bellion, J., & Lajaya, D. A., 2016) spoke about the song:

> A lot of my friends growing up dealt with the things [and] keep all these problems under wraps . . . a lot of these . . . issues are swept under the rug. I love the ‘SECRETLY OUT OF CONTROL’ concept so much. I thought it might help a young kid experiencing these issues, give him or her a sense of support. (n.p.).

I wonder what Erica is trying to say bringing up this song.

We listen to the entire song.

**Erica rocks in her seat, her fingers moving as if**
**playing the piano.**
**The music finishes and she clicks on the browser**
**tab**
**that had “Yellow Submarine”[76] in it. “Let’s sing.”**
**She**
**clicks play.**

I sing the verses, which have become “my” part.

**“‘We all live in’**

“‘a Yellow Submarine, a’

**‘Yellow Submarine,’**

**“Yellow Submarine.”** ‘Yellow Submarine.’

---

[76] https://www.youtube.com/watch?v=krIus0i9xn8

We all live in'

**'a Yellow Submarine,**

**Yellow Submarine,** 'Yellow Submarine,

**Yellow Submarine.'"** Yellow Submarine.'"

"I believe that she processes the world in more abstract cognitive ways, and emotionally, through music, and often draws on song lyrics to express more abstract thoughts, to express her own state, or to describe the state of the world or others. Speech is still difficult for her. Yet, she wakes up singing, goes to bed singing."

**"What is your favorite song?"**

"I have a lot. One of them is a song that is special to my wife and me. It is called 'Crane Wife' by the Decemberists."

**"New tab," she says while pointing to the search bar. "Let's listen."**

**She listens.** I listen.

**She makes on-and-off eye contact throughout the song.**

This song is rather personal to me, and I feel awkward making eye contact. I feel vulnerable, but that may well be what Erica was looking for.

"There is much more going on inside of Erica than she can communicate most of the time. I wish, sometimes, that I could

have more access to her interior world, to experience the world
as she experiences it."

"Well, Erica, I think you have to get going to another appointment."

**"Let's sing"**

"Yellow Submarine?"

**"Yes," she says while finding the correct tab.**
**She clicks play and waits for me to start.**[77]

I sing the verses with some help.

**"'In the town where I**
**was born,'**

"'In the town where I
was born,

'

lived a man who sailed to sea.
And he told us of his life in the land of submarines.
So we sailed up to the sun, 'till we

**'found a sea of green,'**

found a sea of
green,'

'And we lived beneath the wave in our yellow submarine'

**'We all live in'**

'a Yellow Submarine, a'

**'Yellow Submarine,'**

---

[77] https://www.youtube.com/watch?v=krIus0i9xn8

**‘Yellow Submarine.’**

‘Yellow Submarine.

‘We all live in

**‘a Yellow Submarine,**

**a Yellow Submarine,**

‘a Yellow Submarine,

**a Yellow Submarine.**

a Yellow Submarine.

**And our friends are all**
**aboard,”**

And our friends are
all
aboard,
many more of them
live next door. And
the band begins to
play.”

**She mimes playing trumpet.**

I mime playing
trombone.

**“‘We all live in’**

“‘a Yellow
Submarine, a’

**‘Yellow Submarine,**

**‘Yellow Submarine.’**

‘Yellow Submarine.

We all live in’

**‘a Yellow Submarine,**

**a Yellow Submarine,’**

‘a Yellow
Submarine,’

| | |
|---|---|
| **a Yellow Submarine.'** | 'a Yellow Submarine. |
| | As we live a life of ease, every one of us has all we need. |
| **'Sky of blue and sea of green'** | Sky of blue and sea of green |
| | In our yellow submarine.' |
| **'We all live in'** | |
| | 'a Yellow Submarine, a' |
| **'Yellow Submarine,** | |
| **Yellow Submarine.'** | 'Yellow Submarine. |
| | We all live in' |
| **'a Yellow Submarine,** | |
| **a Yellow Submarine,** | 'a Yellow Submarine, |
| **a Yellow Submarine.** | a Yellow Submarine. |
| **We all live in** | We all live in |
| **a Yellow Submarine** | a Yellow Submarine, |
| **a Yellow Submarine,** | a Yellow Submarine. |
| **a Yellow Submarine.'"** | a Yellow Submarine.'" |

There is a long pause after the song fades

"What did you draw?"

**She points to her picture.**

Figure 10. Erica's last picture for "Yellow Submarine.

## Music is a Healing Thing: Duke's Jam

**Pseudonym.** Duke [29 years old]

**Diagnosed disability.** Williams syndrome

**Narrative representation.** A conversation between Duke and me while at a rock show, told in the format of a screenplay in order to capture the cinematic manner in which Duke shared his life during interviews. The conversation is interwoven with musicians on the stage performing some of Duke's favorite songs. The narrative concludes with a performance by Duke of a song we wrote together during our final interview.

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FADE IN

INT. WILLOWFLOWER (A NIGHT CLUB)- NIGHT

SLOW PAN ACROSS WILLOWFLOWER

The WILLOWFLOWER, a narrow and long bar, restaurant, and concert venue, is filling up on this warm, Wednesday evening in MAY. The walls are covered with the art of local artists. Booths line the sides of the club, tables with chairs fill the center, and a few taller standing tables dot the open areas to the sides of the stage. On each table top is a table tent that advertises specials, drinks, and upcoming concerts and events.

PAN STOPS. ZOOM TO STANDING TABLE WHERE A RANDOM PATRON (JESSE) STANDS. CONTINUE ZOOM TO EVENT LISTING ON TABLE TENT

The advertisement lists date and events/concerts for the next week, including:

- MON, 3/8: DJ JUAN's 80's DANCE PARTY (9-11PM, FREE)
- TUES, 3/9: TUESDAY TEAM TRIVIA (9-11PM, FREE)
- WED, 3/10: OPEN MIC w/ KARA (7-11PM, FREE)
- THURS, 3/11: SALSA NICHT (9-11PM, FREE)
- FRI, 3/12: THE MONIE CUTS, feat. Someone with Whom to Ride the River (8PM, $5 Cover)
- SAT, 3/13: An Evening with BEYR & NOON PASTA (8P, $5 Cover)

ZOOM OUT, PAN BACK ACROSS THE LEFT SIDE OF THE CLUB

Regulars pour into their seats for a drink and to hear their friends perform at the weekly open mic night. Some new patrons enter and chat with the hostess situated just inside the club. At the back of the club, a small, low-level stage is brightened by stage lights that sparkle as they reflect on a skeletal band set-up of a drum set, guitar amps, and microphones, which await use by the host and performers.

WILLOWFLOWER is loud with discussions, the clinks of metal utensils on heavy, ceramic plates, and laughter.

PAN RIGHT, CROSSING THE
STAGE, THE BAR, AND OTHER
SEATED PATRONS. STOP AT THE
DOOR AND ZOOM IN.

DUKE, a drummer and purveyor of all things rock, enters. He is an average-sized man in his late twenties with a wild mustache and goatee. He wears his trademark stocking cap, glasses, and hoodie. He hugs old friends and introduces himself to new ones as he zig-zags from one side of the narrow club to another.

JAKE, a bartender, looks up from the bar and lights up as he makes eye contact with Duke.

JAKE
Hey, Duke, a Dr. Pepper, as usual?

DUKE
(reaching out to hug Jake across the bar)
Jake, my man. I’m good right now, thanks!

DUKE makes his way to the stage area of WILLOWFLOWER. He stops to interact with nearly everyone on the way. He walks toward JESSE, a music professor and guitarist, who stands near the stage at a tall standing table, waiting for the open mic night to begin.
Duke positions himself front and center in the room, inches away from the stage, leans back with arms crossed with a wide smile, stage lights glimmering in his glasses. He turns to face JESSE, who is a yard away with no one else around. DUKE smiles and opens his arms.

DUKE
Hey, man, I’m Duke. What’s your name?
(he moves toward JESSE)

JESSE
Oh, hi. I’m Jesse. Nice to meet you.

DUKE hugs JESSE and begins a conversation.

DUKE
(leans on the table and faces the stage)

I go to open mic nights all the time; it's how I meet all my friends. I'm good friends will all the bands, all friends.

JESSE

Really? Wow, how do you know all the bands?

DUKE

Well . . . I'll either help them out, load their stuff in, so it makes it easier for them to, to set up. Or, I'll ask to sit in and jam with them. I play drums. Especially bands I don't know; I like to play with the bands that I don't know.

JESSE

What if they say no?

DUKE

If they don't let me play, it just means they don't trust me yet. I just have to ask nicely and show them they can trust me. Sometimes, they trust me after they see me play a little bit, like with a friend's band that is opening.

This one time there was a band at a charity event and I went up to ask to play. They were not feeling it. Then they saw — this was my favorite show — when I got to play with Will Bowers from the Monie Cuts. I had to play his song "Ineffective Automaton" in front of other people. It was really fun. If they need a drummer, they'd ask me to play and I'll show up and play.

So, with new bands, I just get them to trust me, you know . . . Once I [start] playing, [people are] like, "This guy's good; this kid's good."

This one time, I asked to play with a band of black guys when I was in Georgia. They'd never seen a white guy like me go up there and say, "Hey, hey, let me try this out." We jammed and it was fun . . . I guess it's called trust. They trust me. After that, after they see me play drums, they want to let me just come up there and have one song and have a good time while doing it. And when other people say, "No," I will either just leave . . . I'm done.

KARA, a thirty-something female with a hipster fashion sense (i.e., hand-me-down dress and thick-rimmed glasses) sits down at a keyboard which is front and centerstage. A small group of musicians join her.

KARA

(she pulls a microphone to her lips)

Welcome, everyone, to Willowflower’s weekly open mic night.

(she squints her eyes in the light, shielding them with her palm, and smiles)
Oh, hi Duke!
(she opens her arms)

DUKE leaves the table and steps onto the stage to hug KARA, his arms stretching over her keyboard. He walks the stage, high-fiving each of the band members.

DUKE
Good luck out here. You’ll do a great job. Rock it out.

DUKE hops off the low stage while KARA introduces the band and starts into a slow and sparse cover of Tom Petty’s “Free Falling.” DUKE makes his way back to JESSE.

JESSE
(phased by the nonchalance of what occurred)
You really do know everyone here. How did you meet all these people?

DUKE
(smiles and turns to JESSE)
Oh, I just meet them going to shows at Willowflower, the Silver Antelope, or Diamond’s Galleria. Just hanging out with all my friends. I was hanging out when they were working, getting to know them. Some [of them] are just going to the band show, and, you know, they’re, they get to know, they get to know me. Sometimes people see me play and they are like, “Hey, Duke, you’re great, I’d like to be your friend.”

I stand at the front of the stage, like now,
(motions arms in a sweep motion gesturing to the stage)
to rock out and I get to talk to people like the people in the band. I like just letting them know that they did a good job. I want to, I want them, to make them feel good about themselves. It’s kind of hard being a musician because you sacrifice so much. You sacrifice work or you’re away from family or kid. It’s kind of hard to do that . . . So, I tell them, “Yeah, you’re doing a good job,” you know. I give them a little bit of a confidence boost, you know, saying, “You did a good job. I love your music, keep it up.” Just be a friendly guy.

ZOOM OUT TO SHOW KARA

KARA:

(singing and playing piano)

“Now all the vampires walkin' through the valley
Move west down Ventura boulevard
And all the bad boys are standing in the shadows
And the good girls are home with broken hearts”

ZOOM AND PAN TO JESSE

JESSE

(nodding head along with the music playing)

So, you mostly get to know the musicians, then?

ZOOM OUT TO SHOW BOTH DUKE AND JESSE

DUKE

(slightly dancing in his spot)

No, everyone. I know the bartenders, ticket takers, and the waitresses. One of my best friends is a waitress over at The Cove. I was talking to [her] last night. She was in a little bit of trouble. One of her friends lost her baby. I felt bad for her, her friend and her. So, I was just talking about it, like, "Hey, you know what, I've gone through the same thing. I've lost three, two of my good friends. It was a really hard time to get through." And, you know, being there to comfort her just makes her feel so much better. . . I always like to give advice to people out there, you know, give a little advice if they're struggling a little bit. And I'm, I'm just the guy that does that all the time.

Honestly, I stopped by to get a drink and then I saw her. I was like, I know her ever since I used to work at dining hall [at the local university]. So, we became good friends after a while. And, it’s good to bond with friends. I mean, bonding with friends makes everything more funner. You laugh, you laugh, you cry, you, like, have a good time.

(tugs at his stocking cap, places palm of his hand on his chest)

When I’m with my friends, I like to make them, like, feel good about themselves. Make them feel happy . . . not to worry about anything, you know. Stuff happens for a reason and we always go through it all the time and you can go be there for each other, either for you or me, being there for each other can make it so much better. I come here and just [hang] out with my good friends that like to hang out with me. A lot of laughter. Hanging out, cracking out about, you know, stupid things.

I also meet a lot of people on Facebook. People find me on Facebook and they ask me and I'm, "Sure, you can be my friend and you can look at all the fun pictures I have of all my friends and all the videos I am always doing." Sometimes it is bands I've played with or just people I meet at clubs. I've been streaming my gigs a lot lately and people will find me that way. Sometimes, when people see me play on Facebook or in person, they are just, like, "Duke is just so good at drums," and they just want to be my friend.

FADE OUT

FADE IN

A BOOTH, LEFT WALL OF WILLOWFLOWER,

DUKE and JESSE are seated in a booth, JESSE's back to the outside wall and DUKE facing him with back to the rest of the club. Some time has passed as DUKE and JESSE have gotten to know each other by talking about their jobs and where they are from. DUKE sips slowly on a complimentary glass of Dr. Pepper delivered by DELILAH, a waitress.

DUKE

(Turns away to survey the club, waving at nearly everyone he sees. He sips from his soda, and turns to JESSE)

Yeah, I'm from here, lived here all my life. I'm a brother of 9 kids. Love playing drums. I love going out to hang with my friends. I go out to band shows, playing, and I hang out with my family most every day, especially watching my baby sister. I'm usually a pretty happy and easy-going guy. My friends know me for my saying, "Be stoked." One of my friends even has a picture of me with that under it as tattoo on his arm.

JESSE

So, you're just a happy and friendly guy. I'm sure you've always had a lot of friends and been likeable.

DUKE

Oh, no. I just like to be nice all the time now, but I sometimes get down and angry. When I was younger, I was just, just mean. No one wanted to be friends. I didn't care, didn't care about my life when I was growing up . . . I wanted to have no family, wanted to live alone, I wanted to not go to school. I was unhappy a lot, depressed, and didn't know how to tell anyone, so I was a jerk. I bad-mouthed others and would push and smack people. I was mean and I used to make fun of people. I thought it was cool to make fun of people . . . cuz I was picked on when I was growing up.

(takes a long sip out of his soda)

I wasn't born normal like everybody else. I have Williams syndrome and it's part of why I'm different, I guess. I didn't know it when I was growing up. I didn't know I had Williams Syndrome. It took me a little while to figure it out. I don't know what it does, but I've met other people that have it. I guess it's for the, it's good to have it. You know, I can get excited a lot, I still do. But I can control myself more now. I don't care if I have this disability, it's not gonna stop me from having fun every day. I mean, I can be sad one day and I can be mad the next day and I can still be happy and nice, not treating everyone wrong. Having Williams syndrome doesn't stop me. Now I like to tell people who I am: I have Williams syndrome. I'm fine with that. I like to party.

(he turns around to visually scan the club and then makes direct eye contact with JESSE)

I think I changed when I started going to Young Life.[78] I started learning about God and what He's done, you know. I like being nice. I don't like being mean, I don't like being a jerk to anybody. I just like to be nice all the time. I realized I needed to change my attitude, and I thought, "I don't want to be mean anymore."

(takes a very long sip from his soda)

My friends just made me realize who God was and wanted to learn about God. I'm like, "Yo, I'm just going to be nice now." I was tired of being, like, rude to people and say mean things. At Young Life, I learned who I am and about how God has a plan for me. Now I feel like I can do anything.

(he tugs at his stocking cap, itches his head, and wipes his mustache with his hand as he grabs his mostly empty soda glass)

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[78] Young Life is a local Christian youth group organization that hosts classes and summer camps for young adults in the area. Young Life also has a program specifically created for those with intellectual and developmental disabilities. This program, called "Young Life Capernaum," is described on their website as giving young people in this population "the chance to experience fun and adventure, to develop fulfilling friendships and to challenge their limits while building self-esteem through club, camp and other exciting activities." Duke only attended Young Life Capernaum.

I used to wish I didn’t have this, I thought it was a curse, but it is not. Now I realized that I’m glad that I do have this. If I didn’t have this, I probably would not make any friends.

KARA, who has taken a break from leading the open mic festivities, walks up, sets her hand on DUKE’s shoulder, squeezes it, and takes a seat next to DUKE.

KARA
Hey there, Duke, you gonna play tonight?

DUKE
(he smiles, hugs KARA, and responds)
Maybe, we’ll see
(his face lights up with a wry and knowing smile that suggests he has something planned)
Oh, hey Kara, this is my professor, my new friend, Jesse.
(he motions to JESSE)

KARA
(she shakes JESSE’s hand)
Oh, you keep hanging out with this dude, he’s great. So, what are you two talking about?

DUKE
We’re talking about my life and music.

KARA
(smiles)
Has this kid told you that he’s a beast on the drums? The Duke of Downtown, he is royalty here in the music scene. And, the friendliest dude I know.
(she squeezes his shoulder again)

DUKE
We were talking about my disability. I was saying that I don’t think my friends know about my disability that I have cuz I really don’t talk about it much.

KARA
(looks as DUKE with what may read as a false sense of shock at the information that DUKE has a disability. She had always thought there was something “different” about him.)
Yeah, I didn’t know that. I just think about how great you are as a drummer, how you are at every concert in town, and how nice of a friend you are.
(she begins to get up, seemingly

uncomfortable with the discussion, looking at the stage)
Well, I need to get back before this open mic night goes off the rails. Nice to meet you.
(she waves to JESSE and turns to DUKE)
See you Duke. Hopefully we'll hear you later.
(she begins to walk away)

DUKE
(stands up and walks to KARA, hugging her once more)
Goodbye, my friend.
(turns to JESSE)
Hey, I'll be right back, I'm gonna grab another Dr. Pepper.

DUKE makes his way to the bar to get a refill of his soda. On the way back to the booth, DUKE zig-zags from one person he knows to another, often offering hugs and smiles.

DUKE
(sits down, pulls off his stocking cap, ruffles his messy hair)
Lots of people I know around here.

JESSE
Seriously, how do you know so many people?

DUKE
(pulls his stocking cap back on and sips his soda)
I go to lots of shows and introduce myself. I think people think I'm a cool guy. And then people want to come introduce themselves to me. So, I just get to know lots of people. Most of it, I think, is because I'm cursed with this terrible talent that I love doing. I am just blessed that I have, that I have abilities to play drums. I guess that I am just cursed with it. I will never leave it. I think that when people see me up on the stage and they think, "Wow, Duke's a really great drummer," or when they see me making music, my friends laugh. They think, "That guy must be a blast, those people are having a crack out of him."

JESSE
Yeah, I get that. You're a really friendly guy. I think I've seen you around here a few times, once playing with a band on drums, maybe two Fridays ago. I think you were playing drums, but I seem to remember you playing and singing other things.

DUKE

Yeah, that was when my cousin's and my band was playing. It's called "Bifrost Belief." It's the band that we never practice and we just get together and we just rock the living snot out of things. I play drums, a little guitar, plunk on piano for that band. I can pick up things really easily by ear, so that helps.

But, mainly I'm a drummer. My grandparents got me my first set, I wasn't expecting it. Got my first ever drum set, I was nine years old, back in 1998. Came downstairs one day. I'm like, "What is that?" And my grandparents said, "Hey, that's a drum set." I'm like, "Oh." I never imagined myself playing drums ever. But drums is a really fun thing to play. I always I love playing drums, but drums was the call.

At first, I was worried because I thought, "Drums, I don't think I have any capabilities to play drums," and I didn't have any lessons. Instead, I just played a lot to music I liked and played with friends a lot. I watch YouTube videos tutorial, watch drummers on stage, and just try things out. I get excited when I play; I get to express my feelings, you know, I get anger out of me. And I get, and I get a good crack out of it. And I like when people get impressed at how good a drummer I am. I can just pick up a song just like that, really fast.

A new group of musicians take the stage and tear into a blistering cover of "Brick House."

DUKE

(clapping)

Alright! I love this song. I got to play it once when I was in Alabama two weeks before my grandma passed away. I was at this charity event with my uncle and he suggested I ask if I could play. I was like, "How could I ask the drummer to let me play the drums for one song?" But I did and he was like, "Come on up man." And I killed it. Everyone was dancing, everyone was freaking out. I became good friends with the singer, after a while of talking after the gig. I think that was when I realized that I was and wanted to be a drummer. Like, everyone was just going nuts. They were all cheering and saying, "Duke, that was amazing." I can't believe I pulled that off. We played for 16 minutes, had people up there dancing and I was like, "This is what I like. This is great!"

Since then, I've focused a lot more on learning and practicing. I practice for about an hour every day, at least. I'm lucky that my neighbors let me. I've also gotten a bit more serious when I play. I used to bash the drums, trying to show off by breaking my stuff. I saw some band do it and they got a lot of cheers from the crowd. I don't do that anymore. Now, I get a, a lot of . . . an adrenaline rush, a lot of happiness when I get to play and people cheer for my playing.

(turns with excitement)

You wanna go up there?

(points to the stage and begins to get up)

JESSE

(Gets up)

Sure.

JESSE follows DUKE up to the stage. This time, JESSE joins DUKE in his zig-zag of saying hello to friends and realizes he is meeting many of the musicians he has seen perform around town.

DUKE

(leaving a group of friends,
begins to walk to the stage and momentarily
turns to JESSE and stops)

You know, sometimes playing at a show, or even just going to a show, makes me happy when I'm having a really rough day. Like last Saturday, I was really angry and sad because I'd been thinking about the friends I'd lost. I went and jammed with friend at the Green Amazon club. I bashed the snot out of those drums Saturday night. Oh my gosh, I was just rocking it as hard as I could cuz the guy likes, likes to bash stuff too. He just plays guitar as fast as he can. We'll just jam around. And it was fun and everyone was into it. I always love it when people are . . . watching me . . . and I like when people get impressed at how good a drummer I am. I can just pick up a song just like that, really fast. After the set, some guy came up and said, "Hey, Duke, you guys are great, I'd like to be your friend, show you what I can do, what I've gone through." We chatted and we are friends on Facebook now. I've got a lot of friends on Facebook. I've been livestreaming on Facebook a lot, actually. I think I live-streamed the "Bifrost Belief" gig and I've been live-streaming some other stuff.

FADE OUT

INT. A ROOM IN AN APARTMENT - DAY

FADE IN, ZOOM FROM BEHIND A
PERSON’S SHOULDER/HEAD TO A
COMPUTER SCREEN

A VIEWER is looking at their Facebook stream and comes upon a livestream of DUKE. Ted Nugent's “Cat Scratch Fever” plays in the background.

ZOOMS TO THE FEED SCREEN

VIEWER clicks on a video of DUKE and a guitarist playing a heavy fast jam, heavy with cymbals. The video continues as the viewer, who is no longer seen, scrolls up on the feed, passing images of DUKE, including:

- A candid-style family picture of DUKE, his nine siblings, and his mother and father.
- Numerous selfies posted by DUKE’s friends tagged with the names of countless local clubs.
- Memes of all kinds, often related to music and/or hanging out in clubs (e.g., drinking/being drunk, an activity in which DUKE does not take part, reportedly).
- Selfies of a smiling DUKE with and without a stocking cap on, often in various clubs he frequents.
- Event announcements with text added by DUKE such as: “Cant Waite” or “Am Stoked.”
- Pictures taken from behind a drum set at various gigs and in a recording studio.
- Posts where DUKE thanks family, friends, and local business, such as, “Just found out make sandwich name after me am stoke that’s awesome thank you.”
- Shared posts from friends and media outlets about interviews with DUKE about events.
- An article about DUKE as the “DUKE of DOWNTOWN,” and a link to a short documentary about DUKE.
- Livestream videos of DUKE playing with his youngest sister as he babysits her.
- Livestream reflections where DUKE excitedly talks about upcoming events, past gigs, and gives “shout outs” to those who watch his livestreams.
- Contemplative posts about “retiring form drumming” and/or switching to “guitar” with countless comments by friends trying to talk DUKE out of such a move, always with DUKE relenting.
- Posts that display DUKE’s excitement and sadness over the beginning and ending of relationships, such as one that announcing a beginning with, “So like this girl known her long time,” and another announcing its end, “Never gonna find someone to be with so sad just gonna be alone forever.”

The VIEWER, offscreen, clicks on the breakup post to see the comments. Each comment shows support for DUKE. The VIEWER clicks on the comment box and begins to type:

VIEWER
(typing)

Sorry to hear it, Duke. You'll find someone better. No use crying over people that cause you pain.

The VIEWER clicks off the post and clicks on an archived video of DUKE playing with four other musicians (a guitarist, a bassist, and a violinist) at WILLOWFLOWER.[79] As the video begins, the group plays a Dave-Matthews-Band-inspired jam. The scene crossfades to the present.

CROSSFADE OUT

CROSSFADE IN, DIFFERENT
MUSICIANS IN THE SAME
POSITION AS THE PREVIOUS
FACEBOOK VIDEO, NOW ON THE
STAGE IN WILLOWFLOWER -
NIGHT.

One of the musicians on stage is WILL, a guitarist of the local band Monie Cuts and solo artist, with a low pompadour, thin beard, and curled handlebar mustache.

ZOOM OUT TO DUKE IN FRONT OF STAGE

DUKE dances with a group of people whom he appears to know well based on their warm responses to his presence and their self-initiated hugs. JESSE stands awkwardly in the middle of the dancing, moving slightly, feeling very introverted at the moment. DUKE pulls JESSE to a dance with the group. The band on stage hits the final drawn out cadence. The dancers stop and turn to face the stage. All of the band except Will leave the stage. WILL stands front and center, his guitar dangles as he grabs the mic with one hand and uses his other hand as a visor to block the stage lights. DUKE makes his way to very edge of the stage.

WILL
(motions to DUKE to come up)
Let's welcome THE DUKE up for a song.

Some loud applause erupts from people in attendance who walk to the stage from booths and tables all over WILLOWFLOWER to join DUKE's dancing friends. The few people in attendance who remain seated seem confused by the grand applause and mass movement to the crowded stage area. Some can be seen mouthing, "Who's Duke," to shrugged shoulder responses.

WILL
(turning to DUKE who is seated at the
Drum set, as expected)
Well, Duke, you wanna sing "Ineffective Automaton" again?

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[79] The audio to this video can be heard at https://drive.google.com/file/d/1qJrCJ82eGEwY24UrxPWWTOS2BXworNJt/view

DUKE
(pulls a mic stand nearer to the drum set and grabs the mic)
Yeah.
(he looks out)
Hey everybody.
(motioning to all in the club)
Come up here. We want to rock the house so we need you up here, we need to see you. This is so fun.

PAN TO SHOW CROWD AS THE MUSIC STARTS

DUKE clicks his sticks to count off time and WILL joins in with a vi, IV, V, I chord progression on guitar with voicings, ornamentation, and rhythms that give the song a jangly-indie-rock-meets-Old-Time-folk music feel.

WILL
(steps up to microphone, singing)
"Well, the other day, I took a trip . . .

The CROWD watches, cheering, as WILL and DUKE perform the song. Many in the crowd begin to clap on 2 and 4. DUKE grins from ear to ear and WILL looks back to DUKE as he sings and plays. DUKE joins in on the hook (e.g., "We'll all be ineffective automatons, after all") each time it occurs. After the bridge, a jumpy and syncopated listing of all the odd things people do when they do things without thought, WILL and DUKE begin to repeat the hook. WILL moves back to DUKE and shares his microphone for the last hook.

DUKE & WILL
(sharing a mic)
"We'll all be . . . ineffective automatons . . . after all."

The CROWD applauds loudly as it ends, someone screams, "DUKE!"

WILL
Thanks everybody. Well, since we've got him up here, let's see if DUKE will play us something off the EP he's working on. Well, DUKE?

DUKE
(gets up from the drum set and makes his way to KARA's keyboard situated now just left of WILL, who is situated at the center of the stage)
Yeah, this is called "Music, It's a Healing Thing."
(Turns somewhat to WILL but also addressing the audience)
You can follow along, if you want.

(starts playing “Heart and Soul” and then transitions into playing these chords with a new rhythm and adding a new vocal melody DUKE sings the lyrics:)

So, music is a healing thing.
Helps you get through a bad day if you need it.
You play it in your car really loud.
Or you can play it on TV, like me.

I like to play the songs that could heal me.
Sometimes I sing while I'm taking a shower.
Music is fun to sing and
it's a healing thing with people and me.

Music is healing.
Music is a healing process.
Music is a healing thing.

Music can make you, you want to, start a band and
music can make you want to dance
It'll- it'll make you smile and happy.
Yeah. Music is a healing thing.

Music is healing.
Music is a healing process.
Music is a healing thing.

Since I like to play on a,
play music on the piano because it's awesome now
and it heals me while I do that.
Oh, yeah. Ah-ha. Music is awesome!

It's even fun to play on the guitar.
Oh, yeah. Yep. Music can make people happy
And they can just change their life
Music can do that
Because music is a healing thing

Music is healing.
Music is a healing process.
Music is a healing thing.
Music is a healing thing, oh yeah.

FADE TO BLACK

## Balancing Sincerity and Passion: Birdie on Finding One's Frequency in Life

**Pseudonym.** Birdie [23 years old]

**Diagnosed disability.** Generalized Epilepsy

**Narrative representation.** This description is written in the style of a narrative disrupted with three interwoven storylines in order to adopt and reinterpret Birdie's line-based approach to abstract art and her lived experience. Each storyline is presented in a different color, with colors borrowed from Birdie's artwork (Figure 11). A Spotify playlist to accompany this lifeworld narrative and constructed of music Birdie references/uses/played during our interviews can be accessed here: https://open.spotify.com/user/12157994212/playlist/6FBTo0vuu3OeBF9j5UDseD.

Figure 11. Birdie's abstract work begun during our final interview

Birdie stretches a canvas onto the floor and selects a playlist from Spotify. As she situates herself on the floor, leaning over the canvas and preparing her paints, the song "Atrophy" by the indie rock band the Antlers[80] erupts from the small portable Bluetooth speaker behind her. She comments :

> Do you know this song? I went to go visit my friend who's into music, he's the one that showed it to me—he always skipped it. He was like, "Oh, this is a really sad song," and I

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[80] https://open.spotify.com/track/43MrDsDWklcHkY9aEfENJT

said “Go back. I like sad songs,” they’re emotional, you hear, like, the hits of the notes? As block piano chords play, Birdie strikes the canvas with force, creating a line that resembles a wavelength. Birdie responds to each hit of the piano by refracting the line on the canvas; the music builds in volume and thickness, and Birdie’s lines reflect these changes. A sustained and distorted guitar grows in the background, eventually taking over the entire piece, filling the loft with a sonic wall of feedback and overtones. Birdie, who has been painting while talking about the music stops for a moment, seemingly embraced by the music until the cacophony is shattered by subtle guitar strumming. She emerges from the music and explains that this part does not do it for her, it seems to wreck the balance of austerity and grandeur. She restarts the song.

Birdie pushes pale and watered-down blue paint onto the canvas to balance out the primarily blue lines. She turns and says, “I know this is weird, but, like, if I start with the color blue, like, I feel like I can't fail, 'cuz it's like blue is my best friend.” Blue, Birdie’s best friend, helps her tackle the terror that can attack when approaching a blank canvas. Music, too, is a friend to Birdie in a similar way: “Listening to music acts like a catalyst or a creative stimulant, making that space less intimidating to just jump in. Kind of like jumping into a pool; jumping into a blank canvas.” Music, for Birdie, is a ground for artmaking, temporally decorating the air with sound and allowing for abstract artistic action in a way that, without the music, could seem too intimidating to even begin. Music is also a friend, a companion to Birdie, in making abstract art. Music speaks *with* Birdie, her artmaking acting as her response to the inquiries of her sonic friend. In some ways, music is an extension of friends not present, such as the friend who shared “Atrophy” or the countless trusted friends from whom she collects music.

Birdie listens to songs over and over again, sometimes looping through a small selection of songs recently collected from friends: "I go through a phase; I totally go through phases and I'll like [songs] and I'll save them and then they'll be in my saved song section on my Spotify." Birdie is drawn to music that she feels is "chill," "relaxed," "not too processed," "organic," "raw." She identifies Bob Dylan, the Doors, and jam bands of the ilk of the Grateful Dead along with musicians from indie rock, Brazilian Bossa Nova, and the DIY scene as creators of music with these qualities. These musics seem "timeless" to Birdie because she can listen to them over and over again, finding new beauty and complexity each time. She says, "I'll just mostly listen to [the same music] and then it will expand and I'll find new people and listen to them." Expansions and/or shifts in the music Birdie listens to and paints with/through/alongside occur suddenly; after a time of brewing over the same music, she comes into contact with a chaotic storm of new people and music, each becoming a part of her lifeworld, even if temporarily.

In many ways, Birdie's relationship with and through music mirrors her artistic infatuation with lines, which appear as the basic unit of her abstract art, whether painting, jewelry making, or weaving. Lines are discovered, developed, and discarded—for a time—through play, and, sometimes, mediated by dialogues with/through/alongside music. "I used to do lines like this. Like, and I still do, but, you know, it's almost like I kind of got into this new line, like a hit in a song." A melodic line in the background of "Alaska"[81] by Maggie Rogers surges up from the speaker to meet Birdie's brush; the sonic lines become reinterpreted on

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[81] https://open.spotify.com/track/4DyfJFTQb27adTDdhFeSgD

the canvas or woven together in other pieces of Birdie's art. "[A]fter the weaving piece that I did, I found another line of, like, that's almost like a frequency."

Hunched before a large loom in a room full of looms, Birdie slows her weaving and muses, "Music has a frequency; light has a frequency; movement has a frequency. You have a frequency. We all have a frequency. So, I want that to be the larger meaning of all this work I guess." The voice of Justin Vernon, songwriter and key member of Bon Iver, singing "Beth/Rest"[82] rushes through to fill the silence left by Birdie's comment. Vernon sings, "It is steep, it is stone, such recovery. From the daily press, the deepest nest, in keeper's keep."[83] Birdie pushes the shuttle across the warp, it pulls white gauze.

> I'm weaving my EEG, that I got from my neurologist. It measures my brain waves. They do, they run a couple tests to try and stimulate seizures and such like that. And I just thought it'd be an interesting sort of weave in, kind of an analogy for the web of your brain, I guess.

The gauze references a recent seizure episode which resulted in 20 stitches after Birdie put her hand through a window pane. She says,

> You know, it's been kind of a turbulent time in my life with switching on to a new medication and all that, um, so this has been a very therapeutic piece for me. I just kind of come in here and listen to music and weave.

Artmaking and engaging in music listening provide spaces for Birdie to be herself while dealing with the turbulence that exists in her life. Her weaving of different strands and lines—lines of thread, experience, and music—into a coherent work, a work for which she has a preconceived image, stands in contrast with her current mental state. Whereas she feels in

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[82] https://open.spotify.com/track/6UI6aabe8NSRgTVySHn6CP

[83] (Vernon, 2011)

control of her artwork, her future seems something over which she has little control. Unable to drive due to the possibility of causing harm to herself or others should a seizure occur, and concerns over her ability to live alone for similar reasons cast a shadow of uncertainty and anxiety over the excitement Birdie has over her upcoming college graduation, the job offer to be a gallery coordinator, and all the life changes ahead of her. The current weaving project provides Birdie a chance to reflect, project, and be independent and in control of some aspect of her life.

Independence is important to Birdie. "Location"[84] by Khalid plays as Birdie explains, holding the shuttle in her hand:

> If somebody's going to, like, do everything for you then you're not going to do it for yourself and you're going to handicap you; it's going to handicap you and then you don't do it for yourself and learn how to do it for yourself.

Making this weaving has given Birdie a space to think about what she needs to do for herself. As she does so, she questions the reality of this thing that doctors call "epilepsy" in her life. For her, personally, epilepsy has been many things. As a child, epilepsy made her special: "Like I got to disappear for a little while and go into this place and it was like a moment in my life and I was, like, imaginative as a kid like, 'How- Where do I go?'" In her adult life, epilepsy is the name of her hardships, such as not being able to drive and concerns over living independently. Epilepsy is also "the hand [she has] been dealt" that forces her, for good and/or bad, to be more conscious of and in control of the ways she engages with the world as she avoids seizure-

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[84] https://open.spotify.com/track/152lZdxL1OR0ZMW6KquMif

triggering situations, as she did during the “seizure-free” times she experienced living alone in Paris and in Brooklyn during internships.

> I was seizure free and I think that's because it was like you've got nobody to rely on but yourself. So, I was really indulgent with, like, "Oh, I feel the tiniest bit shaky, I need to sleep. And I'm going to sleep for five hours.”

In this way, epilepsy is almost a foe to guard against, a thief that steals her memories,[85] that can become, if it is allowed to be, a controlling actor in her life. But by controlling her conditions, Birdie can steal away from epilepsy chances for it to be “in control” of her life and dictating what she can and cannot do.

As the EEG pattern[86] begins to emerge on the loom, Birdie grapples aloud about the “realness” of epilepsy for her and for her art:

> I always feel like it's a part of me. I conceptualize it as a part of me. I definitely think it's, It's not epilepsy; that's what the doctors call it, but really what it is *is* how my brain works. And I see that in my patterns of productivity and my patterns socially and I just think that it's really the way my brain works and if we're going to give it a name to identify it and treat it and put me on medication for it, it's going to be epilepsy . . . it's definitely a part of me. It's how my brain works.

Her “patterns of productivity” and, indeed her approach to most things in life, is rather storm-like, a metaphor that Birdie uses to describe both her working self and the type of seizure she is prone to.

> I could best describe myself as like a storm. Like, I brew for a while and I just strike and I get it all done. And that's just how I work. I, I don't know, maybe it's kind of like a seizure where I just like, you know, seizures when you, like, lose control.

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[85] Birdie noted, “When I have a seizure, it will really impair my memory. Like, it will really screw up my memory”

[86] EEG stands for electroencephalography

This "storm-like" quality was first identified by a professor who was trying to explain Birdie's work to a group of peers who were upset with what they perceived as her procrastination on a group project. She is certainly a storm at this moment as she attacks the weaving in front of her with an unbridled passion. As with most of her storm-like seizures, though, there are triggers for this storm of artistic work. Looming in front of her is a deadline for this weaving project if she wants it shown in the student gallery show. But that's not all triggering her flurry of action.

Birdie dips her brush in the reclaimed jam jar that holds diluted paint thinner. "Master of None"[87] by Beach House rises from the speaker and Birdie says, "I've been much more hard on myself because I feel really bad that I'm kind of a burden." She takes in her progress, leaning back, and contemplates, "If I could wave epilepsy away, I certainly would." To "wave epilepsy away" might mean that Birdie would not be the hindrance she feels she is to others. She continues:

> The kind of like weird thing about having epilepsy is, like, it affects people around you more than it affects yourself. I mean, like, it, it causes me fatigue and a headache and stuff. But like emotionally, it affects, like, the people who love me way more than it affects me because I don't see it happen. I don't see how scary it is, I guess.

Birdie knows that her mother and sister worry about her, regularly checking in with her and trying to help her deal with the onsets of unexpected or unmitigated seizure.

In one hand, Birdie hold a line sketch, "This is basically my interpretation of my last EEG." She notes some of the problem points her doctor pointed out to her and she worries aloud about the burden, the emotional toll, she plays in the lives of her friends. This worry is a large one and causes her a great deal of anxiety:

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[87] https://open.spotify.com/track/3stWWPN41byqp8loPdy92u

> I feel bad, like, constantly talking to my fr-friends and venting because I'm- I'm definitely like. I'm definitely the type of person that, like, likes to talk thing out. And I feel, like, guilty for talking to them so much about it because, like, they've got their stuff that they have to do.

Yet, epilepsy also plays a different role in her social relationships, specifically when it comes to having to self-advocate. She notes, "When I'm in a social situation, like, new friends, even old friends . It's hard to just be like, 'Hey, can you turn that music off?' It's hard to do that because you don't want to be a problem." Birdie speeds up her weaving, feet treadling fast, and she begins to remember times in her life when she felt that epilepsy negatively impacted her social life, the burdening of her social identity.

Should she say something to her friends or not? Bassnectar's "Raw Charles"[88] thumps from the speakers and Birdie grows tense in the passenger seat of her friend's car as it rolls down the streets of her mostly-white suburban neighborhood. The throbbing bass and intense beat of rave-like fast dubstep combines with the repetitive sounds made by her "other guy friends in the backseats [who are] being rambunctious, like high school boys . . . can be" as they repeatedly screamed "duh" in time with the bass of the music. She knows that some repetitive sounds, such as this loud bassy music, can be just as much of a trigger as quick motions and lights, especially when she is already stressed, tired, and/or dehydrated, as she is now after an evening of drinking and partying. "This music like a flashing light," her inner monologue runs, "a flashing beat. Just like the flash of a light, that goes, 'flash, flash, flash, flash,' it's this heavy bass going 'bum, bum, bum, bum,' like a strobe light of sound and it is going to set me off." Birdie feels that her threshold is low but remains silent. Being a high

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[88] https://open.spotify.com/track/4C0YXHuue34htSjrnn52Kt

schooler and worried about her social standing and peer perceptions, she doesn't want to say, "'Hey, I'm going to have a seizure," though she feels the need to do so out of self-preservation. She fears both outing herself as being an "epileptic" and/or "crying wolf" if she has no seizure in the end. She has to think carefully if she is "going to play the epilepsy card [and] then, like, handicap" herself. But she feels some of the early warning signs alerting her of an impending seizure: lower right-side headaches, trembling hands, a feel of loss of balance, loss of attention, blurry vision, a sense of paranoia, and the "existential voice" inside of her head that seems like someone is narrating her perceptions and feelings to her. "You are about to have a seizure, you know that. Don't you wish you could just dis-clude[89] yourself? Maybe you should just stay at home, isolate yourself, just to stay safe," the existential voice speaks as a grand mal seizure overtakes Birdie.

Birdie holds the shuttle in her hand as she remembers a time in high school when music acted as a trigger for a grand mal seizure. She speaks of how she felt disempowered to self-advocate, lest she disclose her disability to her friends and lose social status:

> And I like really wanted to tell them, like, "P-please, please, please stop." Like, "That's going to send me off." Because it was like loud hollering sounds just like, duh. "Duh-duh-duh-duh"; sure enough I had a seizure. And I always feel like I maybe I could have prevented that one had I told them, but like I didn't know. They were kind of new friends and, like, I didn't know how to explain that to somebody. I didn't want to be a nuisance or a problem or be, like, this girl with a disability.

Birdie mixes her "best friend" blue paint with some thinner and black paint to create a smoky grey color. She makes tall loop-like lines as The Band's "When I Paint My Masterpiece"[90]

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[89] Birdie makes use of this term to me self-imposed exclusion or isolation from social groups.

[90] https://open.spotify.com/album/5qfuMlbXxz7YsJUkStyNmH

joins the conversation. "I'm also very, like, kind of, an antique-y like person when it comes to music. I like all the old music." Antique-y music, for twenty-something Birdie, has not only what she calls a "timeless quality,"[91] but also a kind of sincerity that avoids putting on airs with flashy or overly processed effects and electronics. For Birdie, sincerity is rooted a sense of living and making art in a way that is wholly authentic to the personhood, background, and values of the art maker. Rather than attempting to be someone else, being sincere in one's art, for Birdie, means that one strives to use the artmaking process as an act of uncovering who she is. An art object becomes a manifestation of who she was or became while making the object. By finding and developing a strong connections to sincerity, a strong connection to who she is, she is finding and making her style. As Birdie's art mentor and teacher said, "Style is what happens . . . it's what you can't control; what comes out of you" through making and being art. Birdie, looks up from the canvas and elaborates:

> Like everybody has a different singing voice. Everybody's handwriting is unique to themselves. Two handwritings might look similar. Two voices might sound similar, but you're never going to know what your voice sounds like until you start singing. And the problem is that people don't think they can sing. People don't think they can draw. I mean I just started playing guitar. And, I'm, you know, 23 years old. So, you know, the problem is that people just don't trust themselves to do it, or they say, "Oh, I can't sing," or "I can't do art. It's so cool that you can do art. I wish I could do that." And it's like, "Well, just do it." So, it's just, you just got to do it.

As she continues to play with her frequency line, she chats about how some newer artists—like Real Estate, whose song "Darling"[92] plays in the background—have a similar level of sincerity in their music. She comments that these musicians know how to balance antique-y

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[91] When asked to explain what she meant by "timeless quality," Birdie clarified by stating that something is timeless when she "could . . . listen to it for forever. Not like, a song, a hit that . . . comes out on the radio that's good that totally [gets] overplayed and killed it [so] it wasn't good anymore." Repeat listenability appears to be a main aspect of what constitutes "timelessness."

[92] https://open.spotify.com/track/36PQh1G6h7n9VWB799fXpl

sounds (e.g., folk instruments and textures) with contemporary digital effects and sounds, "I like electronic to a certain degree. I think it can be a nice accent, it can be a nice spice, but sometimes it can kill the soup: it can make it too salty if it is all electronic." This concern with the balance in music is mirrored in Birdie's artwork and life. To find a moment of balance in music, in one's artwork, and in one's life means to live in a moment of completion, if even for a brief second. In her art, "You find that moment of balance and then you're done. Got to keep putting more layers on [the art piece] and it's about space, it's about composition. It's about balance and it can take you a while because you've got to kind of like subtract and delete and add."

"Balance is important in abstract art, and in life," Birdie says with a nod. Though versed in multiple artistic practices, abstract art is where Birdie's passion lies and where her sincerity as an artist and person best manifests. With a twirl of her brush, Birdie toys with a green-grey line and explains the purpose and meaning of creating abstract art for her, "You are creating a space, an essential experience for someone to enter and that's constructed through your expression and that expression is, is abstract and ambitious, similar to, like, like losing control when you have a seizure." Through creation of a space for others, Birdie exerts control over the artwork while also losing control in a way that allows unbridled sincerity and passion to explode in loops, refractions, and spats on the canvas. Music, again, acts a friend as Birdie creates, "I guess I get to just, like, sit here and listen to my music and have a space where I can just think about everything, you know."

As the EEG-inspired line emerges more from the woven gauze, Birdie thinks back on some of the ways music plays a role in her life. Music, and sometimes podcasts, act as artmaking companion, as onlooker and co-creative force. She also thinks about times when music, or at least some music practices, have been both friendly and antagonistic to her as well. “I used to play piano in high school, so that was a while ago,” she says while she resituates the gauze, “When I used to play piano, just like sometimes when I do abstract painting, these memories come back to me and they could be the most random memories.” Playing piano, like painting, once facilitated access to memories lost as a result of seizure. As she steps on treadles and pulls back the beater quick in pace, she tries to describe some pieces of music she learned on piano, showing a sense of pride when she can remember the “correct” musical terms and noting that “My music teacher would kill me” when she cannot. Though she often wishes she made time to play piano now, it does not seem to have the same draw for her that it once did. Rather, her visual art has taken over the role that piano played as a site for restorative practices.

A new type of musical friend has entered Birdie’s life. As Birdie adds some yellow to her pallet, mixing other colors with her newly cleaned brush to create a color akin to tarnished gold, she looks up, “I’m learning guitar.” She strikes the canvas hard, making a thud as the bristles bend and the ferrule contacts the canvas, adding a thick golden line. Birdie continues:

> We were getting pizza at this restaurant that was doing karaoke and it was like ten o'clock and it was just like a bunch of old people because there's just like a bunch of locals down here in the winter. And, so, I was like, “What the hell?” I've always wanted, so I sang "Jolene"[93] at karaoke, I love that song. It's one of my favorites and, um, and I was like, “Oh my gosh, that was so fun. Like I should, I should, uh, like, start singing or whatever.” Kind of joking around. And then my boyfriend taught me “Jolene” on guitar because it's pretty easy, I really like it. I really like it. I want to play right now.

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[93] https://open.spotify.com/album/5DyOxuvdSmTSNAmkfcsBsj

Birdie thins out the gold and adds a shadow to the thick line that resembles the EEG-inspired line from her weaving, "I always thought that music, or singing and music, was this mystical thing that was too hard . . . It seems more approachable now." She describes the one-on-one attention she receives from her boyfriend[94] and the genuine care she feels from him as he teaches her the guitar, encouraging her. "Know, sometimes [you need] somebody else to give you the confidence you need," she quips and then muses about the intensity of her new passion to strum and sing, strumming so hard she has ripped the skin off of her fingers, as indicated by a bandage now dirty with paint, saying, "and sometimes you need space for self-exploration." She likens her experience learning guitar to her relationships with teachers who were positive catalysts for her visual art as they provided confidence boosts, chances for self-exploration, and one-on-one attention as requested; good teachers, like good friends and music, can match, combine with, positively impact, and/or help one find one's personal frequency.

Birdie intensifies her work at the loom, almost as if overcome by a front in this storm of work. After a few moments of work with only the hushed sound of "Ripple"[95] by the Grateful Dead playing on Birdie's phone, she stops and looks at the loom and at her hand-drawn interpretation of her EEG. She points

> This is the one I have yet to do and that's my last one. I'm going to finish this weaving [and} I have these like little design pieces right here [for next]. I don't know what it's going to look like, but I think that it might end up looking like, uh, a clef in music, you know? But, the larger meaning of this, even though, like personally to me it has a very much deeper meaning for the viewer, the takeaway I would hope is, like, we all have a frequency and everything has a frequency.

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[94] Birdie wanted you to know that she had broken up with this boyfriend by the editing phase of this document.

[95] https://open.spotify.com/track/1OE5l6sedVcIFELMuxQOPI

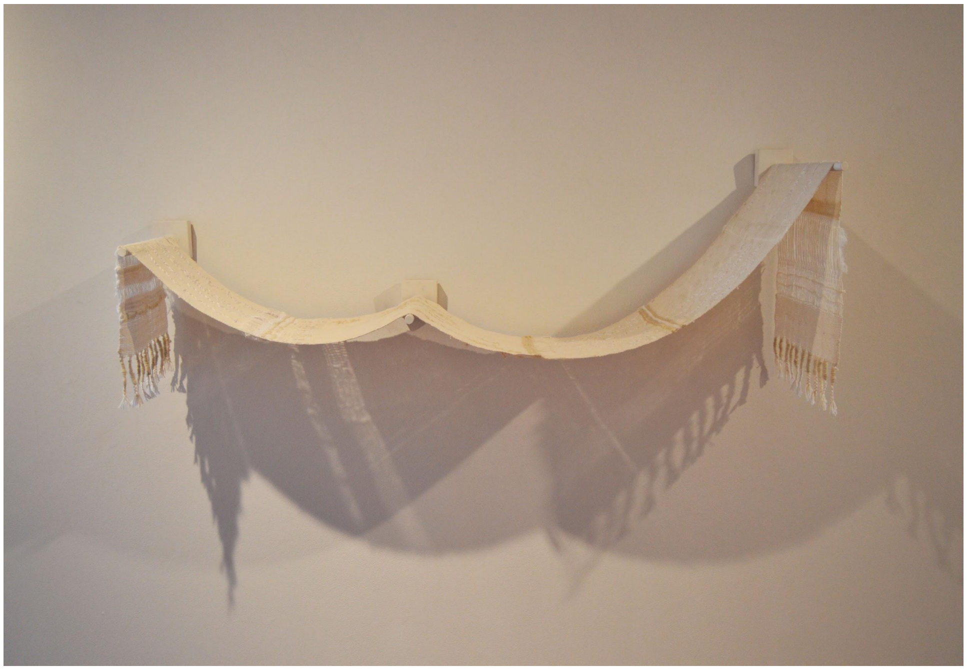

Figure 12. Birdie’s EEG-based weaving entitled “Seizure”

Figure 13. Close up view of Birdie’s EEG-based weaving entitled “Seizure”

### Breaking alone, with others, and against Tourette's:[96] Daren's Breakdance Dream

**Pseudonym.** Daren [21 years old]

**Diagnosed disability.** Tourette syndrome

**Narrative representation.** This description is written as a first-person point-of-view recollection of a late-night individual breaking/bboying/breakdancing practice session recalled by Daren numerous times during our interviews. Although much of the description is rooted in Daren's description of a past event, I have situated it within the present and Daren's current experiences and activities for narrative clarity. An imagined dream sequence and morning scene frame additional aspects of Daren's lived experience of disability in, through, and around music.

The long medley of beats pumps from the small speakers paired to my phone. Beads of sweat merge into streams on my forehead; they drip and pour from my chest, splattering on the mat laid on the floor. I pause briefly, breathing fast and deep to see the digits of my alarm clock blink from 12:59 AM to 1:00 AM. I really should be getting some sleep, I've got a lot to do tomorrow and I won't be any use if I'm worn out, drained, and fatigued. "You know what lack of sleep does," I hear a part of myself speak. Lack of sleep, like stress and anxiety, can make me more prone to . . . well, it can make things harder to control. "I know," I answer myself, but I'm feeling euphoric right now. I seem to have unlimited energy.

I've been practicing my moves for over two hours now. It usually takes me sometimes about a good hour to even warm up. Something that I just have to get through as I tell myself,

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[96] Although the currently acceptable formation is "Tourette syndrome," it was formerly a named syndrome, "Tourette's syndrome," and is often referred to as Tourette's in vernacular. Here I use both formations, one to indicate diagnoses (i.e., "Tourette syndrome") and one to indicate Daren's personification of the diagnosis (i.e., "Tourette's").

“You’ll feel better,” and I usually feel exhausted at this point. Breaking is such a very raw type of emotion or release. So, here I am and I just can’t quit it. I’m hooked and maybe a little bit more won’t wreck me for tomorrow. I’ll turn the music down just a little—I don’t want to upset my parents in the next room—and start with a little two-step groove. I’ll focus on my toprock right now and drill a few moves I’ve been working on before I chain them together for a bit of freestyle. Maybe I’ll add some freeze transitions.

I’m building up momentum. I try out a side chair spin and though I slip a bit and stall, I’m at my peak. I feel the music move through me. It energizes me. It makes me aware of myself in the moment, completely present in the dance. All other thoughts seem to melt away. I am my dancing right now; there is nothing else but me and the music. No prying eyes or drunk outbursts of people who use you as their entertainment like at dance clubs. No judgement or outside evaluation by others trying to figure out why I’m doing what I’m doing or what this or that movement meant. No need for explanation here. It’s just me and the music. Sure, there isn’t someone to battle against, someone to challenge me and provide a reciprocal kind of environment. Yes, my breaking friends and fellow student organization members aren’t here to cheer me on. “Yeah, but there isn’t anyone here I have to teach, no one I have to personalize for but me,” I hear myself remind me. I hit the elbow freeze dead on and move out of it into another a pin drop rest and clean footwork finish.

The music grows and I feel the stress of the day fade. Nothing else is here, it is just me. Me developing my own abilities. Me challenging myself. Me and my body. My head isn’t clouding my living in this moment. Me being the self I want to live in when I can, a self unchained by the expectations of others and the pressures of needing to control something that is me, but not me. Me being just Daren, just me, just a person. Not a dancer, but I’m dancing. Not “x” religion, but I’m religious. Not someone with Tourette syndrome, but I feel it, sometimes. Just me, just Daren.

“Daren, look at the clock,” a little voice speaks and shakes the flow of music through me. The clock blinks “3:05 AM” and I know, though part of me wishes I didn’t, that it is time to call it for tonight. I stop. I towel off the accumulated sweat and put away the mat. I pick up my phone and click off the music that has been on a loop for the last few hours. A silence takes over my room. I climb into bed, sit there, and I reflect. Throughout all the dancing I didn’t have a single twitch, tic, or stray vocalization at all. I didn't think about it at all while I was dancing. I was too much in the flow of the music and the moves, too much out of my head to be conscious of the way Tourette *didn’t* enter my world to stand in adaptive opposition between me and my wants. There wasn’t any space for Tourette in my room tonight because the room was filled the music, my moves, and me.

My head hits the pillow. I think about Tourette syndrome, that psychological and neurological disorder that’s been a part of my world since I was eleven and in 5th grade. When I was younger, there were lots of head twitching, general body twitches, and the vocal tics. The diagnosis seemed to explain those things and that diagnoses led to the 504 plan I used to help me adapt in school until college. Too bad that plan couldn’t help me when I got, or still get, frustrated with a piece of music I was learning or being forced to play on the piano. Frustration and stress elevate it; stress, it just compounds the Tourette’s strength. I’ve learned how to cope, but as much as it has gotten better, it has also gotten worse. Tourette, that adaptive opponent, that opponent that usually seems all-too-prepared to challenge the ways I’ve learned to work with and hide my tics. It’s there, present and changing when things get hard, except when I’m dancing.

I've been dancing since late high school, end of senior year. It's a lot different from when I play piano and for those five years I played violin, actually. Although I was forced to learn piano, just like all my Asian friends were forced to play by their parents, I like to play, especially soundtrack music. It's a way to express myself, and I enjoy that, and I enjoy improvising around themes from soundtracks. To me, playing piano is really a mental thing and I'm prone to tics when I'm really mentally focused. A lot of head jerks seem to come when I'm playing piano, especially while wearing headphones.

But, when I dance, I don't notice Tourette. It, like, goes away. Dancing is very physical and, oddly enough, I just don't feel Tourette when I'm dancing. I don't know, maybe I don't pay attention to it while I'm dancing? But when I think back after I'm dancing, I'm like, "I, I didn't twitch at all." That was the case tonight, for sure.

My eyes close. I think, maybe aloud, "I'm so grateful for dancing in my life." And I sleep a deep sleep. And, I dream.

Suddenly, I'm at a dance battle between a solitary and self-focused version of myself (the alone me) and one that is dedicated to service and helping others (the *social/service me*). It's a heated battle, but it's not mean-spirited. There's intimidation and each me fronts their confidence, trying to show up the other. The me who would rather be left alone, left to practice by myself for personal betterment, left to not have to worry about others' expectations and assumptions, is skilled in uprock techniques, with a nice bag of power moves to draw on. The other me is eager to teach, eager to be a physician's assistant so I can help people with neurological disorders. This me seems to be all about downrock, familiar with the 6-step and its variations.

The <u>alone me</u> starts off with a jerk as if to say, “I’m in it to practice and get better, not in it for some social objective.” <u>Alone me</u> seems a bit more creative with his choices of moves and how he strings them together, freed from the overbearing judgement of others. He flips, out of nowhere, and lands, ending with a bow and arrow burn.

The *social/service me* emulates some of the toprock from <u>alone me</u>, moves into the same flip, but lands into a downrock freeze stand. He spins and his moves seem to scream, “Yeah, Mr. <u>Alone</u>, if you’re so on your own and into it for the ‘personal development,’ why are you in this student organization, this social club, anyway? It isn’t like you to need others for personal growth.” He kicks sarcastically and fires back a sad and drooping version of the <u>alone me’s</u> bow-and-arrow move that is equally dripping with sarcasm.

<u>Alone me</u> whips through a furious combo of moves. The combo seems to scream at *social/service me*, ”You know, they say you’re just in the whole service thing because of Tourette.” His moves are playful, but snarky and pointed, reiterating the playful way my family pokes fun at my career goals as a physician's assistant and my personal medical history and experiences with healthcare workers in my youth. Still, though, it is kind of a low blow and not completely in keeping with the heated-but-not-mean-spirited air of a breaking battle, but the *social/service me* has had to develop thick skin. The <u>alone me</u> makes a subtle kick to signify he’s done.

The *social/service me* jumps right in, feverishly responding by distorting each of the moves the <u>alone me</u> made. His kicks, flips, and lifts all seem to say, “Yup, it isn’t feeling humbled, finding a greater sense of gratitude and sense of self through helping others. Don’t lie, it may be hard and exhausting, but you like teaching and being president in the org. and serving others in internships.”

As the two continue to battle, more and more people surround them. The crowd attention and the less-than-positive tilt of the battle have me feeling weak. I, the composite of the alone me and the *social/service me*, am generally skittish about any unneeded attention. It drains *me*, weakens me, and makes me, I, feel less in control of the situation, less in control of what the onlookers are seeing, thinking, and reading into everything. In this moment of weakness, I feel a new presence enter the battle, one that I feel and that others infer through what they see, but that the ***me-s*** seem to not acknowledge as they continue their battle. **Tourette syndrome**, my dream state personification of the adaptive opponent in my life, steps into the cypher.

Alone me goes for a hard jerk movement but the muscles of his upper body have tightened and his head whips back. "What was that?" someone in the crowd seem to whisper. Alone me brushes it off, building more, but clearly planned, head jerks and stylized neck cracks into his repertoire. Alone me can disguise it, but I see the shadow hand of **Tourette syndrome** at play. I feel it because he is me. I feel the need to control what is going on, the need that is racing in Alone me's mind.

*Social/service me* jumps in and dances at the same time as alone me. He goes through a series of moves that use lots of hand coordination. As he goes for another armchair lift, his lifting hand seems to tremble, just enough to make him rock in his lift. He jumps to another lift and uses his non-dominant hand, trying to avoid the twitch, the tremble. It works for a while, but then Tourette syndrome jumps in again, adapting to his change of hands and now taking short-term control enough to make him kick out of the lift.

The crowd has begun to notice the twitches and I feel like I'm losing more control of the situation. I feel their judgement as they see things that look "out of the norm" to them. The ***me-s*** continue, trying to disguise twitches as they add more flexes, yawns, and cracks to their moves. As the crowd focuses on these moves and on the battle and breaking as a whole, I feel their eyes shift to me. I'm seen, though I've been hidden thus far. The eyes of the crowd seem to ask for an explanation. I begin to feel that I owe them one, though I'd rather not provide it.

I begin to talk, "Well, it's just this twitch I have," and, "He's just stretching." In that moment, I feel **Tourette syndrome** turn its gaze to me. Preempting its touch on my vocal folds, I clear my throat. I open my mouth and the crowd disappears. It is just me and Tourette syndrome now standing in a cypher of our own. I look at it and it is almost sentient as it adapts to my moves, predicting and counteracting each kick, lift, jerk, and flip in the moment. It's almost like it knows what I'm about to do. It's just standing in the way every time, always against me in that sort of way. It feels like such an obstacle, an opponent. But, I remember, that it is a part of me as much as is apart from me. It isn't really a separate entity, but it's how it feels and it is hard to explain without personifying it.

I wake up briefly, putting an abrupt end to these dreams. I get up and grab a glass of water, then return to bed. I sleep a heavy, dreamless sleep. Any memory of my dream fades away.

I wake up to the sound of my alarm and I'm surprised by how awake and clear-headed I feel after the late evening breakdance practice session. I feel energized as I pack and prepare for my volunteer medical mission trip to the Dominican Republic.

### Diversity, Access, and Inclusion at the Potluck of Life: Sienna's Life in Action

**Pseudonym.** Sienna [21 years old]

**Diagnosed disability.** Legally Blind

**Narrative representation.** Sienna often spoke of the "Potluck of Life," in which people are welcomed to share what they have and partake in what others have brought. In this sketch, Sienna attends an imaginary potluck in which they (Sienna's preferred pronoun) perform with their band, Kiss My Grass. Throughout, Sienna refers to bandmates and related individuals, all of whom have been given pseudonyms. Sienna's phenomenology is presented in Verdana, 24-point font, which is legible for persons with low vision.

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A long table set with a blue tablecloth with white spots waits empty in a park nestled between the Allegheny and Blue Ridge mountain ranges. This table is soon filled with the crock pots, casserole dishes, and baskets of food emblematic of a potluck.  People roll in, following the contours of the hills, each step is a conversation between their feet and the land. Sounds of a solo banjo player/singer drift through the air, “Rock me momma like the wind and the rain. Rock me momma like a south-bound train."[97]

As each person approaches the table and adds their contribution to the potluck, they encounter Sienna perched on a stool, dressed in their "bluegrass Ellie May outfit." Sienna plays and sings, "Running from the cold up in New England, I was born

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[97] (Dylan & Secor, 2004)

to be a fiddler in an old-time string band. My baby plays the guitar, I pick a banjo now."[98] As the gathering potluck goers sing the hook of "Wagon Wheel," Sienna turns and says, to no one in particular, "There's just something about Appalachia. I love the wild's lack of structure."

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[98] (Dylan & Secor, 2004)

The lack of structure of the setting seems fitting for Sienna, and the music they play seems to fit naturally too, not only because much of the music was created in or around the area and references the old-time pieces that are mainstays of folk musicking of the region, but also because these tunes are a form of music that, for

Sienna, allows all people to join in, giving everyone their own part to play in the musical conversation. Sienna continues, "And if I die in Raleigh, at least I will die free,"[99] before being joined by the accumulating potluck goers on the refrain, "Rock me momma like a wagon wheel. Rock me momma

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[99] (Dylan & Secor, 2004)

anyway you feel. Hey, momma rock me."[100]

Marie situates herself and her bass next to Sienna and begins to play noticeably faster. "I've gotta hop on the bandwagon," Sienna thinks, while smiling at Marie, "I gotta pick up the pace if I'm gonna keep up with this conversation."

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[100] (Dylan & Secor, 2004)

Sienna continues to pluck, smiling as they see[101] and hear other band members make their way into the musical mix. "I'm nothing without the band because they support me," they think, "I know that if I mess up—if I miss a beat or a word, the band will slow down and they will re-accommodate and get

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[101] Sienna is "legally blind" and can see with the assistance of strong corrective lenses and other adaptive equipment. As such, it is important to note that "legal blindness" does not always equate to "total blindness" (American Foundation for the Blind, 2018). Legal blindness is articulated by the Social Security Administration (2003) and many people who are deemed "legally blind" may have residual functioning, also known as residual vision.

back on track to where I am.” As a drummer and guitarist join in, Sienna whispers to themself, “They know me. They know that I get super stage fright when I sing out of character.” The crowd bellows out a last refrain, “Hey, momma rock me.”[102]

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[102] (Dylan & Secor, 2004)

More people make their way to seats as Ishmael, a gangly teenager wearing a t-shirt that says, “I have Autism, what’s your super power?”, steps between Marie and Sienna. The trio, with Ishmael on guitar, slow down to start playing “Bury Me Beneath the Willow.” Ishmael sings, “It’s many a night while you’re sleeping,” and

Sienna begins to wax nostalgic, lost in thought, still plucking the banjo. A vivid memory of the opening night of *Into the Woods* during their junior year in high school springs to mind. There they stand, in the spotlight, singing, “Wake up! Stop dreaming. Stop prancing about the woods; It's not beseeming."[103] Sienna can feel the gaze of the audience as they stir the emotional chemistry between self, set, music, and audience with a subtle arm gesture. Their arm movement twitches their cane, which catches the spotlight, splintering light across those

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[103] (Sondheim et al., 1999)

seated in the front rows of the auditorium.

As Sienna sings, an internal voice counts each physical step, "Ten, eleven, twelve, right step one, right step two, thirteen."[104] They measure each step carefully, attempting to miss the low-lying tree trunk set curiously in their

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[104] Sienna noted, "It is a stereotype that blind people count our steps. It is not an efficient way to navigate . . . When on stage, I sometimes count steps . . . but that is due to the fact that the props are all in the same place every time. While navigating off stage, I never count . . . I just want the reader to know that this is only used specifically in theatre and that is not how I normally navigate."

path on the stage. “This is so weird, counting is so stereotypical, but I guess only in the theatre,” Sienna thinks to themself as they sing, “No one lives in the woods. There are vows, there are ties. There are needs, there are standards. There are shouldn'ts and shoulds.”[105]

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[105] (Sondheim et al., 1999)

“Luckily,” another internal voice notes, “the director let me use my cane and hired an orientation and mobility instructor, unlike that last time. At least this director didn’t ignore my difference.” The director of the last musical thought it was “inclusive” and artistically challenging to dictate to Sienna that “your character isn’t blind and doesn’t use a cane.” A rush of rage and sadness invades their consciousness as they remember how they badly they felt after  that comment: “Oh, I guess I can’t be an actress because I have a cane and, like, most characters don't use a cane?”

Sienna continues singing in their memory, “Just a moment, One peculiar passing moment. Must it all be either less or more? Either plain or grand? Is it always 'or?' Is it never 'and?'"[106] Another internal voice interjects, "As if my difference doesn't matter, as if you can wish it away or remove it so you don't have to think about it, plan accordingly, and, most of all,

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[106] (Sondheim et al., 1999)

think about your own difference. As if you are the standard and it is either your way or nothing else." The memory fades as they sing, "Why not both instead? There's the answer, if you're clever."[107]

"Then perhaps she'll think of me," Ishmael sings, slowing for the final, drawn out cadence. Sienna

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[107] (Sondheim et al., 1999)

snaps back into the present, looks around, and adjusts their thick glasses which have slipped in the rising mugginess. They see the outlines of food containers and think about how the foods stuffed into these containers are as diverse as the large crowd gathered.

More musicians have arrived—some carrying support canes, others wearing hearing aids, and some chatting in American Sign Language. They unpack various bluegrass and old-time music-related instruments. Sienna and the rest of “Kiss My Grass,” a music therapy-based bluegrass band for young adults who are deaf/hard of hearing, blind/vision impaired, and deafblind, move to a small open space surrounded by picnic tables filled with chatting potluck attendees.

The full band situates itself and jumps into a distinctly unexpected cover of Angel Haze's "Battle Cry." The old-timey-tinged background subsides to a sparse drum and guitar accompaniment as Julio raps, "It seems like yesterday that

I was nothin'. Then all of a sudden, I'm a volcanic eruption. Then all of a sudden, it's like spontaneous combustion. And I'm all up in your face yellin', ‘Bitch, you can't tell me nothin’.”[108]

After playing in the introduction, Sienna sits out for the rest of the song. Sitting out, taking the role of

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[108] (Haze, Furler, & Kurstin, 2014).

a listener, reminds Sienna of their pendulum-like life, “My role as a human being is to take space but also make space," Sienna thinks. This moment requires their identity as banjo player for “Kiss My Grass” to give up space for other identities within the band.

The respite from playing gives Sienna a moment to consider their various identities, identities that combine and intersect differently based on the particularities of the time, physical space, and social context in which Sienna is engaged: “I’m a woman; I’m disabled; I’m asexual[109] pan-romantic; I’m Jewish; I’m Middle

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[109] Sienna noted that “many individuals believe that asexual people do not have sex; some do some don’t and for numerous reasons.” As such, Sienna wished “to debunk misconceptions about asexuality” here. University of California, Davis’s Lesbian, Gay, Bisexual, Transgender, Queer, Intersex, Asexual Resource Center defines asexual as “A sexual orientation generally characterized by not feeling sexual attraction or a desire for partnered sexuality. Asexuality is distinct from celibacy, which is the deliberate abstention from sexual activity. Some asexual people do have sex. There are many diverse ways of being asexual” (N.P.). “Asexual” is the “A” in LGTBQIA.

Eastern, white-passing.” Each one of these identities alone can be a basis for empowerment or oppression, depending on the physical and social arrangements, and doubly so at the intersections of identities.

As a pre-licensure social worker, Sienna is conscious of how their identities might connect with, or not, the identities of those with whom they interact at micro, macro, and meso levels of the profession. As a social justice advocate, Sienna is conscious of how they catalyze their identities based on the cultural capital valued in any work context. As a musician, Sienna is conscious of how their musical identities, and assumed skills, are read, misread, and/or not read by teachers and organizers. Sienna can feel the readings of teachers and organizers based on how adaptive and/or proactively inclusive the settings are arranged. As a social person, Sienna is all too conscious of how their identities are read and misread in everyday life.

Sienna thinks of the times when nondisabled others read their disability, marked by their cane and/or thick glasses, and categorize them as weak and in need of help. They think of times when their identity as woman is read by others in a way that overly sexualizes them, making them an object for others' gaze and use.

Sienna thinks of times when the intersection of their identities as disabled and woman interact with the physical and social material of the moment to marginalize them, dehumanize them, and desexualize them. In these cases, their identity as woman seems secondary to the negative reading of their identity as disabled by nondisabled and disabled others. Individually or intersectionally, socially-applied identities can be not only marginalizing, but also totalizing: “I am a person with a disability, but that's not my whole story. There's so much more than that.”

Yet, Sienna also remembers times when they have been able to wield their intersecting identities for personal empowerment, to draw attention to issues of collective importance, and to find belonging with others with similar identities. For instance, when advocating for disability accommodations, their identity as disabled might be at the forefront, giving power to their work. When discussing rape and sexual assault of female students, their identity as an assaulted female provides a level of authority in discussions with others. When calling attention to the desexualization of disabled females, their intersectional identity can be a boon based on the social capital valued in the moment. In these moments, their voice can erupt as a tool to speak with and for other marginalized persons.

Sienna hears the applause indicating the end of the Angel Haze cover and drawing them back into the present. “Sometimes I get lost in the moment,” they reflect. Sienna begins a frailing pattern on the banjo to introduce the band’s cover of “Folsom Prison Blues.”

“Such an interesting song,” Sienna thinks, “it speaks about feeling trapped and highlights so many stereotypes of people in prison.” They think of the ways stereotypes have trapped them and their friends. The negative stereotypes about disabled persons, being weak and feeble, and/or in need of the help are a regular and unwelcomed companion in Sienna’s life. They constantly fend off unwanted help.

“I feel like they look at me and the first thing they see is someone who's incompetent, or someone who's in need of a help from an able-bodied person . . . but that's not true at all,” they contemplate. “I like to tell people that, if they see someone with a disability, don't ask them if they need help unless you would ask that same question to someone who wasn't disabled.”

“That’s not to say that anyone with a disability would rather never be warned of obstacles, such as unexpected potholes in the way. You’d hope that someone would offer that kind of warning to anyone.” Sienna continues to contribute musically to the cover while lost in thought about the impact stereotypes have had on their life, as if doubly conscious of both their external/social world and their internal world. “The trick here is that because of visible or observable things, someone builds up a set of assumptions about what I can do, what I need, and who I am. Then they heap these assumptions, these needs, and these identities on me and on others too."

Applause catches Sienna by surprise, collapsing them into the present. They re-adjust their banjo to prepare for the next tune. This may be Sienna’s favorite song right now—to listen to and to play—a cover of Disturbed’s cover of “The Sound of Silence.”[110] A slack-key guitar intro sets up the cover, bringing Sienna to a feeling of calm. Ishmael steps up to sing the opening line, “Hello darkness, my old friend, I’ve come to talk with

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[110] (Simon, 1965/2015)

you again." This song always gets Sienna excited as it seems to resonate with Sienna's social justice-guided life. They envision standing in a crowd in which microaggressions[111] and exclusion run rampant in the silence of ignorance and narrow-mindedness. Stereotypes encourage this silence,

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[111] Sue et al. (2007), speaking specifically from the perspective of racism, define microaggressions as "brief and commonplace daily verbal, behavioral, or environmental indignities, whether intentional or unintentional, that communicate hostile, derogatory, or negative racial slights and insults toward people of color. Perpetrators of microaggressions are often unaware that they engage in such communications when they interact with racial/ethnic minorities" (p. 271). Pierce, Carew, Pierce-Capodilupo, et al. (1978) suggest these are "subtle, stunning, often automatic, and non-verbal exchanges which are 'put-downs'" (p. 66.)

allowing people to make nasty assumptions, to act on them in ways that are hurtful, and to avoid listening to the voices of those in the crosshairs. Sienna wants to emulate David Draiman, the lead singer of Disturbed, and shout, "Fool, said I, you do not know, Silence like a cancer grows."[112]

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[112] (Simon, 1965/2015)

But, what impact, if any, they wonder, would shouting out do in the face of "People talking without speaking, People hearing without listening."[113]

"Are people listening to the lives, the voices, of disabled persons when they assume that blind musicians are just naturally

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[113] (Simon, 1965/2015)

able to play all sorts of instruments without a whiff of lessons or previous experience,” Sienna muses. They think of a time when someone voiced such a stereotypical assumption and their answer, “No, I can't. I never learned how to play that instrument. I wasn't born knowing how to play the mandolin. I don't know how to play the mandolin. I am in a bluegrass band and I'm blind and don't know how to play the mandolin. I'm sorry. There's a lot of strings, okay?” Sienna laughs, “I picked the banjo because it has a string less than the guitar, and the bass 'cause it has a string less than that one. Um, but, but the trombone, I can't play the trombone. I never learned."

Ishmael sings, "Take my arms that I might reach you. But my words, like silent raindrops fell."[114] "Do people listen when they take these and other stereotypes as the truth . . . seeing persons with disabilities as weak and in need of

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[114] (Simon, 1965/2015)

help from people who don’t have disabilities,” Sienna whispers to themself.

Their activist voice rises, “Stereotypes encourage microaggressions that, through doing, speaking, and the physical set up of spaces, deny persons with disabilities personal identities, privacy, independence.

Stereotypes desexualize and infantize disabled persons and make action that assists or raises up disabled persons more about the satisfaction and inspiration of the nondisabled person. But, if people would just listen," they think, "beyond just hearing, actually listening to understand what people with disabilities say, they’d know better.”

Still lost in thought as the music plays, Sienna thinks, “I can do most things on my own and I’ve learned to accommodate myself, so if they want to help, they could proactively ensure I have access to the same things and actions they have and then get out of my way.

If people would listen and know that I have sex—yes, even people with disabilities have sex—and treat me as a sexual being and as an actual adult, an adult person, they might get it.” Their face becomes somewhat flush as the intensity boils over, “If people would listen that I have my own stuff going on and don’t need them to add to it because they want to feel good about themselves or that I’d rather not have them be inspired by me because I somehow exceed the pathetically low expectations they have of me . . . be inspired when I, and anyone, does something that is actually remarkable, not when we do something that makes you think, ‘Well, if they can do it, I can too.’ I mean, people are inspired I can read at all but is that something to be inspired by (with or without Braille)? What does that say about the expectations you have for me? Instead of being inspired by that, you could offer me some choices on how I can read and learn the music—like offering Braille notation—and be inspired by my killer skills. It's just so frustrating." Sienna joins in as others in the band sing, "But my words, like silent raindrops fell, And echoed in the wells of silence."[115] Sienna plays their banjo as the song fades out.

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[115] (Simone, 1965/2015).

The band sets aside their instruments to eat. They greet the gathering of family members, teachers, and friends who have come out to the potluck. Over by the sweet tea is the local pizza shop owner, Mr. Shen, who gave the Kiss My Grass their first gig and, in preparation for that moment, ensured that the two-story shop in the 1800s building would be at least easily accessible on main level for the band and their guests. He had never condescended or patronized them when introducing the band. He had also been cool enough to give them, a group that had played their instruments for two weeks, a place to grow and share their music. Now, Kiss My Grass played at Mr. Shen’s pizza shop regularly, and Mr. Shen was welcoming, respectful, and proactively accommodating.

Standing over near the pies is Mrs. D., Ishmael's music teacher, who has given him time, care, attention, and voice in what and how he learned. Sienna remembers distinctly how Ishmael wanted to play guitar and sing “The Black Parade” by My Chemical Romance for the school talent show. Despite the fact that Ishmael had never held a guitar or sang in public, Mrs. D. looked at Ishmael and said, “All right, the concert is four weeks away, so we should probably start practicing.” The sense of pride in

Ishmael’s voice after he played his mediocre version of “Black Parade” on stage and the pride he had in saying, “Look, I can play guitar now,” are burned in Sienna’s mind. Mrs. D. was supportive and realistic, not sheltering Ishmael from constructive criticism, and adaptive as she helped Ishmael meet a personal goal. That meant all the world because it showed she cared.

The thing about Mrs. D. and Mr. Shen, Sienna thinks as they move through the potluck group, is that both let the members of Kiss My Grass bring what they had to the table. Both also made it so everyone could get to the musical table if they wanted to share.

Potlucks: a fitting metaphor for what a truly accessible and inclusive community can be.

Sienna muses, “If you have a potluck, everyone brings their own special recipe. So, you know, like, maybe their cornbread is the best in the county and they have, like, three blue ribbons and you would never had known that unless you had a potluck, because you might have told them to bring chicken if you were having a set menu. But, with a potluck, you get the chance of surprise as people get to bring their favorite and cherished recipes. People get to share themselves instead of catering to the wants of an organizer. With a potluck, people can bring their identities, their strengths, their interests, and all of themselves to share. They get to sample from what everyone has brought and they get to leave a little—well, let’s be honest—a lot more, with chances to listen, really listen with mind, body, and soul, to learn and understand more about life.

Instead of being confined in boxes

or to a set menu, we all get fed more when there are more people at the potluck of life.”

## “Stories to Tell the Rest of Your Life”: Ice Queen’s Trophy Room

**Pseudonym:** Ice Queen [19 years old]

**Diagnosed disability:** Inattentive Attention Deficit Hyperactive Disorder, Generalized Anxiety Disorder, and Diagnosed Emetophobia (fear of vomit)

**Narrative representation:** Ice Queen walks us down an envisioned “trophy” case. Each trophy represents an important musical experience. She explains to us how she “earned” each trophy and its significance in her life.

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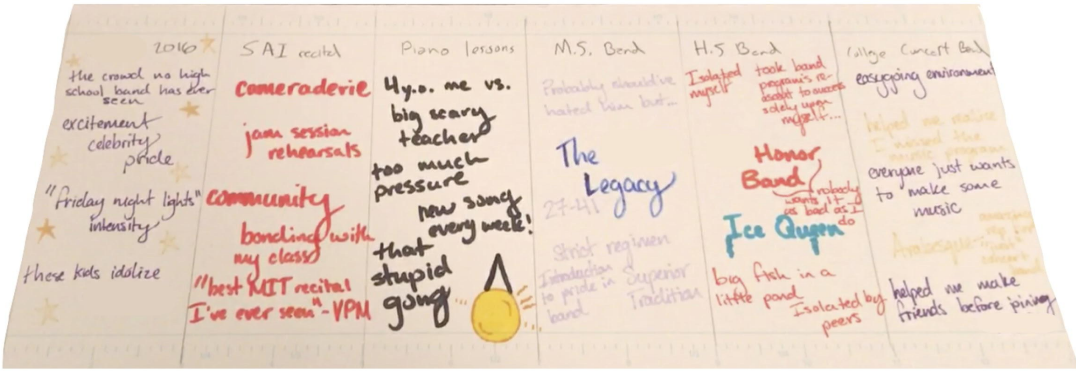

Figure 14. Ice Queen’s five important musical experiences

### ***Trophy 1: A button pin emblazoned with blue text reading “Cavalcade of Winners” and golden text bearing the name of the university.***

Excitement, Celebrity, Pride: The crowd at Cavalcade of Winners must have been a crowd that no high school band has ever seen. It was certainly huge from my perspective on the field. It was at night, it was dark, the stadium lights felt like spotlights almost, and there were hundreds of high schoolers in the stands absolutely losing their minds for us, just for the university marching band. It had that “Friday Night Lights” sort of feel, but it wasn’t *just* a football audience, it was hundreds of high schoolers who were obsessed with our marching band and they were losing their minds. It wasn’t *just* a football audience that sees the pretty pictures on the field and hears the fun music. These high school marching band kids understood the intricacies of the show and the musical aspects of our performance. It wasn’t *just* a football crowd that doesn't really know or care about the deeper technical stuff, it was a ton of kids that want to be like us, want to be in our place, and get what’s going on. The Cavalcade of Winners really is this big celebration of marching band and the pride that comes from being involved in quality experiences like this, experiences that give you stories to tell the rest of your life.

I joined the marching band during my sophomore year in college and played a completely different instrument than my performance major instrument, flute. I taught myself the saxophone because I guess I wanted to be heard. No one can hear the flutes in a 450 member band. Also, I picked a different instrument because I wanted to distance myself from my high school experiences. I wanted to distance myself from relapsing into the Ice Queen in my actions, and I saw flute and being in leadership as something that might make me relapse and distance myself from the section and band. I did all this after a year—my freshman year—being a music performance major and having trouble practicing solo rep, which would give me a lot of anxiety, especially when I noticed or, like, realized that I needed to change something. I was absolutely miserable being all alone at college and finding that I was struggling with just focusing on homework, during class, keeping my focus on the task at hand. I didn't reach out to people. I didn't know anybody in the music program. I didn't have any friends. I was just, like, really absolutely miserable and depressed all the time.

I’d had issues with anxiety for a long time, especially separation anxiety from my mother. I’ve also struggled for a long time with a fear of vomit. When I was in middle school, I couldn’t even go to sleep-away camps, long trips, or things like that because I couldn’t be away from my mom. I had a hard time with band trips because of my phobia—that was something that worried me about joining the college marching band originally. So, I often isolated myself from friends and bandmates. Add to this, I entered college not thrilled to be going to any school, but thinking I was going to be a performer—me, a marching band and large ensemble kid, thinking I wanted to be a solo performer—and I just thought, “I’m not gonna have time for this [marching band].” So, I shut an important part of my happiness out of my life and trudged along. I got more and more anxious, and being away from my family, and my mom, was really hard on me. I started to have fairly large problems with focusing. This hadn't started in college, but it sure worsened exponentially. I've had focus issues for a long time, but my high school's competitive environment made me feel like I simply didn't measure up intelligence-wise instead of realizing I might have a learning/processing disability. So, anyway, I started slipping in my classes, which made me more depressed. I began to question my choice of school, selected major, and self-worth to the point where I almost quit—but I didn't want the people in my hometown to judge me anymore than they already did, so quitting wasn't an option. And I was essentially alone.

I joined this marching band because I missed marching and I felt that I needed a change in my college life, something exciting and motivating. Good thing for that, too, because that's where I meet all the ΣAI[116] sisters and decided to join. Anyway, there's a lot of great things about being in the marching band. I mean, first, it's a fun way to end the day with our rehearsals each night. Weekends are always exciting with football games and exhibition performances. Also, for me, it provides a routine and something to look forward to all the time which keeps my head on straight. Marching band had given me purpose and direction in high school and it has here in college too, but I've done it completely different as I've connected with people way more. It also helps that everyone comes together on their own terms. We all get to pick to be here and that gives it a community vibe that is really meaningful. We all connect through rehearsals, sectionals, camps, trips—which I would have never guessed I could have handled in the past because of my phobia of vomit, and in social times after rehearsals. Seeing what we end up putting on the field and seeing all the people around you, you get this sense of communal pride everyone has in being a part of something much larger than themselves.

### *Trophy 2: A framed certificate proclaiming Ice Queen's membership in Sigma Alpha Iota situated atop a pale blue T-shirt adorned with floral pattern Greek letters "ΣAI"*

Camaraderie and Community: We were a strong "member in training" (MIT) class for ΣAI. At our recital, the membership VP told us that it was "the best MIT recital [she'd] ever seen." I think it was that

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[116] ΣAI or Sigma Alpha Iota is an international music service "fraternity." See https://www.sai-national.org/

good because we took the time to bond. That's wasn't easy for me given my past leadership and self-isolation experiences, but I learned a lot about what sisterhood is. I mean, I have a sister of my own, but sisterhood in ΣAI kind of takes on a different sense in this kind of situation. It's more about camaraderie and community. I got really close to the other MITs and learned a lot about them, especially through preparing for our recital and our service project, which was taking the recital to a local retirement home. There's nothing like being forced into a practice room in preparation for a recital to get people to open up to each other. There had been retreats, but not everyone was there—including me once—so our practicing sessions really were where I got to know everyone. They were real bonding experiences and I left knowing about each of them and seeing how talented they each were. They were almost like jam sessions, in a way, with us all chatting, playing, and sharing in that practice room.

I won't lie, I was worried about the recital: worried we wouldn't have enough to fill our hour time slot, worried everyone wouldn't come through, worried about the organization of things. But they all really came through in the end. I mean, I ended up feeling kind of like I was annoying to everyone else because I was, like, organizing everything and bugging people as I got the setlist together, made programs, and all the preparation stuff. But they really didn't mind. They didn't see it as me trying to be the authority, they could just tell that I wanted to get stuff done so they just gave me the reins.

I also ended up playing on, like, two-thirds of the pieces, but most of it I was collaborating. Like, I played piano for a bunch of people. I've played for a long time—since I was five—but not really accompanied. It's hard. You have to follow someone else, but by doing it you get to play some incredible music. One of the girls sang "Part of Your World" and another sang a song from *Phantom of the Opera,* and it was amazing to work with them to make the songs come out. It's weird when you're accompanying someone because you have to keep track of another person, which kind of sucks when you're used to being in control, but it's still really fun and I've never done that before. So, it was a weird experience because I was trying to be as "in it" as I could be, appreciating the musical moment, and still giving the poor girl the accompaniment she needed. I think just me playing the piano was a big thing, a way to connect with the other girls because they know I’m a flute player—a lot of them are in concert band where I have solos—but no one knew that side of me, the pianist side of me. The experience of playing, putting together, and practicing for that recital was really important for me and helped me have a place to open up and get to know my MIT sisters.

Having a big sister [ΣAI Big Sister] was also really important too, because she’s in the same studio as me and she’s just really kind. She’s someone I can turn to. So are the other sisters in my MIT class and in the chapter. I needed people to go to. I needed support because I almost didn’t come back after winter break of my freshman year because of all the difficulties I had the prior semester with anxiety, depression, loneliness, and the growing presence of ADHD, which I didn’t get diagnosed with until winter of my freshman year. I don’t know how I managed the rest of that semester, but when I finally pledged in my sophomore year, the sisters had given me an anchor and kind of forced me into connecting. I didn’t have that before and I was just kind of trying to do it on my own, which had always worked but wasn’t anymore. The sisters were there for me when I decided to switch out of music to psychology and there to support me when I realized what I’d always known: that music had to be some part of my life and career. So, in my sophomore year, I switched to music industry. The sisters even convinced me to join the marching band. Through this community, ΣAI, I found another community, the marching band, and they have both really been healing for me. With ΣAI, I have people I can hang out with, confide in, and be with.

Having people there for me was important during the semester in my sophomore year when I took the risk to join the marching band, which, in turn, gave me the opportunity to get to know the sisters of ΣAI and eventually join. I had just had some of the worst few months of my life. After a semester of falling behind, experiencing an increase in my focus problems, feeling depressed and anxious, and self-isolation, I hit what I kind of consider my rock bottom. You hear music majors talk all the time about reaching a point and starting to lose the love of music. The stress of practicing for hours on technique exercises, not even rep, not feeling like you are getting anywhere with your teacher, having to do all that busy work, and not feeling like you have time for an outside life, you know, just gets to you. That definitely started like, slowly chipping away at me, and I started thinking, like, "Why am I doing this?" And that was kind of what started the thought process of, like, changing my major and all that good stuff.

I was on academic probation and I was considering dropping out. I was just not happy at all. My doctor recommended that I get tested for ADHD and so I did that winter break. I kind of have a mixed feeling about the diagnosis. I was somewhat relieved that I was going to be able to get medication and that it wasn't just my intelligence being an issue—as in, it was something that could be altered and not just that I wasn't smart enough for classes. So, I came back to school just taking Gen. Eds. and doing concert band with new medication. I also switched from music performance to psychology, which made music something I got to choose to do. I was sort of hopeful but I was also really exasperated at that point, and it was before I had given the medication a chance to help me out. But, once I got into that routine and realized that it was possible for me to do well in school, or better than I had done in the past, that was the main reason I stayed, at first. But, maybe, the whole marching band thing helped me stay.

You know, people join service, social, and professional music fraternities because they love music and they want to try to connect to or give back to a community, to further these communities through music. It's a common factor that unites a room full of people. It almost gives you an immediate in to starting a conversation with people. You share common loves and have common activities to maybe do together. You can hang out, play together, or put on a show without having to go through all the "getting to know you" steps only to find out they don't like the same things as you, you know? Through sharing similar loves and interests, I've found and connected to people, these sisters, in a way that's unique. Being in this chapter of ΣAI, and being with my class, has helped me go from considering leaving school to feeling like I can't imagine going anywhere else and having an experience even remotely similar in terms of quality.

### *Trophy Three: A clear glass trophy carved with the figure of a smiley face balloon and the text "The Granchio Legacy: 27/41"*

Superior Foundation: Middle school concert band was all about pride, being proud of something I was a part of. Well, that and following my sister, because when I was little, everything I did was because of my sister. I wanted to be exactly like her, so I joined band in middle school. Mr. Granchio taught band in middle school and his brother taught band at the high school. They were kind of like the dynamic duo of band directors in my home down for quite some time. They were both working for something like 30 years. I never got to work with the older Mr. Granchio, the high school teacher, because he retired like six years before I got to high school. After he left, the band program just sort of went down the drain. It's surprising to think that they were so well-liked by students, but we worshiped them. They made us proud to be in band.

Mr. Jack Granchio was my teacher and he had a really specific system in place for how they taught and there was a different schedule for every day of band class. Some days we would learn rhythm. We would do rhythm exercises from this book to the point where we knew all of them by heart. It was a really strict program. He didn't put a lot of focus on making music. He expected us to make music on our own, and he would just kind of go with it and encourage it. So, the training I got in middle school was really good. But, I think, for me, it was more about the sense of pride he instilled in his kids. It was really cool to be a part of that program, to be part of something.

Mr. Granchio was strict. He just had this really dry sense of humor and would make cracks at us all the time. He was just this grumpy old man who acted like he hated us. He called my class "airheads" and just poked fun at us. At the end-of-the-year concerts, the eighth graders always gave him presents. My present to him was a papier mache balloon with a smiley face on it. After all, he did call us "airheads," so I made him an airhead. He hung it from the ceiling in his band room. At the concerts, he would also give out these awards, kind of personalized things. I remember in seventh grade I got a "musicianship award" and the "Gilmore Award for outstanding musician who showed leadership qualities," something like that. It was really important to me.

You know, middle school band can be something that people don't really take seriously, but he gave us a sense of pride. We were good. We put on a good product onstage. He had gotten 27 consecutive superior ratings at concert assessment. We had these shirts one year that said 27/41 on it: 27 consecutive superior ratings, I don't remember what 41 stood for. We would wear those shirts, like, all the time. And we were super competitive with the orchestra, which was also very good, about our "wins." I don't know how much the competitiveness and the drive to get superior ratings shaped us as an ensemble, or me, but I think it was really important, at least for me, to have that foundation of something I could be really proud of. Mr. Granchio's middle school concert band was something of which I was and am still proud.

It was good to have something to succeed in and be proud because it balanced out the hard times. I'd had a hard time focusing and succeeding in math from, like, day one. I always felt like, "Mmm, I can't do this, it makes no sense" anytime I even started my math homework. Also, I had never been good at history because I've always had a hard time remembering dates and stuff like that. Also, and maybe it's over dramatizing the situation, but I felt bullied socially from middle school on. I wasn't in the "in" crowd. We didn't live in the "nice" part of town. I didn't take all the hardest classes, and my parents weren't college professors or big-time administrators. But fine arts had always been something I could fall back on to be successful at. Mr. Granchio helped me celebrate that thing I was successful in and buy into something that was also successful: our competitive program.

I mean, I can barely remember middle school at this point, but being in a program like that, where Mr. Granchio was putting a lot of emphasis in process over product and trying to give students a strong education because we wouldn't be getting to work with his brother in the high school since he retired, well, it made me see how important caring about band was, not just doing it. In the end, I ended up being just obsessed with band when I was in middle school and I never wanted to leave it because we were so good. I was worried about high school because they had had two different band directors since Mr. Granchio's brother retired and the lack of leadership made the program go down the drain. I wanted to stay in something I was proud of. It helped shape me as a leader and the way I approach band.

### *Trophy 4: A large wooden plaque bedecked with a large seal with the word "Virginia Honors Band" cast around it. A small metal rectangle is affixed to the bottom of the plaque that reads "Awarded to: Ice Queen"*

Big Fish in a Little Pond: During my time in high school, I became not so affectionately known as "Ice Queen." I felt that I had something to prove. We hadn't been a Virginia Honor Band[117] in about six years since Mr. Granchio had retired, and I wanted to get to that level. I wanted to have something to be proud of in the area of my life that had always been where I succeeded, in music. So, I made everybody's life a living hell, for pretty much no reason other than because of my own drive to win. I felt driven to get us up to the top, to have something to be proud of, like in middle school. I thought I was the only person capable or who cared enough, who was passionate enough to get us back to that level.

I was never one to have many friends in high school because of the way I carried myself. I was very introverted and, also, I came across as very high and mighty, so no one ever talked to me. I didn't talk too much of anyone in my grade, but I knew the upperclassmen because they knew my sister. Fun fact, one of the people that knew my sister said of me, something like, "Yeah, she's hot like her sister but she walks around like she owns the place." I didn't even know that I gave off that vibe--kind of uppity--and though I was probably a little hurt, I thought, "Well, I can work with this," and just took almost a certain kind of pride in giving off that vibe. That vibe kind of gave me notoriety, too, and all the attention that comes from it.

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[117] According to the Virginia Band and Orchestra Directors Association (2015), "The Virginia Honor Band recognition and award was the result of a project and survey . . . The survey was in conjunction with the establishment of a state marching band festival. As part of the end result of such a festival, the recognition of bands displaying a comprehensive program was the intent of the Virginia Honor Band Award. Bands achieving superior ratings at the state marching festival and district concert festival were to be recognized with the highest honor that can be bestowed upon bands by the VBODA" (http://www.vboda.org/index.php/resources/2013-12-10-04-18-15/honor-band.html).

Things got a bit worse in sophomore year in high school when I became the flute section leader. I had auditioned to be drum major and I was not particularly happy about this section leader placement, but I decided that I was going to be the best damn flute section leader in band, ever. So, I took the role way too seriously. I was leading a section of five flutes but I was acting like it was this massive military outfit, I mean, we wouldn't even be heard on the field.

Things got full-on "Ice Queen" when I did become drum major in junior year. Now, I talked a big game in the interviews about being the leader that everybody liked and being able to bring the band together. But, when I started as drum major, I subconsciously put myself up on this pedestal above everyone else because our band—well, maybe me—had a lot of goals that I wanted to reach by my senior year. In this way, I isolated myself from my peers and I kept digging this hole deeper. I got so wrapped up in myself that I couldn't see the light of day and could no longer make connections with people because I held myself up so high. I never really had those bonding experiences people usually talk about from high school band. It was really hard for me to connect with people. And the more wrapped up I got in myself and my own experience, the more entitled and uppity I got about it.

I think a lot of how I acted was because of insecurity I had about my academic success,  I had always struggled with some academic things, issues with my focus, and had kind of been bullied for that in the past. I think that was why I got so intense about marching band because I wanted everybody to see me on the podium with my uniform, the leader of the band. I didn't feel like I could measure up intelligence-wise with my high school colleagues, but maybe I could be successful as the leader of the band. So, anyway, I started slipping in my classes, which made me more depressed. I didn't get to know anyone. I was not friends with any of them. Looking back on this and putting myself in their shoes, they just saw me as the girl barking orders from the podium. Of course, they hated me, I see that now, but when I was in that role, I was oblivious and just assumed they didn't care enough. I was such a bitch.

Well, senior year rolled around and we made it. We were a Virginia Honors Band again. Yay? I got what I wanted, but I realized toward the end of the year before graduation the kind of "legacy" I was going to leave for myself, the Ice Queen. I was a TA in the band room—which means I just hung out with my band director—and I was talking about graduation and just broke down crying in his office. I just realized what I had done and what I hadn't—mainly not connecting with other people in the band in pursuit of my goal. I had isolated myself from so many people. It was like a lightbulb had gone on and I realized how this was a problem and how much I lost by being driven at all costs for this one "title." I had served myself and not served others, not served the program.

### *Trophy 5: A small trophy ornamented with a tiny gong and the words "Piano Lessons"*

That Stupid Gong: My mom told me that the reason my parents put me in piano lessons was because my favorite song, when I was three years old, was "Super Freak." I would tell them to come and I would make them dance while I banged out the worst cluster chords of some sort on this old piano that had belonged to my dad's great-grandmother. I'd be banging and shouting, "Super freak, super freak," and, "Mommy, Daddy, dance!" So, my parents signed me up for piano lessons when I was four and I can remember being excited and really wanting to play piano.

I cried at my first piano lesson because my teacher was really mean. So, my first and only piano teacher made me cry on my first lesson and on many of them. This was also my first ever private lesson experience and I had this dude who was a jazz pianist that only had experience teaching teenagers and up. He tried teaching me classically and I don't think he had any idea of how to work with kids. He terrified me. And, he had this gong on his wall. If you got something wrong, he circled it one time. You got it wrong again, he'd circle it again. If you got it wrong again after that, he'd gong you. I think I only got gonged one time, but he would also just do it without warning, and so I cried a lot in piano lessons. He was terrifying.

I dreaded every week's lesson. I hated them. Up until I was ten, I would go over to this 30-year-old dude's apartment, which wasn't really the kind of place where a kid should be. He put so much pressure on because we would do a song a week out of my little Suzuki book—every week. The thing that really made him upset was that I would memorize everything because I was really bad at reading. So, I would read the notes once, memorize it, and then just play it and stare at my hands the whole time He would put a paper on my hands to keep me from looking. He would always say, “What are you doing? Why aren’t you looking at the music?” I got really good at memorizing things and playing by ear. I could recognize if something was wrong immediately. I never understood why it was such a problem that I would just read the music once and memorize it, but, yeah, it was.

I mean, I never could focus enough to practice much, but when I was, like, 10 years old, I was really good. But I hated it so much and I ended up hating the piano because of him. I still wonder if my disability had anything to do with it, with how I responded to the materials he was giving me and learning a new song every week. I often wonder what would’ve changed if my parents had addressed him and had said, “She’s different, she’s got some different requirements that you need to change your curriculum for.” I don’t think he would’ve changed anything, but it makes me wonder. I feel like it sounds like this traumatic thing that I’m telling you, but it hasn’t affected me that much, other than, like, having this big regret in quitting. I still play. I play when I get to feeling depressed or anxious. I play when I’m practicing flute and I get frustrated by not getting anywhere, not improving. I play, but I wonder if I would be able handle him now.

### *Trophy 6: A framed program for Concert Band with Ice Queen’s solo highlighted*

Easy-Going Environment: Oh, Concert Band! There's no pressure whatsoever to like, be outstanding, and I think without that pressure, like, we're still able to put on a really good concert and make really good music, and our concert last semester was amazing. There are a lot of fun people—and they're really easy-going—who are there on their own terms. There are no requirement to be there--well, except music majors and they should love it because it is their career path--and there is time to goof around, but when work needs to get done, they can get serious, and it does. It never feels like a stressful thing or, or like they're bossing anybody around. It's super fun. It's a really small time commitment: an hour and 15 minutes twice a week. And there’s a lot of people from the marching band in it and being in the concert band really helped me get to know people before I joined the marching band.

Concert band, funnily enough, is the lowest band, but it's usually the one that sells out. Last concert, I had a bunch of solos, especially this beast of a solo on Hazo's “Arabesque.” It was really a chance for me to shine. I've always been a person who likes attention. That's some of the reason why I did what I did in high school in marching band--to get notoriety. But with concert band solos, I can get more positive attention while also being a part of something bigger. What's funny is that though it is so easy-going in this ensemble, I was really worried about my big solo on “Arabesque.” I didn't want to mess it up. Messing up the solo could mean a lot of things because there are so many artistic choices that I'm making with it on my own. If I don't have enough vibrato in one part, or some other tiny little detail wrong, that could diminish the quality. Well, diminish the quality for me. I've learned that audiences will be impressed with anything like that, even just playing well in front of 500 people. But still, I felt like I needed to prove myself to at least the director who was on the fence about playing the piece because there's such a meaty flute solo. When I got first chair, I felt like I had something to prove with that solo, plus, it's so exposed and it's pretty difficult. That, and everyone knows this piece, well, like, most everybody. I'm sure I wanted to impress some of the people in the group in some way. I think I was trying to impress myself and prove to myself that I could do it after the semester of hell and the winter break of getting diagnosed with ADHD. I think I also need to convince myself that I needed to make music part of my career path again. I guess I did since I ended up switching from psychology to music industry shortly after the concert in which I played my solo.

## Learning to be Culann: Culann, Contradictions, and Congruent Musics

**Pseudonym.** Culann [54 years old]

**Diagnosed disability.** Attention Deficit Hyperactivity Disorder, Major Depressive Disorder, and Specific Learning Disability (Dyscalculia)

**Narrative representation.** An envisioned road trip with Culann from Anniston to Birmingham, Alabama. On this ride, Culann tells his story and shares his music as he negotiates the road and the other vehicles on it. Culann selected "Gabriela" font as one best fitting him and his story because it is, to paraphrase Culann, "somewhat epic but not hyper-masculine." For reading ease, lyrics are written in single-spaced *italics.*

Culann's commentary and music are right justified. Moments of what he describes as incongruent musics and forces are left justified (opposing cars).

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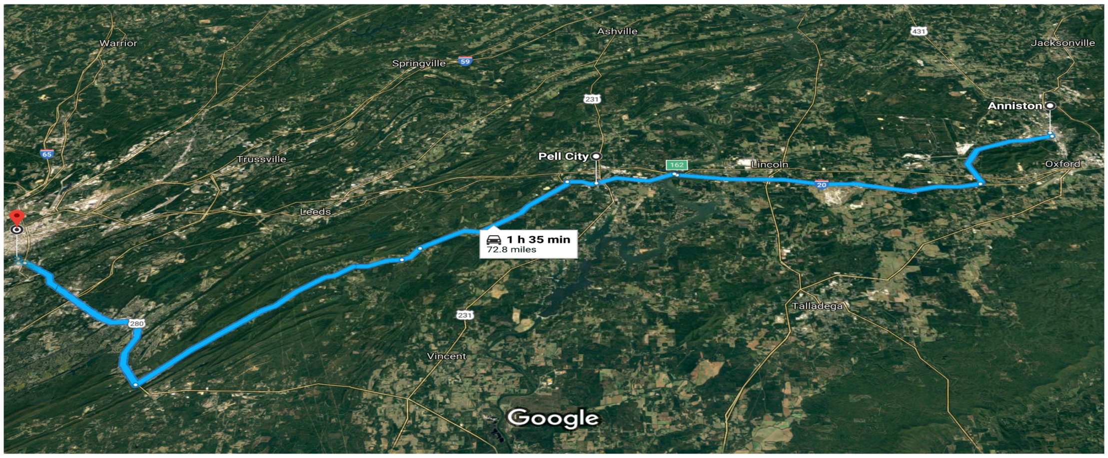
### Prologue to a Road Trip



Imagery ©2018 Google, Landsat / Copernicus, Map data ©2018 Google 5 mi

Figure 15. Culann route for our envisioned road trip (Google, 2018)

Culann leans on his Subaru Forester, which is parked just outside the shuttered gates of Fort McClellan. "You ready?" Culann says as he climbs into the driver's seat. "I've got some music for you." He pushes the "Engine Start" button, picks up his iPhone, opens Spotify to his prepared playlist,[118] and selects the play button. "I Was Wrong" by Social Distortion[119] rings out over the car's speakers:

*When I was young, I was so full of fear,*
*I hid behind anger, held back the tears.*
*It was me against the world, I was sure that I'd win,*
*The world fought back, punished me for my sins.*[120]

"So, I was really pissed off at the world in the '90s. But there was a point when I kind of realized that being pissed off wasn't really getting me anywhere," Culann says before singing along:

*"I was wrong, self-destruction's got me again.*
*I was wrong, I realize now that I was wrong."*[121]

He continues, "This song is like an affirmation and exhortation to not give up, to keep, you know, keep on keeping on. So, you see, I was pretty much in a lot of pain back then, but I didn't accept it and deal with my shit."

Culann slows the car to a stop. Foot on the break, he rolls down the windows letting the autumn air breeze through just as "The

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[118] A version of this playlist, curated by the author, containing music Culann noted as being "congruent": https://open.spotify.com/user/12157994212/playlist/2Y0O1PwsetpwMnWrIWQyvq?si=rGfAI6xeRPCwUKjHCl_0VQ

[119] (Ness, 1996) https://open.spotify.com/track/1Lpmme6uCsPJIdcbR5aePx?si=15GNI_olSrC9nbperfkv-g

[120] (Ness, 1996)

[121] (Ness, 1996)

Breaking of the Fellowship"[122] drifts from the speakers, joining the hiss of the wind from the windows. "Yeah, I guess it was just in the '90s when I had my Frodo and Gandalf moment. You know, the part in *The Fellowship of the Rings*[123] when Frodo is complaining about having the ring."

*Frodo: "I wish none of this would happen."*

*Gandalf: "So do all who live to see such times, but that is not for them to decide. All you have to decide is what to do with the time that is given to you."*

Culann hits the gas and turns onto Highway 78 toward Pell City.

**A Road Trip for Musical Congruence**

Culann fumbles for his phone with one hand and forwards the playlist to the next song, without more than a side glance. Nirvana's "Smells Like Teen Spirit"[124] blares from the car's speakers. Culann takes a right and the car sails down US-431. "You know, in the 90's, when I was starting to really become me, if you asked me, 'Culann in the early 90s, how did you feel? Express it in music.' I'd say this," motioning to the phone, "I feel like this: the rage and the anger. I really, really was pissed off." He pauses, "I just kept finding myself in incongruent settings, with incongruent people, and incongruent music. Finding things that weren't congruent with who

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[122] https://open.spotify.com/track/1ykbtFnlIjmIFnZ8j6wg6i?si=-f9eRKLJQvSPr6pm_cZsSw
[123] (Osborn, Jackson, Walsh, Sanders, & Jackson, 2011)

[124] https://open.spotify.com/track/5ghIJDpPoe3CfHMGu71E6T?si=Ii_D1CbrTaa7ps5D3yWoWQ

I was deep down. Like, in the 80's, when I was supposedly 'growing up,' what was considered 'manly' and proper just wasn't . . . ," Culann stops in mid-sentence and swerves hard to the right and on the gravel shoulder.

A red, supercharged, 1984 Chevrolet Camaro Z28 appears from over the ridge, riding the centerline hard and drifting further into Culann's lane. The smell of burning motor oil and the sound of Warrant's "Cherry Pie" guitar riff invades the air. The car approaches 20 meters, 15 meters, 10 meters, and the driver becomes visible: a young, white man with a large hair-sprayed mullet, wearing neon sunglasses and a vest, no shirt. The car careens toward Culann's car, never slowing, yielding, or moving to the side. Poison's "Nothing But a Good Time" comes over the car's radio and the driver shouts, "Skinny, fucking loser" at Culann. The rear of the car is decked with two silver "mud flap girl"[125] emblems and a thick trail of exhaust.

Culann says, coughing at the mix of exhaust and dust, "Like that, you know, the hyper-masculine shit of 'We're gonna have some sex, yeah we're gonna party and, woo, we are gonna have a good time.' The thing was, that was not my life, but that was the soundtrack in the background of my life. Meanwhile, I'm dealing with things like suicide, being depressed, parents that had abandoned me, and all that shit. So, when grunge came around, it

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[125] A silhouette of a nude female leaning back resting on her hands.

was like, 'Well, everybody's miserable now,' and I was thinking, 'This is great, I'm miserable too!' Kurt Cobain was miserable and he was sick as fuck with the '80s masculinity."

Culann hits the gas and turns the wheel sharply, pulling the car from the shoulder. The sound of tires on gravel joins the opening, low, and chorus-effected riff of Nirvana's "Come As You Are" until Culann is firmly on the road. The subtle rumble of the tires on pavement makes way for Cobain's voice:

*Come as you are, as you were,*
*As I want you to be,*
*As a friend, as a friend,*
*As a known enemy.*

*Take your time, hurry up,*
*The choice is yours, don't be late.*
*Take a rest as a friend,*
*As an old,*
*Memoria, memoria,*
*Memoria, memoria.*[126]

"You know," Culann says, "Cobain went on MTV's *Headbanger's Ball,* this show that had all these hair metal dudes all the time, and he wore a huge, yellow prom dress. It was a big 'fuck you' to the image of what was a man at the time—an image skinny, sensitive me didn't fulfill. Cobain just didn't care, he wasn't trying to present himself as this badass, macho rocker who was always happy. He was unhappy, he was hurting with irritable bowel syndrome, he

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[126] (Cobian, 1992) https://open.spotify.com/track/4P5KoWXOxwuobLmHXLMobV?si=E_TDBe0MQD-muF6dec8IJw

was fed up, and so was I. The music just resonated with me. I felt like what I was listening to was congruent with the person I was inside, the person that had been in the mental hospital as a teenager, the person that was always rejected by others. You know, like always in the outgroup. I guess I was just never a 'cornflake girl.'"[127] He rhythmically speaks:

*"Never was a cornflake girl.*
*Thought that was a good solution,*
*Hanging with the raisin girls."*[128]

"Never was in the 'in crowd.' I was in the out group. You see, I was picked on a lot because of how I looked, how I talked, and how I acted. We'd moved from Germany to Anniston, Alabama and I had this strange, almost New York-like accent. I was skinny and couldn't put any weight on—even when my father bugged me to. I was strange and depressed. In 9th grade, I tried to commit suicide and I was committed to a hospital for a short while and put in the 'emotionally conflicts' class when I came back. My parents thought I'd just be fixed by going to the hospital and being in a special class. They were still living this straight, idyllic American life, filled with country music and this vision of the All-American boy that I should be—essentially a University of Alabama football player type."

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[127] https://open.spotify.com/track/1300POeOaj8qho30FRHjgf?si=X-6hNhfLSVyrfA5BrPVfEA.

[128] (Amos, 1994)

The car approaches a long, tall hill and Culann shifts into low gear before continuing, "But here I was, a scrawny kid that kept attempting suicide, like I did in my junior year. That time, I went to the hospital for six weeks. But, there, I found people who listened to me. I found other teenagers who would hang out with me. And the girls, they were actually talking to me and hugging me. I was told, 'No, you are a human and you have some cool qualities about you.' I had this really emotionally fulfilling experience in the hospital where I was humanized. It was almost like a religious high."

Culann takes a sip from his water and the playlist ticks over Radiohead's "Creep."[129] Culann eases on the break as the car coasts down a short dip in this larger climb in the Talladega Mountain range before he picks up the speed again. "Yeah, so I found out that I wasn't alone, I wasn't the only creep out there. So, I thought, 'Fine, fuck it. I'm a creep. that's okay. I'm cool with that.'"

A large, white 12-passenger van gradually appears on the horizon. The slow-moving van is driven by an adult dressed in white. As it passes by, we hear the sounds of REM's "Shiny Happy People"[130] and adolescents happily

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[129] (Radiohead, Hammond, & Hazlewood, 1993) https://open.spotify.com/track/6b2oQwSGFkzsMtQruIWm2p?si=frWMtBlNTnalHj4IGxmmcg

[130] https://open.spotify.com/track/1v2zyAJrChw5JnfafSkwkJ?si=55CfKRFbQLmOolu4RfZnmg. Culann identified this song as one that he liked, but that represented the ill-fit of him at the time of his hospitalizations. While REM was well-known for their Indie and slightly stoic music, this hit was very incongruent with their aesthetic and has been largely abandoned by the band.

chatting with each other from the crowded back seats.

The text on the back door— "Grandview Medical Center,
Child & Adolescent Care Unit"—can be read in the
reflection of Culann's rearview mirror.

"So, I go to this hospital and I realize, like what REM sang," half-singing,

*Everybody hurts . . .*
*If you feel like you're alone*
*No, no, no, you're not alone."*[131]

"But, then, I come out of the hospital back into this toxic environment of horrific high school and my family life. I was just lost again. My dad kind of looked at me like I was a broken car, the psychologists were the car mechanics, and I had been at the hospital to be fixed. He didn't get that mental illness was something that needed to be managed. It *is* a chronic condition and you need to learn to live with it. He just thought I was fixed and good as new. So, he went back to pushing this country-music and military informed lifestyle, which was hyper-masculine and hyper-disciplined. I wasn't that. I was this crazy guy and my dad was this NCO club[132] old soldier." Culann grips the wheel as he looks at the horizon.

*I was sittin' in Miami pourin' blended whiskey down,*
*When this old gray black gentleman was cleanin' up the lounge.*

*There wasn't anyone around 'cept this old man and me.*

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[131] (Berry, Buck, Mills, & Stipe, 19911992)
https://open.spotify.com/track/6PypGyiu0Y2lCDBN1XZEnP?si=dsxbOHQlSWWaOKX3tviDCg

[132] NCO stands for "Non-commissioned officer" and an NCO club, as described by Culann, was "a place where soldiers would unwind by drinking cheap beer and bourbon, sharing crude jokes, and fighting" to an all-country music soundtrack.

*The guy who ran the bar was watchin' "Ironsides" on tv.*[133]

The "boom-chick" bass and drum of this 1970s "down on your luck" country songs comes streaming from a slow-moving Ford truck made of mostly rust and bumper stickers that emerges over a ridge in the left lane. The truck prominently displays insignias alluding to the driver's military career. The driver appears stoic and nearly emotionless behind the wheel, moving only to exchange 8-track tapes. The beat-up truck passes, moving slow and never wavering from its straight and in-the-lines path, and the opening riff of Johnny Cash's "I Walk the Line" fades in a thick cloud of exhaust smoke.

A concerned and nervous quarter-smile appears on Culann's face as he loosens his white-knuckle grip on the wheel. He takes a breath and his face loosens before he speaks. "You see, my dad was like 'Folsom Prison' Johnny Cash while I was like . . ." he says while flicking his phone now situated in the console, he forwards the track a few times until a slow and somber guitar comes on the stereo, ". . . I was like this, 'Hurt' Johnny Cash.[134] We were both similar, but so different. One a 'stand straight and fly right' man's man and the other, me, this kind of damaged, slouching, pile of sadness." We listen to Cash singing Trent Reznor's verses as we drive. As we come up to the end of the long climb up the mountain, the guitar, piano, and strings swell and Cash's voice begins to crackle with emotion:

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[133] (Hall, 1972)

[134] https://open.spotify.com/track/28cnXtME493VX9NOw9cIUh?si=3W_wVO7tRdiqcxHKFbTyRw

*What have I become*
*My sweetest friend?*
*Everyone I know*
*Goes away in the end.*

*And you could have it all,*
*My empire of dirt.*
*I will let you down,*
*I will make you hurt.*

*If I could start again*
*A million miles away,*
*I will keep myself*
*I would find a way.*

We continue  in silence until Culann breaks the tension, "So, anyway, I get out of the hospital and I'm in this toxic environment and I start looking for something to give me what I had felt in the hospital that I sure as hell wasn't getting at school or at home. So, I glommed on to the Baptist Church. I was 16 and the church had a bunch of young and friendly-seeming girls. I guess I was really just 'flirting for Jesus.' And, you see, I'm a very literal person. So, when the church told me that life was like as if God and Jesus were superheroes and Satan was a super villain and you can help them out, cuz, God's always needing your help to do stuff, which I never really understood cuz he's God, so why would he need my help. And if something bad happens, it's because you did something to make something bad happen. So, this was one of the most horrific things you could tell a mentally ill person because it was all about self-loathing and self-hatred, especially if nothing was going right in your life. You feel it's all you and you're just an awful person who keeps fucking up."

Culann flicks at his phone. The crunch of a guitar pops out of the speaker, quickly joined by bass, drums, and the unmistakable howl of Eddie Vedder of Pearl Jam, ushering in "The State of Love and Trust."[135] "So, you add to that, there is this strange push to get teenagers to sing for Jesus in the church I went to. I'm not really into performing, anyway, and I really don't like being told what to sing and how to feel about it, especially when I didn't really feel it. I mean, I'm not particularly good at singing, which I was acutely aware of back then, so it was just shit piled on top of shit. I didn't want to be there. I didn't want to be doing that thing. But the really funny thing about the Southern Baptist church was they're really all about singing and performing these little skits. To me, they try to be 'all about art,' but it really isn't about the art, anyway." Culann slows the car, squinting into the horizon.

Around the bend ahead, a church bus appears from a haze of dust. The bus is filled to the brim, with saccharin-sweet smiling faces filling up each of the porthole-like windows. As the bus approaches Culann from the other lane, we can just make out an adult standing just behind the driver. Though muffled, we can hear his screams above the old hymn "At the End of the Day": "Sing! Smile! You've got to emote! Don't forget to move." The group continues, attempting to follow his orders. The sound fades along with the bus in the rear-view mirror.

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[135] (Vedder, McCready, & Ament, 1992) https://open.spotify.com/track/6dnmovOCP7vG4ysCvX2ub4?si=T_9DkwO_ShWCvkhELhpTgQ.

Culann cranks the stereo volume to overpower the fading church singing.

Vedder's voice is rough but soothing, even at the high of volume:

*And I listen, yeah, for the voice inside my head*
*Nothin', I'll do this one myself*
*Oh, ah, and the barrel waits, trigger shakes*
*Aimed right at my head, don't, won't you help me*
*Help me from myself*[136]

Culann glances at the vanishing bus in the rearview mirror and says, "You know, I've never had a good experience when I'm forced to sing or dance. I hate it when artists decide to evangelize non-artists with their art. You know, like in *Dead Poet's Society* when they say, 'I choose not to walk.'[137] I choose not to dance; I choose not to sing. Why can't people just respect that fact?"

"So, when I was in the church, not only did I feel all this self-loathing, but I felt bad doing this singing and dancing crap because I was forced to be incongruent with myself. I wasn't being the person I wanted to be, so it caused all these discordant feelings of shame, embarrassment, irritation, anger, and just negativity. It wasn't too long before I got out of all of that and started to reject the music of other people. Through that, I rejected the incongruent expectations of what it should mean to be me. For me, I had to leave the church to start that. That began with me thinking, like Joan Osborne said,

*"What if God was one of us?*
*Just a slob like one of us.*
*Just a stranger on the bus.*

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[136] (Vedder, McCready, & Ament, 1992)

[137] (Haft, Witt, Thomas, & Weir, 1989)

*Tryin' to make his way home?"*[138]

Culann takes a long sip from his water and clicks the playlist forward. The sound of an acoustic guitar, tubular bell, and a cello introduces the Smashing Pumpkin's "Disarm."[139] More strings swell as Billy Corgan sings

*I used to be a little boy, so old in my shoes.*
*And what I choose is my choice.*
*What's a boy supposed to do?*[140]

Culann continues, "Add to my religious exit, my folks basically abandoned me and moved back to Germany." The lyrics surges again:

*"Leave you like they left me here."*[141]

and Culann continues, "So I was living hook and crook on my own at 19."

*Bitterness of one who's left alone,*
*oh, the years burn.*
*Oh, the years burn, burn, burn.*[142]

"You know, my father kind of abandoned me emotionally way before that. I've talked to my two half-brothers from England and they say, 'Well, Dad left us,' kind of in a whiney 'Father of Mine'[143] way.  And I tell them that it wasn't really a picnic being with him when I was. They may have been more fortunate."

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[138] (Bazilian, 1995)
https://open.spotify.com/track/1xNmF1Uep5OGutizZSbKvd?si=g5X3p7rrQzWK9ZSDnh8v2Q

[139] (Corgan, 1994)
https://open.spotify.com/track/2lXHg7BtTNoP39AezyCSfL?si=5l6ghDMKQrSrR4wxEaujLQ

[140] (Corgan, 1994)

[141] (Corgan, 1994)

[142] (Corgan, 1994)

[143] By Everclear
https://open.spotify.com/track/2hx4ptqsE8dboLH3NCLmaN?si=jV_GwH3ESrG_LmP8R71CeQ

*The killer in me is the killer in you*
*My love*
*I send this smile over to you.*[144]

Culann pulls off Highway 78 and turns right onto Wolf Creek Road, just outside of Eden. "Anyway, so, I was all alone and I moved to Birmingham, which is the place you live if you don't like Alabama but you still have to live there. I was living and working at this Baptist Center at the UAB[145] as the janitor. I was confused and pissed off at God, but I needed money. It was around this time that I got into Tori Amos. She has this song called 'God.'"

Culann fumbles for the phone to find the song. As he pushes play, the cacophonous introduction invades the space between us in the truck as Culann nods his head. We listen together as the lower mountains cascade by and dissolve into the horizon.

*God sometimes you just don't come through.*
*Do you need a woman to look after you?*
*God sometimes you just don't come through.*

*You make pretty daisies pretty daisies love.*
*I gotta find what you're doing about things here.*
*A few witches burning gets a little toasty here.*
*I gotta find why you always go when the wind blows.*[146]

Culann interrupts, "Fuck knows what she's writing about here, but for me it was a big middle finger to the church and all the fake people. I used to pump this song late at night while I was mopping up. The thing about music for me is that no

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[144] (Corgan, 1994)

[145] University of Alabama, Birmingham

[146] (Amos, 1994)

song is completely congruent with me, but a little snatch here and a little snatch there, a line, a riff, those things connect. The funny thing about Tori Amos, specifically, is that I shouldn't be congruent with her music because most of her fans are like 12-year-old girls, northerners, and/or people from the LGBT? community. But, I'm this this older, southern, straight guy and I love Tori Amos; I even followed her tour one summer. You know, Tori is beautiful and her covers in the 90s were just almost ethereal. I have a total thing for redheads with blue eyes. Not only that, but her lyrics and music and the concerts, just the total package. The thing is, she doesn't give a shit, especially in her feelings toward religion. I really needed to know it was okay to not give a shit at that point; I was dealing with so much."

In a rather jarring sonic exchange, the opening strains of "I Dreamed a Dream" from *Les Misérables* as performed by the Glee Cast[147] interrupt Culann. "Ha!" Culann acknowledges the incongruity of this piece with the other music he's been playing, "This song, man, I know it is kind of outside of my other music, but I fucking love this song because this song is just like my life." We listen and Culann speaks along with the last verse,

"I had a dream my life would be
so different from this hell I'm living,
so different now from what it seemed.
Now life has killed the dream I dreamed."[148]

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[147] (Schönberg, Boublil, & Kretzmer, 1980/1985) https://open.spotify.com/track/4QDo30WQZZJle0Up1mC8ez?si=-rfeZVKCRcu6YUMRuGuvrQ

[148] (Schönberg, Boublil, & Kretzmer, 1980/1985)

Culann returns to discussing his life, “You know, I had this dream of a normal life as a smiley kid, but here I was on my own as in my late teens/early twenties, living in this hell. I decided to just say, ‘Fuck it,’ and build something new. I had my own ‘Get crazy with the cheese whiz,’[149] moment and just embraced my own loser-dom. So, as I was ‘losing my religion,’[150] literally and figuratively, I was also starting to learn how to be Culann. The great thing was as I was meeting myself, I was meeting my bee people—[151] all the misfits of the UAB.” Just as he says this, “Lithium” by Nirvana begins and the poignant opening line joins the conversation:

*I’m so happy because today,*
*I've found my friends;*
*they're in my head.*[152]

Culann interjects, “Well, my friends were in my head and outside of it. All these misfits couldn’t give two shits that I had been in a mental hospital nor were they into forcing things upon me. Rather, they shared their interests with me if I wanted. So, then I learned about building computers from my friend Dan, and MIDI music and philosophy from his girlfriend Jean, and I got into fantasy and Dungeons and Dragons.”

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[149] This line comes from Beck’s song “Loser” (Beck & Stephenson, 1993): https://open.spotify.com/track/5PntSbMHC1ud6Vvl8x56qd?si=klepUK-lQj-tgXvYXVNs1w

[150] A reference to REM’s song of the same name which uses the saying to mean to lose one’s temper: https://open.spotify.com/track/31AOj9sFz2gM0O3hMARRBx?si=fCxwVhkWRnSc0TtFB0cB4Q

[151] This is a reference to the music video “No Rain” by Blind Melon: https://www.youtube.com/watch?v=3qVPNONdF58

[152] (Cobain, 19911992)

"It was really important that I had all this stuff to explore because it gave me an escape from my past and all the shit that was going on as I slowly went through college. You know, school can be tricky when you have an invisible disability like my ADHD and  a learning disability because your social cues are off and, sometimes, your interests are incongruent with your talents. Take me, for example. If I didn't have this learning disability in math, I would have been an engineer. I would be doing some engineering, math-crunchy, building something, 'cuz that's what I like to do. But, I'm here in a helping profession talking with people about their needs and feelings, which is not something I necessarily like to do. So, rather than letting my wants fight my abilities, I just found something I could do professionally and found leisure in building computers and playing computer games."

Culann swerves to miss a pothole, and then bears right onto Bear Creek Road. His playlist automatically progresses to "Peaches"[153] by the Presidents of the United States of America as the sun sets ahead of us. The jangly guitars call out.

*Movin' to the country,*
*Gonna eat a lot of peaches*
*Movin' to the country,*
*Gonna eat me a lot of peaches*
*Movin' to the country,*
*Gonna eat a lot of peaches*
*Movin' to the country,*
*Gonna eat a lot of peaches.*[154]

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[153] (Ballew, 1995)
https://open.spotify.com/track/3VEFybccRTeWSZRkJxDuNR?si=KkHaT2bURv2HSysEXUAmJQ

[154] (Ballew, 1995)

"Yeah," Culann cheers, "Sometimes you just need a song about something as dumb as peaches, you know? You need something that lets you escape, lets you just have some time away. Take this song, it is about peaches. It isn't some stupid, sappy love song, like Michael Bolton; it's about peaches. Listening to it allows you to leave everything behind and think about peaches; you get an escape." He speaks along,

*"Millions of peaches, peaches for me.*
*Millions of peaches, peaches for free."*[155]

"I think the need to escape is why I dove into fantasy and comics and away from country music. It's like I tell my half-brothers that love old country, 'It ain't so great when you're actually living that life.' So, I've never really liked the actual reality of reality—well, my reality, that is.

Now, history, I love that reality. I can dig into history. I can literally see the past, see stuff happening. It's a talent of mine. You cannot train me to be a good singer. You cannot train me to play guitar because I don't have the motor dexterity, I don't have the ear. Reading music looks a lot like math to me and I don't know if you could teach me the language. But, history, yes! I mean . . . "

Culann pulls off to a historical marker and parks. ". . . I could tell you about the battle that happened here or," he grabs for his phone, flips his glasses up,

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[155] (Ballew, 1995)

resting them on the top of his head, and searches. With a flick of his finger, "Big Fellah" by Black 47[156] floats from the speakers,

*Mo chara is mo lao thu!*
*Is aisling tr nallaibh,*
*Do deineadh arir dom,*
*Igcorcaigh go danach,*
*Ar leaba im aonar.*[157]

As the Gaelic stanza fades, distorted guitars, a front and center drum beat, and horns/strings pick up the pace. Culann looks up eagerly and continues, "I could tell you all about Michael Collins who was a part of the Irish resistance. He was killed by his fellow Irishmen during the Irish Civil War. His nickname was 'The Big Fellow,'" Culann points to the speakers.

*"Hey, big fellah,*
*where the hell are you now when*
*we need you the most?*
*Hey, big fellah,*
*C'mon.*
*Tabhair dom do lmh.*[158]

"Love this song because of the way they take a historical event and traditional Irish music sounds but add the horns and more contemporary sound. It's like 'Zombie,'[159] where you take a story from history about the 'The Troubles' in Ireland and smash it into contemporary music and art. If I could do that, take music and history and make something new out of it, I'd be all over it. That's

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[156] (Kirwan, 1994) https://open.spotify.com/track/1YLWLi1ugIUAziPOWELvVJ?si=zTI3O0zNQd2peHVf3jZbIQ

[157] (Kirwan, 1994)

[158] (Kirwan, 1994)

[159] By the Cranberries https://open.spotify.com/track/2IZZqH4K02UIYg5EohpNHF?si=OA-F2tALSwGE9iiX_FukZQ

something I have the talent for, you see. I wish I had more chances to do what I have a talent for and for things that I wanted to do back in school, but just like at home and church, I was told what to do, want to like, and how to like it." Culann shifts the car back in gear. We merge onto the road again, flowing along the curves and hills.

*We fought against each other,*
*two brothers steeped in blood.*
*But I never doubted that your heart*
*was broken in the flood.*
*And though we had to shoot you down*
*in golden Bal na Blath,*
*I always knew that Ireland lost*
*her greatest son of all.*

*Hey, big fellah,*
*where the hell are you now,*
*When we need you the most?*
*Hey, big fellah,*
*C'mon.*
*Tabhair, Tabhair dom do lmh.*[160]

After a few minutes of speechless listening, Tom Petty and the Heartbreakers' "Learning to Fly"[161] seems to draw Culann out of a semi-meditative state.

*Well I started out down a dirty road.*
*Started out all alone,*
*And the sun went down as I crossed the hill,*
*And the town lit up, the world got still.*

*I'm learning to fly, but I ain't got wings,*
*Coming down is the hardest thing.*

*Well the good old days may not return,*[162]

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[160] (Kirwan, 1994)

[161] (Petty & Lynn, 1991) https://open.spotify.com/track/17S4XrLvF5jlGvGCJHgF51?si=ffGP43MiS5KyoVWWe-7CIg

[162] (Petty & Lynn, 1991)

"So, I'd found my misfit friends, and began to find myself. This is when I started to drive around a lot, which I still do. For no apparent reason, with no apparent destination, just because I was in the mood, I'd go for a long drive. I'd have these hour-long drives listening to Tori Amos, Pearl Jam, or Nirvana, you know, stuff like that. As I listened and drove, I learned about me and learned to be me. Like this . . . "

Culann picks up the phone and selects "Under the Bridge"[163] by the Red Hot Chili Peppers. The opening, crystal clear guitar riff clips the air. "I used to listen to his and drive all around Birmingham and the little towns surrounding it."

*Sometimes I feel like my only friend*
*Is the city I live in, The city of angels.*
*Lonely as I am, together we cry.*[164]

And I know this song is about L.A., but to me it was about Birmingham and finding my bee people and myself. When I am scared, depressed, lonely and happy, I like looking at Birmingham as the city that saved me."

*I don't ever want to feel,*
*Like I did that day.*
*Take me to the place I love,*
*Take me all the way.*

*I don't ever want to feel,*
*Like I did that day.*
*Take me to the place I love,*
*Take me all the way (yeah yeah).*
*Ooh no (no no yeah yeah),*
*Love me I say yeah yeah.*[165]

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[163] (Kiedis, Balzary, Frusciante, & Smith, 1991)
https://open.spotify.com/track/3d9DChrdc6BOeFsbrZ3Is0?si=HtjVrxC0RXqKrAtQVc7pHA

[164] (Kiedis, Balzary, Frusciante, & Smith, 1991)

[165] (Kiedis, Balzary, Frusciante, & Smith, 1991)

"I still drive around. I have this hour commute to work which is stressful because of the highway, but I take the country roads home. I listen to my music and I think about how I've pretty much lived, you know, a life of a lot of contradictions. I'm always in these, kind of like, weird spaces where I'm not either this nor this. Like, take my politics and my gun ownership; I'm a liberal that owns a gun and shoots at the club from time to time. I'm an older person with the emotional mentality of someone 10 years younger than me—that's why I've always connected with people something like 10 years younger than me. I'm a straight army brat who likes Tori Amos. Or just take my mood: I'm happy often because of strange things. It's like that Garbage song, 'I'm Only Happy When It Rains,'[166] you know. I'm a relatively nice and funny guy who likes to make dumb jokes, but I seem to be drawn to sad music. For instance, I remember when my wife and I first got together. She was a bit Cowboy Junkies fan, so we would put them on and make out. But, like, the one song that I really remember and tie to my wife from that time is 'I'm So Lonesome I Could Cry.'[167] I guess part of learning to be me was to find congruence in the contradictions."

Culann merges onto Interstate 280 and we listen and try to sing along to REM's "It's the End of the World As We Know It (And I Feel Fine)."[168]

*"That's great, it starts with an earthquake,*
*Birds and snakes, and aeroplanes,*
*And Lenny Bruce is not afraid.*

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[166] https://open.spotify.com/track/0c1iL21nLuQNZTWiijOZUG?si=1abmk9L5Sjebh_soktqA6Q

[167] (Berry, Buck, Mills, & Stipe, 1987) https://open.spotify.com/track/4DOFK5Or3UFHEEQ9NzMOIP?si=apE8eSKIRPG8xZBaN671eA

[168] https://open.spotify.com/track/2oSpQ7QtIKTNFfA08Cy0ku?si=BYMSiYJ9QIO-m2H3H_vH7Q

*Eye of a hurricane, listen to yourself churn."*[169]

The rest of the song, with its fast-paced lyrics, washes over us, until we can join in singing again at the end:

*"It's the end of the world as we know it,*
*It's the end of the world as we know it,*
*It's the end of the world as we know it, and I feel fine."*[170]

The song fades out and the city of Birmingham opens up in front of us. Culann takes the exit marked "Vulcan Park" and muses, "You know, I think it is important to find people, places, music, and aspects of yourself that are congruent with who you are; things that make you feel like you, make you feel like everything clicks. There can be congruence in contradiction, but that congruence has to be there. And things can change. Like, I listen to these songs a lot, this is part of the mixtape of my life, but the level to which these things are congruent with who I am right now has changed. Like this . . ."

Culann pulls to a stop in a parking lot that is guarded by a large cast-iron statue of the god Vulcan. He grabs his phone and as we walk to a clearing in the trees he clicks play. Tori Amos's cover of "Smells Like Teen Spirit" plays quietly in the night air:

*Load up on guns, bring your friends*
*It's fun to lose and to pretend*
*She's over-bored and self-assured*
*Oh no, I know a dirty word*
*Hello, hello, hello, how low*
*Hello, hello, hello, how low*
*Hello, hello, hello, how low*
*Hello, hello, hello*

*With the lights out, it's less dangerous*

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[169] (Berry, Buck, Mills, & Stipe, 1987)

[170] (Berry, Buck, Mills, & Stipe, 1987)

*Here we are now, entertain us*
*I feel stupid and contagious*
*Here we are now, entertain us.*[171]

"This song was congruent with my experiences, the Nirvana version, that is. The thick guitars and anger doesn't seem as congruent anymore. But, this version, I think I like Tori Amos's version better now. It fits me." The song plays out and Culann motions to different buildings and features visible in the skyline of Birmingham, discussing the rich history of this place where he felt so congruent and his place in it.

*With the lights out, it's less dangerous.*
*Here we are now, entertain us.*
*I feel stupid and contagious.*
*Here we are now, entertain us.*[172]

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[171] (Nirvana, 2015)

[172] (Nirvana, 2015)

### Epilogue to Phenomenologies of Others

In this chapter, I have attempted to provide narratives that map the lifeworlds of participants in relation to their experiences of disability in, through, and around music. As you read and think with and through the lifeworld narratives, I encourage you to walk with and engage in dialogue with the participants. The purpose of presenting the co-generated data in this manner is to provide means by which you might be “given” their experiences (e.g., Stein, 1998) and come to know their "actual situation of life, the complete presence of the reality in which [they participate]” (Buber, 1965, p. 115). As you are “given” the experiences of others (e.g., Stein, 1998), you might also find the participants manifesting in your own consciousness and being included in your thinking and doing in relation to disability, the lives of DP/PwD, and pedagogical inclusion (e.g., Buber, 1965).

# CHAPTER FIVE: AN ENVISIONED CONVERSATION

The purpose of this study is to trouble existing conceptions of disability that ground music education literature and practice by exploring the personal experiences of disability in, through, and around music of specific DP/PwD. I seek to uncover and share “plausible insights” (van Manen, 1990, p. 9) into how disability is experienced in, through, and around music experiences of participants. These insights might allow readers to complicate and trouble taken-for-granted assumptions of what disability can mean and be “like,” and through this troubling open new inclusive practices in music education. In the previous chapter, I bridled my voice in order to “refuse a single authorial consciousness” (Allsup, 2017, p. 11). I sought to give space for participants to speak and exist in such a way that you, the reader, could walk with participants and, via lifeworld narratives, be given (e.g., Stein, 1989), partially, their lifeworlds and experiences of disability in, through, and around music.

In Chapter Four, I presented the phenomenologies of others (i.e., participants in this study). In this chapter, I engage in a phenomenological self-study of the meanings related to the central phenomenon that have manifested in my lifeworld during this study. This phenomenological self-study is a mapping of new terrains or insights in my lifeworld as I have come to be conscious of participants, their experiences, their ways of being, and their ways of knowing. Below, I map these terrains by sharing interconnected meanings among the experiences of participants with disability in, through, and around music (van Manen, 1990), and I draw connections among and between the experiences of participants, my own insights and recognitions, and the theories I have encountered during my studies. These connections, however, are not simplifications of essences or structures of lived experiences, as van Manen (1990, p. 87) would define them. Rather, I present the terrains of my evolving understanding and connect these understandings to theory and existing research as an ever-changing *through* experience (Vagle, 2014) shaped by the unique confluences of space, relation, and practice (Lubet, 2010). My aim in this chapter is to decenter monophony and clarity in order to center polyphony in which “themes merge with other themes [and] identities collide and fracture, grow new limbs and regenerate” (Allsup, 2017, p. 16).

Adopting a bricoleur mindset (e.g., Kincheloe & Berry, 2004) and with a desire to value polyphony and center participants in their uniqueness, I crafted this chapter as an envisioned conversation between participants and myself. To be clear and as explained in Chapter Three, this envisioned conversation did not actually occur in any physical sense or through a digital meeting, but it did occur and continues to occur in my consciousness. In crafting this chapter, I took on an approach similar to narrative analysis (e.g., Bruner, 1986; Polkinghorne, 1995). As I engaged in what I call distanced contemplation, I write and rewrote (e.g., van Manen, 1990), seeking to understand participants and craft a “series of constructions . . . [a] storied production . . . [that] is the retrospective or narrative explanation of the happening that is the topic of the inquiry” (Polkinghorne, 1995, p. 19). My purpose in this chapter is not necessarily to (re)present the actual lives of participants, as in the past chapter, but to share insights that have manifested in my lifeworld related to the phenomena through the construction of a narrative or, in this case, a conversation. I sought to capture, temporarily, a sense of movement between and among the participants’ meanings that are always in the process of becoming and the meanings that are “running all over the place” (Vagle, 2014, p. 41) in my own consciousness. The voices of the participants remain present and centered here, as the conversation is comprised primarily of direct quotes.

Two primary insights arise within the conversation: (a) the different ways participants describe and understand their experience of disability in, through, and around music (e.g., disability as individually experienced and/or identified with, disability as socially constructed, disability as a central part of oneself, and disability as apart from oneself), and (b) the roles that music plays in the experiences of these participants and in their lives in general (e.g., music as a medium to connect with others, music as a medium to find oneself, and music as a means of personal expression and control). In this chapter, participants’ speech retains the font, size, and about alignment used in each of the lifeworld narratives as found in the previous chapter.[173] As such, the participants are present, as present as they are in my consciousness, through the conversation. Yet, my presence in the conversation below is a complication.

In this chapter, I continue to draw on a post-intentional phenomenological frame (e.g., Vagle, 2014) with a commitment to giving you others' experiences/lifeworlds (e.g., Stein, 1996). In this chapter I also represent my lifeworld, my insights, as shaped by participants' experience of disability in, through, and around music. As I do this, I reaffirm and rearticulate my relational ontological positionality in this study as informed by Buber (1957, 1985, 1965). In order to represent my being-with, I live through three roles in the discussion that follows. First, I am "Jesse the researcher-participant" who exists as a character in the envisioned conversation, engaging with participants in the dialogue. This Jesse, identified as "*I-Thou* Jesse" in the dialogue, is the Jesse speaking and being with participants collectively as I have been with them individually during the inquiry process. Second, I am "Jesse the scholar" who speaks to you more directly from a position of some distance from the dialogue, noting insights, sharing my own understandings, and making connections to existing literature. This Jesse is labeled with "*I-it* jesse*"* and his text is presented in1½ spaced white font with grey background.[174] These two roles are different "I's" which come together with other aspects of my being that are outside the lines of this document and which allows a third *I*—the *I* who is writing—to be present with the *you* who is reading. This third "I" is "JESSE the facilitator" who organized the data to construct an experience for you, the reader, of eavesdropping on an imagined dialogue among participants. This JESSE, who is speaking to you now, arises out of the interaction of the two I's described above and their

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[173] While the conversation in this chapter may be difficult to read because of the rapid changes in fonts, sizes, and alignments, this reading difficulty is purposeful in that it: (a) better reflects the conversational format with different participants speaking in different ways and (b) decenters "normality" and "unity" in favor of centering difference and divergence. You may find yourself thinking that Sienna contributes more and that her contributions are more important because of the larger size of font. Yet, this is an illusion.

[174] An alternative format version of this envisioned chapter can be found in Appendix K. This version does not include the "*I-it* jesse" interruptions and allows a reader to follow more directly the conversation. All "*I-it* jesse" comments are included in this appendix as endnotes.

actions and interactions with participants and literature. By working in this way, I intend to model a type of inclusive being, inspired by Buber (1958, 1965), through which I construct, engage within, and stand outside of a meeting between the participants, myself, and you. As a guide for the reader, I include Figure 16 as an overview of the findings, insights, and topics included below.

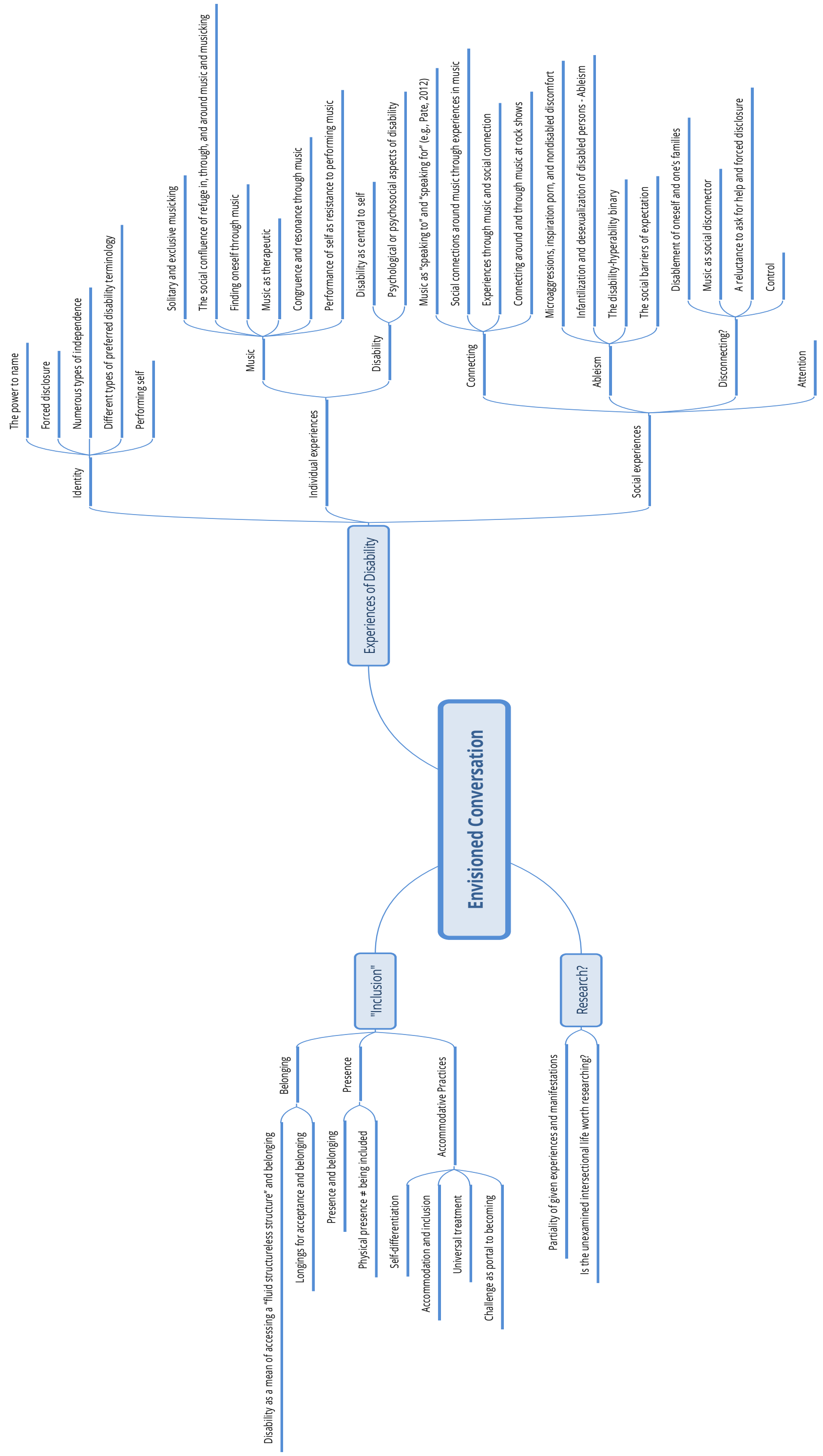

Figure 16. Overview of an envisioned conversation

### Prelude to an Envisioned Conversation

It's a sunny day, and Silver Goat Coffee shop is light on customers. In the back corner, past the counter and behind a large concrete column, Jesse moves cushy chairs and sofas into a circle. Sienna surprises Jesse, tapping him on the shoulder and greeting him before setting her banjo and cane down and claiming the sofa. Culann enters, hands in pockets, with his neutral "not a smile but not a frown" expression. He nods to Sienna and stands to chat with Jesse about the newest episode of *Westworld*. Daren opens the door and holds it for the next customer, who happens to be Ice Queen. Ice Queen waves at Jesse and goes to the counter to order a coffee. "Hello Professor Rathgeber,"[175] Daren says earnestly as he finds a seat. Ice Queen sits down a few minutes later, blowing on her cappuccino, and waves to Jesse before taking a sip.

**Erica** follows her father [e-father], a faculty member at a local college, through the side door. Her hands are at her chest, fingers moving as if playing an invisible piano. "Do you want something to drink or eat, **Erica**?" e-father asks. "**Hot cho-co-late**," she responds before noticing Jesse in the corner. She smiles and makes her way to the group. Sienna moves her banjo and cane to make room for **Erica** on the sofa. They introduce each other as DUKE rolls in, scooter helmet in hand and knit stocking cap on his head. He greets the baristas, one of whom comes around the bar to give him a hug. He turns to introduce himself to e-father and another customer waiting at the bar. e-father strikes up a conversation with DUKE, as he's seen him around. "Are you going this way," e-father asks, pointing to the group in the corner. "Yup," DUKE responds as they continue to chat. DUKE walks up to Jesse, arms open, and says, "My man, my friend, the professor," and hugs him. "Here, Erica," e-father hands her

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[175] Daren was uncomfortably about calling me "Jesse" and insisted on referring to me as "Professor" even though I do not make use of titles as a teacher, scholar, and community member.

her drink and begins to walk away, "I'll be sitting over here to let you all talk, I've got grading to do anyway." Just as Jesse is about to get everyone's attention, Birdie enters, floating in with a sense of urgency, her floor-length patchwork skirt billowing in the air as she jogs to the group:

Birdie: Oh, I'm sorry I'm late, I had an issue with my ride [takes a seat and pulls out her water bottle]. Sorry everyone [takes a sip of water].

*I-Thou* Jesse: No worries, just more time to settle in and get some tea and coffee.

Culann: Well, Jesse, here we all are, in words of Rocket the Raccoon, "Bunch of jackasses standing in a circle"[176] [said with a small, wry, quarter-grin]. Well, sitting in an oval.

*I-Thou* Jesse: Yeah, I figured it might be useful to get you all together to talk with each other about what disability is like in, through, and around music for you.

DUKE: That's really hard [adjusts stocking cap].

Sienna: Well actually, it is hard to explain, but it is probably harder to do, since we aren't actually here

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together. We’re in Jesse’s head [shakes head and raises eye brows in a half-mocking manner].

*I-Thou* Jesse: There is that, I suppose. The thing is, I’m feeling odd about analyzing all of your experiences and splitting them up into clearly defined thematic boxes when I could just have you here to talk.

Ice Queen: But we never met [motioning to everyone with a quizzical facial expression].

*I-Thou* Jesse: Well, you kind of have, both in the last chapter and in my consciousness. Since you’ve all partially manifested in my consciousness, I’ll just take it for granted that you’re at least somewhat acquainted.

Birdie: Oh, yeah, I get what you’re saying. It’s like a meeting of different frequencies. Or, maybe this is *your* weaving project! [pointing at *I-Thou* Jesse with a smile and a nod]

Daren: Sure, I could see how this might be interesting. In all the research I've seen while I've been a research assistant for my professor, there are always themes or some kind of science-y analysis.

*I-Thou* Jesse: I hope people might find their own themes and maybe bump into other things that are built into our chat. Hmm, maybe I can do a bit more . . .

*I-it* jesse*:*
. . . I'll comment from a more distant position with research observations, notes from my reflective journals, and draw connections to existing literature in grey boxes like this. When I do so, I am acting in part as an omniscient narrator . . .

*I-Thou* Jesse: . . . Mostly, I think the way you all respond to each other in this conversation will create an ongoing chain of overlapping themes. So, if you're all game, then I could just throw some questions out and we can roll with it. [looks around for confirmation]

All: [nodding in agreement]

*I-Thou* Jesse: Okay, so how do you see yourselves in your experiences in, through, and around music in general?

DUKE: Jesse, this is a conversation at a coffee shop, not a "document," right? [with ear-to-ear grin]

*I-Thou* Jesse: Yeah, well, this conversation isn't really happening at a coffee shop. This coffee shop doesn't exist anywhere except in my consciousness and now in this document.

Birdie: Wow, [hands making explosion gestures on side of head] trippy.

### As Envisioned Conversation

*I-Thou* Jesse: So, I guess we can start by discussing music, in general, such as the types of music you do or the music experiences you have and what those experiences mean to you.

**Erica: [begins to twist in seat] I live to make music. I like to sing with people. [sitting back and turning to Jesse] Let's sing.**

Sienna: What do you want to sing? I've got my banjo.

**Erica: [turns to Sienna] What song do you want to sing?**

Culann: Yeah, I don't sing, I'm not a singer [shakes head]. Let's not make this some hippy, dippy sing-along shit, man [shakes head].

*I-Thou* Jesse: Okay, maybe we don't sing right now . . .

Ice Queen: Well, if we aren't going to sing [smiles], I guess I can answer your question [leans in with elbow on thighs and hands clasped together below chin]. Music is just kind of everything to me. I mean, it is the only thing in my life that I've always seemed to excel at. Music is the thing that I can fall back on when I'm having a hard time with academic classes in college, like classes that require memorization of facts and dates. I'm not very good at things like history because I just can't remember dates and stuff like that. But I'm really good with memorization in music. I feel comfortable playing, even when I'm playing hard music, and I feel like when I perform, I'm myself and I'm proud of myself. Pride, especially. Music gives me a chance to be proud.

Culann: So, I can memorize dates, names, and facts about history, but if you made me perform, I'd suck. [wagging finger and pointing as if directing] "Smile, Culann, move like this. Emote," that shit isn't me. I don't sing, I don't dance. It's kind of like that Phil Collins song, "I Can't Dance." Being forced to perform really can be alienating and upsetting. Now, leave me alone and give me my music, my iPad, I'd be fine. To me, music is more about the meaning of the lyrics, anyway [leans back in chair and crosses arms].

*I-it* jesse*:*

*Performance of self as resistance to performing music:* Culann was clear throughout all of our interactions that performing music is not "congruent" to him, specifically when it involves being forced to perform music and related actions that run counter to how he sees himself. Although performing music might allow Culann to mask his "difference" in certain settings and to manage social interactions (e.g., Goffman, 1959), doing so would not allow him any sense of expressive control over how he performs his self. Performing resistance here is "congruent" with Culann's sense of self, regardless of how stigmatizing or isolating it may be in a particular setting. Culann's strongest social relationships came when he found a group in which he could engage in genuine performances of his self and his musicking (i.e., resisting overt performance *in* music and engaging *through* music listening and *around* music by discussing lyrics). Interestingly, Culann does sing along with music when he is by himself and/or when with his friends. Yet, in experiences when required to "perform" music via singing or dancing, Culann would rather perform resistance. Resistance provides him an alternative way to *be* within a setting.

Resistance provides way of subverting or at least challenging the control of a leader who may have narrow definitions of what musical "performance" and identity performance are and can be *in* music. Culann's performance of resistance may point out the illusory rigidity of perceived options for musical and identity performance *in* music (e.g., Butler, 1990) and the ways that different performances of both music and identity—if they can be separated—can allow for experiences of social inclusion and/or exclusions *in* and *through* music. Indeed, Culann's repeated performance of resistance *in* music and the "negative" responses of leaders points out the problem of "compulsory able-bodiedness" (McRuer, 2006a, p. 301), if Culann's descriptions of his musical performance inability are true. The leaders who ask Culann to be *in* music in ways that are incongruent with his functioning, interests, and identity may be affirming compulsory able-bodiedness without noticing it. What additional ways of being and performing *in* music might be available for Culann and for others if compulsory able-bodiedness were not enforced? In music learning settings, what new opportunities might be available to all learners without the force of compulsory able-bodiedness?

Culann: I'll be listening and I'll pick up bits and pieces of words and ideas that I feel are congruent with who I am, bits and pieces that, you know, help me know myself more and feel more comfortable being Culann. I'll hear a song, like "Father of Mine" by Everclear and the line, [points] "I will always be weird inside, I will always be lame," will just stick out because it's like I feel this way [points up], even though the context may be completely different. Like, Tori Amos and Pearl Jam, too, they are basically expressing what I feel in ways that are far more poetic that I could. You know, I may not be able to say, "I feel like this . . . "

> [jabs down at table with finger] and be accurate, but I could say, "I feel like Pearl Jam." It isn't totally analogous because I know people like Everclear, Pearl Jam, or Tori Amos aren't talking about me, but these bits of pieces feel like me regardless of where they come from.

*I-it* jesse*:*

*The social confluence of refuge in, through, and around music and musicking:* For both Ice Queen and Culann, experiences *in* and/or *through* music can be places of personal refuge, a music asylum (e.g., DeNora, 2013), if you will. For Ice Queen, experiences *in* music via performance are central to her identity and these experiences often allow for activities in which she finds herself most empowered and agentic. Whereas academic experiences may be difficult and social connections through non-musical experiences require risk and vulnerability, experiences *in* music via performance are both welcoming and challenging for her. Ice Queen has always found experiences *in* music, specifically those involving performance, to be easier than experiences *in* other academic areas. Because of this, she feels more empowered to take on challenges, such as playing difficult solos in concert band.

While Ice Queen prefers experiences *in* music via performance, for Culann, performance experiences *in* music are places of hostility, inadequacy, and anti-agency in which he is forced to use his voice and body to contort and conform to the edicts of others, many of whom have regularly told him that he lacks "talent" for performing while they require him to do so. Culann finds refuge through listening and through using music to "speak for him." Culann finds himself and others *through music* via listening, analyzing, and researching and making use of music and musical phrases from songs he finds congruent. Expressing himself *through music*, particularly song lyrics, can be a powerful way for him to be vulnerable while also safe because the music speaks, rather than him, directly. Performing himself *through* music allows him a kind of translucent mask by which to manage social interactions, should his vulnerability open him up to unwanted attention.

Considering Lubet's (2011) social confluence theory, one might wonder whether meaningful experiences in, through, and around music provide Ice Queen and Culann with places in which they find themselves more as agents than as subjects. Experiences *in* music, for Ice Queen, and *through* music, for Culann, are filled with comfort and personal challenge consistent with their intersectional identities and ways of being and doing. With their preferred experiences *in* and *through* music, both participants rarely feel disabled socially or individually and neither are required to mask (e.g., Goffman, 1959). Given that each needs a different type of experience to feel comfortable, one might consider how inclusive constructed musicking experiences are for each person through the lens of social confluence (e.g., Lubet, 2009b). This plausible insight challenges conception that there can be a universal approach to inclusive music teaching.

Sienna: Yeah, but the context of the music matters, too. [straightens in seat, looking at group] When I listen to music, I feel a connection with the singer, the songwriter, and their contexts. When I listen, I don’t really take the lyrics for myself, but I try to listen to what that person is saying. When I listen, I experience a passion for humanity because I feel like I’m making space for the personal experiences of other people to come into my life. [motions out with both hands] I hear the joyful, dark, deep, and emotional times in their lives through the songs. I think listening to music, like Imagine Dragons’ “Demons,” Sister Haze’s “Battle

Cry," "When It Happens
to You" by Lady Gaga
and the Hunting
Grounds, and "Take Me
To Church" by Hozier . . .
I hear stories and voices
that I might never have
thought of if it hadn't
been for the music.

*I-it* jesse*:*

*Experiences through music and social connection:* Sienna comments that listening to or performing a piece of music that addresses some issue of social marginalization or oppression can open up ways to connect with others *through* music. For example, *through* listening to or performing the music of Hozier and Sister Haze, Sienna finds ways to connect their experience of disability, shaped by oppression and marginalization, with other persons or groups who may have experienced different ways of being/knowing (e.g., experience homosexuality and experience racism) that are also shaped by oppression and marginalization. As suggested by rhizomatic theorists (e.g., Kuppers, 2009, 2011), social connections occur at the intersections of different identities or types of experiences as well as at intersections of DP/PwD's lived experiences of disability.

Sienna: I just love it, too, when
artists use their privilege
to speak for their
community or to be an
ally and speak for people
who don't usually have
the chance to do so

otherwise.

Birdie: [closes eyes and nods slowly in agreement]

**Erica:** **[sits up and sings] “We're secretly out of control, nobody knows it, but my mom's got a problem with oxy's and she's angry cause my dad's office door's always closed, but I stopped knocking . . . We're secretly out of control, nobody says it.”[177]**

*I-it* jesse*:*

*Speaking through lyrics*: When Erica speaks *through* singing the lyrics of others, she is perhaps more straightforward with her intention than some might expect of her based on visual “stigma” symbols (e.g., Goffman, 1963) and her verbal communication. When she sings songs as a response to questions or discussions, the relevance of the song to the conversation may seem overt sometimes. At other times, her meaning might require the listener to possess knowledge about the background of a song or some specific context not available at surface level. Her musical memory, described as her “musicle” or musical muscle by her parents, appears vast, and she uses it to communicate her complex inner world in ways that may not be apparent through speech. If approached only from an IFCD-informed perspective, one might fail to see Erica’s musicle and her way of speaking *through* music, and then question her functional abilities based on external measures of her cognition and speech (e.g., Scambler, 2012) and deem her deviant. This apparent deviancy might lead to policy-informed decisions about her placement in education and social settings as well as the treatments she might be in need of to “fix” the deviancy (e.g., Rioux & Valentine, 2009). Placements and treatments might cast her in a subaltern role in which her utterances may never be recognized (e.g., Campbell, 2005; Nagi, 1991). Her role might then lead to her

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[177] (Bellion, Douglas, Evigan, Kirkpatrick, & Martin, 2016)

totalization as only a person “with a developmental disability of unknown etiology” and block others from coming to be-with her *in*, *through*, or *around* music, thereby blocking her from manifesting in others’ lifeworlds in ways that are true to her being.

Birdie: Wait, I’ve heard that, what is it?

**Erica: Jon Bellion. What’s that song, Jesse?**

*I-Thou* Jesse: Hmmm, you played this for me a few times. Ah, “Morning in America,” I think . . .

**Erica: [smiles] Yes! [singing] “We're secretly out of control, nobody knows it. Yeah, we're secretly out of control and everyone knows. Oh, it's morning in America.”[178]**

Sienna: Hmm, I never thought about that song, but, yeah, it does address the troubling opioid crisis in

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[178] (Evigan, Douglas, Martin, Kirkpatrick, & Bellion, 2016).

# this country and relationship problems…

Birdie: [nodding] I think I get where you're coming from, Sienna, with the whole "voices of other people" thing. Like, I think about frequencies in my art work, and lines. When I'm listening to music and doing abstract painting, I, like, get a chance to feel some new frequencies [smiles and then looks down to pick at her skirt].

*I-it* jesse*:*

*Music as "speaking to" and "speaking for"* (e.g., Pate, 2012): Sienna and Birdie spoke of the ways they came into contact with different voices and vibrations *through* music listening. Pate (2012), noted that during music listening, a person might find moments in which the music resonates deeply with their being in a way they feel that the music, or the music makers, speak to them. For Sienna and Birdie, music seems to allow new presences to enter their lifeworlds as people, perspectives, frequencies, and lines to take shape. These manifestations might "tear [them] out of [themselves] . . . throwing [them] beyond [themselves] into the dry dust of the world, on to the plain earth," to paraphrase Sartre (1947/1970, p. 4), to exist in their internal worlds and walk among the worlds of others who speak to them through the music. For Culann, the songs of his playlists may speak *to* him in a similar way to the experiences of Sienna and Birdie. Yet, his experiences seem more marked by ways that *through* music he finds a way to speak *for* himself. Culann encounters lyrics, ideas, specific musics, and people that resonate with his being and allow aspects of himself to become tangible *through* the music.

Pate (2012) notes that the "speak to"-"speak for" couplet is highly complex and not a simplistic binary in that things that speak *for* one appear to speak *to* them first, before these other voices and "things" become integrated into one's self-concept, which then affords speaking *for*. For example, the moment Culann heard Kurt Cobain's music, Cobain seemed to speak to him, to disclose his miserable state *through* music. This resonated with Culann's sense of self and being, providing him with an "other" who had similar characteristics that manifested in Culann's lifeworld. At the same time, Cobain provided Culann words and music he could use to create, affirm, and recreate himself—words through which he might come to manifest in the lives of others. Culann came into the presence of others and found ways to connect with others *through* music.

Birdie: Sometimes the frequencies in the music give me new lines to play around with in my art [mimes painting in the air]. Like I'm able to concentrate on painting, but then I'll hear a note and, like, it will change the way that I apply paint, like, heavier, lighter. And sometimes, it's like the frequency of the music, the frequency in the art, and the frequency of my mind [points to head] sort of come together. There's something about painting–and [smiles] I always listen to music when I paint– because there will be these snippets of my life that come back to me so vividly.

*I-it* jesse*:*

*Music as therapeutic 1:* Birdie finds her use of music to be therapeutic. *Through* therapeutic uses of some kinds music, Birdie can experience decreased negative symptoms associated with epilepsy and, in some cases, the therapy can be rehabilitative such as when it helps her regain memories lost through seizures. She commented that she felt the therapeutic aspect of her experiences *through* music might be lost if she were taught to listen analytically to the music. Birdie's control of her therapeutic uses of music is important here; she does not receive specific treatments of music based on medical diagnostics. She uses engagement with specific music to help her deal with negative aspects of her impairment. In this way, Birdie affirms the role her body/mind plays in her experiences of disability and alludes that her experiences of disability do not fit clearly with strict social-focused conceptions of disability.

| | |
|---|---|
| Birdie: | These memories come back to me [eyes soften] and they could be the most random memories from childhood. But they come back to me . . . I get to relive this part of my life again because I'm remembering this and I totally forgot that it happened. Maybe that's one of the reasons I'm so drawn to abstract painting. Well, that and there's a sense of control and looseness I get from painting abstract. I don't have to worry about what it's going to be, just paint through it and it will turn out to be a work of art eventually. It's something that I do have control over. You know, seizures are abstract, kind of, but I don't have control over them, they have control over me. But, like, [shifts head to side and looks off to distance] I have control over my paintings. |

*I-it* jesse*:*

*Congruence and resonance through music:* Culann's notion of "congruence" and Birdie's discussion of feeling some things resonating with her could be interpreted from an intersectional perspective (e.g., Crenshaw, 1991; Erevelles & Minear, 2010; Moodley & Graham, 2015). Things that are congruent and that resonate with these participants may be things that connect with multiple aspects of their intersecting identities. For Culann, moody music, music that is epic and tells tragic stories, and lyrics and music that support a questioning of gender role norms all feel congruent for him. These musics intersect with his self-image and subjective experiences rooted in his diagnosis/disabled identity, interest in fantasy/geek identity, and feelings of not being typically "masculine" in his gender role. Birdie is drawn to music and artistic engagements that resonate with aspects of her being and identity. She finds abstract painting to be resonate with (but not triggering of) her seizures, which she also describes as abstract; music such as the Antler's song "Atrophy" deeply resonates with Birdie as do musics she judges to be "timeless" and "authentic." The song "Atrophy" also includes sections that Birdie described as mellow and "a wall of noise," descriptions of sound that might resonate with Birdie's experiences with disability. Beyond concerns of genre preferences, Birdie and many other participants in this study note the importance of finding music and musical activities that resonate with their personhood in an almost ineffable manner. In these ways, participants such as Culann and Birdie may find a reflection of their identities, and their disabilities, *through* music and, thus, be able to find themselves *in* the music.

*I-Thou* Jesse: Daren, Birdie's mention of control reminds me a little bit about your experiences with breaking—breakdancing—versus playing piano.

*I-it* jesse*:*

*Control:* The importance of having "control of" aspects of one's life is prominent in many of the accounts of participants. Culann, Duke, Ice Queen, and Birdie noted the importance of having control over the musical activities in which they engage or the music they hear. Control over one's personal or social identity was also an important facet of accounts of Sienna, Daren, Erica, and Birdie. Birdie and Daren noted concerns over "playing the disability card" and/or otherwise being forced to disclose an attribute that might become a social identity that was stigmatized and might "spoil" their identity (e.g., Goffman, 1963), thus losing "maintenance of expressive control" of their social identities (e.g., Goffman, 1959, p. 33). Culann's attempted suicide in this teen years forced a disclosure but this led to his access to a youth hospital where he found people to connect with *through* and *around* music. Sienna's status of being blind gave them access to a residential school with a school-based, community music therapy program that they prized. Yet, neither of these disclosures were completely voluntary.

Daren: Well, [crosses arms] I guess I can see what you mean there, but I don't think I'd call it control, [shifts in seat] as such.

*I-Thou* Jesse: How would you describe it then? I mean, from the outside, it seems like you have control when you're breaking in a way that you might not in piano playing, since you’re more prone to ticks when you’re playing piano.

Daren: Yeah [nods] I get what you mean. Maybe what you’re talking about with the whole “control” thing is the physicality of breaking/bboying [uncrosses arms], which kind of shuts out my experience of my Tourette’s. I don’t want to make it seem like I don’t like playing piano. It’s a good outlet when I’m stressed. But I can get frustrated when I’m trying to figure out a new soundtrack piece on piano and that added stress elevates the chances of a tic because Tourette is more psychological than neurological sometimes.

*I-it* jesse*:*

*Psychological or psychosocial aspects of disability:* Daren, and others, note the psychological and social aspects of disability experiences in, through, and around music as being of more concern than the diagnostic aspects of disability. These “hidden” psychological and psychosocial aspects of disability may not be observable to others and can easily be overlooked by others, especially if those others are focused on diagnostic criteria or stereotypical symptoms. There is a great deal of interplay between one’s impairment, their psychosocial and psychosocial states, and their disability identity (e.g., Shakespeare, 2014; Lubet, 2011; Kuppers, 2011).

Daren: There can be a lot of head twitching when I’m playing piano and learning a piece, when I’m stretched mentally. I think that might be because I have headphones on, it happens mainly when I have headphones on. Other than that, the main twitches would be just general body twitches mainly when I'm learning some new or getting something down. As for dancing, it's a little, actually a lot different. It's still an expressive outlet for me, but when I dance, I, sort of, don't notice my Tourette's. It goes away. You know, maybe bboying is just such a physical thing that I just don't pay attention to my Tourette's. I don't even think about it [shrugs]. It's when I reflect after I dance that I'm just like, "I, I didn't twitch at all." That's not why I break, but I'm grateful for it.

*I-Thou* Jesse: Well, why do you breakdance, Daren, why do the rest of you do what you do with music? I mean, maybe your "whys" might relate back to the question of "what are music experiences like to you"?

Daren: It's fun [shrugs]? It's something I look forward to doing. I really enjoy practicing. Also, like I said, it's an outlet for me and a way to release stress. I like having this thing, freestyling specifically, to look forward to after a long day of classes and homework.

*I-it* jesse*:*
*Music as therapeutic 2:* Similar to Birdie's experiences *through* music, which she found to be therapeutic, Daren uses music and movement therapeutically to shape his experience of disability *in* music. Not only this, but his experiences can be motivating to him. The choice to engage in something that is intrinsically motivating is a powerful one that many participants discussed as necessary for their experiences in, through, and around music. Lack of choice about the kind of music and the kinds or types of experiences in, through, or around music could be disabling, as in the case of Culann when forced to perform. Lacking choice or, more directly agency, could place a participant in a problematic subject position as a dependent other (e.g., Reindal, 1999).

Ice Queen: [leans toward Daren] I've never done breakdancing, but I thought it was something people did socially. Do you, I mean, can you breakdance alone?

Daren: I can see where you would think that [shakes head]. The public knows breaking mostly from in the form of street performances or battles. [tenses face] In battles, you are facing strangers and other people who are often professionals. That can be nerve-wracking. I do think you can freestyle alone, though. I practice alone sometimes, but while I'm at college, I practice three times a week with this student organization dedicated to bboying/bgirling, I was sort of the president by default for a while. The thing about that is you have to teach newcomers. I don't mind teaching, it can be fun and challenging, but I'm more in the breakdancing student org to have a place and time to practice. I don't think I'll do much social breaking when I graduate, I mean it isn't like I'd travel to go to a battle. I just like to freestyle on my own.

*I-it* jesse*:*

*Solitary and exclusive musicking:* Daren articulates his enjoyment of solitary experiences *in* music. Rather than longing for social experiences or to be "included" in group activities, Daren enjoys engaging with music and breaking on his own, seeking social connections when they serve his interests. Culann noted a similar desire for solitary experiences *through* music. When they explored music as they wished, alone or with social engagement at their discretion, Daren and Culann were no longer bothered by the stress of controlling or masking their identities and/or behaviors that may be stigmatized in social groupings (e.g., Goffman, 1959, 1963). Choice of social engagement arose for other participants as well. Sienna, though a fan of inclusive social music experiences, enjoyed being a part of an exclusive music group for disabled musicians/musicians (i.e., the school-based, community music therapy bluegrass band)—a group of people who share similar music experiences and, possibly, experiences of disability. For some DP/PwD, contexts that are "exclusive" may be more welcoming/hospitable and, potentially, more preferred than mainstreamed contexts (e.g., Rathgeber, 2017). Potentially, exclusive settings or solitary settings may afford spaces where the need to mask or control disability-related identities and symbols can be relaxed. From an intersectional perspective, exclusive groups can provide DP/PwD with chances to interact with peoples whose identities and experiences might be congruent or resonant with the other social actors.

Ice Queen: Yeah, I certainly understand the want to do things on your own or, well, for yourself. I think I used to do a lot of music things for only *me* when I was in high school.

*I-it* jesse*:*

*Numerous types of independence:* Ice Queen characterized independence in three different ways when she said, "do things on your own or, well, for yourself . . . I used to do a lot of music things for only *me.*" "On your own," 'for yourself," and "for only me" are three different expressions of independence in her experience. Thinking aligned with IFCD suggests that to be independent is to be some sort of completely autonomous agent who is a productive member of capitalist society (Reindal, 1999). Yet, here, Ice Queen defines independence as (a) choice, (b) self-determination, and (c) self-motivated and/or self-serving, the latter of which was not necessarily positive for her.

Ice Queen: I was mean to other people in marching band in high school because I wanted something where I could get recognized, you know being "the girl that got the band to win again." I thought that would be the only way I could gain any sort of notoriety or attention, and I've always been a person who likes attention. So, I was really intense. It was kind of a selfish thing—not to say, Daren, that you dance alone for selfish reasons. But I think now a lot of my music experiences have given me a chance to connect with other people.

I'm not in love with being a solo performer, but I love playing in large ensembles and having these friends that I share experiences with. Like I got into ΣAI and even college marching band because it allows for an easier way to connect with others. People join professional music fraternities because they love music and they want to give back to their community through music. I feel like having, um, having that common factor of music in a room full of members takes away the barriers between people. You can just start a conversation [smiles and brings hands together] and find out what other things you have in common. People join marching band because they all love marching and you can immediately bond over that, over playing together and putting on a show. You don't have to meet someone new and like, later on, find out that they are into the same thing as you, you know?

Daren & Birdie [nod in agreement]

*I-it* jesse*:*

*Social connections* *around* *music* *through* *experiences* *in* *music :* While Sienna spoke of listening and performing as a way to experience connection *through* music, Ice Queen notes how her experiences *in* music via performances and her experiences *around* music in ΣAI and after rehearsals provide ways to connect with others. Here, the connection is still facilitated by shared intersectional identities, such as being a female musician interested in service or being an alto saxophone player in a college marching band, yet the *around* music connections only arise, for Ice Queen, because of experiences *in* music via performance. She may not feel direct connections with individuals *in* music; although she feels a general sense of comradery and group unity in performance, experiences *in* music provide for opportunities to connect *around* music.

*I-Thou* Jesse: Culann, music has been a social connector for you as well, right?

Culann: Yeah, and a social disconnector, if you know what I mean.

*I-it* jesse*:*

*Music as social disconnector:* As much as many of the participants discuss how experiences in, through, and around music can allow for social connection, Culann and Birdie note that that certain experiences can manifest social disconnection. For Culann, if music, whether genre or activity, is not congruent with who he sees himself to be, then he can feel isolated or alienated. Birdie “dis-cludes” herself from certain settings (e.g., raves, loud music clubs, concerts), kinds of musics (e.g., music that has “flash beats” and music that seems inauthentic), and specific people who engage with these musics and/or in these settings. Similar to the social confluence of disability and inclusion/exclusion (Lubet, 2009a, 2011), solitary and social experiences in, through, and around music, for these participants, had to do with the music used, the musical activity engaged, the music itself, and the physical environments and the interactions of those elements with their disabilities as they experienced them.

Culann: [shrugs and leans back] Like, if the music isn’t congruent with who I am or if the experience puts me in a place where I’m supposed to do something that is incongruent with my personality or that I don’t have natural talent *for*, then it can be pretty alienating.

*I-it* jesse*:*

*The disability-hyperability binary:* Culann was adamant in his belief about natural talent for specific skills and musical activities. He discussed talent as natural ability or potential that people possess which makes certain activities easier for them. He did not suggest that one cannot engage in an activity without talent for it, but he was concerned with how people might not consider talent in educational settings. Specifically, he felt that not all people had talent for singing, and so attempting to get all people to develop a similar level of skill in singing was an impossible task, to him, and one that might be over-stressed in music learning. He hoped that people would be encouraged to find their own talents. Culann also noted how having a learning disability can stand in the way of finding or realizing one’s talent.

Culann felt he had a talent for spatial reasoning and the imagination necessary to be an engineer, but his learning disability (dyscalculia) made it impossible for him to use this talent to connect with a career path. Lubet (2009a, 2009b, 2011) addressed the complex interplay of disability and “talent,” which he refers to as an assumed hyperability. Lubet also describes the way in which the disability-hyperability binary is an artifact of an exclusionary and highly Western conception of music education as professional development rather than music education as the human musical development (Lubet, 2009b).

Culann: *But I think finding my music, was part of me being able to connect with others, since I had something to share, and was part of me connecting with myself. Shit, maybe being me and making friends is part of the same sort of process, you know, one dependent on the other.*

*I-it* jesse*:*

*Finding oneself through music:* When Culann found “his” music, he began to find himself. The aspects of the music that were congruent with his feelings manifested into his lifeworld, providing a structure for himself to manifest in more clarity into his own lifeworld.

Sienna: Well, making music is a big way I’ve gotten to know other people [leans on the arm of the couch].

I mean, I know bluegrass isn’t for everyone, but playing in a bluegrass band means you’re surrounded by people who enjoy the same music, or, at least if they didn’t, they pretend they do. The whole structure, but almost a fluid structureless structure, of bluegrass and Old Time music, I feel, is about connecting and supporting each other. Each person, each individual instrument plays their part. Everyone agrees on a key, a tune, and a tempo, so that’s a thing to connect with others through. Unlike in an orchestra that is a well-oiled machine working toward perfect phrasing, in bluegrass you just kind of play with and then play off people and they kind of bounce around ideas. Like, you could be playing one

thing and then someone

else plays something else

and you’re like, “oh,” and

so you hop on the

bandwagon. That

informality is important

for me to feel in the

music.

*I-it jesse:*
*Disability as a means of accessing a “fluid structureless structure” and belonging:* Sienna notes here how their experiences of disability, specifically with a diagnosis, has given them

access to a meaningful way to be *in* music and connect *through* music. Much like the participant in Bell's (2017) study, Sienna did not experience disability in a salient way *in* music via playing in bluegrass group. Unlike the participant in Bell's study, however, Sienna first had to experience disability *around* music by disclosing their impairment or having it disclosed for them, which then allowed access opportunities to be *in* and *through* music in the bluegrass band—something that she experienced as a "fluid structureless structure" provided by belonging in the group of people and by Sienna's assumption of the openness of bluegrass music. *In* this musical practice, Sienna is given space and time to connect with others *through* a shared interest in the practice and/or repertoire. *In* and *through* the music, Sienna finds a sense of belongingness (e.g., Anant, 1966), having a "'we' or 'us' feeling" (p. 22).

*I-Thou* Jesse: That brings something up that maybe we can explore more: connecting with others. **Erica**, I think about how you connect with others and even speak what's on your mind through song. I know that you like to use lyrics to speak for you and you connect with others by singing with them. I mean, we have a song we bonded over . . .

**Erica: [beaming] "Yellow Submarine!" [points] You sing!**

*I-Thou* Jesse: Well, maybe not right now. But, are there other songs that you connect with others?

**Erica: [twists in her seat] Songs from *Pirates of Penzance, Jr.* with my friends, Marilyn and Jayda and Samuel and Wyatt . . . I like singing with people. [singing] "Yellow Submarine!" [singing] "In the town, where I was born,"[179] let's sing . . .**

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[179] (Lennon & McCartney, 1966).

*I-it* jesse*:*

*Presence and belonging:* Being with Erica means being present with her *in* music making, to be doing music, rather than talking about and thinking about music or music making. Although one might assume limited communication and connection due to her limited linguistic abilities, Erica uses singing and sharing music with others to find belonging *in* music. *Through* musical presence, Erica appears to feel some sense of her needs being met and meaningful participation with another person in a rather quick manner (e.g., Anant, 1966). Presence *in* music provides for belonging *through* music. Her experiences of disability manifest different means of communicating and connecting.

Birdie: Oh [pats legs in excitement and smiles], I *love* the Beatles, too. Maybe we should be friends. After all, your friends kind of like the same music as you and that's why they're your friend—because you like the same music.

DUKE: Yeah, I like singing with my friends. I sometimes even go onstage and sing a song or two. Sometimes I play drums with them, or at open mic night. I've got a couple of bands with my friends and I've made friends in rock lotto. I love jamming with my friends, old and new.

*I-Thou* Jesse: And I think that's an important point here, DUKE. You go out to clubs where you'll find people who have voluntarily come out to listen to live music with other people. Most people who are at these clubs are there for a similar reason and might share similar interests. And this is something you've chosen to be involved with...

Ice Queen: Yeah, there is something different about picking to be involved in something and not being required to be involved. It's weird, but given how intense I can be about accomplishing, I tend to pick low pressure experiences and easygoing environments when I’m deciding which groups to play in. There’s something nice about making music with really fun people who are really easy going, and like, when work needs to get done, they can get serious, and it does. It never feels like a stressful thing or, or like you’re being bossing anybody around, but it isn’t just a free-for-all. It's just, when stuff needs to get done it does. Um, and they're still able to make time for goofing off and whatnot. I feel like there are chances in these groups to go above, so if I just want to get this one thing accomplished, then I can actually do that, and it's a lot more rewarding. It feels like you can personalize the experience for yourself, somewhat.

*I-it jesse:*
*Self-differentiation:* Ice Queen discusses the importance of being able to choose the level and intensity of her musical engagement. This aspect of choice has strong connections to the concept of “alternative zones of inclusion where people can assert their own versions of ability and normality” (Adkins et al., 2012, p. 513) and the power to make a choice concordant with their needs and desires. Rather than having one’s path differentiated for them by music teachers, Ice Queen and other participants desire to have options that they can choose from, much like a someone playing a videogame can decide upon the difficulty level or, in open world or role playing games, the chance to literally tailor the adventure to fit their interests and personal situations.

Ice Queen appreciates the ability to self-differentiate or self-select the level of challenge of her experiences *in* music. Yet challenge and even repertoire are not the only dimensions that participants appreciated having choices and opportunities to self-differentiate. Culann and Daren indicated they appreciated being able to self-select their social immersion, their social “inclusion” *in*, *through*, and *around* music. Being able to engage in small groups, large groups, and alone was an aspect of self-differentiation prized by participants.

DUKE: Yeah, yeah, yeah. I get that.

*I-Thou* Jesse: So, choice of challenge level . . .

Culann: . . . [sits up in chair] and choice to engage at all . . . [nods and slouches back in chair]

Daren: . . . it's nice to have choice of how you interact in music, you know like having a choice in bboying, not singing, or performing, like Ice Queen likes . . .

Ice Queen: [grins and eyes light up, nods]

Sienna: . . . and choice of music style! [nods and crosses arms]

DUKE: Yeah! I like choosing to go out to band shows. I drive my little scooter all over and go to a few shows a night sometimes. It's part of me. I choose to stand close to the band and be part of the music. Sometimes I come earlier to get know the people in the bands, if I don't already know them, or to hang with my friends in the bands that I already know. Either I'll help them out, you know, load their stuff in, to help them out. Between sets, I'll go hang with my friends in the audience. I like making them laugh and helping them out when they need my help. They all get a crack out of me.

*I-Thou* Jesse: `DUKE`, I seem to remember you talking about liking to play too and enjoying all the attention you get from the audience and the trust you build with bands that you sit in with, bands you often have just met.

Birdie: [leans over to Duke with wide eyes] You play with bands you just met? Wow, I don't know if I'd be that brave to ask. I'm just now getting the courage to, like, umm, do karaoke in public. That's so beautiful.

`DUKE:` `[tugs at his stocking cap and grins, nodding] Karaoke would be fun, maybe we can do that together, some time. Singing with my artist friend, Birdie, sweet! Well, yeah, I play in some bands and sit in with my friends' bands a lot, or I'll just ask a band I don't know if I can sit in for a song. They usually say "yes." I like playing with new people because it makes me feel like they trust me or I get to prove that they can trust me. I like playing drums, or whatever too, because everyone cheers me on and they are blown away, because I get up there and I beat the snot out of the drums. Afterwards, people tell me how good they think I am, they say, like, "Wow, DUKE, that was amazing," or, like, "You're such a good drummer."`

*I-it* jesse*:*

*Connecting around and through music at rock shows:* Attending rock shows and hanging out at concert venues afford Duke opportunities to connect with others *around* music. The venues attract Duke because of the music, and by attending he makes chances to connect to people by helping bands unload, supporting and making friends laugh, and playing. Being on stage and playing drums provides Duke with spaces for being *in* music and to connect *through* the music with others who might give him praise. Duke's performances also may challenge other concert-goers' assumptions about disability—if they read Duke's "stigma symbols" (e.g., Goffman, 1963)—and may open for concert-goers additional viable ways of doing music and being musical through engaging with Duke and his performance of disability (e.g., Laes & Westerlund, 2018).

*I-Thou* Jesse: There's something in the way you and Ice Queen talk about your experiences that has to do with getting positive attention. I don't think, though, that everyone else likes the attention. **Erica**, do you like the attention you get when you make music?

**Erica:** **[close mouth grin] Maybe. [wide smiles] I like to sing.**

e-father: [stands up and walks over to the group] Oh, she can be quite the ham, right **Erica**? Remember singing in church when you got everyone to join in?

**Erica:** **[nods in affirmation]. Yes. It was fun, singing with everyone. [singing] "Blessed assurance, Jesus is mine. Of what a taste of glory divine." I sang with the kids.**

*I-it* jesse*:*

*Attention:* Erica, Ice Queen, and Duke enjoy how positive attention can manifest in their experiences *in*, *through*, and *around* music. Ice Queen noted a long-standing need for attention. The positive attention she receives *through* music may buck her own internal anxiety and worries about her own competency in other areas of her life. For Erica and Duke, positive attention manifests when they perform in contexts or in ways counter to other social actors' expectations; positive attention manifests when their mask/front (e.g., Goffman, 1959) disappears in ways that are not too disorientating for other social actors. Though this is only conjecture, I worry about whether Duke and Erica become "inspiration porn" (e.g., Grue, 2016) in these moments. The attention, while received in a positive manner, may occur because of low expectations and ableist assumptions audience members have. In these situations, do Erica and Duke manifest in their realness in audience members' lifeworlds, or do they manifest as "wondrous," "sentimental," or "exotic" (e.g., Garland-Thomson, 2002) specters? Regardless of intentions/assumptions of audience members, though, Duke and Erica feel empowered by positive attention.

e-father: [smiles at Erica, then faces all of the group] I thought I could share a quick story—sorry for eavesdropping: One Sunday when **Erica** was basically non-verbal, she got up with the youth and led the congregation in a song. No one stepped up to the microphone to lead, so she did and became the song leader. She led the verses, shared the mic with other children sitting up front, and encouraged the congregation to sing on the chorus by not singing. [turns to Erica] That was the first time many in the congregation had ever heard you make a sound and there weren't many dry eyes after that and lots of applause.

**Erica:** **[bashful smile] I sang at a talent show. [sings] "Nikosi Sikelel' iAfrika."**

e-father: [turns to Erica and shakes head slowly] Yeah, I wanted to send a video of that performance to a speech therapist you had when you were younger who said you [finger quotes] "didn't have much going on cognitively and would likely never talk." [faces the full group] But . . . [stops shaking head and smiles]

Sienna: Disgusting. You see, it’s that kind of thing, the low expectations that people have that let them write off disabled people. When we do anything that can make nondisabled people feel good about themselves, they call us an “inspiration.” All that

inspiration porn stuff.

*I-it* jesse*:*

*Infantilization and desexualization of disabled persons - Ableism*: There were numerous times when I infantilized Erica in my mind, questioning the songs she listened to because of references to drugs and sex. These moments felt odd, even insulting to Erica, in reflection, because she is a teenager, she goes to public school, has friends, and access to YouTube and the internet. Why would her “disability” make me think of her as not a teenager? Not only had I infantilized her, I desexualized her, thinking of her unintentionally as a being without sexual feelings. Sienna often railed against the way nondisabled people think that disabled people cannot or do not have sex. As Sienna shared, “Persons with disabilities also have sex. They do, believe it or not . . . Well, some do, it is a personal choice . . . They’re normal people with normal people desires . . .  Who would have thought?” Both infantilizing and desexualizing, with their paternalistic subject positions and social actions neutralized in power relationships, demonstrate the elements of tacit ableism that circulate in social interactions (e.g., Campbell, 2008; Hahn, 1986; Strickling, 2002).

Sienna: [embarrassed] Oh, I’m

sorry…

A short moment of tense silence ensues as Sienna, Ice Queen, Daren, Culann, and Jesse realize that Sienna has mentioned “porn” in front of 14-year-old Erica. Her father alleviates the tension, saying:

e-father: [laughs] For what? . . . Hmm, [contemplatively] inspiration porn? I'll have to look into that . . . Well, I didn't mean to interrupt. Back to grading, the faculty member's life and all.

Sienna: … well, ummm … okay Jesse you had asked about attention. You know, I enjoy the attention from being on stage and singing, as long as I'm *allowed* on stage [looks around].

Yeah, some people are afraid I’ll fall off, so I might not get allowed on the stage or have a part at all, and that is a form of exclusion which makes me feel like they really just don’t want me there because of my disability.

So, when people treat me like a human being…

Birdie: [claps and nods] Yeah, right on.

Sienna: I know, is that too much to ask? [laughs] So, it can be really great to get up on stage when I am in a musical and portray someone else, to be someone else and tell someone else’s story. Hopefully the audience sees the character and doesn’t think about my disability, well, unless I’m portraying a person with a disability. There’s this want for attention as an actress and singer in that moment, not as someone that is disabled, because in that moment, I’m an actress and a singer first, that’s who I would be portraying in that moment.

*I-Thou* Jesse: Okay, so there can different facets of attention at the same time. Positive attention when people see you as the identity you intend to perform around receptive and supportive people. Negative attention when your performance is not recognized or understood you would hope due to stereotypes and stigma. But, what about not wanting any attention?

Culann: *[leans forward, raises hand and nods] Yes! For some reason, people always want me to do things like dance or sing in public, but I’m more of an observer. I love to observe and listen to artists* talk about their work and why they do it. But, I do not want to, like, dance. I like to watch people dance, but I just don't dance. I mean, I don't want to be in the position where people are looking at me in the first place. Because, when I'm forced to do musical things in public, it adds to the pressure I feel and I end up just saying to myself, "Okay, Culann, don't look crazy, don't act crazy, just get through this." When I was younger, that could give me a panic attack. Now that I'm in my early fifties, I would just dig inside of myself.

Daren: [sits up, twists head side to side quickly to crack neck] Well, I don't think about "looking crazy," even with my jerks and ticks, but I don't personally like a lot of attention, either. Umm, for a start, when I was young and was forced to play piano, we would have to do these little recitals for our families. Those weren't a very exciting thing. I do get anxiety and performing made me anxious, so it wasn't enjoyable to me. That's why I don't really like performing for people. I'm perfectly fine with just being kind of, just, under the radar. As for dancing, it's sort of the same except the social aspect of the org. That can be a reciprocal kind of environment where I teach and learn, a supportive group, sort of. But even thinking about facing strangers in a battle would just be too much attention on me.

*I-it* jesse*:*

*Performing self:* Participants commented directly and indirectly about the performativity of their senses of self. Some performances were true to their sense of self. Other performances involved purposeful fronting (e.g., Goffman, 1959) to mask their "self" for various reasons. Still other performances were forced and informed by the contours of ableism.

Duke's performance of self is either unfettered by worries of masking because he performs his true self all the time or he happily performs a role created for him by discourse. Birdie performed her authentic self, storm-like and all, even when her performance was disruptive and/or had "violent repercussions" for other social actors who would have to adapt to her performance (e.g., Peers, Brittian, & McRuer, 2012, p. 301). She would dis-cluded herself when she perceived that she could not perform authentically, although this very well may be a masking performance (e.g., Goffman, 1959) through the front of absence from social space.

Sienna's performances are interesting in that they purposefully mask their "self" to suit the role, literally when on stage, or the social position in which they find themself. Sienna is clear that they want to be seen as whatever performance they are giving. If they are performing as the Baker's Wife in *Into the Woods* (Sondheim et al., 1999), they want to be seen as that. If they are performing as a social worker, a disabled advocate, or as a mixture of multiple roles/identities, that is what their self is in that moment. The performance of their self was not through repetition but was shaped and reshaped by context.

Culann's performance of resistance was subversive and displaced the naturalized and reified notions of being *through* music (paraphrasing Butler, 1990) that were at work within the contexts in which he enacted his performance. He also masked (e.g., Goffman, 1959) *in* music when he was worried that aspects of his "mental illness" would become visible to a judgmental crowd (i.e., to avoid "looking crazy"). Daren masked throughout his experiences of disability *in*, *through*, and *beyond* music, including with his friends until he felt he owed them an unmasking, often because of the presence of numerous stigmas.

Erica performs her unique self *in* music, singing to be and to connect with others. Her performance, however, can be misrecognized, as it was by a past speech therapist and by educators. To understand Erica's performance of her self, one must enter the music with her and/or find other ways to be present with her. Otherwise, one might impose a performance interpretation on Erica that reinforces ableism and obscures the reality of her as she is.

*I-Thou* Jesse: Culann, when you say something about not “looking crazy” in public, it reminds me of how people can not want things related to their disability to cause them any attention. Daren, I seem to remember you saying something about how you would mask your tics and how you don’t really like disclosing your disability to even close friends.

Daren: I can understand how you would get that [shakes head]. Yeah, I don’t really tell people about my disability [crosses arms]. When I was younger, especially when I had a lot more tics, I would disguise them with yawns, stretches, and things like that. If someone asked, I would just say, “Well, it is just this little twitch I have” and then direct their attention to something else.

Birdie: [tilts head to the side] Oh, I wonder if you experienced something similar to me [crosses and extends legs out]. I’m always afraid to tell people, well, just people I’m not close friends with, about my epilepsy because I don’t want to, like, play the epilepsy card and, like socially handicap myself by becoming “*that* girl with epilepsy.” I don’t want to be a hassle that everyone has to feel like they have to rework everything around. It is kind of a bummer, though, because I end up not feeling like I can stand up for myself in social situations to protect myself, you know?

*I-it* jesse*:*

*Disablement of oneself and one's families:* Birdie's conception of how epilepsy can be harder on her friends and family than herself provides an interesting extrapolation of the social dimensions of disability. Disability impacts Birdie's friends and family and this, in turn, causes her anxiety. Birdie may be considered "socially disabled" in that she feels unable to advocate for herself or feels anxiety over the need for help, which she sees as a burden; the narrative of being an independent social actor who does not need others is a barrier for her and potentially an example of internalized ableism (e.g., Campbell, 2008). Yet, the extent to which her friends and family viewed her impairment as disabling to or for her seemed troubling to Birdie and may deserve greater attention by researchers. Birdie's account articulates the need to consider disability from an interactional rhizomatic perspective (e.g., Kuppers, 2009, 2011)—to consider how disability is experienced by the "disabled person" as well as by their social support network. e-father made a passing reference to a similar complex interaction of disability when he interacts with music teachers, therapists, and other caregivers in Erica's life. These recognitions by participants expand Shakespeare's notion that "people are disabled by society and by their bodies" (2014, p. 75); "people" in Shakespeare's quote could include both DP/PwD and nondisabled people.

*I-Thou* Jesse: Birdie, you said something to me before about worrying about "playing the epilepsy card" and "being *that* girl with epilepsy." When worried about "burdening" other people, it seems like you feel tension about disability as an identity, or you feel tension about the stigma of being seen as "disabled."

Birdie [nods emphatically]

Daren: Yeah, I get that part. For me, I don't really identify as being "a person with a disability" or "having Tourette Syndrome," even though I do have Tourette Syndrome [raises shoulders]. I just want to be known as "Daren," you know? I actually wouldn't even identify myself as a dancer or as someone who plays music, as Asian, as being religious, or as someone who has Tourette's. I would just say, "I'm me and I'm a person." I have all these things, like my religion internally. But I wouldn't want to put that out front. I don't really tell people about my Tourette's, only friends if I feel like I owe them an explanation.

*I-it* jesse*:*

*Forced disclosure:* Daren specifically addresses the way in which he may feel forced to disclose his disability, specifically when he is unable to manage the visible physical signs of Tourette syndrome or stigmatized social interpretations of those signs of Tourette (e.g. Goffman, 1963). Other participants note experiences of or risks of forced disclosure. For Birdie, self-advocacy for her own safety is at risk when she is *around* specific kinds of music others choose because to ask for an alteration of the music or musical experience may require that she "play the epilepsy card" and, thus, be forced to disclose her disability to others. Sienna's account of how they can be treated differently due to the presences of stigma symbols, such as when they use their cane or wear thick glasses, may force some amount of disclosure. Yet, Sienna also felt able to use disclosure for personal empowerment, to yield disclosure in order to access social capital (e.g., Bourdieu, 1985) in specific situations.

Daren: I know some people that might be offended and think that not telling them means that I don't trust them [flicks hands to the side]. So, the friends that would be offended, I might tell or tell earlier. I have friends that don't really care. You know, there is sort of a stigma about Tourette's, it's a bit of a silly one, but, I don't really tell many people. The whole thing can be pretty frustrating and it gives me a lot of anxiety.

Birdie [nodding with index finger on chin] I feel that. You know, like Culann said, "don't look crazy," this is something like that with me, where I don't want to look weak or weird, or something like that, around people I just met. The tricky thing is that as much as I worry about being "*that* girl with epilepsy," I see so much of "epilepsy" in who I am. I always feel like it's a part of me, it is how my brain works and I see it in my patterns of productivity and my patterns socially. I just think it is the way my brain works.

*I-Thou* Jesse: Birdie, you just said, "part of me." You know, most of you talked about how "disability" is sometimes "a part of" who you are, and some of you talked about how it could be "apart from you," this other thing or entity in your life.

Birdie Yes, because it *is* a part of me [motions to her heart]. It's how my brain works and when I talk about it as being something outside from myself like when I say, "my epilepsy makes me . . .," I'm really just talking about the things that it sets me back on. That's- that's *apart* from me [pointing to the open space next to her]. Like epilepsy not letting me drive. You know what I mean? That's just, that's *not* who I am. That's just a factor in my life, I guess. But epilepsy is a big part of me, and a big part of my abstract artwork, especially how my process can be like this "storm-like" thing [taps head] where I finish everything in one big burst, just like how seizures are. I don't know, it is just really hard to untangle these things.

*I-Thou* Jesse: DUKE, what do you think? Is your disability a part of who you are and how other people know you?

DUKE: [adjusts stocking hat] I don't know. I don't think people know 'cuz I don't talk about it much. I didn't know I had a disability [hands moving in a circular motion] growing up and it took me a little while to figure out I wasn't born normal like everybody else. I thought it was a curse, but it is not. I don't really care if I have this disability, it's not gonna stop me from having fun every day. I've met some people out there that have this disability and they don't seem to have as much fun as I do, but it's fun! I used to be like, "I wish I didn't have this," but now I realized that I'm glad that I do have this disability. If I didn't have this, I probably would not make friends.

*I-it* jesse*:*

*Being and being through disability:* In interviews, Duke did not go into too much detail about "disability" but he did suggest that his disability, Williams syndrome, may have helped him make friends *around* music. While I do not suggest a cause-and-effect relationship between Duke's diagnosis and his life, a cursory investigation of characteristics of persons diagnosed with Williams syndrome suggests that his impairment may play a greater role in his lived experiences and personal identity than he discusses: "Williams syndrome (WS) is a genetic condition that is present at birth and can affect anyone. It is characterized by medical problems, including cardiovascular disease, developmental delays, and learning challenges. These often occur side by side with striking verbal abilities, highly social personalities and an affinity for music" (Williams syndrome Association, 2018). Duke's being-in-the-world appears to be experienced through or highly shaped by WS. Yet, although many of these seemingly positive "symptoms" seem to resonate with Duke, assuming a negative IFCD risks the danger of losing Duke and blocking his concrete being and manifestations in the lifeworlds of others.

Ice Queen: I usually think of my disability as an adjective. Well, It's weird to talk about it as a disability just because, like, learning disability and the term disability has the connotation of, like, when I hear it, I think automatically physical things. I usually say, "I'm ADHD," and if I go more into detail than that, I mean, sometimes I'll say, "I have ADHD, Inattentive," but it really doesn't come up that much, or at least enough where I would think about it. But, yeah, I think I usually say something along the lines of, "I'm ADHD" or "I have it." [shrugs] I haven't really thought about it that much. I know that getting diagnosed was a big deal for me because it explained so much of what I was experiencing and made me feel like I wasn't alone.

*I-it* jesse*:*

*Depression and anxiety as a background, as not manifest, or the newness of diagnosis*: For Ice Queen, "ADHD" was more salient in her experiences than depression and anxiety. Although she had lived with and through depression and anxiety since early childhood, she did not discuss these diagnoses much. In retrospect, I wondered whether her experiences in music are firmly grounded in or filtered through depression and anxiety to the extent that she cannot conceptualize them without the impairment or if the newness of her ADHD diagnosis made the more salient feature of her experiences. My reliance on participants sharing their stories and meanings with me and the limitation of only three interviews also limited getting to know Ice Queen and her lived experiences in a more substantial way.

Birdie: [squints and nods] I get you. [nods more] Having a diagnosis can be helpful with medical treatments and other stuff, but diagnosis isn't all of it, you now. Like, it's not [finger quotes] "epilepsy," for me. [points to open space next to her] That's what the doctors call it. But, really, it's how my brain works [taps head with index finger], it's how I work.

Maybe it *is* kind of an adjective, I guess, but, like, maybe "being Birdie" is a better term for what it is to me.

Ice Queen: Yeah, I just don't know if ADHD is that much a part of who I am [leans head], but it does describe some of my experiences [clasps hands with elbows on thighs], so that's why I think of it as an adjective, well, I use it as an adjective when I choose to bring it up. I try not being a huge downer around other people, so I'll sometimes say something about how I can't focus and that it must be ADHD, but then I have to clarify that I actually have a diagnosis, because people sometimes just say it as a joke, you know, "Like I'm OCD," and things like that, and that drives me crazy.

Sienna: [stiffens, shakes hands, and blurts out in an intense tone] Not to mention that saying "I'm OCD" if you're not is offensive, and so is

saying something drives

you crazy can be

offensive . . .

Culann: . . . [shakes head and leans forward] Ahhh, I don't know about that. I mean, I am crazy. I'm okay with that. I just don't want people to treat me like I'm crazy, well, like they think you're supposed to treat crazy people. I'm weird and different—crazy, and I'm okay with that now. I've gotten comfortable in my own skin. I just don't like when people think of me as crazy in the "evil, worthless, emasculated, sexless, grotesque creature" sort of way [stares at Sienna].

*I-it* jesse*:*

*Different types of preferred disability terminology:* Disability terminology is highly contested. What is offensive to one person and what is preferred by another person may be one and the same. Disability and the labels one uses may play an important role in one's personal identity (Ladau, 2015), and how one chooses to identity oneself was a highly important issue for participants in this study. Bloggers and disability rights advocates such as Brown (2011), Monje (2012), and Sinclair (1999/2013) along with scholars such as Bickford (2004) and

McRuer (2006b) advocate for empowering DP/PwD to make decisions about their preferred terminology rather than enforcing hegemonic norms articulated in policy and legislation.

Sienna: [loosens stiffness and softens tone] Okay, it is important to embrace your identity. For me, being blind is part of my identity, but I don't want my disability to define me as a person. I do want my identity as a person to be defined by my experience with disability. The whole identity thing gets really important because of the solidarity it can give you with other people who have experiences similar kinds of oppression. I’ve experienced oppression based on my different identities at different times and in different places. Looking at how people treat me

differently based on their
assumptions and biases about
different identities helps me
feel how society has taught
them to think and act. You can’t
really be mad at someone if
they were taught a certain way.
I have to get mad at the teacher
not the student. For instance,
I’m blind [she touches and

shakes her cane and points to her thick glasses] and I experience oppression based on my identity as disabled in my music experiences because of strange stereotypes people have and/or the way that people don’t accommodate with me in mind.

*I-it* jesse*:*

*Accommodation and inclusion*: Sienna's idea of "accommodating with [them] in mind" is rather similar to Buber's (1965) concept of inclusion in which a teacher acts with the student's existential being inhabiting their consciousness, rather than empty stereotypes guiding their practices. I found it interesting how infrequently participants spoke about "inclusion" as being structurally "included" in group (i.e., mainstreamed). Rather, they often spoke of a desire to be included in the lifeworlds of others as full and actualized social beings. They spoke of wants for meaningful relationships and belonging. I explore these issues in greater detail in Chapter Six.

Sienna: People think that I can play every instrument just because I'm blind, or that I'm just automatically an amazing musician because I can't see the same way as other musicians. That's a "good stereotype," I guess because it at least

assumes more rather than less,

like most disability stereotypes

and the whole “IP” thing

[glances sideways at Erica]. But

I can’t play an instrument

unless I’ve learned how to, just

like anyone else [shakes head

quickly].

*I-it* jesse*:*
*The resilience of naturalized bias and internalized ableism*: In our imagined group conversation, Sienna shies away from saying “inspiration porn” in Erica’s presence, using an

initialism. In our interviews for this study, Sienna specifically noted the problem of desexualization and paternalization of disabled persons, yet, they also demonstrated that although they were conscious of these biases, they were not outside of the reach of the highly embedded nature of them in their social life. I often found myself thinking paternalistically about participants, thinking that I should help them when no help was requested and conceiving of some of them in infantilizing ways. Regardless of Sienna's consciousness of disability rights issues and my own reading and investigation about disability oppression, we both demonstrated paternalistic tendencies rooted in ableism (e.g., Hahn, 1986), specifically with regard to Erica, a person with a "cognitive impairment." This paternalism extended by people "woke" to disability issues illustrates the resilience of biases and may be symptomatic of internalized ableism. Regarding internalized ableism, Campbell (2008) noted: "The experience of disablement can, arguably, be spoken of not in terms of individualized personal tragedy but in terms of communal trauma, where the legacies of ableism pervade both the conscious and unconscious realms" (p. 155). Perhaps, to draw on the parlance of the times: you can be "woke" to a source of oppression and still be "asleep" in your actions. For music educators who might be inclined toward social justice work, it is possible to work consciously to dismantle ableist structures while unconsiously perpetuating ableist structures.

Sienna: In musical theatre [leans back and relaxes], I've met people who either think I can't act well because I'm blind, or people who won’t allow me to adapt things based on my blindness. That last thing, the lack of allowing me to accommodate myself, is really ridiculous when I have this bag of accommodations I’ve had to develop because others don’t accommodate for me.

*I-it* jesse*:*

*Self-differentiation 2 (accommodative freedom)*: Participants noted a wish to be proactively accommodated for, yet to have the freedom to reject the accommodation—and to self-accommodate—either for no specific reason or because the accommodation was more oppressive than helpful. As Sienna noted, many participants would rather be offered accommodations than not, but they wished to have control in the decisions of whether and/or how to use the accommodations. Without control, accommodations become the kind of social barriers to inclusion and actualized personhood that Oliver (1983) articulated as a kind of harmful helping. In, through, and around music, Jellison (2012) advocated for something akin to self-differentiation urging for music classrooms and practices where DP/PwD could "experience autonomy, demonstrate competence, and make decisions about music, music making, and other music activities in their lives "(p. 67).

Ice Queen: [turns to Sienna] I've heard there is Braille music notation, do you read that, or does anyone ever give you music written in Braille?

Sienna: Yeah, I can read Braille sheet music, but I can't play an instrument that requires two hands and read Braille at the same time. I don’t often get offered Braille notation, which I would appreciate, but when I get it, I need time to take it home to read and memorize it. That way, I can pay attention to the music, be involved in the musical conversation, you know, focus on being in the moment musically. But not all blind people can read Braille notation. Even if offered a diagnosis-specific accommodation, not everyone would be able to use it, want it, or have a choice in the matter. All you have to do is ask

first, you know [nods and

gestures to the group].

All participants: [nods and “Uh-huh, yeah, yes” in strong agreement]

*I-it* jesse*:*

*Diagnoses and stereotypes blocking participants’ manifestation in the consciousness of others:* Participants shared that they wished people would meet them and know them, rather than assume things about them based on diagnostic criteria or stereotypes. Participants wished that others could encounter them in their concrete realness, to allow them to manifest in others’ lifeworlds through deep interaction. Unfortunately, participants implied that they had various experiences in which stigma symbols, bias, ignorance, and assumptions based on their diagnostic criteria and/or stereotypes seemed to manifest as a proxy for them in the lifeworlds of others. By not meeting the person but meeting the diagnosis or stereotype, nondisabled persons disallow concrete manifestations of nondisabled persons in the lifeworlds.

DUKE: [continues nods] Yeah, I ask people what they need all the time. Sometimes people need me to listen to them, sometimes they need someone to make them laugh, sometimes they need some help carrying their gear.

Sienna: And it is helpful if people would just ask everyone, not just those they think [air quotes] “look” like they need help or else you might commit a microaggression by offering help that might be unneeded or unwanted.

*I-it* jesse*:*

*Universal treatment:* Participants make it clear that would rather not be treated differently because of their disability, but that they wish that all persons would be offered supportive and empathetic relationships that would help them flourish personally in a given setting or practice. Sienna, with their comment, gets to the heart of the “universal” in “universal design:” *all* are offered help and personalization, not just those “with a disability.” Participants alluded to a way in which difference could become visible and normalized in social settings.

Ice Queen: [raises hand] Wait, “microaggressions,” what? Why would you not want help? If someone is offering help, why not accept it (hands out at side of body]? I mean, I don’t really ask for help a lot, well, I didn’t, and I used to take everything onto myself. It can be really great to get help, especially if you’re terrified to ask for it or if you don’t have good connections with people to feel like you can ask them for help.

*I-it* jesse*:*

*A reluctance to ask for help and forced disclosure*: Ice Queen, as with Culann and to some extent Erica, have noted a reluctance or inability to ask for help. For Erica, the issue, articulated by her parents, is that she communicates in a way that is not recognized by many. For Ice Queen and Culann, as with Daren and Birdie, the reluctance to ask for help and/or to be self-advocates may be rooted in a worry over forced disclosure and social stigma (e.g., Goffman, 1963). Perhaps, also, ableism informs narratives of self-sufficiency and independence as Swain and French (2000) describe. Once catalyzed in discourse, these narratives subject DP/PwD to internalize ableism (Campbell, 2008), blocking requests for assistance and pride in interdependence.

Sienna: [purses lips] Umm, so, like, I understand what you mean, but being offered help can be as bad as not being offered help. If the person offering the help is doing it because they have a low expectation of you and see you as not human enough to do something for yourself. Just like so-called “positive stereotypes” such as “blind people are good at music”— which isn’t true for every blind person. As a blind person, that stereotype can make me feel bad like I’m not *really* blind because I don’t have that [air quotes] “good at music” superpower that everyone thinks is so central to being blind. Microaggressions are little things people do or say that come from negative understandings of people in minority groups. Just like overt versions of oppression, microaggressions come from ablebodied privilege and misconceptions about experiences of disability. So, I get people suggesting that I’m not really blind because I can see some things when they are large print and I have my thick glasses on: that’s a microaggression. Or, I’ll be stopped and asked by strangers if I need help walking when I am using my cane or they offered help they wouldn’t extend to anyone else or even to me if I *wasn't* using my cane. It can make me feel like they look at me and the first thing they think is that I'm incompetent or need their help because I'm somehow lesser than an abled-body person.

That’s a microaggression.

Ice Queen: [squints] I don’t think I get it completely, because I’ll take help if it is offered, since I don’t often ask for it. But, okay.

Culann: [Motions to Ice Queen with one hand] Basically, don’t be a dick to anyone because you’re ignorant about disability [crosses arms and leans back].

**Erica: [shakes head] “And I was like baby, baby, baby oh, Like baby, baby, baby no!”[180]**

e-father: [moves back over to the group and interjects] Yes, exactly! People will often speak to **Erica** as if she were a small child instead of a teenager going into high school. That one always infuriates me. Yes, she might like children’s songs and puppets, but that doesn’t mean she is an infant.

Daren: It’s like that stigma that I was talking about earlier. I can get anxious because I don’t want people to treat me “special” and treat me like I’m not capable because of my Tourette’s. I’m a person, like them.

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[180] (Bieber, Steward, Nash, Bridges, & Milan, 2009)

Sienna: Microaggressions can be anxiety-producing. Erica, that whole thing about being treated like a child, I hate being patronized. Like, so, I'll read in braille or using large print and everyone applauds 'cause I can read [exasperated look].

They're excited because I can read [shakes head]. And although they think it's a compliment, it's actually hurtful 'cause it means they have a really, really low expectation of what I can do. Um, like, I'm over here trying to graduate college and become a social worker and save the world and they’re just excited that I can get out of bed and remember my own name. Throw playing banjo or singing on stage into the mix, and I blow people’s freaking minds because they expect so

little of me.

Ice Queen: [nods enthusiastically] Okay, yeah, I understand what you mean now. It is sort of like when guys in the band assume that I, [sarcastically] a “frail girl,” need help carrying things. I mean, come on, if I can carry 80 pounds of books, a computer, a flute and a saxophone, along with other stuff around in my backpack, I *think* I can manage it, dudes [rolls eyes].

Birdie: Yeah [wide eyed], and I, like, worry about being self-sufficient. [with worried tone] I want to be able to take care of myself and not be a burden on my friends and family. But, like, helping each other is kind of what friends and family do, right? My best friend told me one time after she had taken care of me and I was really apologetic. She was like, “Birdie, it’s okay, we’re put on this earth to help each other.” I believe that too and I try to help people as much as I can because they help me.

*I-it* jesse*:*

*Universal/unconditional inclusion*: While participants offered numerous examples of microaggression, the comment offered by Birdie illustrates the type of “universal” inclusion for which participants longed. This type of inclusion often manifested for participants in personalized and non-oppressive types of help that did not force disability disclosure or add to social stigmatization. This type of inclusion involved participants having a high level of choice and self-differentiation. Sienna discussed something akin to unconditional inclusion, acts/gestures extended to all regardless of one's identities, differences, or subject positions. There is danger in this, though, as "treat all the same" may result in whitewashing or able-washing, when the kind of help one expects to be useful is shaped by identities, differences, and subject positions.

DUKE: Yeah [grins and nods] it's always nice to help people and make it easier for them, [looks to Sienna] when they need it [points out].

**Erica:** **[twists in seat, looking to Birdie, singing] "Help me if you can, I'm feeling down. And I do appreciate you being round. Help me, get my feet back on the ground. Won't you please, please help me?"[181]**

Birdie: [nods as if grooving to Erica's beat] Yeah, I like that! I always felt that song really, like, connected with me on some deep level.

Culann: Ahhh, the whiny Lennon! I can get behind that feeling of wanting to shout out for help, although I'd rather get help that doesn't require a lot of touchy-feely bull. But, still, I get what Erica is driving at. It's the whole asking for help thing, not just receiving help. I feel like one of the big things here is this terrible compulsion some people have to try to get between people and their, I don't know, their "struggles," or something like that. It's like people look at you, they see you're crazy or something, and they see—or think they see—the "struggles" you might confront

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[181] (Lennon & McCartney, 1965).

and they just, just try to make things better for you but it is really for themselves. You get people that want to keep you from struggling and do crap that's not helpful, because actually helping you succeed is too hard or too inconvenient for them, so they just kind of sit you in this safe little bubble in the padded little kiddie corner and say, "Well, you're in the room, so that's enough, right?"

*I-it* jesse*:*
*Physical presence ≠ being included:* Bledsoe (2015) reminds us of the ways music teachers may "confuse presence with inclusion" (p. 22). Culann's comments indicate that people may confuse physical presences with real or relational presence (i.e., the presence of a person in their concrete realness). Perhaps, from a Buberian (1965) perspective, inclusion requires real presence, meeting of the "*I-Thou*" kind in which both *I* and *Thou* connect in a state of *being-with* one another fully without analyzing one another.

Culann: [leans forward with hands on thighs] Then, you have people who try to remove your struggles because they just don't think you can do it. But, the "struggle" or the challenge—maybe that's a better word? . . .

Sienna: [shakes head] Umm, yes. Let's not give people any reason to talk about

"overcoming struggles"

and make more [glances

to Erica] "IP" to make

abled-bodied people feel

better [pointing] . . .

*I-it* jesse*:*

*Microaggressions, inspiration porn, and nondisabled discomfort:* Keller and Galgay (2010) described the way that people may commit microaggressions by being self-serving in their help. Here, Sienna shared how narratives of disabled persons "overcoming" challenges are often celebrated by nondisabled people in a way that overemphasizes disability and normative success over difference and individual personhood. Here, "overcoming" means that DP/PwD are no longer bound by their impairment, which decreases the tension nondisabled social actors feel when faced with disability (Grue, 2016). The disabled person becomes "nondisabled" in the moment of performance of overcoming and nondisabled viewers force a kind of mystification (e.g., Goffman, 1959) upon disabled actors in order to manage nondisabled discomfort and angst in the presence of what they may interpret as a negative identity position. Inspiration porn, for Sienna, is self-serving for nondisabled persons. For more information on inspiration porn, see Stella Young's (2014) "Inspiration porn and the objectification of disability: Stella Young at TEDxSydney 2014."

Culann: Well, [nods slowly, uncertain] sure. Okay, so follow me here for a bit. You know how Frodo tells Gandalf that he wishes he'd never gotten the ring in the *Fellowship of the Rings?* Well, even if you haven't, the whole *Lord of the Rings* is about Frodo destroying this power ring. That's his purpose. There are lots of shitty, awful things in his way, but he was supposed to destroy the ring. The challenges in his way of fulfilling his purpose is what makes him at the end. What if Gandalf just destroyed the ring for Frodo? It would have saved him the hassle of having to watch after those damn little hobbits and it would have kind of [air quotes] "saved" Frodo from having any pain or challenge. But it would have robbed Frodo of his purpose and he wouldn't have become who he needed to become.

*I-it* jesse*:*

*Challenge as portal to becoming:* Culann noted that challenges allow people not only to become who they will become, but also to find out who they are. Numerous participants commented that, all too often, people thought that helping them meant removing all challenge from their path, which was not something they wished for. Rather than true affordances, they often were met with paternalistic and infantilizing "help" in the form of ableist microaggressions (Keller & Galgay, 2010) that got in their way.

*I-Thou* Jesse: Okay, but, then I have to ask, since, Birdie, you brought it up in our interviews. Would you want disability to be a part of your life if you had a choice?

Birdie: [shakes head] I would wipe it away [wiping gesture] if I could just for my family because it freaks them out. They are scared and worried a lot about me. But, I couldn't, because it is me. I can't know any other way to be.

*I-it* jesse*:*

*Disability as central to self:* Birdie's comment, later reiterated by Sienna, indicates the way that disability can be central aspect of the lived experiences of DP/PwD. Since disability is part of Birdie's present, it is impossible for her to fully conceptualize a present without it. Disability shapes one's internal, external, individual, and social experiences. Disability may be so central to one's sense of self because it provides "unique ways of interacting with the human condition . . . showing that [disability] is not an add-on to the human condition, it's an active modifier of it that gives it depth" (Monje, 2012, n.p.).

Ice Queen: [nodding slowly, raises hand to gesture to Birdie] Maybe that's the point. We can't know what life would be like without our disabilities. It's part of our lives and, maybe, part of us.

Culann: [leans back and slouches] A big and problematic part, for sure. I mean, having a learning disability basically means you can't do what you want to do. You have to do what you can do. And, unfortunately, you know, we got to eat so we got to do something for a job. Right now, I'm in a helping profession, which is okay, I guess. It isn't the most rewarding job, but it is the job I can do. Sometimes I wish I was an 1840s mountain man, because you could be crazy, you could be ADHD and have a living, because you're just doing so many different things to subsist. It seems like you have to be a fucking genius to live in America now, all cerebral and specialized—without any learning disability—just to not be poor. Even with all the disability equality laws, it seems like you can be physically disabled—be in a wheelchair or be an amputee—and get a job, because all you really need is a brain, you don't really need a body all that much but you need a brain. You need a full functioning brain and you need a good personality and you need to be there, mentally. So, having cognitive disabilities and a shit personality makes that part of life hard.

Ice Queen: [visibly shaking] I need my body to do what I want to do with performing and marching. Without that, I'd be limited, I think.

DUKE: I need my body too. I need both, you know?

**Erica:** **[singing and swaying in Culann's direction] "'Cause all of me loves all of you. I love your brains and all your edges, all your perfect imperfections."[182]**

Birdie: [nods at Erica] Yeah, all of me, my mind and body. [wide-eyed and turns to Culann] I think you have some big assumptions about mind/body and are making some bad hierarchies here between

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[182] (Stephens & Gad, 2013)

people with physical disabilities and people with learning disabilities. I don’t think it’s that simple.

Sienna: [shaking head] I think you’re really discarding the difficulty people with physical or sensory impairments have navigating contemporary life. Barriers still exist that make it hard.

Daren: Hmm, maybe it is just that we each have to find what works for us and your quirks. Like, I know that bboying is both mental and physical, and I need both, but I focus on the physical and because of that, it fits me well. Or, maybe I fit it well

*I-it* jesse*:*

*The social barriers of expectation.* Culann points out that social structures and expectations about ability and personality are barriers for him based on his impairment, echoing Cameron (2012), Oliver, Sapey, and Thomas (2012), and other advocates of SFCD. Through policy, social expectations, institutional edicts, and informal social structures, Culann, and all participants, is subjected to social marginalization (e.g., Finkelstein, 2001, Rioux & Valentine, 2006; Shakespeare, 2014). Yet, as Shakespeare (2014) noted, that marginalization feels, looks, and is very different for each participant. Culann and Birdie are clear about their experiences of marginalization, Daren addresses stigmatization, Ice Queen implies social pressures related to her disability, and e-father noted instances of ableism and worries over social isolation. Duke does not directly address social barriers or marginalization, although, at the time of writing this chapter, he has had to move out of his beloved town because his parents do not think he can care for himself—although he often cares for and has cared for his infant-now-toddler sister for long periods of time. Ice Queen does not equate her impairment with social isolation, although, as noted in "*Depression and anxiety as a background*" above, it may be that other impairments/differences ground her experience to the extent that she has internalized the barriers as being inside her and not socially situated.

Culann: I don't know. I still stand by what I said, but whatever. Maybe we should ask someone that uses a wheelchair, is an amputee, or [air quotes] "physically impaired" what they think about bboying and what they think about daily life. Maybe bboying ain't so inclusive as daily life is for some of them [crosses arms].

| | |
|---|---|
| *I-Thou* Jesse: | But, we can't really know that since no one here uses a wheelchair, is an amputee, or is physically impaired, or has those identities . . . |
| Sienna: | [interrupts] *. . . and* no one here is really a person of color. Or someone that identifies as LGTBQ . . . I mean, I'm asexual, but still. |

*I-it* jesse*:*

*Is the unexamined intersectional life worth researching?:* Cho, Crenshaw, and McCall (2013) suggest the need for intersectional analysis to consider the ways that different identities and types of oppression connect and run in parallel to each other in order to reject "single-axis thinking [that] undermines legal thinking, disciplinary knowledge production, and struggles for social justice" (p. 787). Disability researchers such as Erevelles and Minear (2010) and Moodley and Graham (2015) advocate for intersectional inspections of the lived experiences of disabled persons in order to avoid approaching disability from a single axis. As the participants note in this imaged conversation, they were a rather homogenous group of people: mainly white, mainly cisgender, mainly straight, mainly middle class, all naturalized citizens of the United States, and all native English speakers. Additionally, some participants had similar diagnoses: neurological disorders (i.e., Birdie and Daren), ADHD and/or mood disorder (i.e., Ice Queen and Culann), developmental disabilities (i.e., Erica and Duke).

Ice Queen: [wait finger] Maybe, no one that *has* openly identified as being LGBT. I know I didn't bear all of my soul to Jesse. Remember, we're not really here, we're just figments of Jesse's overactive imagination and it isn't like we got a *full* understanding of all of who we are by him researching with us. Maybe we shouldn't assume, you know.

*I-it* jesse*:*

*Partiality of given experiences and manifestations:* As Stein (1989) noted, one cannot be given the experiences and lifeworlds of others completely. All phenomenologies of others can only be partial and the manifestations found should always be seen as tentative (Vagle, 2014). Others cannot fully manifest in one's lifeworld, but additional interactions with others can make manifestations more and more concrete (e.g., Buber, 1965).

*I-Thou* Jesse: True, I just wanted to make sure we were clear that we can't possibly explore all the intersections of disability in our little group—well, make sure I made it clear . . . not that we could ever explore all of disability as it is so different for all people.

Sienna: Yes, you know, as they say, "If you've met one person with autism, you've met one person with autism." You could replace "autism" with "disability" there. All people are different, so all experiences are different.

**Erica:** [singing in delayed response to Culann] "You don't know you're beautiful, oh oh. That's what makes you beautiful. So, come on, you got it wrong. To prove I'm right, I put it in a song."[183]

Birdie: Right on!

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[183] (Kotecha, Yacoub, & Falk, 2011).

Daren: [crosses arms shaking head] Okay, yeah. It's helpful to uplift yourself, but sometimes other people impact how you feel. There are many times when I may not be in control of the social situations I'm in all the time. Like, stigma, I can't control the way Tourette's has stigma attached to it and how people respond to my twitches. Dealing with stigma is really stressful because I feel like I have to be really careful to not let anyone see anything that is stigmatized because that would draw problematic attention to me. It would be nice to not have to deal with the stigma. [turns to Jesse] You know, earlier you asked about the whole "part of or apart from" thing, and I guess I do think about Tourette as being "apart from" me because, kind of like—who was it that talked about disability as apart when we were talking about the setbacks?

Birdie: [raises finger] Yeah, that was me. I was talking about how I think about epilepsy as this thing that stops me from driving and bothers my family.

Daren: Yeah, that was it. So, beyond the stigma, Tourette's is almost sentient for me. It adapts to all the things I do to control it. That's kind of how I explain it. I don't mean to scare someone, like, "I have something inside of me," no, no, I, no, no, not that. But, it's almost like it knows what I'm trying to do, it's just standing in my way every time. I don't know if other people with Tourette's are like that. It's just how I think it is for me. It can stop me from doing things, you know like Culann was saying about feeling like his learning disability stopped him from doing work meaningful work.

DUKE: Man [smiling and reaching out to Daren] having Williams syndrome doesn’t stop me. I think it’s good I have it [takes off his sweater and adjusts his Tom Petty t-shirt].

*I-Thou* Jesse: Like Sienna said, everyone’s experience is so different.

Sienna: Okay, this is about music, right? [stares at Jesse] Then maybe this question is away from the whole point because, even if we wanted to *not* be disabled, we don’t really have that choice.

*I-Thou* Jesse: Yes, sorry to venture off. Yes, the whole project is about experience of disability in, through, and around music. So, the focus is disability *and* music.

Sienna: [nods sharply and takes a breath] Okay, well then, I think music is about sending direct and subliminal messages to each other, to express ideas so to communicate and connect with the world. Maybe that should be the focus of music experiences then. It isn’t just your question, but I wish people, especially teachers, would just accept me instead of trying to change me or

fix me.

*I-it* jesse*:*

*Longings for acceptance and belonging:* Participants noted desires to be accepted as who they are, in their complexity and concreteness, including in, through, and around music. Who they are does involve disability, but the what disability was and what manifested through their experiences with disability were always shifting, never stable or consistent. Participants noted that they wanted people to accept them and be with them, rather they trying to remediate them. They wanted people to see them as "real" (e.g., Garland-Thomson, 2002) and to recognize them as of equal worth (e.g., Anant, 1966). They wanted to belong, but to belong without the need to fit the needs, desires, and performances expected of them by other social actors.

Sienna: Umm, if doctors haven't

been able to change my

disability yet, the odds

are that teachers won't

either. Also, odds are I might not want to change my disability. If I had the option to be sighted, I probably wouldn't take it. I would have developed into a completely different person, and this Sienna wouldn’t exist. Rather than trying to fix us or fix things for us, accept us, accept our disability, accept that it's a part of our identity. Accept that you can't change that and we can't change that and we can't turn it on and off. We definitely can't do it just because you want to [pounds fist on arm of couch]. Accept us even if it's inconvenient for you.

**Erica:** **[singing] "Oh there ain't no other way, baby I was born this way [pointing to torso]. Baby I was born this way [pointing to head]. Oh, there ain't no other way."**[184]

DUKE: Gaga! [smiles] Oh, yeah, "born this way" [walks to Erica to give high five and sits back down].

Culann: [sarcastically] Great . . . that song. You know I get it, but there is some aspect of me that wishes I hadn't been born this way . . .

Birdie: [frowning but quickly smiling and turning to Erica] Yeah, Erica, "right track baby I was born this way."[185]

*I-Thou* Jesse: It might be hard for people to understand that you may be "born this way," that this is complicated in a positive and negative self-identity perspective, and that you wish that people "accept [you] even if it's inconvenient for [them]" . . .

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[184] (Gaga, Shadow, Garibay, & RedOne, 2011).

[185] (Gaga, Shadow, Garibay, & RedOne, 2011).

Sienna: . . . [sits on the edge of the couch] Listen, the thing is that we are not our disability. Our disability is part of who we are, maybe a big part for some of us, and it impacts every experience we have because it isn’t something that we can turn on and off. But, so

are our other identities.

We are human beings,

first and foremost.

*I-Thou* Jesse: That's a really important point: you are human beings because of and regardless of your identities. So, how do you identify? How do you name who you are and, through that, name your world?

*I-it* jesse*:*
*The power to name:* Freire (1968/2000) noted that "To exist, humanly, is to name the world, to change it. Once named, the world in its turn reappears to the namers as a problem and requires of them a new naming. Human beings are not built in silence" (p. 88). Participants valued chances to name their worlds and their lives. They shared their ways of identifying and, through that, they share a great deal about their lives, their experiences of disability, and the patterns and relationships of their experience that are salient to them (e.g., Shakespeare, 2015, p. 3). How participants identify may speak much of how they conceive of disability (e.g., Cameron, 2014), their sense of belongings (e.g. Anant, 1966; McDermott & Varenne, 1995), and their intersectional situatedness (e.g., Crenshaw, 1991; Kuppers, 2014).

Birdie: I'm a female, epileptic, music loving, houseboat living, storm-like visual artist. Call me Birdie.

Duke: I’m the Duke of Downtown. I have Williams syndrome. I’m so stoked, my friend.

Sienna: Who am I? Depending on where I am, what I’m doing at the time, and the social capital valued in the moment, I’ll put one identity above the other based on the situation. I can tell you that I experience the world through many different overlapping identities: I'm a woman, a cisgender woman. I'm disabled. I’m queer. I am asexual panromantic. I am Jewish, um, I'm Middle Eastern, white passing. However, regardless of all of those identities, I am a human being. And that identity, alone, means that I am, I have dignity and worth.

Ice Queen: I'm a flute playing, proud female, sister of ΣAI, marching band fanatic, AHDH, college student, Ice Queen.

Culann: *Ah shit, I'm just plain crazy. I have a learning disability, I'm a history buff, I dig fantasy, and feel like 90's grunge and alternative music is the pinnacle of music. If you took a look at my D&D player sheet, it says I'm Culann, a Wood Elf Ranger.*

Daren: I'm Daren. Just Daren.

**Erica: I'm Erica. Sing with me?**

## CHAPTER SIX: OPENINGS

The purpose of this study was to trouble existing conceptions of disability that ground music education literature and practice by exploring the personal experiences of disability in, through, and around music with specific DP/PwD. I sought to uncover and share "plausible insights" (van Manen, 1990, p. 9) into how disability is experienced in, through, and around music experiences of participants. These insights might, then, allow readers to complexify and trouble taken-for-granted assumptions of what disability can mean and be "like" in, through, and around music, and these troublings and complexities might then ground inclusive practices different than those prevalent in music education historically. Questions that guided this inquiry were:

(1) How do participants experience disability in, through, and around music?
    (a) What manifests through experiences with disability in, through, and around music?
    (b) How do participants perceive, interpret, and describe their experience of disability in, through and around music?
(2) What plausible insights related to disability can be gained by attending to participants' experiences of disability in, through, and around music?
(3) What plausible insights related to inclusion can be gained by attending to participants' experiences of disability in, through, and around music?

In Chapter One, I introduced the interlocking personal, research-based, and theoretical problems related to disability and inclusion that ground my motivation for taking on this study: (a) the ways in which the over-reliance upon a single theoretical frame to understand disability can essentialize disability and the lives of DP/PwD in music research and practice, (b) the ways my personal identities and experiences related to disability empower my curiosity and need to take on this study, and (c) the ways that existing theories of inclusion in music education literature and practice are grounded in problematic understandings of disability and relationality. I also introduced the relational ontology of Martin Buber (1958) and outlined his concept of inclusion (1965), which combined provide a framework for inquiry, analysis, and being in this study. In Chapter Two, I opened dialogue with existing literature in order to (a) consider multiple ways to understand disability (e.g., IFCD, SFCD, and ICD), (b) explored disability identity naming discourses, and performativity in disability studies and music education, and (c) presented numerous ways that researchers in and outside of music education have explored disability with an attention to the lived experiences of DP/PwD. In Chapter Three, I outlined the flexible, phenomenological-bricolage approach to inquiry I used to meet with participants and come to know their experiences and lifeworlds. I also noted my narrative-informed (e.g., Bruner, 1987; Clandinin & Connelly, 2006, 1990) means of constructing co-generated data into lifeworld narratives as well as the narrative analysis-informed process (e.g., Polkinghorne, 1995) I used to make sense out of the co-generated data.

In Chapter Four, I offered lifeworld narratives, the phenomenologies of others, in which readers may come into contact with the participants and their lifeworlds as shaped by their experience of disability in, through, and around music. In one lifeworld narrative, Erica shared song lyrics and drawings to communicate her feelings and desires. In another, a screenplay depicting the larger-than-life Duke in his natural habitat—a concert venue, Duke talked about friendships and music making. In another, Birdie wove together music, memories, and different lines/frequencies, depicted in different text colors and accompanied by her sound track and her art . In another, bboying Daren practices his moves late into the night and during a dream/nightmare. In still another lifeworld narraive, banjo-playing Sienna mused about diversity, access, inclusion, and identities at a metaphorical potluck of life. In another, Ice Queen displayed her imagined trophy case and told stories to last a lifetime as they intersect with her experience of disability. And, in another lifeworld narrative, Culann mused about how music and social experiences could be filled with congruence and contradictions during a musical road trip through the mountains. In Chapter Five, which I describe as a phenomenology of self, I revealed the intersections my lifeworld and the lifeworlds of the participants through an envisioned conversation interspersed with contemplations about connections between and among them and points of resonance with literature and theory. The imagined conversation and interspersed contemplations serve as a means of making sense of the co-generated data of the study.

In this chapter, I seek to make an opening for further thinking and dialogue. I offer commentary in this chapter that (a) shares the sense I have made out this project, (b) connects to existing literature and perspectives, and (c) opens up what could be an on-going dialogue related to experiences of disability in, through, and around music. I attempt to make sense of participants' experience of disability and my experience with these "foreign experiences" (e.g., Stein, 1989, p. 2). First, I comment on plausible insights (e.g., van Manen, 1990) into disability developed through this inquiry, including: (a) the interactions of individual facets and social facets in experiences with disability, and (b) disability identity, self-identification, and intersectionality. Second, I am a teacher as much as a researcher, and so I offer plausible insights into inclusion as grounded within the participants' experiences with disability in, through, around and even beyond music. Drawing on Buber (1957, 1958, 1965), in this second section I discuss belonging, offer pedagogical suggestions made by participants, and outline anti-ableist pedagogy that includes affirmation of disability and relational presence, Lastly, I share plausible insights I have gained regarding relational ontologically-grounded research and writing, again drawing on Buber's work.

## On Disability

In this study, I sought to uncover and share plausible insights into how disability is experienced, interpreted, and understood in and through music or around music and music-adjacent experiences of participants. The co-generated data of this study suggest that disability is shaped neither by only social facets of experience or by only individual facets of experience, but rather, is a constantly flowing, intersecting, and changing web of both types of facets. Social facets inform how individual facets structure the experiences of disability of DP/PwD and vice-versa. Shakespeare notes,

> disability is always an interaction between individual and [social] factors . . . a holistic understanding is required. Put simply, the experience of a disabled person results from the relationship between factors intrinsic to the individual, and extrinsic factors arising from the wider context in which she finds herself. Among the intrinsic factors are issues such as: the nature and severity of her impairment, her own attitudes to it, her personal qualities and abilities, and her personality. I accept that contextual factors will influence

> these intrinsic factors: impairment may be caused by poverty or war; personality may be influenced by upbringing and culture, etc. Among the contextual factors are: the attitude and reactions of others, the extent to which the environment is enabling or disabling, and wider cultural, social and economic issues relevant to disability in that society. Understanding and measuring the impact of environmental factors on participation turn out to be harder in practice than it is in theory. (2014, pp. 74-75)

Experiences of disability are shaped and reshaped by the interaction of internal and external factors, by individual body/mind construction/function and by social interactions. These structuring facets are always already playing a role in experiences of disability in, through, and around music, and, as such, these interacting facets shape and reshape how DP/PwD learn and make music. Individual and social facets also shape music teaching and music learning practices and experiences, and these practices and experiences may be affirmational of disability or paint disability as a tragic and negative construct.

In the section that follows, I share some plausible insights related to disability as shared by participants. The co-generated data in this study illustrates multiple examples of participants describing the interaction of individual and social factors related their experiences of disability. In addition, participants shared many ways that they identified themselves and performed different social roles. Below I explore both disability as interactional and disability as identity and share suggestions for future research related to each.

#### Disability as interactional.

"Disability is always an interaction between individual and [social] factors . . . a holistic understanding is required." (Shakespeare, 2014, p. 74)

Individually-focused conceptions of disability position disability as an outcome of individual impairment; socially-focused conceptions of disability position disability as the outcome of a mis-fit between persons with impairments and social structures. Interactional conceptions of disability (e.g., McDermott & Varenne, 1995; Mitra, 2006; Smeltzer, 2007; Lubet, 2011; Shakespeare, 2014; Kuppers, 2011; McRuer, 2006b) situate disability at the constantly changing intersections of multiple individual/internal and external/social facets. In this study, I took on an interactional perspective to understand the complex experiences of disability of participants.

Through this, I have followed Shakespeare's (2015) suggestion for researchers to "start [inquiry] by trying to figure out things about the lives of disabled people and the disabling barriers that they face, and then draw on theory, where required, to explain the patterns and relationships which are uncovered" (p. 3). In this section, I consider the structuring facets—or "factors" (e.g. Shakespeare, 2014)—of participants' experience of disability in, through, and around music. Participants descriptions of their experiences suggest that they experience disability and understand these experiences as being interactional and constantly fluctuating based on the particulars of "place, time, activity, and encounter" (Lubet, 2010, p. 21). Their experiences and ways of making meaning of their experiences suggest that disability might best be considered as neither individually-centered, as with IFCD, nor socially-situated, as with SFCD. Below, I address the different kinds of structuring facets that might impact DP/PwD's experience of disability, and I illustrate the interaction of these facets as manifested through participants' experiences with disability.

***Encounters with self: Individual facets in disability experiences.*** Shakespeare (2014) asserts that "people are disabled by society and by their bodies and mind" (p. 5). Findings of this study demonstrate that experiences of disability are structured by internal/personal facets such as the construction, function, and physiological/psychological state of one's body/mind. The individual and socials lives of DP/PwD are always already being structured by the body/mind through which one experiences life (Merleau-Ponty, 1945/2005) and disability (Shakespeare, 2014). As such, disability may be an individual issue, but an individual issue wrapped up with social issues. Participants in this study described how their individual bodies/minds shaped their experiences of disability in, through, and around music, and how such experiences forced them to encounter themselves in different ways in their lifeworlds.

When speaking about how dyscalculia acted as a barrier to his interests in engineering and computer programing, Culann rejected the common feel-good notion that anyone can do anything if they just put their mind to it and try. Culann found this notion, which implies a SFCD-based worldview, to be a flat out lie. His personal realization that some things he wanted to do he could not do caused him a great deal of discomfort. His self-realization occurred during his teen years as he found that his mind did not process information in a way that would position him to be successful in fields he was motivated to study. Culann also discussed his dislike of being the center of attention and having others stare at him; this kind of attention exacerbated his anxiety, forced him to become hyper-conscious, and to strive to act in ways that would not disclose him as being “crazy.” Performative musicking experiences were not enjoyable and often alienating for Culann, possibility because they drew attention and made negative aspects of disability vividly and violently manifest in his lifeworld. Also, Culann noted that he did not feel musically “talented” and elaborated about how people’s mind/body functions allow them to do certain things while also being barriers to other things. Yet, he had a rich lifeworld *in* music listening and a rich social life *through* music listening. He preferred being *in* and *through* music listening because he had agency to choose music and music experiences more “congruent” to his “talents,” needs, and interests.

Daren’s experiences with Tourette syndrome are structured by his body/mind; individual facets more than social facets are prevalent in his experiences of disability. Feeling tired or stressed weakens his ability to keep control over how his body/mind functions and allows, from his perspective, Tourette syndrome to take control. Although Daren knows that Tourette syndrome is an internal aspect of his body/mind, when he loses intentional control over his body/mind in the form of twitches and/or sniffs, his body/mind feels controlled by an alien other: the adaptable and combative Tourette’s. Daren identified playing piano as a practice that is far more mental than physical and emotional, requiring focus and decoding of notation, and resulting in stress at times of nonsuccess. Such a practice can weaken Daren’s control and give the reins over to “Tourette’s.” It is perhaps useful to note that Daren’s experiences of disability *in* music via piano playing may well be highly shaped by his negative experiences with his piano teacher and his feelings of stress from the weight that his parents put on Daren’s success on piano when he was younger. When bboying, however, Daren rarely feels the impact of Tourette syndrome, something that he attributes to the largely physical, reactive, and creative bases of this form of musicking. He is *in* music, sometimes to such an extent that neither individual facets nor social facets of disability manifest in his lifeworld.

Duke's body/mind construction and functioning, shaped by Williams syndrome, seem to allow for him to have experiences of deep engagement with things he loves: music making and social relationships. Persons diagnosed with Williams Syndrome often display "highly social personalities and an affinity for music" (Williams Syndrome Association, 2018). For Duke, social relationships and musical experiences were essential aspects of who he was and what he did as a human. He jammed with bands—*in music*, he was there for friends—*around* music, and he was "so stoked" for all experiences that involved one or both of these features. Duke did not speak about his diagnosis much and Williams Syndrome seemed to be part of the water in which he swam. His experiences of disability, as such, were his experiences with life.

The individual facets of participants' experiences with disability in, through, and around music mattered to them. If this were not true, then Ice Queen would not have recognized her ADHD medication as being of any help in allowing her to focus on her work in the practice room. If experiences with disability were not shaped by individual facets, then Birdie would have no problem listening to music with a "flashing beat." Indeed, if Erica's body/mind difference was of no consequence, then the support she receives based on policy and funding from IDEIA (2004) would be of limited use except for the purposes of social inclusion and representation. It is useful to heed Shakespeare's (2014) call to understand that one's body/mind matters and does structure how they experience disability and all aspects of life. Perhaps, though, one might heed this without relying upon narratives that situate all persons' body/mind constructions and functions in relation to an idealized normate and, then, separating people by how far they are from this normate (Garland-Thomson, 1997) in order to construct ingroups and outgroups—those included and those in need of inclusion. Rather, we might consider individual *differences* in bodies/minds to be far more a universal than *conformity* of bodies/minds.

***Encounters with others: Social facets in experiences of disability.*** Kuppers (2014) asserts that “disability is relational, it speaks to relations between people” (p. 21). Various social facets of experience and types of relationships structure how DP/PwD experience disability in, through, and around music. Social facets such as accessibility of spaces, adaptability of institutional policies, and openness of relationships and interactions with other social actors might shape the extent to which one experiences disability positively, negatively, or as a mixture of positives and negatives. And while accessibility of spaces and adaptability of policies may have deep impacts, some participants in this study suggested that interpersonal interactions and relationships had a far more powerful structuring impact on their experiences of disability (e.g., Kuppers, 2014) than individual facets or other kinds of social facets. Participants in this study experienced disability negatively when other musickers or other people acted on ableist assumptions or imposed ableist norms and/or when they encouraged disability-blind and non-adaptable ways of thinking and doing.

When Sienna’s musical director noted that their character “didn’t use a cane,” the director twisted Sienna’s usually self-empowered conception of their disability by casting their cane in negative light, pointing it out not only as *not* normal but also suggesting that it was *not* necessary. Sienna’s director imposed an ableist conception of white canes, implying and reifying the cane as a stigma symbol. Speaking and acting from a power position,  the director demonstrated a concern that the presence of the cane might call out the character Sienna played as other or different and, in turn, identify Sienna as being a person “possessing an attribute that makes [them] different from others in the category of persons available for [them] to be, and of a less able kind” (Goffman, 1963, p. 3).

Canes as well as other assistive technologies such as wheelchairs, adaptive instruments, and hearing aids can be used or not, sometimes, and this use allows DP/PwD a certain control over their social interactions with regard to stigma symbols. Yet, sometimes DP/PwDs' bodies and ways of interacting with the world can be cast as stigma symbols by other social actors, and stigmas remove control for DP/PwDs in social settings. For example, Erica's appearance and her way of interacting with others, particularly her way of communicating in and through song, may be read by other social actors as different from the expected norm and, as such, others may identity Erica, herself, as a stigma symbol. By doing so, these social actors remove Erica's control over how others receive her and impose problematic roles for themselves and her. This imposition may foreclose both Erica's being and the ability of others to embrace her in their lifeworlds. Negativity of others may manifest in Erica's experiences of disability in social settings.

Social interactions can also be shaped by environmental factors such as: (a) physical accessibility of spaces (Kuppers, 2001; Lubet, 2011); (b) media representations such as inspiration porn and disability stereotypes prevalent online in television shows, movies, and books (Garland-Thomson, 2001; Grue, 2016; Mitchell & Snyder, 2000); (c) institutional norms that govern which ways of being and ways of knowing are deemed worthwhile in different settings (Brantlinger, 1997; Siebers, 2008); (d) and microaggressions spoken and enacted by social actors that impose and reinforce oppressive norms upon DP/PwD (Keller & Galgay, 2010). Yet, environmental structures, media, institutional norms, and microaggressions had less direct salience with regard to participants' experiences of disability in this study than did the social experiences that occurred within and grew from interactional network of these facets. Simply stated, negativity manifested more frequently in participants' experiences of disability through direct interaction with others who acted in negative or harmful ways, often informed by or related to environmental structures, media representations, institutional norms, and socially circulating microaggressions.

Although DP/PwD may experience disability negatively, this does not mean that disability is an essentially negative social phenomenon. Social encounters can be empowering and greatly positive for DP/PwD when they occur outside of the forceful touch of ableist assumptions and/or ableist norms. Although ableism can touch all social encounters via accessibility, policy, media, and the like, DP/PwD can experience disability in a positive manner in social encounters in which actors (a) affirm the positivity of disability, disabled identity, and/or disability symbols; (b) affirm the control of DP/PwD over information regarding their own being, diagnosis, and identity; and/or (c) are present with, relationally, DP/PwD, allowing their unique beings and becomings to arise organically (e.g., acts of "inclusion" in Buber, 1965). Yet, affirmation can also be a means of drawing unwanted attention for some DP/PwD if not offered in ways they welcome.

The narrative of disability as personal tragedy may appear to be a dominant narrative in contemporary society, but that narrative can be subverted and replaced with one rooted in affirmation of disability as a natural aspect of human diversity (Cameron, 2012; Oliver, Sapey, & Thomas, 2012). Most participants in this study did not want to be seen as "not disabled," but they also did not want to have their disability seen as a stigma or sign of a "spoiled identity" (e.g., Goffman, 1963) or a malfunctioning way to be-in-the-world. Birdie worries more over how epilepsy impacts others in negative ways than how it impacts her; she sees how her personal affirmative frame for epilepsy is *not* shared by her friends and parents. Her "storm-like" way of being may often be criticized by other social actors, but when one of her professors described her way of being positively in front of her classmates, that professor presented an affirmational frame that resonated with the one Birdie possessed. Further, the professor offered it at time and in a way that Birdie welcomed. As positive as that experience may have been, one might wonder to what extent the professor still placed Birdie in a subaltern position. For her to experience disability in a positive manner, or to have disability deemed positive by others, Birdie required a nondisabled person in a position of power to deem that her way of being, which is deeply tied to her epilepsy, was an officially sanctioned way of being. While unfortunate at times due to perceived or real power inequities, hierarchical affirmations of disability may be one way that those in privileged positions, such as the professor and myself as writer in this document, can use their privilege in empowering ways.

Unfortunately, some people in privileged positions attempt to be affirmational by sharing inspiration porn. Videos such as “8-Year-Old Violinist Excels Beyond Measure Despite Hand Disability” (HooplaHa, 2017) and “Disability Shows No Limit - Inspiring!” (Bored Tuber PH, 2016) do little more than reaffirm “personal tragedy” narratives and highlight “overcoming” as a metanarrative (Young, 2014). Such cases of representation deal in

> objectifying disabled people for the benefit of nondisabled people . . . to inspire [them], to motivate [them], so that [they] can look at [disabled people] and think, “Well, however bad my life is, it could be worse. I could be that person.” (Young, 2014, n.p.)

These ableist objectifications of DP/PwD as individuals whose narratives and presences should serve nondisabled audiences in one way or another devalues the individuality and personhood of DP/PwD and mystifies disability in a way that hides both the social facets that construct disability (Grue, 2016, p. 840) and the socially-mediated experiences of disability of DP/PwD. All representation, then, is not positive representation. Those in privileged positions ought to be careful when they attempt to use their privilege for the benefit of DP/PwD and, as much as possible, seek the advice from DP/PwD so that they do not unilaterally work in ways that work against the affirmation of disability and the lives of DP/PwD.[186] Working with and/or being guided by DP/PwD regarding issues of access, policy, and representation would allow everyone to encounter disability and the lives of DP/PwD in a way that rejects the “presumptions of tragedy [and] presumptions of dependency and abnormality . . .  [and instead portrays] disabled people’s experiences as valid individuals, as determining their own lifestyles, culture and identity” (Swain & French, 2000, p. 578).

***Considering disability and interaction.*** Attending to disability as not only socially constructed but also individually experienced allowed me to attend to the actual lives of

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[186] bell and Rathgeber (forthcoming) discuss inspiration porn and music in greater depth and caution music learning and music makings regarding representation, stating “Though intending to be affirmational, the nondisabled viewer/listener becomes a part of the inspiration porn apparatus by disseminating the video, becoming an inspirational pornographer in their own right” (n.p.).

participants, rather than discount certain facets of their experiences with disability that might not fit into a theoretically tidy frame (i.e., the "social model" or the "medical model" as noted by Oliver, 1983). Conceptualizing disability as an interactional experience allowed me to see how individual and social facets swirl around, converge, run parallel, and diverge. Although all participants' experiences can be read from an interactional perspective, Birdie's experiences of disability *around* music are perhaps the most salient to discuss. Birdie experiences epilepsy in a very individual way. Her physiological and psychological state can make her weak and hypersensitive to sudden changes in her social setting. When weakened or hypersensitive, even her favorite music played at too high a volume might trigger a seizure. In this way, internal facets impact her ability to engage with music. Certain musics, such as music with "pulsing beats" like rave music, can trigger seizures regardless of Birdie's state. Birdie dis-cludes herself from settings where this music occurs and does not engage with people who play this music. In this way, external facets interact with individual facets to yield exclusion and self-isolation. Birdie is also both prideful of her "storm-like" and seizure-like way of being, but also worries about how it impacts her family, demonstrating the way her individual qualities interact with social attributes and her social relationships. To trace the roots of either an individual or a social facet of her experiences would certainly lead one to an intersection or even an intersection of intersections. As such, it is perhaps less important to "diagnose" or track down the cause of disability than it is to notice the multiple and interacting facets of individual and social life that present themselves as disabling to DP/PwD (Shakespeare, 2015).

***Need for additional inquiry on the interaction of individual and social.*** While writers have addressed the social dimension of disability (e.g., Abramo, 2012; Bell, 2014, 2017; bell & Rathgeber, forthcoming), focusing on social dimensions alone may be as limited from a research standpoint as focusing on individual dimensions alone. Additional research is needed in which researchers attend to the interplay of individual and social dimensions of disability within a specific context or practice. Such research might employ theoretical frames culled from sociology, philosophy, cultural studies, ethnic and racial studies, gender studies, and LGTBQ studies. Using an interactional perspective to ground a theoretically-informed analysis of disability and experiences of disability may allow researchers to consider the specific mechanisms and norms that construct disability and disabled/nondisabled subject positions within different music making and music learning contexts and practices. Studies drawing on interactional conceptions of disability in dialogue with theoretical frames from other disciplines could allow music researchers to attend to disability from the perspective of DP/PwD and also provide nondisabled persons with a means of understanding how disability is experienced by all within a specific context/practice.[187] Multiple analyses of disability from multiple perspectives using frameworks from multiple disciplines might broaden the basis of knowledge in both music education research and practice, as well as trouble and complexify conceptions of inclusion.

#### On Disability Identity.

> "[T]he fundamental unit of identity is social confluence—that is, the role in which an individual finds herself at any given time. This role is subject to redefinition at a moment's notice, as soon as one proceeds to the next encounter." (Lubet, 2011, p. 1)

DP/PwD experience a great deal of labeling and identification by others, be they medical experts, school teachers and professionals, parents, friends, and/or researchers. Shakespeare (2014) suggested that labels and identities are, on the whole, more interesting for others than important for DP/PwD. While this may be true given the kind of hyper-attention and value that researchers, social and familial relationships, experts, and professionals appear to bestow upon labeling and identifying DP/PwD sometimes as a means of tracing their difference from an assumed normate reference point (Garland-Thompson, 1997). Labels act to point toward specific diagnosis-specific practices (e.g., pedagogies and accommodations). Such a labeling—and the power to label—minimizes how labels and identities can be empowering for DP/DwD when

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[187] Birdie comments that she felt that epilepsy was more difficult for her friends and family and this assertion might be future explored from an interactional-informed distanced contemplation in and outside of music.

DP/PwD hold naming rights for themselves. For many of participants in this study, labels and identities mattered greatly and the power to self-identify was especially cherished and guarded.

Some participants articulated multifaceted identities with no *single* aspect of identity held as more important than another at all times. For these participants, certain facets of their identity were always present, but different facets were important to different degrees based on the specificities of time, space, activity, and relationship (e.g., Lubet, 2014). One aspect of identity may become more salient in one setting and fade to the background in another setting. Sienna noted how they purposefully emphasize one aspect of identity based on which might hold more social capital in a specific social setting. The actions or social roles performed by participants at a given time indicated the identity they hoped to present; Birdie is an abstract painter while painting, Sienna is an actress playing “x” role when onstage, Duke is a drummer when jamming with his friends at Willowflower, and Ice Queen is a sister of ΣAI when with her sisters. These identities do not disappear when not performed, however; Birdie is still “a female, music-loving, storm-like visual artist with epilepsy” if she is riding her bike, because these identities are always at play to some extent and because they name integral aspects of her lifeworld.

Other participants seemed to conceptualize a more integrated and/or undifferentiated self. For Daren, Duke, and Erica, their names were their preferred means of identification. Daren’s social identity is “just Daren,” and although he may have numerous other personal identities, such as “Christian” or “Korean,” he chooses not to intentionally uses these labels in social settings. When pressed, Daren did say he conceptualizes himself as a person “with Tourette’s,” yet it was clear he would rather people just get to know him in all of his inarticulable concreteness. For Duke, identities are badges of social belonging that describes larger social groups in which he finds himself.

Duke resisted articulating separate identities for the most part, although he did imply performative identities rooted in actions such as being a drummer because he drums. Erica either chose not to identify herself using characteristics or badges of identities, or she did not have words or images by which to adequately articulate who she was, is, and will be. Some might wonder if Erica has the "capability" to identify herself due to her seemingly impaired communication and mental functioning. Yet, maybe it isn't that Erica is incapable of identifying herself, but rather that some—or many—are incapable of comprehending how Erica identifies herself, speaks, and/or *is* in the world. Ableism has a way of privileging certain means of communication and being, and it may very well be that assumptions about Erica's inability to name herself and her world has more to do with ableism impairing others' abilities to meet her in in the ways in which she communicates about herself. It seems that, for Erica, her identities develop through her direct interactions in, through, and around music *with* others. Who she is is highly contingent upon whom she is with and what they are doing. Her identities may be complex to describe through words, yet they can be experienced through interacting with her through music. Music provides Erica a mechanism to communicate and the lyrics of others provide her ways to articulate her thoughts and, when she generated new lyrics, a framework from which to speak herself.

Culann was certain of his identity as a "crazy person," a particularly potent term with a problematic past that regularly appears on lists of ableist language (e.g., Cohen-Rottenberg, 2018; List of disability-related terms with negative connotations, 2018; Molloy, 2013). Culann prized this identity, relishing in the social shock it produced and giving "crazy" a different face than others might envision. In this way, Culann's means of identifying seems to be one of reclaiming and reconstructing a historically pejorative term, similar to the use of "Crip" or "cripple" in contemporary disability communities and in "Crip theory" work (e.g., Sandahl, 2003; McRuer, 2006b; Mirk, 2015; Peace, 2011). It may be that Culann deploys "crazy" in a way similar to those who use the term "Crip" in order "to challenge oppressive norms, build community, and maintain [one's] self-worth" (Sandahl, 2003, p. 38), although he may not conceive of it as such. And although Culann may be quick to self-identify as "crazy" and to chastise others who try to correct him, he feels unease in the idea of being “seen as crazy” in social settings. In this way, it seems that the identity label is less important than who is able to do the labeling and why.

All of the participants relished chances to be the labelers and namers of their lives. How they identify themselves and the labels they use act as shorthand for how they interpret disability and/or how they wish themselves to be manifested in the lifeworlds of others. Through labeling, participants also identified the distance disability may have from their personal self-conceptions. When described as “a part of” them, there was no distance between the participant and the “thing” that was disability in their lifeworld. As “a part of them,” disability was a facet of them, of their lifeworld and embodied selves, and thus not another thing-in-the-world external to themselves. Ice Queen’s description of “ADHD” as a personal adjective, Culann’s insistence that he was crazy, and Duke’s pride in his Williams syndrome may have been indicative of this type of hermeneutic understanding of disability. When described as “apart from” them, however, participants interpreted disability as being a separate thing-in-the-world with a particular distance between the lifeworld observer self and disability. In this way, disability acted as another entity, as with Daren and what he described as the adaptive sentience of his “Tourette’s,” or as the collective shape of a constellation of oppressive personal and social barriers, as may be the case for Sienna and her disability and access advocacy.

These interpretive differences of diability among participants may connect to common though different discourses of disability: “impairment,” manifesting a “a part of,” and “disability,” manifesting as “apart from.” Yet making a distinction between impairment and disability can seem too clear-cut, from a phenomenological standpoint, specifically when considering Birdie’s interpretation of disability as both “a part of” and “apart from,” based on the social confluences in which she finds herself. Similarly, for Duke and Erica in general, and for Ice Queen regarding depression/anxiety, disability may not manifest as either “a part of” or “apart from” them in a specific manner, or they may not have words with which to describe these aspects of their lifeworlds, or, perhaps, disability is just not the same kind of thing-in-their-world as others might imply, but rather an undifferentiated facet of life as lived, as being-*with*.

Affording DP/PwD the ability to identify themselves, to name the contours of their lifeworlds, and to present their identities and selves, grants them a level of agency they may not otherwise be granted by institutional structures and social norms. To be able to say, “This is who I am on my own terms and through my own means of communicating/being” may allow DP/PwD to carve out more productive subjectivities for themselves and, through that, to present positive ontologies of disability. Doing so may also help them to reject enforced and internalized ableism which often compels PD/PwD, “to fabricate ‘who’ they are—to adopt postures and comportments that are additional to self” (Campbell, 2008, p. 157). In addition, when nondisabled others impose “postures and comportments” on PD/PwD through acts of identification/labeling, they impose upon PD/PwDs a label, and that labeling illustrates the others’ conception of who the PD/PwD is. Such identification may foreclose who that person can be to the other and to any within an earshot of the labeling. Want for labeling (or not) by DP/PwD may be empowering and community building to both the labeler and the labeled when both value the label or have common identity intersections. Yet, those in earshot may still experience foreclosure when they do not have context for the labels and for the persons involved in the labeling-labeled process.

In this study, participants requested the chance to identify/label themselves and the chance to explain, if they wanted to, their labels to those within earshot. Certain labels may be important for securing assistance and supports, such as diagnostic and governmental labels, yet these labels may or may not be meaningful to or descriptive of the lifeworlds of DP/PwD. It is not that labels and identities of disability do not matter, rather, they matter a great deal as does *who gets to decide* how one is labeled and identified. Labels and identifications matter, *and* labels are consistently problematic in the face of tacit ableism which forwards these identifiers as positivistic terms of precision with shared and objective meanings that are applied consistently. Identity is constantly shifting, changing in the act of being, and labels mean more than their diagnostic definition or common usage would suggest. As such, if music educators wish to affirm “that the person has many characteristics and qualities of which a disability might be one,” as Adamek and Darrow (2005, p. 8) suggest, learning and following everchanging naming conventions such as person-first language or “identity-first” language might be of less use than “ask[ing] the stakeholders about their own preferences” (Bickford, 2004, p. 125). This does not mean that music educators should willfully disregard or be woefully uneducated in matters related to special education law and policy or students’ IEPs or 504 plans, but, rather, that these data should be placed into dialogue with the explicitly desires and identifications of learners.

***Intersectionality.*** Affirming DP/PwD identity and personhood involves understanding their intersectional positionality, or how individual identities merge, add to each other, and divert from each other. Erevelles and Minear (2010), Kuppers (2014), Moodley and Graham (2015), and Sandahl (2004), among others, note the importance of attending to intersectionality when studying issues of disability and the lives of DP/PwD. Yet, intersectionality was not something I was fully prepared to contend with when I began this study, and, as such, I did not engage with intersectionality in the depth it deserves. I addressed intersectionality in a rather shallow manner, however, it emerged as a far more important issue than I expected at the onset of this study. In addition, my positionality and the literature that I drew from rarely addressed intersectional issues of race, gender, sexuality, class, language, etc. in a substantial manner. Further, on this study, diversity among the participants was limited, diminishing the intersections possible to explore: Four participants were female and three participants were male. Six participants were white or “white-passing” and one was of Korean descent. All participants were from either middle or upper middle class families. All participants were cisgender. All participants spoke English as a first language. All participants were born in the United States and all were born in the southeast of the country. To say that additional research into intersectionality with more diverse DP/PwD is needed is an understatement.

While my intersectional inquiry may be limited, some related issues arose in my engagement with participants and the data. Sienna was explicit about her understanding of intersectionality, noting that their identity included the overlapping facets of being a cisgender woman, disabled, queer, asexual panromantic, Jewish, and white passing. They may feel oppression or empowerment at different intersections of these facets such as when they are cat-called as a white woman, but not cat-called when possessing their cane and being a white disabled woman. Sienna noted how they chose one facet or more to emphasize based on the cultural capital valued in the moment. They shared how their experiences with empowerment and oppression were not only shaped by these identity facets, but also by the social confluence of time, space, activity, and relationality. Some of the participants noted how disability and sexuality intersect and that this intersection has challenged their chances for relationships. Duke wanted to find a girlfriend and all his female friends supported him, but he felt he needed to look for girlfriend like him (i.e. "with a disability") because all the women around him were not interested in him. Sienna discussed her difficulties with finding and keeping a boyfriend, implying that the weight of having to care for her might be a problem to some men. Sienna also shared how they felt nondisabled persons assumed that sexuality was not a part of the lives of DP/PwD. This assumption limits the people to whom DP/PwD might initially turn when seeking sexual and/or romantic relationships.

***Need for more inquiry on identity.*** Intersecting identities and subject positions are shaped and sustained by social confluence (Lubet, 2011) and social performance (Goffman, 1959; Butler, 1990) in specific settings and practices, with specific people, doing specific practices. While some commentary on the importance of identity emerged from this study, additional studies specifically focused on how DP/PwD and nondisabled persons identify themselves and others related to disability in, through, and around music are needed. Such studies might provide broader understanding of disability identities and how people identify themselves and others based on interactional and intersectional dimensions in ways that are more nuanced than this study affords. For example, new co-generated data and studies might call into question prescriptive uses of person-first and identity-first naming conventions in, through, and around music.

Additionally, researchers might explore identity performance and social performativity of DP/PwD in, through, and around music in a focused manner, by drawing on frameworks provided by Goffman (1959) and Butler (1990) along with those developed by disability theorists. Research into how one person's identity and perspective related to disability is specifically governed by conventions and social expectations of their co-actors might shed light on the positive and negative aspects of interactions between DP/PwD and nondisabled persons.[188] Also, Kuppers's (2001, 2011, 2014) take on performativity and the affirmational approach to disability performativity offered by Crip theory (Sandahl, 2003; McRuer, 2006b) might allow future researchers to consider the impact that over-performance of disability through non-passing/non-masking might have. Laes and Westerlund (2017) explored the impact of class presenters who were DP/PwD on preservice music teachers' understandings about disability; other researchers might continue to explore how affirmational counternarratives can challenge essentialized conceptions of disability and the lives of DP/PwD. Attending to different ways of performing disability may allow researchers to subvert stereotypes, misunderstandings, and malpractice related to disability (Kuppers, 2001). Attending to performativity may allow researchers to,

> think through the possibility of subverting and displacing those naturalized and reified notions of [disability] that support [able-bodied/minded] hegemony and [ableist] power, to make [disability] trouble, not through the strategies that figure a utopian beyond, but through the mobilization, subversive confusion, and proliferation of precisely those constitutive categories that seek to keep [disability] in its place by posturing as the foundational illusions of identity. (expanding on Butler, 1990, p. 44)

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[188] As persons with diagnoses that put them in the category of having cognitive impairments, I wondered the extent to which other social actors treated Erica and Duke ethically and with respect. Even through Erica and Duke might judge experiences to be positive, what Erica and Duke missed more less than benevolent intents of other social actors?

Attending to identity, in general, provides a means of understanding the individual and social realities of DP/PwD. How one names or labels themselves is not a trifling matter and it deserves greater attention with relation to DP/PwD in, through, and around music. Much of the existing literature on identification of DP/PwD in music education focuses upon labeling by *nondisabled* teachers and students.[189] Identification from this perspective can miss the realities of PD/PwD (e.g., Shakespeare, 2014), essentialize them, speak for them (e.g., Alcoff, 1991), and may overly rely on ableist discourses of inspiration porn (e.g., Grue, 2016), microaggressions (Keller & Galgay, 2010), and subjectification (e.g., Garland-Thomson, 2002). Rather than obsessing about how nondisabled persons identify and name DP/PwD—as if they/we were zoo animals—one may learn far more about how disability is experienced at the constantly changing confluence of "place, time, activity, and encounter" (Lubet, 2010, p. 21). Beyond "learning," attending to how DP/PwD identify and name themselves and their worlds might open up spaces for individual DP/PwD to share how, in their journey, are "making [themselves] at home in [their] country" (Marcus, 1996).

In relation to music education, music teachers might attempt to know learners' identities—as they feel willing to share—and their interests, desires, and personal needs early in their work with all learners. For example, similar to the ways in which ensemble directors often have auditions to come to know learners' vocal or instrumental proficiencies and characteristics, they might use these times to get to know learners in different ways. Music teachers may also facilitate this "knowing learners' identities" through building identity and self-expressive experiences into curricula in order to to provide all learners with spaces to demonstrate how they understand, and label, themselves and their worlds. Generative music and/or other data, just as playlists and "my musical circles" activities (e.g., Barrett, McCoy, & Veblen, 1997), may provide music teachers with frameworks to empower all learners and to come to know these learners in greater depth.

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[189] See Appendix A

## On Inclusion

Part of the purpose for this study involves troubling pedagogical practices used to include DP/PwD in music making and music learning. Historically, inclusion in music education has been generally focused on mainstreaming, in which educators serve DP/PwD to the extent possible in the same spaces as their nondisabled peers (Kochhar, West, & Taymans, 2000, p. 12). Mainstreaming-based conceptions of inclusion may place DP/PwD in subaltern positions and music teachers into savior positions in which they need to work to bring DP/PwD into existing practices with some alteration. While these practices have done a great deal of good to open up music learning for DP/PwD who might not otherwise have had access to these spaces, practices, and relationships, some music educators adapt without consulting with the people for whom they are doing the including and adapting. Without such consultation, the focus of inclusion remains mainstreaming *with adaption* rather than reconstructing open spaces and options for DP/PwD to be *in* music, learn *through* music, and connect *around* music. Consultation, along with critical evaluation (e.g., Bell, 2017), are often needed far more than new “how-to” and “tips and tricks” related to mainstreaming in general and in diagnostic-specific situations. Consultation may allow for the development of a relational-based inclusion that might move beyond pedagogical “technologies* (i.e., “how-to” and new mainstreaming approaches) in order to foster more open, adaptive, and engaging spaces for music learning and music making for and with DP/PwD.

Music teachers may find it useful to engage in consultation and dialogue-based projects in which they become comfortable with difference and conversing, verbally and nonverbally, with DP/PwD. In music teacher education programs, such experiences might extend practical experiences that go beyond observing and group teaching and move toward working with specific DP/PwD learners on projects requiring collaboration and/or in which music educators act in consultation with the learners in service of the learners. For example, an adaptive instrument project, which may also draw on other pre-professional learners, might help preservice music teachers develop their competencies in consulting with learners in order to meet their desires and needs. Yet, while consultation may be a powerful first step toward more open kind of "inclusion," it is not enough.

In this section, I offer plausible insight regarding inclusion as rooted in the experiences of disability in, through, and around music of participants in this study and articulate different dimensions of what "inclusive" might mean. First, I address belonging, a concept that emerged throughout the study as one of far more importance that it has been given in music education literature related to inclusion. I offer suggestions for future belonging-based research in music education. Second, I share comments given by participants in this study to encourage more inclusive music learning and music making practices. Following this, I articulate a vision of anti-ablest pedagogy informed by participants' suggestions, anti-racist pedagogical thought, and writings on ableism addressed in Chapter Two. Within this section, I identify two specific facets of an anti-ableist pedagogy: affirmation of disability and relational presence. After discussing these issues, I offer concluding suggestions regarding future anti-ableist pedagogy.

**Belonging.** Prior to addressing belonging in experiences of disability in, through, and around music, I provide a brief overview of belonging and belongingness literature. Anant (1966) theorized belonging as a central aspect of human psychological and social life. Sense of belonging, or belongingness, occurs when, according to Hagerty, Lynch-Sauer, Patusky, Bouwsema, and Collier (1992):

> (1) the person experiences being valued, needed, or important with respect to other people, groups, objects, organizations, environments, or spiritual dimensions; and (2) the person experiences a fit or congruence with other people, groups, objects, organizations, environments, or spiritual dimensions through shared or complementary characteristics. (p. 174)

Anant (1966) theorized that one's sense of belongingness is rooted in the fulfillment of one's physical, psychological, and social needs as well as one's feelings of recognition and attention early on and consistently in a social grouping. Participants in this study discussed their feelings or longings for belonging. Below, I address different types of belonging and different ways that belonging was facilitated or blocked because of some individual and/or social facet of a participant's experiences of disability.

The individual and social aspects of participants' experiences of disability as well as their intersecting and socially intersecting identities had a great deal of impact on how they experienced belonging and found meaningful relationships. Certain dimensions, labels, and/or identities afforded them avenues to relationships and groups in which they found belonging while these same or different dimensions, labels, and/or identities might act as barriers. Nevertheless, participants were in search of belonging in, through, and around music. Plausible insights emerged in their searches for belonging that, even if unfulfilled, might inform inclusive practices in music making and music learning settings.

Participants noted how their identification as being "disabled" or "with a disability" often allowed them to gain entrance into certain settings in which they found a sense of belonging. Culann's attempts at suicide and mental illness diagnosis opened a pathway to entering a mental hospital for teens in which he felt truly cared for by the staff and engaged with the other residents/clients. While some might cringe at the idea of such institutionalization or recoil at thoughts of the kind of enforced and medicalized belongingness as described in Goffman's (1961) *Asylum* or Wiseman's (1967) *Titicut Follies*, Culann's experiences inside of the mental institution were empowering and far from the kind of oppression he experienced in school and with family. Sienna, too, benefited greatly from her disability diagnosis in that it gave her access to enrollment at a well-respected and heavily arts-integrated residential school for the deaf and blind. At this school, Sienna gained access to smaller group music instruction, learning the saxophone and banjo with far more individualized attention than might have been possible in the public schools. These musical skills and the residential nature of the school allowed her to develop close relationships with others and to be part of the school's new "bluegrass band," a school-based, community music therapy group launched after Sienna and a number of other students showed interest in playing instruments associated with bluegrass and Old Time musics.

Sienna felt welcomed in this band and in spaces where the band was welcomed to play, through which they developed relationships and a sense of belonging that Sienna continues to seek out after their time in the group.

Duke also gained admission into a disability-specific group in which he found a sense of belonging and communion that would not have been afforded to him had he not possessed a developmental disability label. Duke took part in Young Life's inclusion camp in which DP/PwD received small group and one-on-one attention related to life skills and religion while also having chances to engage in recreation and religious-based experiences with nondisabled, similarly-aged peers. Duke noted that in this space, he "found God," made friends, and learned how to connect with others to the extent that he made conscious choices to alter his seemly anti-social behaviors and developed his abilities to make friends—abilities that have become central to his *being-in-the-world* and drive his musical experiences of playing with others and attending music shows. For Duke, Sienna, and Culann, their experiences of disability included disability-aided belonging in which some aspect of their impairment acted as a means of admission to a meaningful social activity or group to which they felt they belonged. The aspects of their impairment, often identified through medicalized or IFCD mechanisms, acted as forms of symbolic capital and/or allowed them to accrue social capital (e.g., Bourdieu, 1985) that could afford them other chances for belonging in the future. Once they had gained entrance, Duke, Sienna, and Culann noted feelings of acceptance, of being needed, and of finding congruence with other members.

Participants also shared that their experiences of disability could be shaped by worries about *not* finding belonging. Birdie, for example, shared how she felt her diagnosis of epilepsy and the associated symptoms limited her abilities to form meaningful relationships and stood in the way of her experiencing belonging. She was concerned about the emotional toll her epilepsy took on her friends and families, which made her leery to share deeply, thus foreclosing some of her chances to feel belonging with them. Daren felt, in some respect, that revealing his diagnosis would block the growth of/development of any meaningful relationships, which often caused him some stress when symptoms manifested and he felt the need to mask them. Ice Queen commented on how her fear of vomit and anxiety often stopped her from attending band trips and may have caused her to further alienate herself. Erica found her way of connecting by singing songs with others, and her experience in *Pirates of Penzance, Jr.* afforded her a chance to foster old and new relationships. Yet, her parents were very worried that such opportunities might not continue to be open to her and that she would have to seek out other means of belonging as she moved on to high school, where performance expectations and norms of practicing might act as barriers to Erica's participation in musical experiences. In this way, Erica's parents worried that in school she would no longer find musical ways to belong with others in a ways well-suited for her *being*.

The ways that belonging manifested, or not, in participants' experiences of disability in, through, and around music were far from essentializable. Their impairments/diagnoses and their identities interacted with and played into to how they gained or were barred admittance to contexts where they might feel belonging or where they might develop meaningful relationships. For some participants, disabled-only or label/diagnosis-specific contexts were meaningful spaces to encounter belonging, and, as such, their perceived "difference" from a nondisabled and/or normate referent allowed them exclusive access to spaces for belonging. Other participants noted how they felt as if observable manifestations of their impairments, exposure of their labels/diagnoses, and/or negative social identification could limit access to the contexts where they might find belonging (e.g., McDermott & Varenne, 1995). Experiences of disability clearly interacted, intersected, and shaped participants' experiences of belonging.

***Need for additional inquiry on belonging.*** Belonging and belongingness are not central in music education literature related to inclusion. Anant (1966, 1967) and others have theorized and explored the impact that belongingness may have on people's lives. The co-generated data of this study suggest a need for additional inquiry with regard not only to how and where DP/PwD are included but also to what extent they feel belonging. The co-generated data that emerged from this study suggest that sense of belonging matters a great deal. Additional research that uses belonging and belongingness as analytical frames for considering inclusion and community is needed in the music education profession/field. Participants in this study shared feeling needed/unneeded and valued/unvalued. Participants also noted the importance of a feeling of fit and congruence—a word Culann used regularly—with people (i.e., Erica finding and singing with people), identities (i.e., Sienna and her use of identity), spiritual beliefs (i.e., Duke and his experiences in Young Life), groups (i.e., Ice Queen in service organizations, Daren in his breakdance group), and environments (i.e., Birdie and her search for friends that do not go to dance clubs). Greater attention to belongingness might provide new ways of crafting open, engaging, supportive, challenging, and meaningful spaces for all people to learn and make music.

**Suggestions from participants.** In the lifeworld narratives found in Chapter Four and in the imagined conversation in Chapter Five, participants trouble inclusion and inclusive practices directly or indirectly and provide much from which music educators could develop pedagogical practice. During our conversations as part of this study, participants offered rather pointed suggestions for empowering self-determination, self-differentiation, self-selection, non-judgment, individually responsiveness, and openness in music education. While the conversation below is envisioned, the words are direct quotes or subtly altered quotes drawn from the co-generated data in this study:

Jesse: If you could speak directly to music teachers, what would you tell them?

Daren: I think teachers should be open to having an interaction with people first, test things out rather than force us to do something a certain way based on a diagnosis. Also, being patient and adaptable can really help. Like, when I was in sixth grade with my piano teacher, I couldn't really express what I needed, or I didn't feel I could. So, it would help if a teacher was patient with me . . .

Ice Queen: Oh my gosh, yes. Be patient and don't scare us with the threat of a gong.

Culann: [interrupting] Listening, that would be helpful. Like if someone says, "I don't like doing this," maybe a teacher would actually listen.

Daren: And teaching people with disabilities should be really a case-by-case thing, not a by diagnosis type of thing. Listening to the student would help, and maybe listening to the parents, too.

Culann: I wish I could tell my son's music teacher a few things, for sure. I wish I could have told my music teacher some things. I know kind of what I like and what I can do. Some people just don't have the talent to be a great singer, so, don't push everyone to be a great singer. And please don't fucking make me dance if I don't want to dance. You know, just be like, "You don't want to sing? Okay don't sing. You don't want to play anything? Don't play anything. Okay. So, what is it that interests you?" That should count as music, following someone's interests in music.

Jesse: What do you think most music teachers count as music now?

Culann: Singing, dancing, playing instruments in front of people, playing "good music," you know, classical music and shit like that.

Daren: Classical music. Music teachers can be all about pushing classical music on people. I mean, I like classical music, but there is other music that means more to me.

Ice Queen: But kids should have chances to perform and learn about classical music, though. I think that's important. Playing in big ensembles, doing masterworks and concert band literature, which is not always popular, is really important to me, personally. I got into that through music class. It is a really big part of who I am, what I love, and the people I know and how I connected with them.

Daren: Well, even just using music that someone likes can help. And even if the music matters to the teacher, it is nice to know why you are doing something and the passion someone has for what you are doing. It helps build that little connection.

Culann: Maybe, but a chance to choose and to specialize in a way that is congruent with you would be really great. I feel like music class was always about "appreciating" specific music and talent. It's shit like, "Here is experimental jazz and it sounds like someone masturbating with a saxophone for 30 minutes." I mean, I just don't get it, I don't understand it. Granted, I get the musicianship, you know, "This guy knows how to really press his keys to make the noises that he makes," but it means nothing to me. Most of hip hop too, I just don't get. I don't know if you could teach me to get it. It's like reading poems. My wife will read something and say, "Hmm, I see what they're saying in this poem" on some deeper level because of these little references and form things. But, shit, I just don't get to that level of meaning, or I might not if someone is fucking trying to make me get it, to force it on me, you know? Maybe it's this whole realm of knowledge that is just totally inaccessible to me, kind of like math, because of my learning disability. I don't know.

Ice Queen: Well, I don't know. I feel like everyone should learn to appreciate different kinds of music. You won't know what you like if you don't try things. I don't think some people just possess an ability to appreciate different kinds of music because of their disability, you know? I mean, just because I have ADHD, it isn't, like, well, it's not like I can't understand slow music or appreciate complex music that takes a lot of attention.

Culann Yeah, okay, don't get me wrong, I think musicians should be respected for what they can do, but I'd just want a teacher to not spend the time trying to convince me to like something. Now, if a music teacher said, "Okay, find a piece of music that speaks for you in some way, dig into the history of the song and artist, and make some kind of movie about it," I'd be really into that. I think I'm more interested in using music way more than "understanding it," you know. Yeah, I get that you understand things when you use them, but maybe the point should be to learn to use music in a way that is meaningful.

Ice Queen: You seem to be suggesting that some people just have a talent for things and others don't. That doesn't seem right to me. I mean, I like to believe we all can do things if we set our minds to it. Well, we can do most things.

Culann Well, yeah. I believe in talent. There is no fucking way you can turn me into an engineer. You can't do it. I don't have the talent. You can put me in front of a math book and calculators and all the aids in the world, I will not see it. Like, when I was in college, I learned that radicals [i.e., in math] is my wall. I just can't get it, no matter how you present it to me. I can work hard, really hard, and get basic stuff and algebra, but no more. So, that's the thing about a lot of music class, it can look a lot like shitty math. Reading music, I don't know if you could teach me *the* language or how to read music. I just, I know what my brain does. So, um, from my academic perspective as a rehab counselor, when people say you can be anything you want to be, it's like, ah, well, that's bullshit. Um, I can give you a psychological eval. and I can tell you, you can do this, you can't do this. And I kind of think it's a disservice to not shoot straight. I mean, for shit sake, there are just certain things that you can do and things that you can't do based on who you are, how your body functions, and how your brain works.

Jesse: You say that you can't be a singer or be a guitar player, and I feel like it is important to believe that everyone can be . . .

Culann . . . but those are vocations. Maybe music class shouldn't be vocational education, at least not all of them, and be more related to the things people like to do. See, I like to do history, but I am not a historian. I totally get what you're saying and I totally agree to the philosophy that regardless of your talent with music, you can be taught to think about things in a musical fashion. Um, if someone really sucked at singing but liked to sing, more power to them. But, I think it is important to *find out* that someone likes singing. You know, ask, "So, what is it that interests you," and go from there with them. It should be okay to suck at music. It should be okay to not really understand why this is a great piece or why this isn't a great piece. But, you know, you should be learning how to apply music to something in your life.

Birdie: Yeah, like, music class can be about helping people to, like, you know, find their own style. My mentor used to say, "Style is what happens." You know? It’s what comes out of you and it can, like, sort of change. Give people a chance to find their style. Like everybody has a different singing voice. Everybody's handwriting is unique to themselves. Two handwritings might look similar. Two voices might sound similar, but you're never going to know what your voice sounds like until you start singing. People don't think they can sing. People don't think they can draw. You know, the problem is that people just don't trust themselves to do it, or they say, "Oh, I can't sing." Or, "I can't do art. It's so cool that you can do art. I wish I could do that." And it's like, "Well, just do it." So, it's just, you just got to do it. You can learn terminology and technique along the way, but I think the whole thing should be learning to use music to find who you are.

Daren: Right, allow at least a little room for, sort of, creativity. You know, just letting people fiddle around. Let them explore for themselves. If they’re interested, of course, let them explore themselves. Help them find their niche, I guess. It sounds simple, but, like, this creates some intrinsic motivation and fun. I remember learning piano and my teacher used these Suzuki books. All we did was these little technique things and the creating thing was something for later. But, it can be hard to deal with these repetitive things that don’t seem to be meaningful because in the present point of view at the time, it is just bad, feels bad, and it just doesn't seem to have any payoff. I mean, I've learned more technique from learning to bboy on my own and seeking things out when I need them than I feel like I did with those piano lessons. I got to fiddle around from the beginning with bboying. So, yeah, give people chances to fiddle, explore themselves, and find their own niche.

Sienna: And that would require a teacher to ask, not assume. It's great to do the research, it's great to have research-informed practice, but if something doesn’t work for a student, it doesn’t work. We, as people with disabilities, can be so little involved with how our lives are run, sometimes, that, um, it feels wonderful when people ask us directly

# what we want *and* what we need.

Duke: Yeah, and trust us. It’s nice to feel like other people trust you. Being trusted by a teacher would help you trust them so they can help you get through it and make it. Even starting with something easy instead of something really, really hard.

Daren: Like I said before, it is about approaching people on a case-by-case way. You do that, get to know us, and we might learn that we can trust you enough to tell you what we need and want. I even wonder if teachers should have any knowledge of our diagnosis, because having that stuff before meeting someone could get in the way of really getting to know them, maybe. I don’t even tell most people about my Tourette’s, but I felt that teachers, before college, just sort of knew about it before they met me.[190]

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[190] Diagnostic labels may or may not specifically be included on IEP or 504 documentation. IEPs generally include: “(a) a [student’s] present levels of academic achievement and functional performance; (b) measurable goals statements (academic and functional); (c) benchmarks and short-term objectives for students who take alternate assessments; (d) how progress will be measured and when reports will be provided (reports must be provided at least as often as reports for students without disabilities are provided); (e) for students participating in alternate assessments, a statement as to why and which assessment will be included; (f) an initial evaluation that is conducted within 60 days of parental consent for evaluation (or within the timeframe chosen by a state); (g) transition services for children 16 years of age or older; and (h) a stipulation that the child must be present when postsecondary goals and transitions are considered—or the child’s interests must be considered” (Hammel & Hourigan, 2017, pp. 67-68). A 504 plan, on the other hand, may include: “strengths and challenges a student experiences, the accommodations required for state-level testing procedures, classroom accommodations and modifications, and any other specific information necessary for the equal inclusion of that student in the classroom” (p. 72). Yet, speaking from personal

E-father: It can be hard, too, if someone doesn't specifically have a diagnosis. For example, Erica doesn't necessarily have "x" and I have seen how frustrating that can be, as a parent, to be proactive. There are many books about "x," "y," and "z" labels, but none of those things fit Erica. But, not having a diagnostic label has forced myself and my wife—and I hope her teachers—to try to get to know Erica's world and her way of processing and doing things.

**Erica:** **[singing] "Getting to know you, getting to know all about you. Getting to like you. Getting to hope you like me. Getting to know you. Putting it my way, but nicely, you are precisely my cup of tea."**[191]

Birdie: Exactly! Get to know us, get to know our frequencies, our styles. And help us find them, if we don't know about them yet. Don't just try to get us to vibrate on, like, your frequency, you know?

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experience as a past P-12 public school music teacher and from the perspective of participants, diagnostic labels can and do circulate outside of these documents. I distinctly remember labels being used during informal discussions in the lunchroom, during IEP meetings, and, generally, as an adjective for certain students. Regardless of the inclusion of diagnostic labels, Daren, specifically, noted concern that the very presence of documentation may force disclosure without his direct consent.

[191] (Rodgers & Hammerstein, 1950). For context, the opening lyrics include: "It's a very ancient saying, but a true and honest thought, that if you become a teacher, by your pupils you'll be taught. As a teacher I've been learning, you'll forgive me if I boast, and I've now become an expert on the subject I like most: Getting to know you."

Sienna: Yes, and be supportive but not afraid to offer ideas and help. Umm, and corrective criticism is fine. I feel like a lot of people are like, “Oh, they have a disability. I don’t want to, like, criticize them because that might make me out as the bad woman,” you know, because they think of people with disabilities as babies that need to be sheltered. That is not true. In fact, it makes it worse because it further isolates us from the social world that is filled with criticism.

> Constructive criticism is great and it’s a useful tool for everyone, including persons with disabilities.

Culann Right. I mean, be honest, it’s not like I’m a fragile little flower. I won’t wilt. I hate it when people walk on eggshells around me. It’s stressful, because it make me feel like I have to demur to them, sort of do this fake [air quotes] “kowtow” so I don’t either upset them or so I don’t do something that confirms their thoughts that I’m fragile. So, yeah, treat me like a human and stop stressing me out with your worries and let me be.

Birdie: And, like Sienna was saying with constructive criticism, know that, like, people may need you to offer different ways of giving that critique. Open critique in front of my peers freaks me out. I would really appreciate more one-on-one experiences that were not so much like “this is wrong” or “you have to do this to get that.” I mean, in general, I don’t like speaking up in class. I wish a lot more of critique and class participation could be based on questions. You know, like, the teacher saying, "Okay, for your, uh, for our meetings or class, please come with a list of five to ten questions and those will be collected as your participation." I think that would be a really helpful thing because questions, like, making questions for teachers might help them get where you are. Getting somebody to ask you a question requires you to be an active listener. You could, like, then figure out how people are processing things differently. It isn’t about giving people all the freedom, because some people will fall off or get scared, like having a blank canvas. You have to, like, know the person, get to know how they can be successful, and tailor things for them. For me, deadlines help, like, hard deadlines.

Sienna: Design for diversity, access, and inclusion. All disabilities are incredibly different and what might be an accommodation for one disabled person can be, um, a barrier for another person with disability. Recognizing that people are different and then accommodating for those differences to make an inclusive

environment.

**Anti-ableist pedagogy.** The stories of and discussions with DP/PwD in specific settings should ground individual pedagogical practice rather than using prescribed pedagogies and approaches based on diagnostic labels. Inclusion of this kind necessitates the continual development of new practices and new approaches. If I have learned one thing from participants, it is that one's approach to living and doing is, or should be, consistently contingent upon the people with whom they live and do, rather than based on assumptions and preunderstandings about specific people or kinds of people and pre-set practices. Although I feel it may be more open or appropriate to ask that you draw pedagogical implications from your meetings with participants in this document, the suggestions of participants in this study call to something larger and more transferable: anti-ableist pedagogy. Below, I discuss what anti-ableist pedagogy might look like by first outlining some of the writings on anti-racist pedagogy as a model. I then note what facets of an anti-ableist pedagogy might be. Prior to this, however, I state Wolbring's (2008) definition of ableism as a reminder:

> [ableism is] a set of beliefs, processes and practices that produce – based on abilities one exhibits or values – a particular understanding of oneself, one's body and one's relationship with others of humanity, other species and the environment, and includes how one is judged by others. (p. 252-258)

***Anti-racist pedagogy.*** Bradley (2006) defined anti-racism as "an action-oriented, educational and political strategy for institutional and systemic change that addresses the issues of racism and the interlocking systems of social oppression (sexism, classism, heterosexism, ableism)" (p. 25). Anti-racism pedagogy involves providing "a safe and facilitated place to engage in this discourse around race and skin tone" (Obeyesekere, 2017, p. 19). Dei (1996) suggested that creating and facilitating such a space would require that teachers possess

> an awareness of personal location, authority, experience, and history [as] the foundation of successful teaching practice. Rather than claiming authority of text, knowledge, or experience, a teacher can share power in the classroom, knowing when to step outside the role of "authority" to engage students collectively in the cause of social change. (p. 180)

This may involve new and challenging discussions with learners, other educators, administrators, and community members regarding issues such as "procedures and processes of liberal discourse by which white racialised positioning is evaluated, justified and performed" (Schick, 2000, p. 95). These procedures and processes impact how teachers, students, content, instrument, and classroom context (e.g., Butler, Lind, & McKoy, 2007) relate and interact with one another. The stance advocated by these scholars certainly requires music teachers who can identify their own positionality and help others to place their positionalities in relation to race, privilege, and systems of oppression (Hess, 2015).

Bradley (2006) identified ableism as an interlocking element of social oppression in her definition and, as such, I do not wish to suggest that anti-racist pedagogy is wholly distinct from what might be anti-ableist pedagogy, as racism and ableism arise in both similar and different ways based on the eccentricities of "place, time, activity, and encounter" (Lubet, 2011, p. 21). Yet, as a focus for activism and pedagogical work toward social justice, anti-ableism is rarely addressed directly and, as Lalvani and Broderick (2013) suggest, "the topic of disability is often missing in discourses of diversity in schools and in multicultural education" (p. 469). As such, working against ableism in music learning and music making settings become intentional for those who directly address disability. Anti-ableist pedagogy may well begin with teacher educators and college students, in pre-service programs, as they come to identify and address their biases because, as Lubet (2014) has stated, "Bias cannot be addressed by elimination . . . only by revelation" (p. 144).

***Outlining an anti-ableist pedagogy.*** What might an anti-ableist pedagogy in, through, and around music look, sound, and feel like? While a full listing of what "could" be may be beyond the scope of this study, I offer some participant and literature-based suggestions below to begin or to add to this conversation in music education discourses. As stated above, anti-ableist pedagogy requires focused attention and dialogue related to positionality, including potentially difficult discussions in which music teachers, learners, and community members identify how they may be both privileged and oppressed by processes and practices that govern disability (e.g. Lalvani & Broderick, 2013) as well as how those processes flow from the confluence of time, space, activity, and relationship (e.g., Lubet, 2011). Building on these ideas, an anti-ableist pedagogue may engage in identifying facets of practices and processes that reify or reinscribe deficit and tragedy-based discourses of disability. Teaching from an anti-ableist position would also mean that one actively works against practices and processes that sort learners and participants by "ability" and that deem those who appear to possess an impairment as inherently unable, including audition practices (e.g., Lubet, 2009) and behavior management protocols (e.g., DeVito, 2006) that reinforce ableist norms under the rubric of "excellence" or "high standards" (McCord, 2017). Through uncovering ableist processes and practices, an anti-ableist pedagogue can facilitate investigation of how disability leads to exclusion in, through, and around music, as well as exploration of the ways in which identity and performative positions construct difference and may create instances of othering.

In addition to the ideas above, anti-ableist pedagogy would certainly involve a teacher identifying and addressing common ableist language and microaggressions that demean DP/PwD and continue deficit and tragedy-based discourses of disability. Rather than policing language by banning certain words, though, an anti-ableist pedagogue would work to become conscious of the things she does, the historical context of words and actions, and their impact on others as a first step, and then, particularly in music teacher education, demonstrating this type of thinking and doing so that others may share their thoughts and not self-sensor or self-silence, thereby fostering a sense of inclusion and belonging in the classroom. An anti-ableist pedagogue would value the agency of DP/PwD with whom she works by empowering them to be the namers and labelers of their worlds and active developers of inclusive practices. DP/PwD could offer counter-narratives of disability (Churchill, 2015; Lalvani & Broderick, 2013), and an anti-ableist pedagogue would seek out additional narratives and representations that affirm the diversity of experiences of disability. All narratives may need to be explored for the ideologies and subject positions inscribed upon DP/PwD within them. Attention to existing narratives may allow for the narratives of learners in classrooms, ensemble rehearsals, and community music settings to come to the collective consciousness.

Through encounters and interactions, people may experience different performances of disability and come to see “different strengths, perspectives, and types of expertise as opportunities for cooperation that not only complement inclusive music education, but also help to move beyond inclusion and towards a democratic, diverse society” (Laes & Westerlund, 2018, p. 43). These experiences may have far more impact on music learners and teachers than study of labels and disability through only textual and hypothetical investigations. As Jellison and Taylor (2007) suggest in relation to pre-service music educators, first-hand interactions are crucial in order for people to come to understand each others’ mutual humanity.

While there are certainly more concrete ways to foster and enact anti-ableist pedagogy, these ideas offer an entry into practice and research. Additional work is needed to: (a) identity more facets of anti-ableist pedagogy; (b) consider its potential as a kind of “pedagogy of social change” (e.g., Hess, 2014); (c) consider how anti-ableism might be a powerful research framework, as Bradley (2006) and Hess (2015), among others, have done with anti-racism in music education; and (d) more firmly consider how anti-ableism interacts with anti-racism from a specifically intersectional perspective with respect to pedagogy and research.

Finally, an anti-ableist pedagogue might borrow from the work of Galloway, Nudd, and Sandahl (2007) and their ethic of accommodation. Using this ethic in group artistic practices, an anti-ableist pedagogue would work to involve all participants already inside the practice and setting—and those wishing to be inside. This may require that all “make difficult changes in . . . practices and environment” (p. 229). Such a pedagogue would practice radical listening which “does not have to happen with the ears . . .  [but also involves individuals] being taken into consideration [and] being attended to” (p. 229). An anti-ableist pedagogue would also engage all in doing the same listening, considering, and attending to in order to make space for those who do not regularly speak or who have been silenced to have a voice and to speak if they so wish. An anti-ableist pedagogue would make “room for difference possible[and] letting go of preconceived notions of perfectibility [in order] to [negotiate a] complex sets of needs” (p. 229). And an anti-ableist pedagogue would encourage creative policy making and policy implementation that opens up the possibility for new works, practices, and body/minds to exist and find belonging in a context. These openings may include the ability of DP/PwD to self-differentiate and self-accommodate in ways that resonate with their physical and cognitive functioning, their individual needs, and their personal desires as learners, and their ways of being-in-the-world/being-with. These explorations into what anti-ableist pedagogy might look like are rooted in existing literatures and theories and draw from existing pedagogies, such as those outlined in Chapter Two. Below I comment more explicitly on anti-ableist pedagogy by addressing two foundational facets of an anti-ableist pedagogy: (a) affirming the social confluence of identity and (b) relational presence.

***Affirming the social confluence of identity/affirming disability.*** An anti-ableist pedagogue, or researcher, would carefully consider how identities, labels, and roles imposed *on* DP/PwD, as well as identities, labels, and roles self-applied and performed *by* DP/PwD, are constantly shaped and reshaped by the confluence of “place, time, activity, and encounter” (Lubet, 2011, p. 21). In this study, both the ways that participants’ identities shifted and how they identified themselves differently suggest that it is important for anti-ableist pedagogues to consider the provisionality of what it means to be and to perform as DP/PwD. Rather than defaulting to naming/identifying conventions for learners, an anti-ableist pedagogy would affirm the complex and multiple meeting points of extrinsic/social and intrinsic/individual elements that structure the lifeworlds of DP/PwD (e.g., Shakespeare, 2014; Kuppers, 2010).

An anti-ableist pedagogue would work to help all people understand how “place, time, activity, and encounter” (Lubet, 2010, p. 21) as well as individual and social elements of life may impact the ways in which DP/PwD are known and seen as well as how they want to be known, act/perform and be seen. An anti-ableist would work to help all within a learning/making context consider how ableism is constructed through confluence and interaction, and how nondisabled actors use confluence and personal positionality to speak for or use DP/PwD in ways that range from explicit oppression—such as might occur if Erica is blocked from joining her High School musical because of her “inability” to perform to the ableist norm—or implicit oppression—such as the use and dissemination of disability stereotypes. Such work would help to open and affirm the social confluence of disabled identity and experience in music learning and music making spaces.

Affirming the social confluence of disabled identity and experience may also require that an anti-ableist pedagogue avoid following imposed and totalizing naming conventions and use, instead, the labels and identities preferred by those within a music setting. Much like using a learner’s personal pronouns and personal name provides the learner with the power of identifying themself, doing so for identities related to disability could empower learners who are DP/PwDs to perform their being-as-they-are, including disability. The power to self-identify and perform their selves in might provide all learners, including DP/PwDs, a lens for understanding “diversity in a broader sense than the mere toleration of difference . . . [and an opportunity to] move beyond inclusion and towards a democratic, diverse society” (Westerlund & Laes, 2018, p. 43).

An affirmation of social confluence and affording DP/PwD the power to perform and name disability and their identities on their own terms works toward an affirmational approach to disability as advocated by Swain and French (2000). Their approach involves: (a) “rejection of the tragedy model, within which [individuals’] experiences are denied, distorted or re-interpreted . . .

[and which challenges] presumptions of personal tragedy and the determination of identity through the value-laden presumptions of non-disabled people," (b) "rejections of presumptions of dependency and abnormality" inherent in tragedy approaches, and (c) focusing on "disabled people's experiences as valid individuals, as determining their own lifestyles, culture and identity . . . [so that] disabled individuals assert a positive identity, not only in being disabled, but also being impaired" (p. 578). By embracing an affirmational approach, researchers, teachers, professionals, medical experts, and policy makers work toward affirming both multiple ways of being and multiple ways of being disabled/having a disability. Doing so might stand in opposition to retaining institutional equilibrium (e.g., Slee, 2008, p. 108) and the practices in institutions that reproduce inequities and stigmatization (e.g., Tomlinson, 1982). An affirmational approach to disability and an acknowledgement of the social confluence of disability and disability identity may also impact and disrupt so-called "inclusive pedagogies" and special education practices that rely upon the assumed efficiency and effectiveness of stable and predictive labels. An affirmational stance may involve adopting a label-free approach to teaching (e.g., Hammel & Hourigan, 2017) and a commitment to rejecting label-based pedagogical practices. An affirmational approach would allow for learner self-differentiation and self-expression, co-developed through numerous face-to-face experiences interacting with and making music with PD/PwD.

An anti-ableist pedagogy could be dangerous in that it could negatively impact the services provided to DP/PwD under the auspices of legislation such as IDEA, Section 504 of the Rehabilitation Act, and the Americans with Disabilities Acts, which rely upon diagnosed differences and expert-applied labels in order for DP/PwD to gain access to supports intended to level barriers to participation in social life (Brantlinger, 2006). Yet, perhaps it is possible to juggle labels and identities imposed by others for the purpose of helping people access supports they want and/or might need, while at the same time, in the words of Daren, "take it case by case" to allow DP/PwD to be known on their own terms. Researchers, teachers, friends, professionals, medical experts, and policy makers may need to bridle their response to diagnostic labels and/or externally-imposed identities and remain open and present to learners who are DP/PwDs.

***Relational presence.*** An anti-ableist pedagogy may also involve affirming music teachers' and learners' relational ontological positions (e.g., Buber, 1958, 1965). Without a such an understanding and commitment, music teachers might lose sight of the importance of meeting learners who are DP/PwD and instead turn their attention toward labeling, seeking out medical expertise related to the labels, and/or searching for prescribed practices or approaches to including specific DP/PwD. With their attention, their intentionalities, focused elsewhere, music teachers may miss the learners and/or never allow the DP/PwD with whom they work to manifest in their full uniqueness in classrooms and/or music making spaces. By "meeting," I suggest the kind of being that is being-with/*Mitsein*, a relational presence.

Participants in this study seemed to call for music teachers to be *with* them, rather than obsess over specific characteristics *of* them that may or may not be in play in, through, and around music. The participants spoke of their desires for music teachers who get to know them, who accept them as they are, who are not fearful of asking them for ideas, who trust them, and who are open to knowing them in their concrete realness. They desire music teachers who allow for and value their presences and music teachers who, through their interactions, are present *with* them. These desires for *presence* are not for the kind of physical presences that Bledsoe (2016) suggests general music teachers misinterpret as inclusion—learners with different interests physically located next to other learners. Rather, participants in this study call for a presence that is spatial, temporal, and relational, and I agree.

What does it mean to be present in this way? In one way, *presence* means to be *with* others and to allow all doings to be shaped by this *withness.* It means acknowledging the ever-shifting nature of being-in-the-world as being-with-others. It means encountering one another and engaging in deeply dialogical types of being, knowing, and doing in, through, and around music. This type of presence is rooted in a relational ontology much like the one Buber (1958, 1965) articulated and which I have discussed throughout this document. In realizing a relational presence as grounds for an anti-ableist pedagogy, I draw on Kramer's (2003, 2013) extrapolation of practice from Buber's philosophical work. Writing directly from Buber's pedagogical work, Kramer (2013) identifies six characteristics that may be central to fostering relational presence in, through, and around music:

> 1. Relationship—Real knowing happens in the midst of a multi-sided relationship, which is present, open, dialogical, and has potential for the future.
> 2. Inclusivity—Inclusion, or imagining what another is thinking, feeling, and experiencing, is the irreplaceable method for learning dialogically.
> 3. Reciprocity—Neither objective, nor subjective. Intersubjective learning happens mutually between persons and content.
> 4. Openness—Educating dialogically results in presence, directness, and responsibility.
> 5. Personalizing—Dialogue with texts, art, nature, ideas, feelings, things requires encountering the other personally.
> 6. Trusting—The educative potency of intersubjective dialogues between/among teachers, students, and material. (p. 80).

Kramer indicates a middle-path that is intersubjective, in that it is neither subjective "in which knowledge develops out of a student's own creative powers" nor objective "in which knowledge is imposed from [outside]" (p. 25) and in this way neither student-centered nor teacher-centered. Rather, learning becomes a dialogic activity and dialogue-centered "in which the educator recognizes each student as a unique person with a distinctive perspective, and in which students encounter and participate with the educators as someone who is relatable to and present for them" (pp. 25-26). Below I use Kramer's characteristics and data co-constructed with participants in this study to further outline relational presence.

*Relationship.* Participants in this study desired open relationships that fostered relational meeting between music learners and teachers. They noted their relationships in music classrooms were often closed when, rather than meeting with them, their music teachers, alone, outlined and directed *the* goals, *the* activities, and *the* processes lived out in the classroom. Although a lack of relationship might occur for many learners in music learning and music making settings, participants in this study implied that educators in their experiences often enforced a one-sided relationship in order either to meet the participants' diagnostically assumed needs or to meet the needs of the context (i.e., the repertoire, the activity, the ensemble), which might involve not "including them" lest they disrupt the context. Bell (2014), a researcher-teacher, shared how a focus on specific outcomes or expected ways of doing things (i.e., playing guitar with "correct" technique) limited his relationship with Phil, the research participant, which in turn limited Phil's success and closed opportunities for Phil to develop on his own terms. Instead of closures, an anti-ableist pedagogy might open up relations between music teachers and PD/PwD to co-create goals and approaches together, meeting each other on a "case-by-case" basis, as Daren, a participant in this study, suggested. Hammel and Hourigan (2017) articulated the need to act relationally when they stated that "Knowing your students and their needs can be far more important than the specific labels included in their paperwork" (p. 203).

*Inclusivity.* Participants in this study shared that their music teachers often attempted to "include" them by imagining stereotypes of a diagnosis detached from their being. E-father shared how he worried that people attended far too much to Erica's diagnostic label than to her being: music teachers often "included" the diagnosis in their actions but not *Erica*, in her complexity, in their lives and practices. Linton (1998) states that "ableism . . . includes the idea that a person's abilities or characteristics are determined by disability" (p. 9), and this ableism seems to be what concerns e-father. Inclusion, or imagining what another is thinking, feeling, and experiencing, is the irreplaceable method for learning dialogically. One might wonder to what extent being a part of the "special education team," as Hammel and Hourigan (2017) suggest, focuses educators on labels and colors initial meetings with learners rather than opening to what learners are imagining, thinking, feeling, and experiencing. I suggest that an anti-ableist pedagogue meet with participants and come to know them, their interests, and their goals before making use of label-based information, unless the participant openly self-discloses that information. Participants in this study were clear about wanting these types of meetings, as were the participants in Abramo and Pierce's (2012) inquiry. In these meetings, an anti-ableist pedagogue would also open up themselves to the learners and help learners come to know the pedagogue, similar to Buberian conceptions of inclusion.

*Reciprocity.* I suggest, as articulated in the last sentence, that reciprocity ought to be a key feature of Buberian inclusion. Reciprocity in this case means not only sharing power in a classroom, but also a sense of belonging and a sense that one can be teacher and student within the span of a few minutes. Reciprocity was rarely a facet of participants' music experiences in schools or formal learning settings (i.e., piano lessons), but it was a facet of their individual and personally-selected musical activities. Reciprocity was a feature of Birdie's favorite music experiences with friends who share musics. Culann noted how closed his music education was in that his choice and presence in a classroom seemed to matter little in relation to the stated objectives and assumptions of the teacher; openness was rarely a factor. Participants were in search of reciprocal relationships that might allow them to feel as though they were valued and that they belonged. They noted the power of learning relationships that were reciprocal in music and characterized these teachers in ways similar to teachers described as critical pedagogy-informed educators (e.g., Freire, 2000; Shor, 1996; Ayers, 2001; Ayers & Alexander-Tanner, 2010). By working toward reciprocal relationships, an anti-ableist pedagogue would shake up the power structures that center nondisability/ablebodiedness (Laes & Churchill, 2018) and allow multicentric (e.g., Dei, 2003) spaces for music making and music learning.

*Openness.* Much of what the participants in this study suggested requires music teachers be open to new ideas and to remain open to navigate the constantly changing aspects of music making, music learning, and life. Participants implied a desire for an open approach to music making and learning. Duke, Birdie, Culann, and Erica, specifically, forced such an open approach in our meetings. They engaged with me—making music, singing, listening, creating playlists, writing songs—and expressed that would like to engage with music teachers in similarly open ways. Sienna's reminder that all disabilities and all people are different also highlights the need for openness. Hammel and Hourigan (2017) move toward openness when they indicate that music educators need “adaptive expertise,” or when they write about “the need for music teachers to adjust their teaching to various settings and change their approach from class to class, year to year and student to student” (p. xviii). Perhaps “adaptive expertise” is a major aspect of openness, but, if the participants’ suggestions are to be valued, openness may be more an “adaptive becoming” that requires one to know that they can never be an expert of another person’s lifeworld.

*Personalization.* Something that all participants desired was personalization of their music learning and music making activities: personalization of genre, activity, goal, and pace. Ice Queen requested “classical music” while Culann requested almost anything but that; Duke wanted rock music and a drum set while Birdie just needed indie music and some headphones; Erica wanted someone to sing with or listen to her play piano while Sienna wanted some bluegrass covers of Disturbed. All the participants shared a wish for a kind of adaptive personalization in the music experiences. Yet, existing pedagogical approaches that resonate with this wish for personalization, such as Universal Design for Learning and Differentiated Instruction, seat power within the teacher and not, as the participants in this study requested, in the hands of the learner. The personalization here is not a “one and done” type of thing or something that can be grabbed out of a diagnosis-based accommodation toolbox and used for anyone with that diagnosis. Rather, personalization is an on-going and unfolding process, one that grants learns power to make decisions and to be in dialogue with music teachers frequently and consistently. Perhaps, as Ice Queen alludes, participants request educators to prepare and work with them to develop what Adkins et al. (2012) may call “alternative zones of inclusion” (p. 513). This does not mean that all existing approaches are null and void, as they may be useful resources. Yet, such resources cannot and should not sublimate the primacy of coming to know a learner first through speech, through play, through creative work, and through communal activities.

Personalization of this sort may sound exhausting for a teacher when faced with large classes, particularly if personalization is extended to each student. Yet, not having a say in one's own learning, being essentialized or totalized as one's diagnosis, and/or being excluded outright can be exhausting, infuriating, and oppressive for many DP/PwD and for nondisabled learners as well. Music teachers/practitioners who use mainstreaming-based differentiation for specific learners who are DP/PwD while never personalizing may inadvertently "other" the learners further, making them "special." By acting in this way, teacher/practitioners might never address the ableist facets at play in classrooms and practices. As challenging as it may be, personalizing for all might be one way to a) remain relationally present to the needs and desires of all learners while b) chipping away at the ableist center of practices and affording a multicentric classroom and practice (e.g., Dei, 2003).

*Trust.* Finally, participants in this study wanted to feel trusted by music teachers and others in music making and music learning settings. Duke noted the importance of trust directly, indicating that trust may be linked to reciprocity. When bands trusted Duke to play with them, Duke was afforded a place to belong, make friends, learn new music, and sharpen his drumming skills while exchanging ideas with the band members. By seeking mutual trust, DP/PwD might feel welcome to open up further and disclose details of their lives that could help music teachers act in more inclusive ways via Buberian relational being with. Fostering trust may also allow DP/PwD to trust themselves to try new things and find their own voices. Trusting DP/PwD requires that teachers listen to the desires, needs, and identities of DP/PwD an communicated by them in words, movements, and behaviors (e.g., DeVito, 2006). Rather than assuming or using only external information (e.g., labels, accommodations, stories from past teachers, assumptions based on stereotypes, or experiences with other people with similar features), an anti-ableist pedagogue would trust the expertise of the DP/PwD with whom they work—to trust them to share, as they are able, their needs, desires, and effective accommodations/adaptations. It is important to note that some DP/PwD, as with anyone, may not directly know what they need/desire or be able to explain those needs/desires, may not express information in ways that are quickly understandable to the pedagogue, and/or may need the assistance of others to share this information.

An anti-ableist pedagogue would practice patience, seek different means of communication, and collaborate with DP/PwD and supportive others to uncover what DP/PwD need and desire as well as what has worked/will work for them. Such an approach may be cultivated in any number of ways, such as: collaborations with DP/PwD in and out of music learning or music making spaces;  practicum experiences in preservice teacher education (e.g., playing alongside and working with DP/PwD students in an ensemble setting or engaging in a collaborative music and identity-based project); in classroom for practicing music teachers (e.g., facilitating an examination of multiple approaches to techniques derived from musicians who are DP/PwD and developing heterogeneous music making and music learning classes or projects that are nonhierarchical), and fieldwork in DP/PwD-focused settings for teachers of all years of experiences (e.g., working with the local Arc or similar center on songwriting projects with participants who are DP/PwD).

The importance of relationship, inclusivity, reciprocity, openness, personalizing, and trusting (e.g., Krammer, 2013) point toward a the need for a relational ontology for music teachers, which involves being *present,* coming to know learners through meeting (i.e., being-with/*Mitsein*) so as to allow them to manifest as concretely as possible within one's consciousness. A recognition of such a relational ontology might allow an anti-ableist pedagogue to practice relational presence with DP/PwD and all learners/people. Participants in this study often wanted someone to be there *with* them, working *with* them, learning *with* them, and making music *with* them. Erica in her desires to sing with someone, was calling for this kind of relational presence. Duke's desire to jam and be with friends highlights the importance of such presence in his life. Birdie relishing of chances to be present with others in and through music, particularly in settings and music that allow her to be cognitively present, communicates her desire to be in relationship. Daren's wish for music teachers to be experimental and take things on a "case-by-case" basis suggests his desire for someone to be with him when and as he need them. Sienna's "potluck of life" and dedication to social justice and universal design speak of her desire for people to be present with her, to join her band. Ice Queen knows that presence means not being inside yourself and she looks for ways to be present and to practice presence. Finally, Culann wants to be able to manifest as he is and have the opportunity to have others present with him as he explores and muses about life. Based on the insights derived from this study, I suggest that a dedication to relational presence may be simple in form, difficult in practice, and profound in its anti-ableist ends.

While participants in this study call for presence and dedication to fostering relational presence in music learning and music making contexts, and while relational presence may have anti-ableist potential, it is important to note that a teacher might not, or perhaps should not, always remain present in this way. While presence is important, music teachers will have to step outside of being present in order to contemplate learners' current progress, needs, and desires as well as to consider next steps for guiding learners toward stated and/or emergent goals. This is the responsibility a hospitable music teacher possesses, as noted by Wiggins (2012) and, indeed, the relational presence I have outlined above shares much with Wiggins' hospitality-informed community approach.

Be it hospitality or Buberian inclusion, the teacher will need to vacillate between meeting/being relationally (e.g., *I-Thou*) present and being <u>not (or less) present and</u> analytical at times (e.g., *I-it*). Buber (1958) explained that though "All real life is meeting" (p. 11) in an *I-Thou* sense, "every *Thou* in our world must become an *It*. It does not matter how exclusively present the *Thou* was in the direct relation. As soon as the relation has been worked out or has been permeated with a means, the *Thou* becomes an object among objects—perhaps the chief—but still one of them" (pp. 16-17). While Buber suggests that rocking back and forth between *I-It* and *I-Thou* is a human's ontological plight, he also shares that this is part what it may mean to be an inclusive and present educator (e.g., Buber, 1968). Inclusion of the Buberian kind begins with genuine meetings through dialogue (i.e., mutual interactions rooted in *I-Thou* being) with one another and with content (Buber, 1968; Shady & Larson, 2010). These *meetings* may allow students to manifest within the teacher's lifeworld and vice-versa (Figure 17). With an *I-Thou* relationship established, a teacher would then be able to step back in order *contemplate* the individual needs and desires of the learners (Figure 18). Then, before returning to meetings, a teacher could plan in ways that embrace Buber's (1965) *inclusion* by calling up both manifestations of students in their consciousness and the insights derived from contemplations (Figure 19).

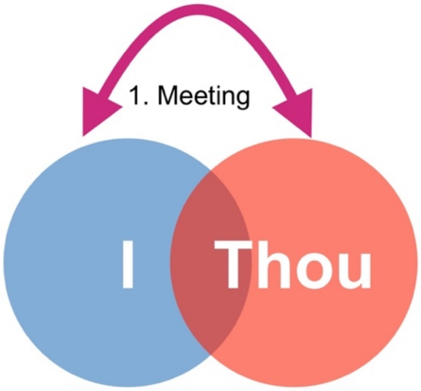

Figure 17. Emergence of relational presence in meetings

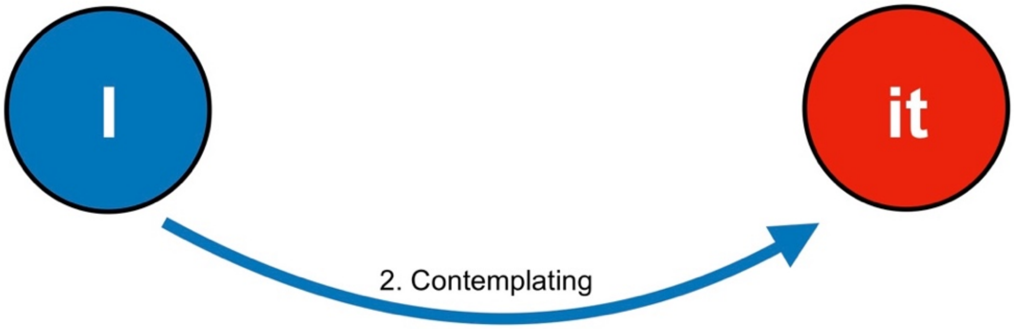

Figure 18. Contemplating in relational presence

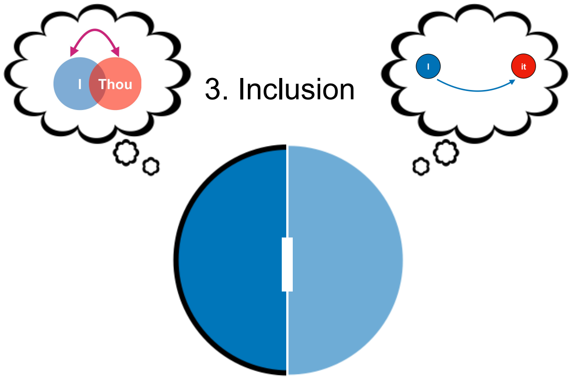

Figure 19. Inclusion in Relational Presence

The process described above is inherently recursive, as shown in Figure 20. A teacher/practitioner (*I* here) and learners who are DP/PwD (*Thou/it)* first meet to come to know and be-with one another. Relational presence emerges to the extent that each “other” manifests as fully as possible and in a complex manner in the lifeworlds of one another during these meetings. Then, the teacher and learner separate into an *I-It* relationship in which the teacher, with the learner manifested in their lifeworld (i.e., the thought bubble in the figure), analyses the growth, needs, and desires (e.g., contemplation). A Buberian notion of inclusion emerges as the teacher considers the learner. This consideration may include drawing on additional resources such as IEP information, working with other educators and specialists, and even drawing on diagnostic information. These additional resources would be placed in dialogue with the learner manifestation in order to make pedagogical decisions, yet the decisions would be provisional until the next meeting so that learner continues to have agency. An in-between *I-Thou* and *I-It* being, which I argue is the state Buber (1965) implicated with his notion of “inclusion,” allows the teacher to develop pedagogical and curricular plans through a dialogue with the information gained through contemplation and presences of the learners included in the teacher’s consciousness, before entering again into an *I*-Thou meeting. This cycle repeats endlessly.

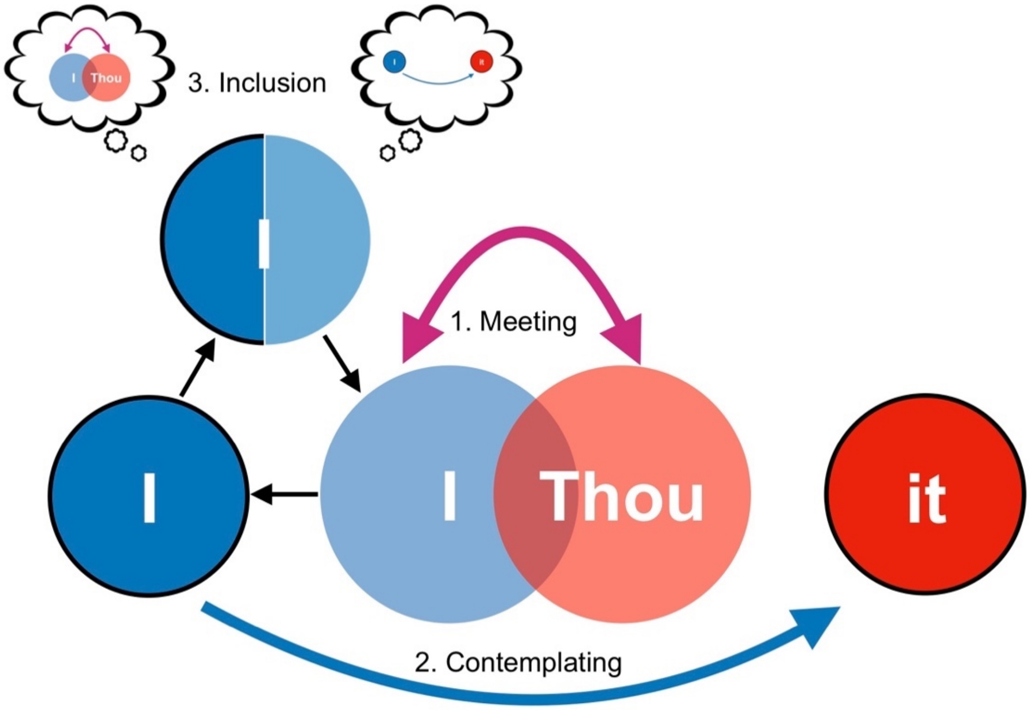

Figure 20. Recursive process of relational presence

**Suggestions for practice.** To provide some starting points for fostering relational presence and enacting anti-ableist pedagogy, I offer suggestions for inservice music teachers below by revisiting Kramer's (2013) six characteristics from above (relationship, inclusivity, reciprocity, openness, personalizing, and trusting) as an organizational framework and by add "representation" as a quality that emerged in the data. In addition, I offer general comments for music teacher educators seeking to enact anti-ableist pedagogy in music teacher education programs.

*Building Relationship.* Fortunately, music educators often have extended experiences with learners over the course of multiple years. Engaging with learners for five to six years in elementary general music, for example, provides music educators with repeated chances to foster meaningful relationships with learners. Because of these opportunities for repeated meetings, it is important that music educators in any setting to come to know all learners as these learners wish to be known early on, lest the educators sustain ableist assumptions and/or perpetuate problematic labels, terminologies, and practices. Music educators might begin courses or semesters with chances for learners to identify themselves as they see necessary (i.e., name, pronouns, other labels, and personal needs), being careful to not create instances of forced disclosure, and even use identification as a prompt for a creative music activity in which leaners explore multiple ways to express their identities and expose their current musical interests, competencies and skills. Additionally, music educators can help foster ongoing anti-ableist relationships in classrooms by helping all learners become conscious of barriers that might diminish access and feelings of belonging for DP/PwD learners. This may also involve helping all learn how to make and sustain meaningful relationships with people who appear different from themselves by developing communication and relational abilities.

*Inclusivity/Concrete Representation.* Fostering “inclusivity” in music classroom may very well involve using inclusive technologies (e.g., differentiated instruction, normalization, assistive technology, and universal design). It may involve consulting a learner’s IEP or 504 documentation, as well as being an active member of planning teams (Hammel & Hourigan, 2017). Yet, as the findings of this study suggest, inclusive technologies and documentation are a very partial picture of who DP/PwD are. Music educators can be inclusive by learning who learners are through play-based and inquiry-based experiences, interview-like discussions, and creative and performance projects in which learners can express who they are and provide concrete representations of their being, needs, desires, and lived experiences. For example, learners might take part in “musical me” activities similar to “musical circles” project described by Barrett, McCoy, & Veblen (1997), in which they express who they are, their likes, their skills, and their needs via musical representations and choices. Along creative and performance-based routes, music educators might engage learners in creating their own music and/or their own adaptations to established repertoire, providing space for them to discuss how their creations represent them as musicians, learners, and humans. In addition to these suggestions, music educators should make music *with* learners, coming to know them in the music. These engagements and interactions might allow all involved to better know each other, thereby affording opportunities for "imagining what another is thinking, feeling, and experiencing" (Kramer, 2013, p. 80).

*Encouraging Reciprocity.* Music educators might foster reciprocity through the use of democratic processes (e.g., Allsup, 2003; Väkevä & Westerlund, 2007) such as shared governance and providing space for negotiation and debate in which educators do not hold fast to the role of sole authority (e.g., Dei, 1996). Yet, caution is warranted, for democratic process might do little but reinscribe ableist norms, as Gould (2007, 2008) warns in relation to issues of gender and difference. In the best instances, reciprocity may involve sharing of power (e.g., Shor, 1996) and may also involve shifting the attention of the majority toward learning and valuing the voices of minorities, such as DP/PwD, so that all might find ways to "meaningfully [engage] the Other and [themselves] on her terms" (Gould, 2008, p. 41). I suggest that to foster anti-ableist reciprocity through democratic practices, a music educator can find ways to work in which majority does not rule, but, rather, the entire group works together to accommodate the needs of all present and all who want to be present in a given class. To be with learners in this way, music educator will need to develop the ability to radically listen to DP/PwD and foster dialogue in the classroom, taking cues from Galloway, Nudd, and Sandahl's (2007) ethic of accommodation, described earlier, in which all in a classroom are active in "negotiating complex sets of needs . . . needs [that often] 'compete' with one another" (p. 229). Music educators might help learners come to understand that "listening . . . means being taken into consideration, being attended to" (p. 229) and not just using one's aural faculties. To foster reciprocity, music educators must develop skills in facilitating genuine dialogue that involves listening of the kind noted above, dialogue that is not always orderly and not always cheery, but often chaotic and prickly. Facilitating such dialogue may help reciprocity grow in an anti-ablest trajectory.

*Creating/Sustaining Openness.* Creating open spaces where music educators can embrace an “ethic of accommodation” (e.g., Galloway, Nudd, & Sandahl, 2007) may be difficult in some music teaching settings. Expectations of school communities for specific kinds of ensembles performances at specific levels, institutional and community histories and traditions governing “how we have always done things,” expectations of students enrolling music courses, instructional methods or pedagogical philosophies, and teachers’ perspectives on what is possible shape the reality of what *is* in music classrooms. Some music educators may find it difficult to consider or enact radical changes to class structure and content given conflicting visions and expectations.  For example, fostering openness toward anti-ableist ends may necessitate adding unexpected instruments and timbres alongside different musics in a wind ensemble, facilitating different vowel sounds and postures in a concert choir, embracing alternative tunings and techniques in a guitar course, and providing multiple ways for learners in a general music class to engage with content and express their learnings beyond compulsory singing/dancing/playing.

Any changes in class structures could be provisional and contingency based on the learners present and/or who wants to be present and their needs and ways of being. An attitude of openness calls for music educators to be able to grapple with ambiguity and consider creative approaches to the complexities of learners and contexts (e.g., Abramo & Reynolds, 2015), and to negotiate potentially conflicting visions of inclusion and musical “excellence” or even what music education is. In addition, openness requires that music educators not only create spaces for all, but also discover which learners are not present and what they want and need related to music education. This may require music educators to investigate desires of school and community people related to music offerings, to engage in dialogue with learners not present, and to create new courses that meet unmet desires.

*Personalizing.* Music educators can help to personalize teaching through drawing on inclusive technologies and documentation, and collaborating with other service personnel.

Universal Design (e.g., Darrow, 2010; 2016; McCord, 2013; McCord, Gruben, & Rathgeber, 2014) may provide a framework to proactively provide options for personalization. Yet proactively-developed options for personalization may negate or subjugate the autonomy of learners who are DP/PwD to personalize on their own or self-differentiate their experiences. Participants in this study were rather clear in their desires to have some control over their accommodations and to have chances to self-differentiate. Music educators might build opportunities for all learners to self-differentiate into projects and experiences, and for learners to share and try out each other's means of differentiation.

Prioritizing personalization may encourage all learners to be active problem-solvers and to feel a sense of control in how they engage with content and express their understandings. Personalization can involve using music that is meaningful to learners who are DP/PwD, giving autonomy to learners in how they annotate music and/or use differents types of visual representation of sound—or not, encouraging learners to explore with different ways to play instruments, giving space and time for learners to develop multi-modal ways of demonstrating what they hear in music and the meanings of music for them,, and using different grips and/or developing adaptive stands for instruments, and more. Beyond these examples, music educators might embrace the old disability rights slogan of "Nothing about us without us" by consistently asking and/or working with DP/PwD to understand their ideas for personalizing music learning and music making experiences.

*Trusting Learners.* Part of embracing "Nothing about us without us" in a music education contexts involves music teachers fostering trust by being trusting. Many learners who are DP/PwD know well their identities, their needs, and their desires and wish for teachers to listen to and trust them when they express these things. When learners who are DP/PwD voice their preference for identity first language or when they express a need for sheet music with color-coded note names or extended time for specific assignments, music educators might respond in ways that communication trust in the learner. When requests for such adaptations are met with comments such as, “well that’s just a crutch,” ableist assumptions abound and trust in the agency of the learner vanishes. When learners when request “crutches,” music educators could trust the learner, honor the request, and then help leaners make use of these “crutches” as well as possible and transition out of using them if they no longer need them. At the same time, music educators may do well to avoid requiring that specific learners use specific adaptations, such as assuming that all blind learners/learners with visual impairments use Braille notation or learners with one hand use specifically adapted instruments or stands to play a trumpet. Rather, music educators can be trusting of learners as they adopt or decline specific resources.

While I remain firm in advocacy for trust in a learner’s request for adaptations, I do *not* suggest that music educators never challenge learners who are DP/PwD. Rather, I suggestthat music educators acknowledge that learners may be more willing to explore challenges within trusting, personalized, open, reciprocal, inclusive, and relational music learning contexts. Within these contexts, music educators might also offer new supports or encourage, without coersion, learners to try adaptations they may have initially declined.

Before moving on, it is important to note that not all leaners who are DP/PwD will communicate their identities, needs, and desires in ways legible to music educators. Some may communicate these through behaviors (e.g., DeVito, 2006), some will communicate through images, some will communicate through music making—as Erica did—or through other means. Being an anti-ableist pedagogue will required that music educators become multi-lingual or multi-modal-lingual in order to best serve and work with DP/PwD. This can be accomplished primarily through person-to-person experiences with learners with different diagnosis, needs, and desires. While such experiences will not help teachers develop “x supports” for “learner with x diagnosis”— remember, as Sienna shared, “If you know one person with autism, you know one person with autism.”

*Disability Representation*. Although not specifically based on a theme in the data, the need for additional disability representation in music classrooms indeed fits within an anti-ableist approach. In order to work against ableist assumptions and narratives of disability, music educators will need to be conscious of the way disability is represented and not in the classroom. First, music educators can consider the ways that disability and DP/PwD can be represented negatively, reinforcing ableist narrative, by asking questions such as the following. Are the presence of DP/PwD in classrooms and ensembles represented in ways akin to "inspiration porn" through publicity materials featuring headlines such as "despite handicap, student succeeds in music"? Are leaners who are DP/PwD considered and spoken of in negative ways and/or positioned as potential foils to "excellence" and either relegated to auxiliary roles or removed when on tour or at ensemble festivals? Are nondisabled peers always positioned to as helpers or mentors of DP/PwD, rather than peers, co-learners, and collaborators? Does ensemble repertoire or class listening examples include ablest terminology or depictions? An anti-ableist pedagogue would work against these negative representations by creating empowering but non-exploitative ways of celebrating inclusion and the success of DP/PWD. They would work to ensure an equitable and meaningful "place in the band" or personally meaningful role in the music making for all DP/PwD. Such music educators would situate DP/PwD's as leaders/helpers for their peers while also dispelling ablest language and actions demonstrated by all within a specific music learning setting. Additionally, anti-ablest pedagogue would

Negative representations, however, is not the only kind of representational problems that an anti-ableist pedagogue would need challenges; absences of representation often speaks louder and has more lasting impact than one can imagine. Music educators might ask themselves the following types of questions. Do ensemble repertoires or listening examples include music by creators who identify as DP/PwD—not just composers who may have or have had disabilities and now could be diagnosed because this would be labeling and assuming, but creators who identify as part of this community? Do musicians depicted in pictures, posters, videos, and other media include DP/PwD? Are musics, musician, or topics addressed in the disability community or disability culture included or discussed in classrooms? Are issues of disability and ableism addressed alongside racism, classism, sexism, and other types of oppression when interrogating music?[192] Are DP/PwD missing in classes? An anti-ableist pedagogy would work to ensure that the absence of representation does not speak volumes by suggesting that DP/PwD are not welcome and by robbing nondisabled persons chances to engage with difference.

*Suggestions for Music Teacher Education.* Music teacher educators can make use of and adapt many of the suggestions above in order to be anti-ableist and model anti-ableist pedagogy for preservice and returning music educators. In addition to these suggestion, I offer four practices geared toward helping enact anti-ableist pedagogy in music teacher education programs: (a) addressing disability from multiple perspectives in coursework, (b) developing creative adaptability, (c) making face-to-face experience with DP/PwD a central aspect of curricula, and (d) recruiting and advocating for the admission of DP/PwD into music teacher education programs. Below I discussed each practice in more depth, providing concrete examples adapted from findings in this study and form the literature reviewed..

The first practice, drawn from anti-racist literature (e.g., Dei, 1996; Obeyesekere, 2017), involves music teacher educators creating space in class and in coursework to engage in discourse around ability/disability as an individual and social construct and identity. Such a space might allow all to consider individual perspectives and experiences, physical barriers to access and inclusion, and the social confluence of “place, time, activity, and encounter” (Lubet, 2011, p. 21) related to disability. Adding disability alongside other constructs and identities connected to systemic oppression (e.g., race, gender, sexuality, and class) may allow preservice and returning music educators to reconceptualize disability as an issue of diversity and social justice (e.g., Lalvani and Broderick, 2013). To begin to address disability, a music teacher educator might start by ensuring that discussions of diversity, social justice, identity, and inclusion include disability as a component; the presences of disability alongside more perhaps more recognized topics such as race and gender may help preservice and returning music educators to conceptualize disability as

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[192] Are these issues addressed at all and/or are musics interrogated as part of music learning?

part of a constellation of identities, constructs, and/or systems of oppression. Second, music teacher educators might create coursework and in class experiences through which learners become conscious of disability as fluid. This may include doing "privilege walks" in which learners identify how they navigate the physical environment and how others with different means of movement and perceptions might confront barriers through the same travels. In addition, music teacher educators might include "disability barriers" commentaries into observation forms and reflections, calling learners' attentions toward physical, personal, social, and confluential barrier that may impede access and participation. Much like Sienna's experiences of drastic change in social experience based on their use or absence of their cane, preservice and returning music educators might come to see the flux of disability around them in and outside of music learning and making spaces.

Another practice that music teacher educators might use to facilitate anti-ableism in their work involves encouraging all learners and colleagues to develop their creative adaptability: to foster their creative thinking and being in relation to adapting to the specificities changing context. In many ways, this is akin to Abramo and Reynolds' (2015) notion of "pedagogical creativity," yet focuses more on how preservice and returning music educators can act creatively related to adapting on a complex set of needs. Specifically, I encourage music teacher educators to develop spaces for learners to develop self-differentiations to class approaches and practice, share their differentiations with others, and collaborate with others to differentiate instruments, notations, arrangements, methods/approaches. Alongside these challenges/chances, music teacher educators can offer prepared differentiation that leaners may choose from in their assignments. For example, learners might engage in a reading assignment in which they are provided written text, audio recording, and video-based versions of the selected reading to choose from while also being prompted to answer specific guiding questions in different ways, such as: in a way that evokes their current emotional state, in a way that that uses only non-verbal communication, or in a way that highlights a personal "talent" or something of which they are personally proud. Another example might include asking learners who are beginning to play secondary instrument to develop adaptations that allows them to use other instrumental skills or knowledges to play the new instrument (e.g., how can you adapt the saxophone so you can play it like a trumpet. Yet another example could include engaging students in skills and knowledge "winding" (Hammel, Hickox, & Hourigan. 2016) activities by taking goals, standards, and specific skills and considering the sequential ways of increasing or decreasing challenges based on the needs of a specific learners. Also, music teacher educators can draw on case studies and vignettes depicting DP/PwD as the basis for curricular planning experiences with preservice and returning music educators, specifically challenging these learners to adapted existing lesson plans (e.g., those taken from pre-packaged curricula and other curricular resources often geared to a "general" audience) to the needs and interests of the learners depicted in the case studies and vignettes. I encourage all preservice music educators to take part in self-differentiation in class presentations alongside learners, as well. Through modeling and prioritizing choice, proactive accommodation, and self-differentiation, preservice music educators can foster an ethic of adaptation that permeates teacher preparation programs and, eventually, becomes more and more common in music making and music learning settings outside of the academy.

My third suggestion for music teacher educators is perhaps the most important one based on this study: provide preservice and returning music educators with multiple and on-going experiences to interact directly with DP/PwD in, through, and around music. All the participants in this study shared wishes for people to get to know them and to be with them in their music experiences. The studies from Hourigan (2007, 2009), Laes and Westerlund (2018), and VanWeelden and Whipple (2005), among others, implicate the importance of meaningful face-to-face musical experiences for preservice educators with DP/PwD as an integral part of music teacher education programs. If music educators are to be able to adapt and "take it case by case," as Daren suggested, then, I argue, that they must have experiences with disability differences to the extent that difference becomes so common that any shock factor which may pull a teachers away from being present, relationally and physically, with DP/PwD fades. This can be accomplished by welcoming local musicians and teachers who are DP/PwD to class as presenters, having practicum experiences for preservice and returning music teachers in either DP/PwD-only or integrated music learning and music making settings, and working on projects in which music teachers consult with or work with DP/PwD related to a mutually beneficial goal. Such experiences, however, need to be on-going and multiple, so they are not seen as exotic, and framed very carefully so that they are note seen as “service” projects that position preservice and returning music educators in an elevated role over DP/PwD. As such, preservice and returning music educators will need to have discussions about disability prior to and throughout these face-to-face experiences in order to interrogate their assumptions and biases that color their thoughts, communications, and other actions relative to DP/PwD. It may be beneficial, to these ends, for music teacher educators to develop connections with colleagues in disability studies as well as local disability rights advocates who are DP/PwD to join classes to discuss issues such as language, identity, barriers, and positionality related to disability.

Finally, I encourage music teacher educators to recruit and advocate for the admission of DP/PwD into music teacher education programs. Music teacher educators might recruit DP/PwD in public high schools, in private service centers, in disability-specific schools and program, and in community programs. DP/PwD may experience challenges through audition structures which may be wrought with ableism (e.g., sight-reading requirements which may be inaccessible to persons with visual impairments or who are blind, assumptions of correct posture and visual styles which may rule out persons with physical differences, or verbal interviews which may be inaccessible for those that may communicate in different ways) and in admission processes which may not take into account a learner’s potential as a music teacher. Yet, music teacher educators can encourage more equitable and adaptable audition practices through practices such as those suggested by McCord (2017) and may find ways to advocate for specific DP/PwD during admission decisions by personally consulting private instructors, directors, admission counselors, and others involved in the process. Bringing more DP/PwD into music teacher education programs will not only diversify the populations of schools of music on paper, it will provide chances for all to live an “ethic of accommodation”  (e.g., Galloway, Nudd, & Sandahl, 2007) and foster inclusive ways of being.

I also encourage music teacher educators to find ways to support leaners who are DP/PwD already present in music teacher education programs. Anecdotally, I have engaged with many preservice music teacher educators with invisible disabilities (e.g., major depression, generalize anxiety disorder, and dyslexia) who struggle in their studies and do not know what resources they might find nor which professors will be adaptable to them. Music teacher educators can support these learners by building partnerships with service providers in tutoring, learning strategies instruction, disability services, and counseling in order to share resources with learners. They can also be relationally present with such learners and help them navigate a system that may not have been built with them in mind. In general, the presence and success of DP/PwD in music teacher education programs may provide models of inclusion in schools of music and help to increase the representation of DP/PwD as music educators in music learning and music teaching settings. Such actions may have strong anti-ableist impacts on music education, broadly.

### On Research and Writing

Who am I? I have been grappling with this question more and more as words flow in trickles and spurts into my journals and onto my screen. Throughout the process of this study, I have found myself feeling different senses of who *I* am emerge through my engagement with participants, literature, and myself. Who *I* am matters, because it “informs the research project. [My] subjectivities and [body] influence what [I] see, what [I] view as important to share, and how others will receive [my] words” (Hess, 2018a, p. 6). While it might be easy to address my positionality by rattling off my identities (e.g., white, cisgender male, married, heterosexual, middle class, bipolar person from a rural, majority white community in the Midwest working as a professor at a public university in Appalachia) and by writing the disclosure section required in contemporary research, I do not know whether that tells you much more about the *I* who is writing this document other than some overly general notions and partial badges of who this *I* might be. Rather, I wonder if it might be better to attend to my subjectivity in relation to the *I* that emerges out of the different relations between myself (*I*) and others (*you*/*it*).

As I have met with participants, further explored the relational ontology of Martin Buber (1957, 1958, 1965) and the empathetic phenomenological work of Stein (1989), and written this document, I have developed some plausible insights about research and writing. In the section that follows, I extrapolate on a Buberian-informed conception of research and writing. I also draw on the multi-faceted *me* activated in Chapter Five in which I identified three *I*'s in the conversational analysis: Jesse the participant-researcher, jesse the scholar, and JESSE the facilitator. These three *I*'s flow out of three relational positions.

**The "I-Thou" I** . First, "Jesse the participant" is the *I* that emerges through my interactions with participants and with literature whereby I engage fully with others in ways that respect their being—not just *their* being but their connection to the undifferentiatable state that *is* being. This *I* emerges as and through being-with (i.e., *Mitsein*) others and the world. Buber (1958) would characterize this *I* as that of an *I-Thou* relationship. Situated as this *I*, I am not "experiencing" the other as much as I am being *with* them, present *with* them in their concrete realness. The *Thou* rises up to meet my *I* from this meeting springs into being. This *I* finds me transformed through meeting: I feel unity and accomplish a kind of knowing that I cannot categorize or express while still within the meeting, but which is nonetheless powerful.

The *I-Thou* Jesse was the one who became present with participants, the researching doctoral candidate who became a human in the presence of others. I found myself called into a *I-Thou* relationship at moments in which my detached researcher persona did not cut it for participants. When I first met Erica, I had questions; I had things I wanted to know; I had ideas about how I would go about asking them, given my problematic assumptions about what she could and could not do and communicate. Yet, in Erica's presence, she called me to just be with her, to follow her, to draw with her as she grabbed a set of markers sitting on a table, to sing with her. In another call to be fully present and mutual, I distinctly remember Duke disarming me as he hugged me when we met, as he requested that our second meeting be a jam session, as he insisted that we write songs during our last meeting through freestyle singing. In yet other examples of the call to be *with*, Birdie and Culann turned our meetings into co-interviews and collaborative musical explorations; they had little need for either a "researcher" or a "biographer," although they knew that being a "research" was my role and the purpose for our meetings. They required presence and interaction, they also may have required time to explore in greater depth, time that I had not planned for in this study. Culann, Birdie, Duke, and Erica called to me to *be with* them, to not withdraw into myself and stand apart from them, but to "enter into respectful and direct relationships" with them (Kramer, 2013, p. 13). How do music education researchers reconcile the demands of teaching, publication expectations, and tenure requirements with the desires of participants who might prefer longer more ethnographic forms of inquiry who insist on the *I* of *I-Thou* relationship? These tensions may require researchers to negotiate with administration, explore grant funding, and/or engage co-researchers, including participants, to engage in relationally-based research projects.

**The "I-It" I.** The second *I* in Chapter Five was the *I* of "Jesse the scholar," who emerged through experiencing participants, through detached attending to discernable qualities of a thing caught in my intentionality. This *I* emerges as and through observation, categorization, analysis, and objectification of others and the world. Buber (1958) would characteristize this *I* as that of an *I-It* relationship. Situated as this *I*, I am may be physically present with an other, but I am distinct from them as they are distinct from me. The *It* remains the object of my consciousness, and I am able only to ascertain that which I can perceive or ideate *about* them. This *I* finds me as becoming knowledgeable about the other; I feel separation and accomplish a kind of knowing that is categorizable and expressible, yet partial.[193]

The *I-It* jesse existed at times marked by separation and distance. This should not be seen as a negative way of being, just one that is different from the *I* of-*I-Thou* relationships and that makes sense in different ways. I set out as a researcher as this *I-It* jesse, even while rooting my conception of research in mutual respect and intersubjectivity. My conceptions of what it meant to be a researcher were contingent upon an *I-It* way of being: separate, analytical, distant, and objective. Some participants preferred this type of relationship during our meetings as a starting point. Sienna was clear to differentiate their experience and their being from mine, and often reinforced these separations through our meetings. Sienna demonstrated little desire for mutuality in our interviews but wanted to have their story told and then expressed clearly in order to represent the types of oppressions, assumptions, realities, and empowerment that DP/PwD like them experienced. In our relationship, Sienna was the narrator and they requested me to be the biographer. Similarly, Ice Queen preferred a more distant and detached relationship. In many ways, she treated me as a teacher, perhaps because I was a faculty member at the university she attended and our interviews occurred in my office located in a building on the campus that she frequented. Ice Queen positioned me in the role of director-like authority. She answered questions and sought for me to prompt her with more and more questions. Daren positioned me in a similar way, perhaps even more so, as he referred to me as “Professor” un-ironically and sought for precision of expression in his story. Daren, Ice Queen, and Sienna positioned themselves to be *It*s to my *I.* Although I strove toward an *I-Thou* kind of relationship with them, it was not reciprocated during the study and our relationship lacked *I-Thou* mutuality. *I* remained bounded by my relationship to *It*.

Through the analysis processes in this study, the *I-It* jesse emerged again. While reviewing, highlighting, copying and pasting, and mind-mapping data gleaned from videos,

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[193] The I-Thou I is also partial, but in a different way from the partiality of the I-it I.

artifacts, and transcripts, I felt myself objectifying the participants. I felt distance. I grappled with the tension between engaging in research and genuinely being interested in each person. This feeling was uncomfortable,[194] but I know it was important to have such a perspective in order to be able to make sense of our meetings and to be inclusive in a Buberian sense: to let their beings manifest, to make themselves home, in my lifeworld. Yet, after numerous opportunities to have *I-Thou* experiences with the participants, I found myself more comfortable and found that I reveled in that *I-Thou* space for as long as I could. But I could not remain in the *I-Thou* of relationship forever, especially while writing. I initially I wrote much of Chapter Five and Chapter Six with a highly *I-It* perspective and voice, only to toss that writing aside in favor of approaching writing and inhabiting, in general, a different perspective, described next.

**The In-Between I.** This different position was a third *I*, the *I* of "JESSE the facilitator" who emerges through constant vacillation between *I-Thou* and *I-It*. This *in-between I* emerges out of the synthesis of meeting others and retreating to "make sense" of meetings. Buber (1958) notes that living is comprised of *both I-Thou* and *I-It* relationships, though suggests that *I-Thou* and the meetings this kind of relationality encourages allows one to touch "real life" (p. 11). As a teacher and as a research writer, I am engaging in a kind of work that cannot be *I-Thou* all the time and which cannot be—because of institutionally-situated power structures, the personal preferences of participants, or for other reasons—the kind of mutuality that Buber categorizes as *I-Thou* and in which I have grown to revel. I am compelled to be an *I* in an *I-It* relationship at times. In fact, spending some time as an *I-It* when accompanied with plenty of time as *I-Thou* facilitates inclusion as a researcher and as a teacher. In other words, the narrow path of between *I-Thou* and *I-It* allows for Buberian inclusion—an inclusion in which one may embrace others, be

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[194] Music educators and researchers might do better to become comfortable with the discomfort that arises when they come into contact with any unknown person in an inclusive way. Perhaps one might run to established approaches for "mainstreaming" too soon if one cannot be comfortable with this discomfort, foreclosing one's chance to be inclusive.

transformed in their presence, still find one's individuality, and still be able to make sense out of an act in between embrace and individuality—to be in the narrow pathway of facilitating dialogue.

Although much of my interactions and work in crafting this document eventually grew from this "third" position, three examples stand apart as being particularly evocative of living in the narrow path of facilitating dialogue. The first example is of writing Daren's bboying and dream-centric lifeworld narrative. I felt a great deal of confusion and anxiety as I attempted to write from his perspective. I noted in my journal:

> It is interesting, with Daren's description, I feel like I'm almost putting him and his experiences on like ill-fitting clothing. In some ways, it is invigorating to lose myself as I write through the life, the feelings, the thoughts of someone else. It is really confusing though, I've had daydreams as Daren, but I've known that I wasn't Daren, I was Jesse in some creepy Daren suit. In one daydream, I'm going through my day and I run into Daren; we talk in a friendly way as if everything is all good. We share notes on the day, and he coaches me to be him. In a twist on this daydream, we run into each other and he is repulsed at this fake identity thief, and he chastises me in a very un-Daren-like way, on my ethics, saying, "How dare you speak for me. I'll speak for myself, thank you very much." I couldn't get to sleep last night because I worried that I was doing something wrong and that I would somehow offend Daren when I shared what I had written. Am I a thief? Why is this experience so different from writing the other descriptions?

I struggled here because I felt that although I was not trying to *be* him, I was taking advantage of his generosity in meeting with me so I could be a researcher and use his story. I felt conflict between *I-It* and *I-Thou*, felt the ambiguity at play. Detachment and distance provided analytical structure for Daren's story, and yet I met Daren in different ways through writing as him. He, more specifically the Daren as revealed through our in-person meetings and through meeting him in writing, manifested in my lifeworld and I felt myself being able to see somewhat through his eyes, to feel somewhat through his skin. This, I suspect, is what Stein (1989) describes as an example of being given the experiences of others to the extent that the lifeworld transforms to allow a space for the "foreign" manifestation. I found Daren and myself in-between he and I, in-between meeting and analyzing, through almost allowing his experiences to move to me, not by waiting for mutual meeting.

Another example of "JESSE the facilitator" and his narrow path arose through my journaling about writing the lifeworld narratives while I came to grips with my position as a writer who could facilitate a meeting between the participants and you, the reader. I noted in my research journal:

> I feel more of an onus to try to let the participants speak and *be* through the text in ways that are true to them. I felt like I needed to write them so they exist and live through letters, words, and punctuation. I wrote these little snapshots, almost like Dungeon and Dragons character sheets, of who they were through what they shared. Now, I feel like my job is to provoke the characters on the page to act in the ways the participants, themselves, would act. Is this research? I don't know, but it is meaningful and seems to resonate with this inner call that I feel radiating from all around. I feel like I just need to get these little stories out there.

Remaining in only *I-Thou* relationships with the participants or even with the data we generated together would give me power as the writer, but it would not allow me to make sense of the meaning and power of our conversations interviews. I had to be distant in order to think about how participants might live as rendered in this document, and *I-It* only sometimes felt *too* distant to be authentic.

A final example of my in-betweenness as "JESSE the facilitator" is presented in Chapter Five, in which I "exist" in three ways in the text. Yet, even the use of this writing device perhaps means that I only existed as the facilitator. In structuring of me in Chapter Five as an *I* in-dialogue, as an *I* in-analysis, and as the *I* who structured the text, I opened dialogue between myself(s), the participants, the literature, and with readers. My reliance upon ambiguity as I let themes contort and distort from participant to participant demonstrates my dedication to opening up meeting and *I-Thou* relationships, and yet the doing of this kind of writing required both my *I-Thou* and *I-It* relationships, presence, and doing. In the middle of these relationships, the in-between *I* and his identity is consistently altered in ways not wholly knowable. As the different Jesse *I*'s and the participants dialogue rushes up to meet you, the reader, in this document, what happens? Do you wish to analyze us? Do you wish to meet us? What will you do and how will you be here in this dialogue?

**Beyond the I: Embracing a Thou.** My discussion above has focused on me, on the "I" as interviewer, person, author, teacher, and research writer. Yet, this "I" is a large limitation and liability in this study. The voices of participants were filtered through my consciousness, albeit through intimate interviews with and editorial control from some participants. This is, in some ways, a problem of research frameworks, such as phenomenology, that rely upon assumptions that participants, specifically participants from marginalized and/or identity groups in which a researcher may not be a member, are unable to speak for themselves or that, if they can, their ways of speaking may not be legible to those in a privileged reader position (e.g., Spivak,1988). And while studies that rely on researchers' voices, such as this one, have merit, I suggest that more attention to and more power for telling their own stories and making sense out of those stories should be placed into the hands of those who are researched.

Research and work with participants in this study informs the following suggestions for a research practice that embraces the "*Thou*" and yields and/or shares narrative and analytical power to/with participants such as those who are DP/PwD. First, researchers do well to address their own privilege and positionality within oppressive systems as well as the identities which inform their privilege and positions prior to and throughout any study (Alcoff, 1991; Fontana & Frey, 2008; Hess, 2018). Examining their own privilege and position may help researchers trouble their impulses, desires, and/or needs to speak *for* participants. Especially for researchers who either do not personally identify or who may not be identified by members as belonging to a group that they will be researching, such a troubling of privilege and position may assist researchers with bridling their preunderstandings and identifying their biases in order to better let participants speak their truths for themselves and allow new meanings to manifest (Dahlberg, Drew, & Nyström, 2001; Dahlberg, 2006; Vagle, Hughes, & Durbin, 2009). Reflectivity of this sort may come about in the form of a journal in which one might track their positionality and pre-understandings, much like Vagle's (2014) use of pre-reflexion statements and bridling writing throughout research.[195]

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[195] I share aspects of my pre-reflexion statement in Chapter One in the section "My Experiences of Disability" and have woven elements of my bridling journal throughout the last three chapters of this document. Given the inclusion of these aspects of my "researcher's journal," it is useful to note how journals inform not only one's writing but can become aspects of one's written projects and need not just live on only

While I speak here specifically about nondisabled researchers researching DP/PwD, I suggest that troubling one's positionality and one's impulses, desires, and needs to speak for others is just as important, for example, when working as a cisgender heterosexual researcher with LGTBQIA+ participants as it is when an adult researcher working with youth. While, positionality is important, I do not wish to suggest that only "insiders" can or should research participants and contexts in which they are members, as emic and etic perspectives are important when trying to understand a phenomenon. Rather, I affirm that one's identity and cultural membership matter and shape how one engages in research. Without attending to positionality, privilege, and even motivation, ethical issues of misrepresentation and use/abuse of power may be far more inevitable and research without such reflectivity may be more damaging to the "researched" than it is empowering. Reflexivity may help researchers avoid research acts that are akin to microaggression and/or inspiration porn that, as participants noted, can than appear to be "helpful" at first blush but are or can be harmful and even damaging. This is not to say, however, that researchers must be compelled to disclose their identities to readers or participants, though this might be helpful in some settings; harm or damage can be done when disclosing some aspects of one's positionality due to biases in different settings. Yet, dealing with research positionality and bridling based on assumptions related to positionality is an integral aspect of researcher reflexivity; researchers must at the very least be self-aware and questioning.

In addition to being aware and constantly reflecting on one's positionality, researchers ought to consider how their methods and tools can reify oppression and/or block DP/PwD and other kinds of participants from sharing and controlling their meanings/understandings regarding a phenomenon. In the proposal for this dissertation, I identified a rather rigidly defined method for the study, a method I hoped would help me get straight to understanding participants' experiences as quickly and as ethically as possible. I had forgotten, or had not yet learned, the

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in a pile of notebooks. Bickmore's (2017) dissertation and articles by Hess (2018) and Nichols (2015), among others, include personal reflective data as key aspects of the finished written work.

important notion that one does not simply begin to understand participants' experiences with disability in, through, and around music without first meeting the participants themselves. Taking up bricolage as researcher (e.g., Kincheloe & Berry, 2004) was the first step that allowed me to break free from methodological *rigor mortis*,[196] and re-reading and reflecting on Buber's (1958; 1965) relational ontology was the second through one-hundredth step that opened me up to letting participants manifest in interesting and unpredictable ways in my work and lifeworld. I needed convincing in order-to become more flexible as a researcher, but doing so allowed me to feel comfortable with sharing power with participants and allowing their beings and their experiences of disability, whether in, through, around or beyond music, to shape and reshape the tools, questions, and ways of writing in this document (Laes, 2017; Fals-Borda, 1995). Rather than relying on specific methods and tools of data generation to govern research, it may be wise for researchers working with DP/PwD to allow the participants, their understandings, and the evolving relationship between participants and researchers to take on the quality of an unfolding process. Such a process requires researchers to develop new ways of (co)generating data and to find ways to work with participants so that they can share their stories and meanings in formats and through words that represent them more than they represent the researcher.

Another way to empower participants who are DP/PwD is to share their truths through community-based participatory research (CBPR) frameworks. Leavy (2017) suggested that CBPR research involves

> collaborative partnerships between researchers and nonacademic stakeholders (e.g., community members). Researchers may partner with established community-based organizations (CBOs); however, this is not always the case. CBPR is an attempt by researchers to actively involve the communities they aim to serve in every aspect of the research process, from the identification of a problem to the distribution of research findings. This is a highly collaborative and problem-centered approach to research that requires the sharing of power. CBPR is generally appropriate when your purpose is to promote community change or action. (p. 10)

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[196] A *rigor modum* (rigid method) or, perhaps better, *mortis modum* (dead method).

CBRP may provide researchers ways to yield power to participants, as both parties become consultants in writing, analysis, publication, and other issues that may otherwise act as barriers to full participation. Hess (2018) suggests that frames such as participatory research may help researchers working with DP/PwD to avoid speaking *for* by working "alongside community in ways that allow participants to frame the research problems and to co-write research findings in collaboration" (p. 14) *with* the researcher. A similar participant collaborative ethic is consistent with narrative inquiry (e.g., Connelly & Clandinin, 2006; Stauffer, 2014), action research (Carr & Kemmis, 2003; Lewis, 1946), participatory action research (e.g., Kemmis & McTaggart, 2005; Kemis, McTaggart, & Nixon, 2013), collaborative research (Bishop, 1995; Cummings & Kiesler, 2005; Lieberman, 1986), and co-operative research (Heron, 1996; Jeron & Reason, 2006). Using collaborative frames positions participants as co-researchers and collaborators who work alongside academic researchers to better understand a phenomenon collectively, to share co-generated data, and to offer suggestions for the future.

Taking one step beyond this sharing of power, researchers might engage with participants who are DP/PwD and relinquish power to speak for participants by acting as consultants and/or editors. This kind of radical research relationship would be one similar to the best kind of relationships between research students and advisors or handbook editors and authors. This kind of relationship would require scholars to open up research for persons who have been researched *about* and spoken *of* through opaque academic journal vocabulary. Regardless of the participatory frame, though, it is useful to realize that not all participants who are DP/PwD may want to engage in these ways. Some may be perfectly fine with sharing their stories but allowing the researcher power in shaping the report, as Rie did with Jeananne Nichols (2015) and as many of the participants did with me in this study. I share these ideas to suggest that imposing any strict "method" upon participants may be oppressive, participatory or not.

I have shared these suggestions for embracing the "Thou" of research and ethically centering participants in research, and summarize them here: First and foremost, researchers ought to be constantly aware of their positionality and privilege in relation to DP/PwD and all research participants. Second, researchers should allow participants and the phenomena under investigation to shape the questions, means of data generation, and approach to representation of co-generated data. Third, and in a more radical step, researchers might also either share power with participants through participatory collaboration or yield power to participants in order to be active in challenging ableist systems in which DP/PwD are situated. These suggestions may assist researchers in avoiding colonialist research that reifies difference and oppressive structures (e.g., Hess, 2018) and moves toward inquiry that treats research as "non-essentializing encounters" with others (e.g., Hess, 2013, p. 86) in projects that draw on polyphony and forward new counternarratives (e.g. Allsup, 2014; Hess, 2018; Vagle, 2014).

It seems fitting given the suggestions above and the overall "embraceful" ethic of offering counternarratives to leave you—and this document—with a poem written by Petra Kuppers. In "Crip Music" (2008), Kuppers discuses different ways one might consider the "Crip:" a lagging behind and mournful character; an exuberant and giggling dancer, and a member of a minority group marching, rolling, ventilator pumping in time. In this way, she troubles the meanings of exclusion and inclusion while she opens up and questions what it may mean to be DP/PwD. Counternarratives such as this, and hopefully those elsewhere in this document, can allow all to trouble disability and trouble inclusion from the perspectives of our individual and shared lifeworlds.

**Crip Music**

A beat behind, sycophant, you
Sisyphus, roll and run
again and again
Sybil whistle tune, mournfully
whistle in the dark
the shoe steps the rhythm
behind, behind, behind you
with the crutch cane stick beat
the cripple who ripples across
the street with the wheel on the rack
rackle and giggle the cripple
till the music stops

we step out
and then, and then, it builds
the sound, and the beat
and the melody of the cane
and the melody of the crutch
and the melody of the wheel
and the tap of the stick
and the tick of ventilators
dilate, pulse
push breath through the street
roll forward and on
the beat in a circle
we move, we move
the line held firm
the song lifting

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# APPENDIX A

# DIAGNOSIS-SPECIFIC LITERATURE RELATED TO MUSIC: AN OVERVIEW

## Cognitive Disabilities

Adkins, B. A., Summerville, J., Knox, M., Brown, A., & Dillon, S. (2012). Digital technologies and musical participation for people with intellectual disabilities. *New Media and Society, 15*(4), 501-518.

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## Speech and Language Impairment

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Flowers, P. J., & Wang, C. H. (2002). Matching verbal description to music excerpt: The use of language by blind and sighted children. *Journal of Research in Music Education, 50*(3), 202-214.

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Moss, F. W., Jr. (2009). *Quality of experience in mainstreaming and full inclusion of blind and visually impaired high school instrumental music students. Unpublished doctoral* *dissertations*, University of Michigan, Ann Arbor, MI. Retrieved from http://login.ezproxy1.lib.asu.edu/login?url=http://search.proquest.com/docview/304928945?accountid=4485

Siligo, W. R. (2005). Enriching the ensemble experience for students with visual impairments. *Music Educators Journal, 91*(5), 31-36.

Smaligo, M. A. (1998). Resources for helping blind music students. *Music Educators Journal, 85*(2), 23-45.

### Emotional and Behavior Disturbances

Darrow, A. A., & Adamek, M. (2016). Behavioral issues in the music classroom: Promoting the successful engagement of all students. In D. V. Blair & K. A. McCord (Eds.), *Exceptional music pedagogies for children with exceptionalities: International perspectives* (pp. 154-175). New York: Oxford University Press.

de l'Etoile, S. K. (2005). Teaching music to special learners: Children with disruptive behavior disorders. *Music Educators Journal, 91*(5), 37-43.

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de l'Etoile, S. K. (2008). The effect of rhythmic auditory stimulation on the gait parameters of patients with incomplete spinal cord injury: An exploratory study. I*nternational Journal of Rehabilitation Research, 31*(2), 155-157.

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Darrow, A. A., & Armstrong, T. (1999). Research on music and autism implications for music educators. *Update: Applications of Research in Music Education, 18*(1), 15-20.

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Hammel, A. M., & Hourigan, R. M. (2013). *Teaching music to students with autism.* New York: Oxford University Press.

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Heaton, P., Allen, R., Williams, K., Cummins, O., & Happe, F. (2008). Do social and cognitive deficits curtail musical understanding? Evidence from autism and Down syndrome. *British Journal of Developmental Psychology, 26*(2), 171-182.

Heaton, P., Hermelin, B., & Pring, L. (1999). Can children with autistic spectrum disorders perceive affect in music? An experimental investigation. *Psychological Medicine, 29*(06), 1405-1410.

Kim, J., Wigram, T., & Gold, C. (2009). Emotional, motivational and interpersonal responsiveness of children with autism in improvisational music therapy. *Autism, 13*(4), 389-409.

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McCord, K., & Fitzgerald, M. (2006). Children with disabilities playing musical instruments. *Music Educators Journal*, *92*(4), 46-52.

Thaut, M. H. (1988). Measuring musical responsiveness in autistic children: a comparative analysis of improvised musical tone sequences of autistic, normal, and mentally retarded individuals. *Journal of Autism and Developmental Disorders, 18*(4), 561-571.

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Hammel, A. M. (2016). Twice exceptional. In D. V. Blair & K. A. McCord (Eds.), *Exceptional music pedagogies for children with exceptionalities: International perspectives* (pp. 16-38). New York: Oxford University Press.

# APPENDIX B

# PERCEPTIONS OF AND ATTITUDES TOWARD DP/PWD IN MUSIC BY NONDISABLED PERSONS: AN OVERVIEW

## Nondisabled Peers

Cassidy, J. W. (1991). Effects of special education labels on peers' and adults' evaluations of a handicapped youth choir. *Journal of Research in Music Education, 39*(1), 23-34.

Colwell, C. M., Thompson, L. K., & Berke, M. K. (2001). Disability simulations and information: Techniques for modifying the attitudes of elementary school music students. *Journal of Music Therapy, 38*(4), 321-341.

Darrow, A. A., & Johnson, C. M. (1994). Junior and senior high school music students' attitudes toward individuals with a disability. *Journal of Music Therapy, 31*(4), 266-279.

Elefant, C. (2010a). Musical inclusion, intergroup relations, and community development. In B. Stige, G. Ansdell, C. Elefant, & M. Pavlicevic (Eds.), *Where music helps: Community music therapy in action and reflection* (pp. 75-90). London: Ashgate Publishing Limited.

Elefant, C. (2010b). Must we really end? Community integration of children in Raanana, Israel. In B. Stige, G. Ansdell, C. Elefant, & M. Pavlicevic (Eds.), *Where music helps: Community music therapy in action and reflection* (pp. 67-74). London: Ashgate Publishing Limited.

Jellison, J. A. (2002). On-task participation of typical students near and far from classmates with disabilities in an elementary music classroom. *Journal of Research in Music Education, 50*(4), 343-355.

Johnson, C. M., & Darrow, A. A. (1997). The effect of positive models of inclusion on band students' attitudinal statements regarding the integration of students with disabilities. *Journal of Research in Music Education, 45*(2), 173-184.

Johnson, C. M. & Darrow, A. A. (2003). Attitudes of junior high school music students from Italy and the USA toward individuals with a disability. *Bulletin of the Council for Research in Music Education,* (155), 33-43.

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Colwell, C. M., & Thompson, L. K. (2000). “Inclusion” of information on mainstreaming in undergraduate music education curricula. *Journal of Music Therapy, 37*(3), 205-221.

Hammel, A. M. (1999). *A study of teacher competencies necessary when including special learners in elementary music classrooms: The development of a unit of study for use with undergraduate music education students.* Unpublished doctoral dissertation, Shenandoah University, Winchester, VA.

Heller, L. (1994). *Undergraduate music teacher preparation for mainstreaming: A survey of music education teacher training institutions in the Great Lakes region of the United States.* Unpublished doctoral dissertation, Michigan State University, East Lansing, MI.

Hourigan, R. M. (2007). *Teaching music to students with special needs: A phenomenological examination of participants in a fieldwork experience.* Unpublished doctoral dissertation, the University of Michigan, Ann Arbor, MI.

Hourigan, R. M. (2009). Preservice music teachers' perceptions of fieldwork experiences in a special needs classroom. *Journal of Research in Music Education, 57*(2), 152-168.

Kaiser, K. A., & Johnson, K. E. (2000). The effect of an interactive experience on music majors' perceptions of music for deaf students. *Journal of Music Therapy, 37*(3). 222-234.

Laes, T., & Westerlund, H. (2018). Performing disability in music teacher education: Moving beyond inclusion through expanded professionalism. *International Journal of Music Education*, *36*(1), 34-46.

VanWeelden, K., & Whipple, J. (2005). The effects of field experience on music education majors' perceptions of music instruction for secondary students with special needs. *Journal of Music Teacher Education, 14*(2), 62-71.

### Inservice Music Educators

Cassidy, J. W. (1991). Effects of special education labels on peers' and adults' evaluations of a handicapped youth choir. *Journal of Research in Music Education, 39*(1), 23-34.

Darrow, A. A. (1999). Music educators' perceptions regarding the inclusion of students with severe disabilities in music classrooms. *Journal of Music Therapy, 36*(4), 254-273.

Frisque, J., Niebur, L., & Humphreys, J. (1991). Music mainstreaming practices in Arizona. *Journal of Research in Music Education*, *42*(2), 94-104.

Gfeller, K., Darrow, A. A., & Hedden, S. (1990). Perceived effectiveness of mainstreaming in Iowa and Kansas schools. *Journal of Research in Music Education, 38*(2), 90-101.

Gilbert, J. P., & Asmus, E. P. (1981). Mainstreaming: Music educators' participation and professional needs. *Journal of Research in Music Education*, *29*(1), 31-37.

Scott, L. P., Jellison, J. A., Chappell, E. W., & Standridge, A. A. (2007). Talking with music teachers about inclusion: Perceptions, opinions and experiences. *Journal of Music Therapy*, *44*(1), 38-56.

Wilson, B., & McCrary, J. (1996). The effect of instruction on music educators' attitudes toward students with disabilities. *Journal of Research in Music Education, 44*(1), 26-33.

# APPENDIX C

# MAINSTREAMING-BASED INCLUSION LITERATURE: AN OVERVIEW

## Research Studies

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Atterbury, B. W. (1987). The perplexing issue of mainstreaming. *Bulletin of the Council for Research in Music Education,* (94), 17-27.

Darrow, A. A. (1990). Research on mainstreaming in music education. *Update: Application of research in music education, 9*, 35-37.

Darrow, A. A. (2003). Dealing with diversity: The inclusion of students with disabilities in music. *Research Studies in Music Education, 21*(1), 45-57.

Dunbar, L. L. (2016). Mainstreaming in American Music Education Journals (1960-1989): An analysis. *Journal of Historical Research in Music Education*, *37*(2), 150-161.

Hammel, A. M. (2001). Special learners in elementary music classrooms: A study of essential teacher competencies. *Update: Applications of Research in Music Education, 20*(1), 9-13.

Laes, T., & Westerlund, H. (2018). Performing disability in music teacher education: Moving beyond inclusion through expanded professionalism. International Journal of Music Education, 36(1), 34-46.

Lapka, C. M. (2005). *A case study of the integration of students with disabilities in a secondary music ensemble.* Unpublished doctoral dissertation, University of Illinois, Urbana, IL.

## Practitioner Resources and Handbook Chapters

### General Mainstreaming Supportive Practices and Competencies

Abramo, J. (2012). Disability in the classroom current trends and impacts on music education. *Music Educators Journal, 99*(1), 39-45.

Adamek, M., & Darrow, A. A. (2010). *Music in special education*. Silver Spring, MD: The American Music Therapy Association, Inc.

Atterbury, B. W. (1986b). Success in the mainstream of general music. *Music Educators Journal*, *72*(7), 34-36.

Atterbury, B. W. (1990). *Mainstreaming exceptional learners in music*. Englewood Cliffs, NJ: Prentice Hall.

Darrow, A. A. (2014b). Promoting social and emotional growth of students with disabilities. *General Music Today, 28*(1), 29-32.

Graham, R. M. (1988). Barrier-free music education: Methods to make mainstreaming work. *Music Educators Journal, 74*(5), 29-33.

Hammel, A. M. (2004). Inclusion strategies that work. *Music Educators Journal, 90*(5), 33-38.

Hammel, A. M. (2008). The big four: Music reading and students with special needs. [Blog post]. Retrieved from http://www.people.vcu.edu/~bhammel/special/resources/articles/big_four.htm

Hammel, A. M., & Hourigan, R. M. (2017). *Teaching music to students with special needs: A label-free approach* (2nd ed.). New York: Oxford University Press.

**Assistive/Adaptive Technology:** Assistive technology (AT), also referred to as "adaptive technology" in some literature, are: "any item, piece of equipment, or product system, whether acquired commercially off the shelf, modified, or customized, that is used to increase, maintain, or improve functional capabilities of a child with a disability . . . [excluding] a medical device that is surgically implanted, or the replacement of such devices" (IDEIA, 2004, § 602). Watts, McCord, & Blair (2016) noted that AT "can range from simple items to sophisticated, multicomponent product systems" (p. 88). AT provides persons with support for: (a) communicating through speech, such as text-to-speech devices and speech synthesizers; (b) communicating through writing, such as pencil holders, speech-to-text or dictation applications, and Braille text editors; (c) accessing and using computers, such as adapted computer controllers that use eye gaze or voice recognition; (d) seeing and reading, such as screen readers, Braille, magnification, audiobooks, and differentiated reading levels; (e) hearing and listening, such as hearing aids and captioning services; (f) remembering and organizing tasks, such as daily planners and note keeping applications; (g) promoting creative expression, such as music instrument grips, adapted music controllers, and computer-based music applications; (h) completing daily living activities, such as zippers and button aides, ergonomic utensils, and safety alert devices; (g) negotiating environmental barriers, such as ramps, sensory-sensitive rooms, and remote control devices; (h) negotiating equipment barriers, such as adjustable workstations, adapted furniture and, body supports; (i) moving around in space and transportation, such as wheelchairs, canes, adaptive instrument mounts and prosthetic devices; (j) and accessing recreational experience such as adapted toys, instrument adaptations, and adapted sports equipment (Watts, 2016; Thompson, Watts, Wokcik, & McCord, 2003). These categories are overlapping in that one device might serve multiple functions.

Adkins, B. A., Summerville, J., Knox, M., Brown, A., & Dillon, S. (2012). Digital technologies and musical participation for people with intellectual disabilities. *New Media and Society, 15*(4), 501-518.

Bugaj, K. (2016). Good news in inclusive string music education: Adaptive strategies for the classroom. *General Music Today, 29*(3), 30-32.

McCord, K. A. (1999). *Music composition using music technology by elementary children with learning disabilities: An exploratory case study.* Unpublished doctoral dissertation, University of Northern Colorado, Greely, CO. Retrieved from http://login.ezproxy1.lib.asu.edu/login?url=http://search.proquest.com/docview/304514228?accountid=4485

McCord, K. (2002). Children with special needs composing using music technology. *Journal of Technology in Music Learning, 1*(2), 3-14.

McCord, K. A., & Watts, E. H. (2010). Music educators' involvement in the individual education program process and their knowledge of assistive technology. *Update: Applications of Research in Music Education*, *28*(2), 79-85.

McCord, K., & Fitzgerald, M. (2006). Children with disabilities playing musical instruments. *Music Educators Journal*, *92*(4), 46-52.

McHale, G. (2016). SoundOUT: Examining the role of accessible interactive music technologies within inclusive music ensembles. In D. V. Blair & K. A. McCord (Eds.), *Exceptional music* *pedagogies for children with exceptionalities: International perspectives* (pp. 105-130). New York: Oxford University Press.

Nelson, D. (2013). Reaching all students via technology. *Music Educators Journal, 100*(1), 26-29.

Randles, C. (2015). Opening doors: iPad musical creativity and the student with special needs. In S. O'Neill (Ed.), *Music and media infused lives: Music education in a digital age* (pp. 73-88), Montreal, QC: CMEA.

Watts, E. H., McCord, K., & Blair, D. V. (2016). Assistive technology to support students in accessing the music curriculum. In D. V. Blair & K. A. McCord (Eds.), *Exceptional music pedagogies for children with exceptionalities: International perspectives* (pp. 85-104). New York: Oxford University Press.

**Collaborating with support staff**

Bernstorf, E. D. (2001). Paraprofessionals in music settings. *Music Educators Journal, 87*(4), 36-36.

Cane, S. (2009). Collaboration with music: A noteworthy endeavor*. Music Educators Journal, 96*(1), 33-39.

McCord, K., & Watts, E. H. (2006). Collaboration and access for our children: Music educators and special educators together. *Music Educators Journal*, *92*(4), 26-33.

**Differentiated Instruction:** Tomlinson (1999) defines differentiated instruction as a pedagogical approach in which

> teachers begin where students are, not the front of a curriculum guide. They accept and build upon the premise that learners differ in important ways. Thus, they also accept and act on the premise that teachers must be ready to engage students in instruction through different learning modalities, by appealing to different interests, and by using varied rates of instruction along with varied degrees of complexity. (p. 2)

Differentiated instruments amounts to differentiation in content, process, and product, all of which are varied in complexity based on the unique needs of specific students (Darrow, 2014a; Tomlinson 1999). Differentiated instruction often comes in the form of multi-tiered instruction such as "Response to Intervention" programs (Reynold & Fletcher-Janzen, 2009). RtI is Based on a three-tier instructional system and regular assessments: all students receive general instruction (tier-one), some students who need clarification receive additional assistance (tier-two), and a few students who need more intensive support have specifically developed instruction and support systems developed for them (Fuchs & Fuchs, 2006). See Bernstorf (2016) for additional discussion of RtI in music education. See Bernstorf (2016) for additional discussion of RtI in music education.

Bernstorf, E. (2016). Reading acquisition frameworks for music and language: Layering elements of literacy for students with exceptionalities. In D. V. Blair & K. A. McCord (Eds.), *Exceptional music pedagogies for children with exceptionalities: International perspectives* (pp. 251-277). New York: Oxford University Press.

Darrow, A. A. (2014a). Differentiated instruction for students with disabilities: Using DI in the music classroom. *General Music Today*, *28*(2), 29-32.

Hammel, A., M., Hickox, R. Y., & Hourigan, R. M. (Eds.) (2016). *Winding it back: Teaching to individual differences in music classroom and ensemble settings*. New York Oxford University Press.

**Ensemble-specific Accommodations**

Lapka, C. M. (2006). Students with disabilities in a high school band: “We can do it!”. *Music Educators Journal, 92*(4), 54-59.

Lapka, C. M. (2016). Including students with disabilities in instrumental ensembles. In D. V. Blair & K. A. McCord (Eds.), *Exceptional music pedagogies for children with exceptionalities: International perspectives* (pp. 197-218). New York: Oxford University Press.

VanWeelden, K. (2001). Choral mainstreaming: Tips for success. *Music Educators Journal, 88*(3), 55-60.

Zdzinski, S. F. (2001). Instrumental music for special learners. *Music Educators Journal, 87*(4), 27-63.

**Normalization:** Bengt Nirje (in Jellison, 2015a) defined normalization as “the normalization of life’s conditions and not the normalization of a person” (p. 53). According to Nirje (1969), normalization is rooted in DP/PwD’ right and ability to have: (a) a normal rhythm of the day, (b) a normal routine of life, such as attending school, (c) a normal rhythm of the year, (d) normal life phases; express one’s desires, (e) experiences of being respected by others, (f) economic equity, and (g) a normal physical setting in which to live. Wolfensberger et al. (1972) created a broader conceptualized normalization, discussing it as a positive ideology included toward considering quality of life rather than focused upon positivism-informed treatment models of disability. From this position, there are two types of normalization: client normalization, which relates to therapeutic intervention to improve the individual functioning and foster independence of the disabled person; and environmental normalization, which requires modification to existing structures and emphasizes the need for accommodation of social spaces to the specific needs of disabled persons (Kumar, 2013; Wolfensberger et al., 1972). The project of normalization is inclined toward reframing disability from social deviancy to general human difference. Wolfensberger et al. state:

> Since deviancy is, by definition in the eyes of the beholder, it is only realistic to attend not only to the limitations in a person’s repertoire of potential behaviors, but to attend as much or even more to those characteristics and behaviors which make a person as deviant in the sight of others . . . It is for this reason that the [normalization] implies . . . that in as many aspects of a person’s functioning as possible, the human manager will aspire to elicit and maintain behaviors and appearances that come as close to being normative as circumstances and the person’s behavioral potential permits. (p. 28)

Jellison, J. A. (2012). Inclusive music classrooms and programmes. In G. McPherson & G. Welch (Eds.), *The Oxford handbook of music education* (Vol 2, pp. 65-80). New York: Oxford University Press.

Jellison, J. A. (2015a). *Including everyone: Creating music classrooms where all children learn.* New York: Oxford.

Jellison, J. A. (2015b). Inclusive music classrooms: A universal approach. In G E. McPherson (Ed.), *The child as musician: A handbook of musical development* (2nd ed.), (pp 361-372). New York: Oxford University Press.

**Universal Design:** Universal Design, a proactive design approach that first appeared in the field of architecture, has impacted curricular thinking related to inclusive curricular and learning space design. Universal Design was first conceived by disabled architect Ron Mace during his tenure at North Carolina State University (Mace, 1998; Story, Mueller, & Mace, 1998) Mace hoped to address new building code standards for public buildings that required increased accessibility for to individuals with disabilities in an artful manner. Mace and other architects were interested in reconsidering what bodies and minds were constructed and allowed through their architectural designs. They also were concerned with the aesthetic qualities of their designs as adaptations to existing buildings were often ugly, less than useful, and not in keeping with the aesthetics of the original design (Mace, 1998). Mace (1997) developed seven principles that encouraged architects and product designers to consider access, flexibility, use, and equity in design so that their creations would be open for use of those diagnosed with impairments and those otherwise considered “normal” by building code standards. These principles include: (a) Equitable use: designs are useable for people with many different abilities; (b) Flexibility in use: designs can be used in various ways; (c) Simple and intuited use: designs can be used easily without much need for prior experience; (d) Perceptible information: necessary information about the design can be accessed through multiple sensory systems; (e) Tolerance for errors: a design is hard to misuse or misuse will not result in unintended actions; (f) Low physical effort: use of design will not cause unneeded fatigue; (g) Size and space for approach and use: designs take into account issues of size and space needed to approach and make use of an object regardless of a user’s unique abilities and needs. After PL 94-142, Mace’s work in Universal Design, scholars began to play with his ideas as applied to schools, resulting in approaches such as: Universal Design for Education (Bowe, 2000) Human-Centered Design (Cooley, 2000; Greenhouse, E. S. (2010), as well as two of the more popular approaches of Universal Design for Instruction (UDI) (Burgstahler, 2007; 2008) and Universal Design for Learning (UDL) (Rose & Meyer, 2000, 2002; & Hitchcock, 2006; Meyer & Rose, 2000).

Darrow, A. A. (2010). Music education for all: Employing the principles of Universal Design to educational practice. *General Music Today, 24*(1), 43-45.

Darrow, A. A. (2016). Applying the principles of universal design for learning in general music. In. B. M. Gault & C. R. Abril (Eds.), *Teaching general music: Approaches, issues, and viewpoints* (pp. 308-326). New York: Oxford University Press.

McCord, K., Gruben, A., Rathgeber, J. (2014). *Accessing music: Enhancing student learning in the general music classroom using UDL***.** Van Nuys, CA: Alfred Music.

McCord, K. (2013). Universal design for learning: Special educators integrating the Orff approach into their teaching. *Approaches: Music Therapy & Special Music Education*, *5*(2), 188-193.

# APPENDIX D

# RECRUITMENT CONTACT SCRIPT

Hello, my name is Jesse Rathgeber and I am Assistant Professor of Music at James Madison University. I am conducting a research study, under the guidance of Dr. Sandra Stauffer at Arizona State University, examining the music experiences of persons diagnosed with disabilities/impairments.

Participation in the study will involve three, one-hour conversational interviews that may involve discussions, music making, drawing, and writing, based on your interest. Additionally, I hope to observe participants in the study during musical experiences for the purpose of further discussion. These interviews and/or observations will be audio-visually recorded for the purpose of transcription.

I am seeking participants and/or recommendations of potentially interested participants. Participation in this study is voluntary. Please call me at (630) 267-3536 or email me rathgejc@jmu.edu if you have any questions concerning the research study, would like to participate, or would like to recommend a potentially interested participant. Thank you for your time and consideration.

# APPENDIX E

# PARTICIPANT ASSENT FORM (FOR PARTICIPANTSCONSIDERD TO BE OF A VULNERABLE POPULATION)

My name is Jesse Rathgeber and I work at James Madison University. I am asking you to take part in a research study because I am trying to learn more about the music experiences of people diagnosed with disabilities/impairments. I want to know about your music experiences and how you feel about them.

If you agree to participate, I will ask you some questions about your music experiences and we can have a discussion during three, one-hour meetings. In our discussions, we might talk, make music, draw, or even write. You will not have to answer any questions of do anything that makes you uncomfortable. With your permission, I will also observe you in a music experience that maters to you so that we can talk about it later. If you do not want to be observed, you can tell me to stop, and I will stop.

You do not have to be in this study. No one will be mad at you if you decide not to do this study. If you say yes now, you can change your mind and say no later and that will be okay. You may ask questions about the study at any time. If you decide to be in the study, your responses will be confidential. I will not tell anyone else how you respond or act as part of the study. Even if your parents or teachers ask, I will not tell them about what you say or do in the study.

I have already asked your parents/guardian for their permission for you to participate in this study. Please talk to them and ask me any questions (rathgejc@jmu.edu) if you wish before you decide whether or not to participate

Signing here means that you have read this form or you have had it read to you and that you are willing to be in this study.

______ Yes, I would like to participate in the study.

Participants' printed name ___________________________________________

Signature of participant ______________________________ Date __________

Signature of investigator______________________________ Date __________

# APPENDIX F

# PARENT/GUARDIAN CONSENT FORM (FOR PARTICIPANTS CONSIDERED TO BE OF A VULNERABLE POPULATION)

My name is Jesse Rathgeber and I am Assistant Professor of Music at James Madison University. I am conducting a research study, under the guidance of Dr. Sandra Stauffer at Arizona State University, examining the music experiences of persons with disabilities/impairments.

I am inviting the participation of your child or dependent in a research study that seeks to examine the music experiences of persons diagnosed with a disability/impairment. Participation includes up to three interviews (involving discussion, drawing, and writing) on one hour each as well as potential observations of your musical experiences for the purpose of generating follow up questions. Your child or dependent has the right not to answer any question, and to stop participation at any time. I am interested in your child's or dependent's perspective as a person with a diagnosed disabilities or impairment and as a person who has music experiences.

If you choose for your child or dependent not to participate or to withdraw from the study at any time, there will be no penalty. Although there may be no direct benefit to your child or dependent, the possible benefit of their participation is having their voice heard.

There are no foreseeable risks or discomforts to your child's/dependent's participation other than those related to remembering and reliving and uncomfortable experience that they may bring up in interviews. All your responses will be confidential. The results of this study may be used in reports, presentations, or publications but your child's/dependent's name will never be used.

I would like to audio and video record interviews and any possible observations. Recordings are for research purposes so I may transcribe what occurs in rehearsals. I will not use your child's or dependent's voice or image in any publications or presentations without your consent. Please let me know if you do not want the interview or observation to be recorded; you also can change your mind after the interview starts.

If you have any questions concerning the research study or your child's or dependent's participation in this study, please call me or Dr. Sandra Stauffer at (480) 965-4374. If you have any questions about you or your child/participant's rights as a subject/participant in this research, or if you feel you have been placed at risk, you can contact the Chair of the Human Subjects Institutional Review Board, through the ASU Office of Research Integrity and Assurance, at (480) 965-6788. Please let me know if you wish to be part of the study.

Sincerely,

Jesse C. Rathgeber

You may choose to sign or not sign any or all of these statements:

By signing below, you are consenting to participate in interviews and observations.

| | | |
|---|---|---|
| Signature | Printed Name | Date |

By signing below, you are consenting for your interviews and observation to be audio recorded.

| | | |
|---|---|---|
| Signature | Printed Name | Date |

By signing below, you are consenting for your interviews and observation to be video recorded.

| | | |
|---|---|---|
| Signature | Printed Name | Date |

By signing below, you are giving consent for the researcher to use an audio clip that may include you in a presentation of this research.

| | | |
|---|---|---|
| Signature | Printed Name | Date |

By signing below, you are giving consent for the researcher to use a video clip that may include you in a presentation of this research.

| | | |
|---|---|---|
| Signature | Printed Name | Date |

# APPENDIX G

# PARTICIPANT CONSENT FORM (FOR PARTICIPANTS NOT CONSIDERED TO BE OF A VULNERABLE POPULATION)

My name is Jesse Rathgeber and I am Assistant Professor of Music at James Madison University. I am conducting a research study on the music experiences of persons with disabilities/impairments.

I am inviting your participation in a research study that seeks to examine the music experiences of persons diagnosed with a disability/impairment. Participation includes up to three interviews (involving discussion, drawing, and writing) on one hour each as well as potential observations of your musical experiences for the purpose of generating follow up questions. You have the right not to answer any question, and to stop participation at any time. I am interested in your perspective as a person with a diagnosed or self-identified disability or impairment who is or has music experiences.

If you choose not to participate or to withdraw from the study at any time, there will be no penalty, and you will continue to participate in the rock band as you have been. Although there may be no direct benefit to you, the possible benefit of your participation is having your voice heard.

There are no foreseeable risks or discomforts to your participation other than those related to remembering and reliving and uncomfortable experience which you may discuss in interviews. All your responses will be confidential. The results of this study may be used in reports, presentations, or publications but your name will never be used.

I would like to audio and video record interviews and any possible observations. Recordings are for research purposes so I may transcribe what occurs in rehearsals. I will not use your voice or image in any publications or presentations without your consent. Please let me know if you do not want the interview or observation to be recorded; you also can change your mind after the interview starts.

If you have any questions concerning the research study or your participation in this study, please call me or Dr. Sandra Stauffer at (480) 965-4374. If you have any questions about your rights as a subject/participant in this research, or if you feel you have been placed at risk, you can contact the Chair of the Human Subjects Institutional Review Board, through the ASU Office of Research Integrity and Assurance, at (480) 965-6788. Please let me know if you wish to be part of the study.

Sincerely,

Jesse C. Rathgeber

You may choose to sign or not sign any or all of these statements:
By signing below, you are consenting to participate in interviews and observations.

| | | |
|---|---|---|
| Signature | Printed Name | Date |

By signing below, you are consenting for your interviews and observation to be audio recorded.

| | | |
|---|---|---|
| Signature | Printed Name | Date |

By signing below, you are consenting for your interviews and observation to be video recorded.

| | | |
|---|---|---|
| Signature | Printed Name | Date |

By signing below, you are giving consent for the researcher to use an audio clip that may include you in a presentation of this research.

| | | |
|---|---|---|
| Signature | Printed Name | Date |

By signing below, you are giving consent for the researcher to use a video clip that may include you in a presentation of this research.

| | | |
|---|---|---|
| Signature | Printed Name | Date |

# APPENDIX H

## INTERVIEW PROTOCOL / QUESTIONS

There questions provided loose guidance throughout interviews.

**General Questions:**

- What would you want someone to know about you when they first meet you?
- What do you do on an average day? Can you lead me through a regular day?
- What are your favorite things to do?
- What do you like to do in your free time?

**General Disability Questions:**

- What disability have you been diagnosed with?
- When were you diagnosed with this disability?
- In what ways does this disability impact your everyday life?
- Do you think other people notice the ways disability impacts your life? How so?
- What do you which other people knew about your disability?

**Music Making Questions:**

- If a stranger on a plane asked you, “Do you like music?” what would you say?
- What roles does music play in your life?
- What types of musical things do you do?
- What specific types of music experiences mean a lot to you? Why so?
- Do you make music? How? When? Why?
- What kinds of music experiences are you passionate about? Why?
- How long have you been involved in these types of music experiences?
- How often do you engage in this music experience?
- What do you enjoy about this making experience?
- What do you dislike about music experiences?
- What do you think about when you are engaged in this music experience?
- How would other participants in this music experience describe you? Describe your music?
- How would you describe other participants in this music experience? Their music?

- What keeps you experiencing music in this way?
- What might make you stop experiencing music in this way?

**Music and Feeling**

- Describe a specifically meaningful musical experience.
    - How did your body feel?
    - How did you feel internally/mentally?
        - How did you feel about yourself?
    - How did you feel socially?
        - Did you feel connected to others?
        - Did you ever feel disconnected?
    - When you were experiencing music in this way, did you find yourself getting lost or feeling in flow? How so?
    - What things might interrupt this?
    - What do you enjoy about this type of music experience?
    - What do you dislike about this type of music experience?
- Describe your best music experience. What made it that way?
- What are some of your more powerful and positive memories connected to music and music-making? Please describe one example event.
    - What did you do? How did you feel?
- Describe your worst experience with music? What made it that way?
- What are some of your most negative memories connected to music and music-making? Please describe one example event.
    - What did you do? How did you feel?
- Do you feel you are successful in your music experiences? How so?
- What makes you feel successful?
- How do you know when you are successful?
    - How does it feel?
- Do you ever feel challenged in your music experiences? How so?
    - What specifically is challenging?
    - How do you know when you are challenged?
        - How does it feel?
- What do your family and/or friends think your music experiences?

- What would they say if they were describing it to you?
- What do you think they say you get out of it?
- What do you think they would say is challenging about it?

**Disability and Music Experiences**

- Do you think your disability impacts your music experiences in any way? How so?
    - (Alternately): How does having [disability label] impact your music experiences?
- How does having [disability label] impact you during your music experiences?
- How does having [disability label] impact others during your music experiences?
- In what ways do you think others' perception of your disability impacts your music experiences?

**Inclusion and Music Experiences**

- When you are engaged in your music experiences with others, how do you feel?
- Do you feel like you belong? Do you feel connected to other members?
    - Why/Why not? How so?
- Do you ever feel excluded, rejected, or as if there are barriers to your participation?
    - Why/Why not? How so?
- What types of things make or would make you feel like you belong during a music experience?
- What types of things make or would make you feel like you are included during a music experience?
- What types of things make or would make you feel like you are accepted by others during a music experience?
- What types of things make or would make you feel like you are excluded during a musical experience?
- What types of things make or would make you feel like you are rejected during a musical experience?

# APPENDIX I

# INTERVIEW GUIDELINES

Developed through suggestions in Brewster (2004), Finlay and Lyons (2001), Lewis and Porter (2004) and Meyer and Rose (2000)

- Ask all questions in a manner that is respectful of and sensitive to the participant.
- Offer participants adequate time to respond.
- Offer participants multiple means by which to answer.
- Ask about specifics examples rather than generalizations.
- Use descriptive language that employs concrete imagery rather than relying upon abstract concepts.
- If necessary, employ images (such as P.E.C.S.) or multimedia means of asking questions or prompting responses.
- Regularly check for meaning of responses and words used.
- Employ open-ended questioning that avoids yes/no types of responses
- Avoid using modifiers when they are not necessary.
- Avoid using negative words such as “no” and “not” in positive phrase questions.
- Avoid subject-object confusions in.
- Avoid giving example answers.

# APPENDIX J

# MEMBER CHECK CORRESPONDENCE

Dear [Participant's Name],
I hope all is well. I am emailing you with a draft copy of your narrative description that I created from our interviews and observation. I took a more narrative approach to the research by constructing a story around themes and quotes from our conversations and observations. For your description, I tried to capture what making music meant and was like for you by [insert description of format and story]. The purpose of this description is to help readers walk with you and consider your lived experiences in, through, and around music (so that is the part that I'm seeking to be as "true" to you as possible).

[insert link]

I request that you send me your comments/edits by [one month after email]. Please:

- Make comments to correct what is in the google doc (again, this is your story).
- Afterwards, please send me an email with your comments as to the extent that descriptions:
    - really gets at what these things are "really like" for you,
    - seem to reflect and resonate with who you are, and/or
    - articulate your feelings about the process of the entire research project.

Thank you for your participation in this study.

Sincerely,

Jesse Rathgeber

# APPENDIX K

# WRITING [    ]: DIFFERENTIATED PROCESSES FOR LIFEWORLD NARRATIVE CONSTRUCTION

### Writing Erica

Erica had recently been nonverbal and often communicated through singing/adapting song lyrics or playing recordings that she saw as fitting for the context. Erica also imprinted specific songs on specific people and mine was “Yellow Submarine,” so we sang this song a lot. We drew with colored pencils and markers to music that Erica shared via YouTube and talked about life. Erica played piano for me at one point. Having videos of our interviews was very helpful as I ended up generating descriptive transcripts with bits and pieces of text. Although these transcripts helped, the videos themselves were far more useful and I watched them over and over again to identity sequences that seemed to capture her experiences of disability in, through, and around music. I also interviewed her parent, which they choose to do over email. I combined sequences from the videos and the answers from her parents to develop a description of one meeting with Erica. Throughout, I included drawings Erica made while we listened to and discussed music and her life to provide another means of representation. Throughout this process, I became conscious of the ways that Erica told her story through here interactions with others and through song lyrics, rather than through her own “original” words. Because of this, I structured Erica’s lifeworld narrative to highlight here interactions and relationships as she tells her story through her words and actions, the accounts of her parents, and my reflections.

I shared a draft of Erica’s lifeworld narrative with her and her parents for them to check. I received an email that stated:

> I only found one typo that caught my eye- from page 9 (I think)- see line below. No need for the question mark after church: “When Erica was basically non-verbal, she was up front in church? with youth who were to help lead the congregation in a song”
>
> I think you did an excellent job. I appreciate your discussion of your unease around the sexually explicit or suggestive lyrics of some of her favorite songs now.
>
> Whoever helps [Erica] in the morning still often has to pretend to be Jesse (what song would you like to sing Jesse?), so I think you are still with her in her submarine. Thank you again for including her in your study.

I fixed the typo.

**Writing Duke**

Duke was a character and a prominent figure in the local music scene so much so that he has had people write songs and news articles about him, make an award-winning short documentary about him, and even have his face tattooed on at least one person's' body. He is excited and larger-than-life and I felt that only a movie could capture his experiences justly. But I am barely a screenwriter, let alone a cinematographer, director, and editor. As such, I decided to write a screenplay that captured Duke as he visited a local concert venue. I make myself a character in it because I met him originally at a concert well before the study and I felt that I could be a proxy or conduit for the reader to see themselves and interact with Duke. I used the tentative meanings/themes from my analysis to structure scenes and fleshed out these scenes with direct quotes from transcripts. Transcript annotations commenting on Duke's body language and the original videos provided rich data to make use of in order to help Duke breath and take life in this screenplay. The screenplay culminates with the lyrics that Duke adlibbed during our final interview, which he felt best represented what music meant to him.

I experienced a few challenges in writing Duke's lifeworld narrative, beyond my own limited screenplay abilities. First, Duke is a relatively well-known entity in the local community and his references to locations, musical acts, and people in the community were specific and important to provide context but sharing them in an unaltered manner would make him rather easy to identify. As such, I had to disguise these contextual aspects, by constructing pseudonyms and aliases. The other main challenge I faced was that Duke presented himself to me as he presented himself in public: as a happy-go-lucky and "stoked" person. I had no reason to think that this was an act: this was Duke. Yet, I worried that his account only presented only the rose-colored-glasses perspective of memory. As Duke is a rather large present online, I looked to see how he presented himself via social media. There, I found the "stoked" Duke as well as the sad and dejected Duke. Duke's social media posts are all public and, as such, I drew on them, with his permission, to add more dimensions to his account.

Upon receiving his draft, Duke responded quickly via text, stating: “I think looks good my friend.” He then shared it with his family, eventually responding “It’s awesome we love it! love it.”

### Writing Birdie

At the time of our first interview, Birdie had just finished a large-scale abstract piece. During our second interview, which evolved from an observation and which was largely planned last-minute at the behest of Birdie, took place during what would become a late night weaving session in which she listened to music and podcasts, discussed life and epilepsy with me, and worked to finish a her project—a woven re-interpretation of her EEG reading using gauze—that was due for gallery placement on the morning. At our final interview, Birdie sat on the floor and painted an abstract work full of the wavelength/frequency lines often characteristic of her work while music played from one of her Spotify playlists. Throughout our discussions, Birdie would tell stories embedded within stories in which she would drop a specific narrative line to articulate a point only to meet up with the dropped point later on. I found that presenting her tentative meanings/themes in a similar manner as fitting her. As such, I constructed three narrative lines, I set them to take place within three different activities which seemed to be emblematic of Birdie’s art, use of music, and becoming: (a) Birdie painting an abstract painting while discussing her life as living independently, working, and dealing with the recent death of her mentor; (b) Birdie weaving her EEG-informed artwork “Seizure” while discussing stress, the impact of epilepsy on her social experiences, and the meaning of frequencies in her art and life; (c) a memory expressed by Birdie on numerous occasions in which music and the stress of a social experiences intersect with a seizure. Birdie’s description rely primarily on quotations. It is useful to note that I played a role in this narrative as I was the person to whom Birdie is speaking throughout, though this is not the case in all the narratives. I provide commentary and explanation at points within the narrative as the narrator. These commentaries and explanations are comprised of paraphrased and synthesized issues articulated specifically by Birdie. I avoid providing researcherly commentary and interpretations as much as possible to re-present her lived experiences rendered here. Yet, in the end, this was all my reading, my interpretation, my writing of her lived experience.

Birdie was very eager to get her draft, texting me regularly for updates on my progress writing it. When she finally received it, she read it almost immediately, responding:

> Wow! very interesting, just got the chance to read! . . . I have some feedback (just stupid things such as changing my boyfriend to ex-boyfriend lol but thats probably not so important to you haha? I really like the bit from the weaving interview most, that was a great session I remember. I realize from reading all the interviews i say the word like a lot haha i will have to work on that.
>
> thank you for including me in this most interesting study!

She later sent me comments clarifying her feelings during proceeding seizure and updating me on her living situation. I edited her lifeworld narrative in light of her clarification, but I struggled with editing the “boyfriend” change. I ended up not changing that and information regarding her living situation because I felt that those aspects shaped Birdie’s life at the time and that changing them would remove important contextual information from her narrative.

### Writing Daren

Writing Daren’s lifeworld narrative was perhaps the hardest. Daren was succinct and often very to the point, even short on answers. He appeared to prefer answering questions with clear specific details rather than having protracted discussions. Daren did provide very deep and rich information related to a few experiences, specifically a late night breaking session. He addressed this experience each time we met and used it as a way to articulate different aspects of his life, including Tourette syndrome, breaking, piano playing, and social experiences. I decided to craft Daren’s lifeworld narrative as a first-person perspective of a very important late night break dance practice session he spoke of on multiple times. Writing from this perspective proved to be challenging. While describing Daren’s late night breaking session in first-person was relatively easy because my process amounted to paraphrasing Daren, the remainder of writing in first-person was much more difficult, even emotionally exhausting at times. Although finding themes and key aspects of Daren’s experience was not particularly difficult as I explored through the transcripts and recordings owing to his succinct nature of speaking, writing as Daren was tiring due to how far outside of my common writing practice and because of the ethical conflicts I felt throughout. Writing Daren's lifeworld narrative felt like a process of putting on Daren's experiences as if they were clothes. As I bounced from transcripts, recordings, and the emerging mind map and my notes, I heard myself grappling with many questions:

> Was I engaging in some version of disabled "blackface"?
> If so, is that the case because of the first-person perspective?
> Would changing "I" to "he" change that feeling?
> If so, why?
> Who am I to speak as Daren and who am I to speak for Daren?

I felt "icky" and excited, in equal measures. As I wrote, this did not subside. Yet, writing from this position made me increasingly more aware of Daren's way of speaking, his vocabulary, and the details of his consciousness that he shared. This led to me envisioning a dream sequence through which Daren articulated his mixed feelings about the and his conflicts between the individual and social aspects of his life. Incidentally, I found myself dreaming as Daren, or as my interpretation of Daren based on what he shared, on many a night as I wrote Daren's lifeworld narrative. Daren did not come off as extensively evocative of details of his life, but trying to put on his language, his thinking, and his interests—almost as if I were an actor portraying a historical person—provided a different way to write and seek to understand Daren's lifeworld.

When he received his draft, Daren was slow and careful in reading the work, commenting on the online version of the document to provide clarifications and ask questions. Daren's comments included:

> I would appreciate it if you can add the terms 'breaking' or 'bboying' more frequently. I know that the popular term 'breakdancing' is what most people recognize but it's a bastardized one. You can keep the word but I would add some of the original definitions too
>
> Voguing: this is a different style of dance with a whole other culture behind it. It does share some background and underground elements, but is not part of hip hop or breaking . . . if you feel the need to add something after then maybe use 'freeze transitions'
>
> L-kick: replace with 'elbow freeze'
>
> Two-step: replace with 'a pin drop reset and clean footwork finish'

I made corrections as he requested. Daren did not share any concluding comments.

**Writing Sienna**

Sienna was a fiery social justice advocate whose empathy toward oppressed minorities preoccupied much of her discussions. They were often purposeful in providing specific stories from their life and musical examples that illustrated different social justice issues broadly (e.g., water rights, income inequality, sexism, and racism) and disability-specific (e.g., ableism, inspiration porn, desexualization, inaccessibility, and universal design). These foci seemed to keep them somewhat closed off from me as they engaged in the role of advocate. It was not uncommon, though, that Sienna would open in the process of telling an advocate-based story, with their body language easing and her sense of humor becoming apparent.

After watching the videos of our meetings multiple times, I identified these moments of vulnerability to construct the “bones” of their lifeworld narrative. These moments were often stories embedded within stories that demonstrates how Sienna experienced and understood disability, community, and place as manifest in, through, and around music. Sienna often spoke of the importance of a “potluck” in relation to Appalachian culture and mused that a good title of her stories might be “the potluck of life.” The potluck, then, seemed like a good metaphor and context to describe her lifeworld narrative. Much of the writing included plucking quotes directly from transcripts with limited alterations. I then added some overtly advocate-based elements to round out the narrative.

Sienna was active in editing her draft. The draft had numerous corrections as to specifics and/or clarifications. They also made comments that called into question the accuracy of the narrative, which provided for a chance to engage in a discussion

> Sienna: “count my steps”: It is a stereotype that blind people count our steps. It is not an efficient way to navigate.
>
> Jesse: I must have misunderstood what you said during our conversation about your stage experiences. Is there a more correct way I might explain this comment to the readers? "I often go with an orientation ability instructor, and I count the steps from here to there, and I measure ... mentally measure in my mind how far I am from which prop,

> 'cause it's not fun when you're on stage and like people are watching you and you trip over like a stool." Thank you for your care and attention.
>
> Sienna: When on stage i sometimes count steps yes. but that is due to the fact that the props are all in the same place every time. while navigating off stage i never count. it is a stereotype that blind people count their steps and i just want the reader to know that this is only used specifically in theatre and that is not how i normally navigate.

Other comments were disability “adjacent:”

> “That I have sex”: this also might be a good place to debunk misconceptions about asexuality. since many individuals believe that asexual people do not have sex. some do some don’t and for numerous reasons.

Although I questioned the need to inject this information into the text as it did not seem to be directly related to experiences of disability in, through, and around music, since Sienna felt it was needed, I included it as a footnote where Sienna could speak more directly to readers, as I did with her comment regarding counting steps.

**Writing Ice Queen**

Ice Queen was, similar to Daren, a rather matter-of-fact participant with a dry sense of humor. She regularly spoke of how she understood her purpose in life was to gather “memories that will last a lifetime,” and these memories she shared with me. Disability manifested much less in her stories than did social connections, which may or may not have been impacted by disability. Rather than interpolate, I directly asked Ice Queen to share with me which memories that would last a lifetime mattered the most and illustrated her experiences of disability in, through, and around music. In response, she created a visual representation, included at the beginning of her lifeworld narrative, and we discussed what she had included. I searched the transcripts for times when she discussed these memories in order to construct robust descriptions of the events. Each memory seemed to revolve around a single or small handful of themes, and I drew on direct quotes from the transcripts to illustrate these themes. I then imagined what physical “things” might represent each of these memories and their meanings, as a thought exercise to help with writing. Through this, and some sketching the trophies real and imagined presented in Ice Queen’s transcripts, I came upon the idea of structuring Ice Queen’s lifeworld narrative as a tour of her trophy hall where she could display each physical representation and then discuss the experience(s) embedded within these symbols.

Ice Queen responded to a draft of her lifeworld narrative very positively. She shared the following comments:

- Perfect! Really captures how much I geek out about [Cavalcade of Winners]
- Perfectly captures my hindsight.
- It looks really great and definitely captures how I would tell the story myself: all over the place.

She also shared come corrections regarding her timeline:

> I made several comments about parts where the order of events got jumbled- I think this must have been a result of me jumping around on the timeline while talking to you. To make it easier, here is a simpler timeline of everything I told you about in college:
>
> > Year 1:
> > Music performance
> > no marching band, absolutely miserable
> >
> > Year 2:
> > Psychology
> > Joined marching band in the fall
> > Joined SAI in the spring because of friends in the sax section
> > switched to music industry
>
> I hope this helps make my story easier to follow.

I made corrections in places, but I did leave some points in that made the timeline a bit “all over the place” to resonate with how Ice Queen shared her lifeworld. The swirl of events and the overlapping nature of how Ice Queen speaks her life seems central to how she experiences life and it echoes her experiences with ADHD. As such, I felt that clarifying some things too much would take away from this in her lifeworld narrative.

Ice Queen also provided some concluding remarks about participating in the study, noting:

> I really loved participating in this and getting to chat with you about why I do what I do, the challenges my disability raises for me in that, and how I have learned to correctly approach those challenges over time. Thank you again for the opportunity to tell my story!

### Writing Culann

Culann was a character and a talker. We knew each other on a somewhat collegial level, which gave him a sense of comfort and openness with me from the beginning. We meet for well over ten hours in total for interviews and to experience music together. Needless to say, there was a wealth of data on which to draw and it kept coming as I continued to write because he would Facebook message me when he wanted to add some more detail. As I transcribed and reread our first and second interviews, I noticed a great deal of repetitions regarding specific experiences, relationships, and places. I was rather pleased to find that Culann had his own "themes" that he wished to explore on a four-hour road trip, many of which were similar to those I had already identified. In this road trip, Culann showed me around historical sites in the Shenandoah Valley and shared a curated playlist of songs that were most meaningful to him. To be honest, this road trip is essentially what I present in his lifeworld narrative, although I have changed the setting, because Culann mused that he wished he could road trip with me in Alabama so I could see the contexts of his music experiences, and added opposing cars to represent incongruent experiences, relationships, and places. It is fitting that the margin play, alteration of lyrics, stories, and opposing cars adds a feel of chaotic energy similar to how Culann described his experiences of ADHD.

As I wrote much of his lifeworld narrative in a space close to Culann's work, he would often come up to me to check in on "his story." This, in addition to his Facebook messages, made the process of constructing this lifeworld narrative feel far more like a co-research experience. Culann was, although, originally adamant that he did not to be forced to read things he had said. He did not want to read his transcripts and was not eager to read a "research report" on his experiences. As I shared with him the road trip story structure I envisioned for his narrative, he began to warm up to the idea of reading it. He grew more and more excited with each paragraph and update report, saying, "now, I'd actually want to read that," and "okay, I can't wait to read this." Upon reading his draft, Culann shared some specific corrections:

Timeline

- 9th grade – Attacked a group of seniors with 2x4 during gym class (we're sitting in the stadium bleachers, unsupervised) who had relentlessly tormented me for weeks.
    - Expelled and placed in an Emotional Conflicts (EC) Class, after I returned
- 10th Grade – 11th Grade EC class shenanigans. Like its own little juvie hall in a trailer by the student parking lot.
- 11th Grade October 1983 Suicide attempt – bottle of pills. Passed out between buildings at school. Rushed to ER. Next day sent for a nice vacation at [the] Hospital . . . Moved to another school after I returned.
- After HS, I compulsively drove as a way to self-reflect and as a way to get away from my problems. I put 100k miles on my vehicle in 2 years. Smashing Pumpkins (Butterfly with Bullet Wings) "…feel like a rat in a cage".

[Other details]

- Dad drove a 1982 Blue Chevy Silverado
- "I guess I was really just 'flirting for Jesus.'" They (the small-town, Weaver HS religious Southern Baptist pretty girls) were flirting for Jesus. I was just the sucker who fell for the con. Tori Amos "Never Was a Cornflake Girl", after I moved to B'ham, I stopped chasing cornflake girls.
- There is no Interstate 280. It's US Route 280. In Birmingham we refer to it simply as "280". It's one of the main arteries leading from Vestavia, Mountain Brook, and Homewood to Southside (B'ham). It's a source of consternation during rush hour, but I had a lot of fond memories on that road. Dated a girl, Nicole (probably the girl) from Vestavia. She was kind of the dark, self-absorbed, doppelganger of [my wife], though they did look different.

I made edits and added these details. Culann was also concerned that he came off as "too jaded." He asked me, "did I really seem that much Jack Kerouac-like? Shit." I worked to add a bit more levity, but much of the "Kerouacian" content came from direct quotations. Culann reported that he "was not aware of the vibe I can give off," but that the narrative represented his experiences.

# APPENDIX L

## ALTERNATIVE FORMAT VERSION OF ENVISIONED CONVERSATION IN CHAPTER FIVE

Birdie: Oh, I'm sorry I'm late, I had an issue with my ride [takes a seat and pulls out her water bottle]. Sorry everyone [takes a sip of water].

*I-Thou* Jesse: No worries, just more time to settle in and get some tea and coffee.

Culann: Well, Jesse, here we all are, in words of Rocket the Raccoon, "Bunch of jackasses standing in a circle"[197] [said with a small, wry, quarter-grin]. Well, sitting in an oval.

*I-Thou* Jesse: Yeah, I figured it might be useful to get you all together to talk with each other about what disability is like in, through, and around music for you.

DUKE: That's really hard [adjusts stocking cap].

Sienna: Well actually, it is hard to explain, but it is probably harder to do, since we aren't actually here together. We're in Jesse's head [shakes head and raises eye

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brows in a half-mocking manner].

*I-Thou* Jesse: There is that, I suppose. The thing is, I'm feeling odd about analyzing all of your experiences and splitting them up into clearly defined thematic boxes when I could just have you here to talk.

Ice Queen: But we never met [motioning to everyone with a quizzical facial expression].

*I-Thou* Jesse: Well, you kind of have, both in the last chapter and in my consciousness. Since you've all partially manifested in my consciousness, I'll just take it for granted that you're at least somewhat acquainted.

Birdie: Oh, yeah, I get what you're saying. It's like a meeting of different frequencies. Or, maybe this is *your* weaving project! [pointing at *I-Thou* Jesse with a smile and a nod]

Daren: Sure, I could see how this might be interesting. In all the research I've seen while I've been a research assistant for my professor, there are always themes or some kind of science-y analysis.

*I-Thou* Jesse: I hope people might find their own themes and maybe bump into other things that are built into our chat. Hmm, maybe I can do a bit more . . .[i] Mostly, I think the way you all respond to each other in this conversation will create an ongoing chain of overlapping themes. So, if you're all game, then I could just throw some questions out and we can roll with it. [looks around for confirmation]

All: [nodding in agreement]

*I-Thou* Jesse: Okay, so how do you see yourselves in your experiences in, through, and around music in general?

DUKE: Jesse, this is a conversation at a coffee shop, not a “document,” right? [with ear-to-ear grin]

*I-Thou* Jesse: Yeah, well, this conversation isn’t really happening at a coffee shop. This coffee shop doesn’t exist anywhere except in my consciousness and now in this document.

Birdie: Wow, [hands making explosion gestures on side of head] trippy.

### As Envisioned Conversation

*I-Thou* Jesse: So, I guess we can start by discussing music, in general, such as the types of music you do or the music experiences you have and what those experiences mean to you.

**Erica:** **[begins to twist in seat] I live to make music. I like to sing with people. [sitting back and turning to Jesse] Let’s sing.**

Sienna: What do you want to sing? I’ve got my banjo.

**Erica:** **[turns to Sienna] What song do you want to sing?**

Culann: Yeah, I don’t sing, I’m not a singer [shakes head]. Let’s not make this some hippy, dippy sing-along shit, man [shakes head].

*I-Thou* Jesse: Okay, maybe we don’t sing right now . . .

Ice Queen: Well, if we aren't going to sing [smiles], I guess I can answer your question [leans in with elbow on thighs and hands clasped together below chin]. Music is just kind of everything to me. I mean, it is the only thing in my life that I've always seemed to excel at. Music is the thing that I can fall back on when I'm having a hard time with academic classes in college, like classes that require memorization of facts and dates. I'm not very good at things like history because I just can't remember dates and stuff like that. But I'm really good with memorization in music. I feel comfortable playing, even when I'm playing hard music, and I feel like when I perform, I'm myself and I'm proud of myself. Pride, especially. Music gives me a chance to be proud.

Culann: So, I can memorize dates, names, and facts about history, but if you made me perform, I'd suck. [wagging finger and pointing as if directing] "Smile, Culann, move like this. Emote," that shit isn't me. I don't sing, I don't dance. It's kind of like that Phil Collins song, "I Can't Dance." Being forced to perform really can be alienating and upsetting. Now, leave me alone and give me my music, my iPad, I'd be fine. To me, music is more about the meaning of the lyrics, anyway [leans back in chair and crosses arms].[ii] I'll be listening and I'll pick up bits and pieces of words and ideas that I feel are congruent with who I am, bits and pieces that, you know, help me know myself more and feel more comfortable being Culann. I'll hear a song, like "Father of Mine" by Everclear and the line, [points] "I will always be weird inside, I will always be lame," will just stick out because it's like I feel this way [points up], even though the context may be completely different. Like, Tori Amos and Pearl Jam, too, they are *basically expressing what I feel in ways that are far more poetic that I could. You know, I may not be able to say, "I feel like this . . . " [jabs down at table with finger] and be accurate, but I could say, "I feel like Pearl Jam." It isn't totally analogous because I know people like Everclear, Pearl Jam, or Tori Amos aren't talking about me, but these bits of pieces feel like me regardless of where they come from.*[iii]

Sienna: Yeah, but the context of the music matters, too. [straightens in seat, looking at group] When I listen to music, I feel a connection with the singer, the songwriter, and their contexts. When I listen, I don’t really take the lyrics for myself, but I try to listen to what that person is saying. When I listen, I experience a passion for humanity because I feel like I’m making space for the personal experiences of other people to come into my life. [motions out with both hands] I hear the joyful, dark, deep, and emotional times in their lives through the songs. I think listening to music, like Imagine Dragons' "Demons," Sister Haze's "Battle Cry," "When It Happens to You" by Lady Gaga and the Hunting Grounds, and "Take Me To Church" by Hozier . . . I hear stories and voices that I might never have thought of if it hadn't been for the music.[iv] I just love it, too, when artists use their privilege to speak for their community or to be an ally and speak for people who don't usually have the chance to do so otherwise.

Birdie: [closes eyes and nods slowly in agreement]

**Erica:** **[sits up and sings] "We're secretly out of control, nobody**

**knows it, but my mom's got a problem with oxy's and she's angry cause my dad's office door's always closed, but I stopped knocking . . . We're secretly out of control, nobody says it."[v]**

Birdie: Wait, I've heard that, what is it?

**Erica: Jon Bellion. What's that song, Jesse?**

*I-Thou* Jesse: Hmmm, you played this for me a few times. Ah, "Morning in America," I think . . .

**Erica: [smiles] Yes! [singing] "We're secretly out of control, nobody knows it. Yeah, we're secretly out of control and everyone knows. Oh, it's morning in America."[198]**

Sienna: Hmm, I never thought about that song, but, yeah, it does address the troubling opioid crisis in this country and relationship

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[198] (Evigan, Douglas, Martin, Kirkpatrick, & Bellion, 2016).

# problems . . .

Birdie: [nodding] I think I get where you're coming from, Sienna, with the whole "voices of other people" thing. Like, I think about frequencies in my art work, and lines. When I'm listening to music and doing abstract painting, I, like, get a chance to feel some new frequencies [smiles and then looks down to pick at her skirt].[vi] Sometimes the frequencies in the music give me new lines to play around with in my art [mimes painting in the air]. Like I'm able to concentrate on painting, but then I'll hear a note and, like, it will change the way that I apply paint, like, heavier, lighter. And sometimes, it's like the frequency of the music, the frequency in the art, and the frequency of my mind [points to head] sort of come together. There's something about painting—and [smiles] I always listen to music when I paint— because there will be these snippets of my life that come back to me so vividly.[vii] These memories come back to me [eyes soften] and they could be the most random memories from childhood. But they come back to me . . . I get to relive this part of my life again because I'm remembering this and I totally forgot that it happened. Maybe that's one of the reasons I'm so drawn to abstract painting. Well, that and there's a sense of control and looseness I get from painting abstract. I don't have to worry about what it's going to be, just paint through it and it will turn out to be a work of art eventually. It's something that I do have control over. You know, seizures are abstract, kind of, but I don't have control over them, they have control over me. But, like, [shifts head to side and looks off to distance] I have control over my paintings.

*I-Thou* Jesse: Daren, Birdie's mention of control reminds me a little bit about your experiences with breaking—breakdancing—versus playing piano.[viii]

Daren: Well, [crosses arms] I guess I can see what you mean there, but I don't think I'd call it control, [shifts in seat] as such.

*I-Thou* Jesse: How would you describe it then? I mean, from the outside, it seems like you have control when you're breaking in a way that you might not in piano playing, since you're more prone to ticks when you're playing piano.

Daren: Yeah [nods] I get what you mean. Maybe what you're talking about with the whole "control" thing is the physicality of breaking/bboying [uncrosses arms], which kind of shuts out my experience of my Tourette's. I don't want to make it seem like I don't like playing piano. It's a good outlet when I'm stressed. But I can get frustrated when I'm trying to figure out a new soundtrack piece on piano and that added stress elevates the chances of a tic because Tourette is more psychological than neurological sometimes.[ix] There can be a lot of head twitching when I'm playing piano and learning a piece, when I'm stretched mentally. I think that might be because I have headphones on, it happens mainly when I have headphones on. Other than that, the main twitches would be just general body twitches mainly when I'm learning some new or getting something down. As for dancing, it's a little, actually a lot different. It's still an expressive outlet for me, but when I dance, I, sort of, don't notice my Tourette's. It goes away. You know, maybe bboying is just such a physical thing that I just don't pay attention to my Tourette's. I don't even think about it [shrugs]. It's when I reflect after I dance that I'm just like, "I, I didn't twitch at all." That's not why I break, but I'm grateful for it.

*I-Thou* Jesse: Well, why do you breakdance, Daren, why do the rest of you do what you do with music? I mean, maybe your "whys" might relate back to the question of "what are music experiences like to you"?

Daren: It's fun [shrugs]? It's something I look forward to doing. I really enjoy practicing. Also, like I said, it's an outlet for me and a way to release stress. I like having this thing, freestyling specifically, to look forward to after a long day of classes and homework.[x]

Ice Queen: [leans toward Daren] I've never done breakdancing, but I thought it was something people did socially. Do you, I mean, can you breakdance alone?

Daren: I can see where you would think that [shakes head]. The public knows breaking mostly from in the form of street performances or battles. [tenses face] In battles, you are facing strangers and other people who are often professionals. That can be nerve-wracking. I do think you can freestyle alone, though. I practice alone sometimes, but while I'm at college, I practice three times a week with this student organization dedicated to bboying/bgirling, I was sort of the president by default for a while. The thing about that is you have to teach newcomers. I don’t mind teaching, it can be fun and challenging, but I’m more in the breakdancing student org to have a place and time to practice. I don’t think I’ll do much social breaking when I graduate, I mean it isn’t like I’d travel to go to a battle. I just like to freestyle on my own.[xi]

Ice Queen: Yeah, I certainly understand the want to do things on your own or, well, for yourself. I think I used to do a lot of music things for only *me* when I was in high school.[xii] I was mean to other people in marching band in high school because I wanted something where I could get recognized, you know being “the girl that got the band to win again.” I thought that would be the only way I could gain any sort of notoriety or attention, and I’ve always been a person who likes attention. So, I was really intense. It was kind of a selfish thing—not to say, Daren, that you dance alone for selfish reasons. But I think now a lot of my music experiences have given me a chance to connect with other people. I’m not in love with being a solo performer, but I love playing in large ensembles and having these friends that I share experiences with. Like I got into ΣAI and even college marching band because it allows for an easier way to connect with others. People join professional music fraternities because they love music and they want to give back to their community through music. I feel like having, um, having that common factor of music in a room full of members takes away the barriers between people. You can just start a conversation [smiles and brings hands together] and find out what other things you have in common. People join marching band because they all love marching and you can immediately bond over that, over playing together and putting on a show. You don’t have to meet someone new and like, later on, find out that they are into the same thing as you, you know?

Daren & Birdie [nod in agreement][xiii]

*I-Thou* Jesse: Culann, music has been a social connector for you as well, right?

Culann: Yeah, and a social disconnector, if you know what I mean.[xiv] [shrugs and leans back] Like, if the music isn't congruent with who I am or if the experience puts me in a place where I'm supposed to do something that is incongruent with my personality or that I don't have natural talent for, then it can be pretty alienating.[xv] But I think finding my music, was part of me being able to connect with others, since I had something to share, and was part of me connecting with myself. Shit, maybe being me and making friends is part of the same sort of process, you know, one dependent on the other.[xvi]

Sienna: Well, making music is a big way I've gotten to know other people [leans on the arm of the couch]. I mean, I know bluegrass isn’t for everyone, but playing in a bluegrass band means you’re surrounded by people who enjoy the same music, or, at least if they didn’t, they pretend they do. The whole structure, but almost a fluid structureless structure, of bluegrass and Old

Time music, I feel, is about connecting and supporting each other. Each person, each individual instrument plays their part. Everyone agrees on a key, a tune, and a tempo, so that’s a thing to connect with others through. Unlike in an orchestra that is a well-oiled machine working toward perfect phrasing, in bluegrass you just kind of play with and then play off people and they kind of bounce around ideas. Like, you could be playing one thing and then someone else plays something else and you're like, "oh," and so you hop on the bandwagon. That informality is important for me to feel in the music.[xvii]

*I-Thou* Jesse: That brings something up that maybe we can explore more: connecting with others. **Erica**, I think about how you connect with others and even speak what's on your mind through song. I know that you like to use lyrics to speak for you and you connect with others by singing with them. I mean, we have a song we bonded over . . .

**Erica: [beaming] "Yellow Submarine!" [points] You sing!**

*I-Thou* Jesse: Well, maybe not right now. But, are there other songs that you connect with others?

**Erica: [twists in her seat] Songs from *Pirates of Penzance, Jr.* with my friends, Marilyn and Jayda and Samuel and Wyatt . . . I like singing with people. [singing] "Yellow Submarine!" [singing] "In the town, where I was born,"[199] let's sing . . .** [xviii]

Birdie: Oh [pats legs in excitement and smiles], I *love* the Beatles, too. Maybe we should be friends. After all, your friends kind of like the same music as you and that's why they're your friend—because you like the same music.

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[199] (Lennon & McCartney, 1966).

DUKE: Yeah, I like singing with my friends. I sometimes even go onstage and sing a song or two. Sometimes I play drums with them, or at open mic night. I've got a couple of bands with my friends and I've made friends in rock lotto. I love jamming with my friends, old and new.

*I-Thou* Jesse: And I think that's an important point here, DUKE. You go out to clubs where you'll find people who have voluntarily come out to listen to live music with other people. Most people who are at these clubs are there for a similar reason and might share similar interests. And this is something you've chosen to be involved with . . .

Ice Queen: Yeah, there is something different about picking to be involved in something and not being required to be involved. It's weird, but given how intense I can be about accomplishing, I tend to pick low pressure experiences and easygoing environments when I'm deciding which groups to play in. There's something nice about making music with really fun people who are really easy going, and like, when work needs to get done, they can get serious, and it does. It never feels like a stressful thing or, or like you're being bossing anybody around, but it isn't just a free-for-all. It's just, when stuff needs to get done it does. Um, and they're still able to make time for goofing off and whatnot. I feel like there are chances in these groups to go above, so if I just want to get this one thing accomplished, then I can actually do that, and it's a lot more rewarding. It feels like you can personalize the experience for yourself, somewhat. [xix]

DUKE: Yeah, yeah, yeah. I get that.

*I-Thou* Jesse: So, choice of challenge level . . .

Culann: . . . [sits up in chair] and choice to engage at all . . . [nods and slouches back in chair]

Daren: . . . it’s nice to have choice of how you interact in music, you know like having a choice in bboying, not singing, or performing, like Ice Queen likes . . .

Ice Queen: [grins and eyes light up, nods]

Sienna: . . . and choice of music style! [nods and crosses arms]

DUKE: Yeah! I like choosing to go out to band shows. I drive my little scooter all over and go to a few shows a night sometimes. It’s part of me. I choose to stand close to the band and be part of the music. Sometimes I come earlier to get know the people in the bands, if I don’t already know them, or to hang with my friends in the bands that I already know. Either I’ll help them out, you know, load their stuff in, to help them out. Between sets, I’ll go hang with my friends in the audience. I like making them laugh and helping them out when they need my help. They all get a crack out of me.

*I-Thou* Jesse: DUKE, I seem to remember you talking about liking to play too and enjoying all the attention you get from the audience and the trust you build with bands that you sit in with, bands you often have just met.

Birdie: [leans over to Duke with wide eyes] You play with bands you just met? Wow, I don’t know if I’d be that brave to ask. I’m just now getting the courage to, like, umm, do karaoke in public. That’s so beautiful.

DUKE: [tugs at his stocking cap and grins, nodding] Karaoke would be fun, maybe we can do that together, some time. Singing with my artist friend, Birdie, sweet! Well, yeah, I play in some bands and sit in with my friends' bands a lot, or I'll just ask a band I don't know if I can sit in for a song. They usually say "yes." I like playing with new people because it makes me feel like they trust me or I get to prove that they can trust me. I like playing drums, or whatever too, because everyone cheers me on and they are blown away, because I get up there and I beat the snot out of the drums. Afterwards, people tell me how good they think I am, they say, like, "Wow, DUKE, that was amazing," or, like, "You're such a good drummer."[xx]

*I-Thou* Jesse: There's something in the way you and Ice Queen talk about your experiences that has to do with getting positive attention. I don't think, though, that everyone else likes the attention. **Erica**, do you like the attention you get when you make music?

**Erica: [close mouth grin] Maybe. [wide smiles] I like to sing.**

e-father: [stands up and walks over to the group] Oh, she can be quite the ham, right **Erica**? Remember singing in church when you got everyone to join in?

**Erica: [nods in affirmation]. Yes. It was fun, singing with everyone. [singing] "Blessed assurance, Jesus is mine. Of what a taste of glory divine." I sang with the kids.**[xxi]

e-father: [smiles at Erica, then faces all of the group] I thought I could share a quick story—sorry for eavesdropping: One Sunday when **Erica** was basically non-verbal, she got up with the youth and led the congregation in a song. No one stepped up to the microphone to lead, so she did and became the song leader. She led the verses, shared the mic with other children sitting up front, and encouraged the congregation to sing on the chorus by not singing. [turns to Erica] That was the first time many in the congregation had ever heard you make a sound and there weren't many dry eyes after that and lots of applause.

**Erica:** **[bashful smile] I sang at a talent show. [sings] "Nikosi Sikelel' iAfrika."**

e-father: [turns to Erica and shakes head slowly] Yeah, I wanted to send a video of that performance to a speech therapist you had when you were younger who said you [finger quotes] "didn't have much going on cognitively and would likely never talk." [faces the full group] But . . . [stops shaking head and smiles]

Sienna: Disgusting. You see, it's that kind of thing, the low expectations that people have that let them write off disabled people. When we do anything that can make nondisabled people feel good about themselves, they call us an "inspiration." All that inspiration porn stuff.[xxii] [embarrassed] Oh, I'm sorry . . .

A short moment of tense silence ensues as Sienna, Ice Queen, Daren, Culann, and Jesse realize that Sienna has mentioned "porn" in front of 14-year-old Erica. Her father alleviates the tension, saying:

e-father: [laughs] For what? . . . Hmm, [contemplatively] inspiration porn? I'll have to look into that . . . Well, I didn't mean to interrupt. Back to grading, the faculty member's life and all.

Sienna: . . . well, ummm . . . okay Jesse you had asked about attention. You know, I enjoy the attention from being on stage and singing, as long as I’m *allowed* on stage [looks around]. Yeah, some people are afraid I’ll fall off, so I might not get allowed on the stage or have a part at all, and that is a form of exclusion which makes me feel like they really just don’t want me there because of my disability. So, when people treat me like a human being . . .

Birdie: [claps and nods] Yeah, right on.

Sienna: I know, is that too much to ask? [laughs] So, it can be really great to get up on stage when I am in a musical and portray someone else, to be someone else and tell someone else’s story. Hopefully the audience sees the character and doesn’t think about my disability, well, unless I’m portraying a person with a disability. There’s this want for attention as an actress and singer in that moment, not as someone that is disabled, because in that moment, I’m an actress and a singer first, that’s who I would be portraying in that moment.

*I-Thou* Jesse: Okay, so there can different facets of attention at the same time. Positive attention when people see you as the identity you intend to perform around receptive and supportive people. Negative attention when your performance is not recognized or understood you would hope due to stereotypes and stigma. But, what about not wanting any attention?

Culann: [leans forward, raises hand and nods] Yes! For some reason, people always want me to do things like dance or sing in public, but I’m more of an observer. I love to observe and listen to artists talk about their work and why they do it. But, I do not want to, like, dance. I like to watch people dance, but I just don’t dance. I mean, I don’t want to be in the position where people are looking at me in the first place. Because, when I’m forced to do musical things in public, it adds to the pressure I feel and I end up just saying to myself, “Okay, Culann, don’t look crazy, don’t act crazy, just get through this." When I was younger, that could give me a panic attack. Now that I'm in my early fifties, I would just dig inside of myself.

Daren: [sits up, twists head side to side quickly to crack neck] Well, I don't think about "looking crazy," even with my jerks and ticks, but I don't personally like a lot of attention, either. Umm, for a start, when I was young and was forced to play piano, we would have to do these little recitals for our families. Those weren't a very exciting thing. I do get anxiety and performing made me anxious, so it wasn't enjoyable to me. That's why I don't really like performing for people. I'm perfectly fine with just being kind of, just, under the radar. As for dancing, it's sort of the same except the social aspect of the org. That can be a reciprocal kind of environment where I teach and learn, a supportive group, sort of. But even thinking about facing strangers in a battle would just be too much attention on me. [xxiii]

*I-Thou* Jesse: Culann, when you say something about not "looking crazy" in public, it reminds me of how people can not want things related to their disability to cause them any attention. Daren, I seem to remember you saying something about how you would mask your tics and how you don't really like disclosing your disability to even close friends.

Daren: I can understand how you would get that [shakes head]. Yeah, I don't really tell people about my disability [crosses arms]. When I was younger, especially when I had a lot more tics, I would disguise them with yawns, stretches, and things like that. If someone asked, I would just say, "Well, it is just this little twitch I have" and then direct their attention to something else.

Birdie: [tilts head to the side] Oh, I wonder if you experienced something similar to me [crosses and extends legs out]. I'm always afraid to tell people, well, just people I'm not close friends with, about my epilepsy because I don't want to, like, play the epilepsy card and, like socially handicap myself by becoming "*that* girl with epilepsy." I don't want to be a hassle that everyone has to feel like they have to rework everything around. It is kind of a bummer, though, because I end up not feeling like I can stand up for myself in social situations to protect myself, you know?[xxiv]

*I-Thou* Jesse: Birdie, you said something to me before about worrying about "playing the epilepsy card" and "being *that* girl with epilepsy." When worried about "burdening" other people, it seems like you feel tension about disability as an identity, or you feel tension about the stigma of being seen as "disabled."

Birdie [nods emphatically]

Daren: Yeah, I get that part. For me, I don't really identify as being "a person with a disability" or "having Tourette Syndrome," even though I do have Tourette Syndrome [raises shoulders]. I just want to be known as "Daren," you know? I actually wouldn't even identify myself as a dancer or as someone who plays music, as Asian, as being religious, or as someone who has Tourette's. I would just say, "I'm me and I'm a person." I have all these things, like my religion internally. But I wouldn't want to put that out front. I don't really tell people about my Tourette's, only friends if I feel like I owe them an explanation.[xxv] I know some people that might be offended and think that not telling them means that I don't trust them [flicks hands to the side]. So, the friends that would be offended, I might tell or tell earlier. I have friends that don’t really care. You know, there is sort of a stigma about Tourette’s, it’s a bit of a silly one, but, I don’t really tell many people. The whole thing can be pretty frustrating and it gives me a lot of anxiety.

Birdie [nodding with index finger on chin] I feel that. You know, like Culann said, “don’t look crazy,” this is something like that with me, where I don’t want to look weak or weird, or something like that, around people I just met. The tricky thing is that as much as I worry about being “*that* girl with epilepsy,” I see so much of “epilepsy” in who I am. I always feel like it’s a part of me, it is how my brain works and I see it in my patterns of productivity and my patterns socially. I just think it is the way my brain works.

*I-Thou* Jesse: Birdie, you just said, “part of me.” You know, most of you talked about how “disability” is sometimes “a part of” who you are, and some of you talked about how it could be “apart from you,” this other thing or entity in your life.

Birdie Yes, because it *is* a part of me [motions to her heart]. It’s how my brain works and when I talk about it as being something outside from myself like when I say, “my epilepsy makes me . . .,” I'm really just talking about the things that it sets me back on. That's- that's *apart* from me [pointing to the open space next to her]. Like epilepsy not letting me drive. You know what I mean? That's just, that's *not* who I am. That's just a factor in my life, I guess. But epilepsy is a big part of me, and a big part of my abstract artwork, especially how my process can be like this “storm-like” thing [taps head] where I finish everything in one big burst, just like how seizures are. I don't know, it is just really hard to untangle these things.

*I-Thou* Jesse: DUKE, what do you think? Is your disability a part of who you are and how other people know you?

DUKE: [adjusts stocking hat] I don't know. I don't think people know 'cuz I don't talk about it much. I didn't know I had a disability [hands moving in a circular motion] growing up and it took me a little while to figure out I wasn't born normal like everybody else. I thought it was a curse, but it is not. I don't really care if I have this disability, it's not gonna stop me from having fun every day. I've met some people out there that have this disability and they don't seem to have as much fun as I do, but it's fun! I used to be like, "I wish I didn't have this," but now I realized that I'm glad that I do have this disability. If I didn't have this, I probably would not make friends.[xxvi]

Ice Queen: I usually think of my disability as an adjective. Well, It's weird to talk about it as a disability just because, like, learning disability and the term disability has the connotation of, like, when I hear it, I think automatically physical things. I usually say, "I'm ADHD," and if I go more into detail than that, I mean, sometimes I'll say, "I have ADHD, Inattentive," but it really doesn't come up that much, or at least enough where I would think about it. But, yeah, I think I usually say something along the lines of, "I'm ADHD" or "I have it." [shrugs] I haven't really thought about it that much. I know that getting diagnosed was a big deal for me because it explained so much of what I was experiencing and made me feel like I wasn't alone. [xxvii]

Birdie: [squints and nods] I get you. [nods more] Having a diagnosis can be helpful with medical treatments and other stuff, but diagnosis isn't all of it, you now. Like, it's not [finger quotes] "epilepsy," for me. [points to open space next to her] That's what the doctors call it. But, really, it's how my brain works [taps head with index finger], it's how I work. Maybe it *is* kind of an adjective, I guess, but, like, maybe "being Birdie" is a better term for what it is to me.

Ice Queen: Yeah, I just don't know if ADHD is that much a part of who I am [leans head], but it does describe some of my experiences [clasps hands with elbows on thighs], so that's why I think of it as an adjective, well, I use it as an adjective when I choose to bring it up. I try not being a huge downer around other people, so I'll sometimes say something about how I can't focus and that it must be ADHD, but then I have to clarify that I actually have a diagnosis, because people sometimes just say it as a joke, you know, "Like I'm OCD," and things like that, and that drives me crazy.

Sienna: [stiffens, shakes hands, and blurts out in an intense tone] Not to mention that saying "I'm OCD" if you're not is offensive, and so is saying something drives you crazy can be offensive . . .

Culann: . . . [shakes head and leans forward] Ahhh, I don't know about that. I mean, I am crazy. I'm okay with that. I just don't want people to treat me like I'm crazy, well, like they think you're supposed to treat crazy people. I'm weird and different—crazy, and I'm okay with that now. I've gotten comfortable in my own skin. I just don't like when people think of me as crazy in the "evil, worthless, emasculated, sexless, grotesque creature" sort of way [stares at Sienna].[xxviii]

Sienna: [loosens stiffness and softens tone] Okay, it is important to embrace your identity. For me, being blind is part of my identity, but I don't want my disability to define me as a person. I do want my identity as a person to be defined by my experience with disability. The whole identity thing gets really important because of the solidarity it can give you with other people who have experiences similar kinds of oppression. I’ve experienced oppression based on my different identities at different times and in different places.

Looking at how people treat me differently based on their assumptions and biases about different identities helps me feel how society has taught them to think and act. You can’t really be mad at someone if they were taught a certain way. I have to get mad at the teacher not the student. For instance, I’m blind [she touches and shakes her cane and points to her thick glasses] and I experience oppression based on my identity as disabled in my music experiences because of strange stereotypes people have and/or the way that people don’t accommodate with me in mind.[xxix] People think that I can play every instrument just because I’m blind, or that I’m just automatically an amazing musician because I can’t see the same way as other musicians. That’s a “good stereotype,” I guess because it at least assumes more rather than less, like most disability stereotypes and the whole “IP” thing [glances sideways at Erica]. But I can’t play an instrument unless I’ve learned how to, just like anyone else [shakes head quickly].[xxx] In musical theatre [leans back and relaxes], I’ve met people who either think I can’t act well because I’m blind, or people who won’t allow me to adapt things based on my blindness. That last thing, the lack of allowing me to accommodate myself, is really ridiculous when I have this bag of accommodations I’ve had to develop because others don’t accommodate for me.[xxxi]

Ice Queen: [turns to Sienna] I’ve heard there is Braille music notation, do you read that, or does anyone ever give you music written in Braille?

Sienna: Yeah, I can read Braille sheet music, but I can’t play an instrument that requires two hands and read Braille at the same time. I don’t often get offered Braille notation, which I would appreciate, but when I get it, I need time to take it home to read and memorize it. That way, I can pay attention to the music, be involved in the musical conversation, you know, focus on being in the moment musically. But not all blind people can read Braille notation. Even if offered a diagnosis-specific accommodation, not everyone would be able to use it, want it, or have a choice in the matter. All you have to do is ask first, you know [nods and gestures to the group].

All participants: [nods and "Uh-huh, yeah, yes" in strong agreement][xxxii]

DUKE: [continues nods] Yeah, I ask people what they need all the time. Sometimes people need me to listen to them, sometimes they need someone to make them laugh, sometimes they need some help carrying their gear.

Sienna: And it is helpful if people would just ask everyone, not just those they think [air quotes] "look" like they need help or else you might commit a microaggression by offering help that might be unneeded or unwanted.[xxxiii]

Ice Queen: [raises hand] Wait, "microaggressions," what? Why would you not want help? If someone is offering help, why not accept it (hands out at side of body]? I mean, I don't really ask for help a lot, well, I didn't, and I used to take everything onto myself. It can be really great to get help, especially if you're terrified to ask for it or if you don't have good connections with people to feel like you can ask them for help.[xxxiv]

Sienna: [purses lips] Umm, so, like, I understand what you mean, but being offered help can be as bad as not being offered help. If the person offering the help is doing it because they have a low expectation of you and see you as not human enough to do something for yourself.

Just like so-called “positive stereotypes” such as “blind people are good at music”—which isn’t true for every blind person. As a blind person, that stereotype can make me feel bad like I’m not *really* blind because I don’t have that [air quotes] “good at music” superpower that everyone thinks is so central to being blind.

Microaggressions are little things people do or say that come from negative understandings of people in minority groups. Just like overt versions of oppression, microaggressions come from ablebodied privilege and misconceptions about experiences of disability. So, I get people suggesting that I’m not really blind because I can see some things when they are large print and I have my thick glasses on: that's a microaggression. Or, I'll be stopped and asked by strangers if I need help walking when I am using my cane or they offered help they wouldn't extend to anyone else or even to me if I *wasn't* using my cane. It can make me feel

like they look at me
and the first thing they
think is that I’m
incompetent or need
their help because I’m
somehow lesser than
an abled-body person.
That’s a
microaggression.

Ice Queen: [squints] I don’t think I get it completely, because I’ll take help if it is offered, since I don’t often ask for it. But, okay.

Culann: [Motions to Ice Queen with one hand] Basically, don’t be a dick to anyone because you’re ignorant about disability [crosses arms and leans back].

**Erica:** **[shakes head] “And I was like baby, baby, baby oh, Like baby, baby, baby no!”**

e-father: [moves back over to the group and interjects] Yes, exactly! People will often speak to **Erica** as if she were a small child instead of a teenager going into high school. That one always infuriates me. Yes, she might like children's songs and puppets, but that doesn't mean she is an infant.

Daren: It's like that stigma that I was talking about earlier. I can get anxious because I don't want people to treat me "special" and treat me like I'm not capable because of my Tourette's. I'm a person, like them.

Sienna: Microaggressions can be anxiety-producing. Erica, that whole thing about being treated like a child, I hate being patronized. Like, so, I'll read in braille or using large print and everyone applauds 'cause I can read [exasperated look]. They're excited because I can read [shakes head]. And although they think it's a compliment, it's actually hurtful 'cause it means they have a really, really low expectation of what I can do. Um, like, I'm over here trying to graduate college and become a social worker and save the world and they’re just excited that I can get out of bed and remember my own name. Throw playing banjo or singing on stage into the mix, and I blow people’s freaking minds because they expect so little of me.

Ice Queen: [nods enthusiastically] Okay, yeah, I understand what you mean now. It is sort of like when guys in the band assume that I, [sarcastically] a "frail girl," need help carrying things. I mean, come on, if I can carry 80 pounds of books, a computer, a flute and a saxophone, along with other stuff around in my backpack, I *think* I can manage it, dudes [rolls eyes].

Birdie: Yeah [wide eyed], and I, like, worry about being self-sufficient. [with worried tone] I want to be able to take care of myself and not be a burden on my friends and family. But, like, helping each other is kind of what friends and family do, right? My best friend told me one time after she had taken care of me and I was really apologetic. She was like, "Birdie, it's okay, we're put on this earth to help each other." I believe that too and I try to help people as much as I can because they help me.[xxxv]

DUKE: Yeah [grins and nods] it's always nice to help people and make it easier for them, [looks to Sienna] when they need it [points out].

**Erica:** **[twists in seat, looking to Birdie, singing] "Help me if you can, I'm feeling down. And I do appreciate you being round. Help me, get my feet back on the ground. Won't you please, please help me?"[200]**

Birdie: [nods as if grooving to Erica's beat] Yeah, I like that! I always felt that song really, like, connected with me on some deep level.

Culann: Ahhh, the whiny Lennon! I can get behind that feeling of wanting to shout out for help, although I'd rather get help

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[200] (Lennon & McCartney, 1965).

that doesn't require a lot of touchy-feely bull. But, still, I get what Erica is driving at. It's the whole asking for help thing, not just receiving help. I feel like one of the big things here is this terrible compulsion some people have to try to get between people and their, I don't know, their "struggles," or something like that. It's like people look at you, they see you're crazy or something, and they see—or think they see—the "struggles" you might confront and they just, just try to make things better for you but it is really for themselves. You get people that want to keep you from struggling and do crap that's not helpful, because actually helping you succeed is too hard or too inconvenient for them, so they just kind of sit you in this safe little bubble in the padded little kiddie corner and say, "Well, you're in the room, so that's enough, right?"[xxxvi]

Culann: [leans forward with hands on thighs] Then, you have people who try to remove your struggles because they just don't think you can do it. But, the "struggle" or the challenge—maybe that's a better word? . . .

Sienna: [shakes head] Umm, yes. Let's not give people any reason to talk about "overcoming struggles” and make more [glances to Erica] “IP” to make able-bodied people feel better [pointing] . . .[xxxvii]

Culann: Well, [nods slowly, uncertain] sure. Okay, so follow me here for a bit. You know how Frodo tells Gandalf that he wishes he’d never gotten the ring in the *Fellowship of the Rings?* Well, even if you haven’t, the whole *Lord of the Rings* is about Frodo destroying this power ring. That’s his purpose. There are lots of shitty, awful things in his way, but he was supposed to destroy the ring. The challenges in his way of fulfilling his purpose is what makes him at the end. What if Gandalf just destroyed the ring for Frodo? It would have saved him the hassle of having to watch after those damn little hobbits and it would have kind of [air quotes] “saved” Frodo from having any pain or challenge. But it would have robbed Frodo of his purpose and he wouldn’t have become who he needed to become.[xxxviii]

*I-Thou* Jesse: Okay, but, then I have to ask, since, Birdie, you brought it up in our interviews. Would you want disability to be a part of your life if you had a choice?

Birdie: [shakes head] I would wipe it away [wiping gesture] if I could just for my family because it freaks them out. They are scared and worried a lot about me. But, I couldn't, because it is me. I can't know any other way to be.[xxxix]

Ice Queen: [nodding slowly, raises hand to gesture to Birdie] Maybe that's the point. We can't know what life would be like without our disabilities. It's part of our lives and, maybe, part of us.

Culann: [leans back and slouches] A big and problematic part, for sure. I mean, having a learning disability basically means you can't do what you want to do. You have to do what you can do. And, unfortunately, you know, we got to eat so we got to do something for a job. Right now, I'm in a helping profession, which is okay, I guess. It isn't the most rewarding job, but it is the job I can do. Sometimes I wish I was an 1840s mountain man, because you could be crazy, you could be ADHD and have a living, because you're just doing so many different things to subsist. It seems like you have to be a fucking genius to live in America now, all cerebral and specialized—without any learning disability—just to not be poor. Even with all the disability equality laws, it seems like you can be physically disabled—be in a wheelchair or be an amputee—and get a job, because all you really need is a brain, you don't really need a body all that much but you need a brain. You need a full functioning brain and you need a good personality and you need to be there, mentally. So, having cognitive disabilities and a shit personality makes that part of life hard.

Ice Queen: [visibly shaking] I need my body to do what I want to do with performing and marching. Without that, I'd be limited, I think.

DUKE: I need my body too. I need both, you know?

**Erica:** **[singing and swaying in Culann's direction] "'Cause all of me loves all of you. I love your brains and all your edges, all your perfect imperfections."[201]**

Birdie: [nods at Erica] Yeah, all of me, my mind and body. [wide-eyed and turns to Culann] I think you have some big assumptions about mind/body and are making some bad hierarchies here between people with physical disabilities and people with learning disabilities. I don't think it's that simple.

Sienna: [shaking head] I think you're really discarding the difficulty people with physical or sensory impairments have navigating

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[201] (Stephens & Gad, 2013)

contemporary life. Barriers still exist that make it hard.

Daren: Hmm, maybe it is just that we each have to find what works for us and your quirks. Like, I know that bboying is both mental and physical, and I need both, but I focus on the physical and because of that, it fits me well. Or, maybe I fit it well.[xl]

Culann: I don't know. I still stand by what I said, but whatever. Maybe we should ask someone that uses a wheelchair, is an amputee, or [air quotes] "physically impaired" what they think about bboying and what they think about daily life. Maybe bboying ain't so inclusive as daily life is for some of them [crosses arms].

*I-Thou* Jesse: But, we can't really know that since no one here uses a wheelchair, is an amputee, or is physically impaired, or has those identities . . .

Sienna: [interrupts] *. . . and* no one here is really a person of color. Or someone that identifies as LGTBQ . . . I mean, I’m asexual, but still.[xli]

Ice Queen: [wait finger] Maybe, no one that *has* openly identified as being LGBT. I know I didn’t bear all of my soul to Jesse. Remember, we’re not really here, we’re just figments of Jesse’s overactive imagination and it isn’t like we got a *full* understanding of all of who we are by him researching with us. Maybe we shouldn’t assume, you know.[xlii]

*I-Thou* Jesse: True, I just wanted to make sure we were clear that we can’t possibly explore all the intersections of disability in our little group—well, make sure I made it clear . . . not that we could ever explore all of disability as it is so different for all people.

Sienna: Yes, you know, as they say, “If you've met one person with autism, you've met one person with autism.” You could replace “autism” with "disability" there. All people are different, so all experiences are different.

**Erica:** **[singing in delayed response to Culann] "You don't know you're beautiful, oh oh. That's what makes you beautiful. So, come on, you got it wrong. To prove I'm right, I put it in a song."[202]**

Birdie: Right on!

Daren: [crosses arms shaking head] Okay, yeah. It's helpful to uplift yourself, but sometimes other people impact how you feel. There are many times when I may not be in control of the social situations I'm in all the time. Like, stigma, I can't control the way Tourette's has stigma attached to it and how people respond to my twitches. Dealing with stigma is really stressful because I feel like I have to be really careful to not let anyone see anything that is stigmatized because that would draw problematic attention to me. It would be nice to not have to deal with the stigma. [turns to Jesse] You know, earlier you asked about the whole "part of or apart from" thing, and I guess I do think about Tourette as being "apart from" me because, kind of like—who was it that talked about disability as apart when we were talking about the setbacks?

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[202] (Kotecha, Yacoub, & Falk, 2011).

Birdie: [raises finger] Yeah, that was me. I was talking about how I think about epilepsy as this thing that stops me from driving and bothers my family.

Daren: Yeah, that was it. So, beyond the stigma, Tourette's is almost sentient for me. It adapts to all the things I do to control it. That's kind of how I explain it. I don't mean to scare someone, like, "I have something inside of me," no, no, I, no, no, not that. But, it's almost like it knows what I'm trying to do, it's just standing in my way every time. I don't know if other people with Tourette's are like that. It's just how I think it is for me. It can stop me from doing things, you know like Culann was saying about feeling like his learning disability stopped him from doing work meaningful work.

DUKE: Man [smiling and reaching out to Daren] having Williams syndrome doesn't stop me. I think it's good I have it [takes off his sweater and adjusts his Tom Petty t-shirt].

*I-Thou* Jesse: Like Sienna said, everyone's experience is so different.

Sienna: Okay, this is about music and music education, right? [stares at Jesse] Then maybe this question is away from the whole point because, even if we wanted to *not* be disabled, we don't really have that choice.

*I-Thou* Jesse: Yes, sorry to venture off. Yes, the whole project is about experience of disability in, through, and around music.

Sienna: [nods sharply and takes a breath] Okay, well then, I think music is about sending direct and subliminal messages to each other, to express ideas so to communicate and connect with the world. Maybe that should be the focus of music experiences then. It isn’t just your question, but I wish people, especially teachers, would just accept me instead of trying to change me or fix me.[xliii] Umm, if doctors haven’t been able to change my disability yet, the odds are that teachers won’t either. Also, odds are I might not want to change my disability. If I had the option to be sighted, I probably wouldn't take it. I would have developed into a completely different person, and this Sienna wouldn’t exist. Rather than trying to fix us or fix things for us, accept us, accept our disability, accept that it's a part of our identity. Accept that you can't change that and we can't change that and we can't turn it on and off. We definitely can't do it just because you want to [pounds fist on arm of couch].

Accept us even if it's inconvenient for you.

**Erica:** **[singing] "Oh there ain't no other way, baby I was born this way [pointing to torso]. Baby I was born this way [pointing to head]. Oh, there ain't no other way."[203]**

DUKE: Gaga! [smiles] Oh, yeah, "born this way" [walks to Erica to give high five and sits back down].

Culann: [sarcastically] Great . . . that song. You know I get it, but there is some aspect of me that wishes I hadn't been born this way . . .

Birdie: [frowning but quickly smiling and turning to Erica] Yeah, Erica, "right track baby I was born this way."[204]

*I-Thou* Jesse: It might be hard for people to understand that you may be "born this way," that this is complicated in a positive and negative self-identity perspective, and that you wish that people "accept [you] even if it's inconvenient for [them]" . . .

Sienna: . . . [sits on the edge of the couch] Listen, the

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[203] (Gaga, Shadow, Garibay, & RedOne, 2011).

[204] (Gaga, Shadow, Garibay, & RedOne, 2011).

thing is that we are not our disability. Our disability is part of who we are, maybe a big part for some of us, and it impacts every experience we have because it isn’t something that we can turn on and off. But, so are our other identities. We are human beings, first and foremost.

*I-Thou* Jesse: That's a really important point: you are human beings because of and regardless of your identities. So, how do you identify? How do you name who you are and, through that, name your world?[xliv]

Birdie: I'm a female, epileptic, music loving, houseboat living, storm-like visual artist. Call me Birdie.

Duke: I'm the Duke of Downtown. I have Williams syndrome. I'm so stoked, my friend.

Sienna: Who am I? Depending on where I am, what I'm doing at the time, and the social capital valued in the moment, I'll put one identity above the other based on the situation. I can tell you that I experience the world through many different overlapping identities: I'm a woman, a cisgender woman. I'm disabled. I’m queer. I am asexual panromantic. I am Jewish, um, I'm Middle Eastern, white passing. However, regardless of all of those identities, I am a human being.

And that identity, alone, means that I am, I have dignity and worth.

Ice Queen: I'm a flute playing, proud female, sister of ΣAI, marching band fanatic, AHDH, college student, Ice Queen.

Culann: Ah shit, I'm just plain crazy. I have a learning disability, I'm a history buff, I dig fantasy, and feel like 90's grunge and alternative music is the pinnacle of music. If you took a look at my D&D player sheet, it says I'm Culann, a Wood Elf Ranger.

Daren: I'm Daren. Just Daren.

**Erica:** **I'm Erica. Sing with me?**

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***"I-it* jesse" commentary**

[i] I'll comment from a more distant position with research observations, notes from my reflective journals, and draw connections to existing literature in footnotes. When I do so, I am acting in part as an omniscient narrator . . .

[ii] *Performance of self as resistance to performing music*: Culann was clear throughout all of our interactions that performing music is not "congruent" to him, specifically when it involves being forced to perform music and related actions that run counter to how he sees himself. Although performing music might allow Culann to mask his "difference" in certain settings and to manage social interactions (e.g., Goffman, 1959), doing so would not allow him any sense of expressive control over how he performs his self. Performing resistance here is "congruent" with Culann's sense of self, regardless of how stigmatizing or isolating it may be in a particular setting. Culann's strongest social relationships came when we found a group in which he could engage in genuine

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performances of his self and his musicking (i.e., resisting overt performance in music and engaging through music listening and around music by discussing lyrics). Interestingly, Culann does sing along with music when he is by himself and/or when with his friends. Yet, in experiences when required to “perform” music via singing or dancing, Culann would rather perform resistance. Resistance provides him an alternative way to be within a setting.

Resistance provides way of subverting or at least challenging the control of a leader who may have a narrow definition of what musical “performance” and identity performance are and can be in music. Culann’s performance of resistance may point out the illusory rigidity of perceived options for musical and identity performance in music (e.g., Butler, 1990) and the ways that different performances of both music and identity—if they can be separated—can allow for experiences of social inclusion and/or exclusions in and through music. Indeed, Culann’s repeated performance of resistance in music and the “negative” responses of leaders points out the problem of “compulsory able-bodiedness” (McRuer, 2006a, p. 301), if Culann’s descriptions of his musical performance inability are true. The leaders who ask Culann to be in music in ways that are incongruent with his functioning, interests, and identity may be affirming compulsory able-bodiedness without noticing it. What additional ways of being and performing in music might be available for Culann and for others if compulsory able-bodiedness were not enforced? In music learning setting, what new opportunities might be available to all learners without the force of compulsory able-bodiedness?

[iii] *The social confluence of refuge in, through, and around music and musicking:* For both Ice Queen and Culann, experiences in and/or through music can be places of personal refuge, a music asylum (e.g., DeNora, 2013), if you will. For Ice Queen, experiences in music via performance are central to her identity and these experiences often allow for activities in which she finds herself most empowered and agentic. Whereas academic experiences may be difficult and social connections through non-musical experiences require risk and vulnerability, experiences in music via performance are both welcoming and challenging for her. Ice Queen has always found experiences in music, specifically those involving performance, to be easier than experiences in other academic areas. Because of this, she feels more empowered to take on challenges, such as playing difficult solos in concert band. While Ice Queen prefers experiences in music via performance, for Culann, performance experiences in music are places of hostility, inadequacy, and anti-agency in which he is forced to use his voice and body to contort and conform to the edicts of others, many of whom have regularly told him that he lacks “talent” for performing while they require him to do so. Culann finds refuge through listening and through using music to “speak for him.” Culann finds himself and others through music via listening, analyzing, and researching and making use of music and musical phrases from songs he finds congruent. Expressing himself through music, particularly song lyrics, can be a powerful way for him to be vulnerable while also safe because the music speaks, rather than him, directly. Performing himself through music allows him a kind of translucent mask by which to manage social interactions, should his vulnerability open him up to unwanted attention.

Considering Lubet’s (2011) social confluence theory, one might wonder whether meaningful experiences in, through, and around music provide Ice Queen and Culann with places in which they find themselves more as agents than as subjects. Experiences in music, for Ice Queen, and through music, for Culann, are filled with comfort and personal challenge consistent with their intersectional identities and ways of being and doing. With their preferred experiences in and through music, both participants rarely feel disabled socially or individually and neither are required to mask (e.g., Goffman, 1959). Given that each needs a different type of experience to feel comfortable, one might consider how inclusive constructed musicking experiences are for each person through the lens of social confluence (e.g., Lubet, 2009b). This plausible insight challenges conception that there can be a universal approach to inclusive music teaching.

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[iv] *Experiences through music and social connection:* Sienna comments that listening to or performing a piece of music that addresses some issue of social marginalization or oppression can open up ways to connect with others through music. For example, through listening to or performing the music of Hozier and Sister Haze, Sienna finds ways to connect their experience of disability, shaped by oppression and marginalization, with other persons or groups who may have experienced different ways of being/knowing (e.g., experience homosexuality and experience racism) that are also shaped by oppression and marginalization. As suggested by rhizomatic theorists (e.g., Kuppers, 2009, 2011), social connections occur at the intersections of different identities or types of experiences as well as at intersections of DP/PwD's lived experiences of disability.

[v] *Speaking through lyrics:* When Erica speaks through singing the lyrics of others, she is perhaps more straightforward with her intention than some might expect of her based on visual "stigma" symbols (e.g., Goffman, 1963) and her verbal communication. When she sings songs as a response to questions or discussions, the relevance of the song to the conversation may seem overt sometimes. At other times, her meaning might require the listener to possess knowledge about the background of a song or some specific context not available at surface level. Her musical memory, described as her "musicle" or musical muscle by her parents, appears vast, and she uses it to communicate her complex inner world in ways that may not be apparent through speech. If approached only from an IFCD-informed perspective, one might fail to see Erica's musicle and her way of speaking through music, and then question her functional abilities based on external measures of her cognition and speech (e.g., Scambler, 2012) and deem her deviant. This apparent deviancy might lead to policy-informed decisions about her placement in education and social settings as well as the treatments she might be in need of to "fix" the deviancy (e.g., Rioux & Valentine, 2009). Placements and treatments might cast her in a subaltern role in which her utterances may never be recognized (e.g., Campbell, 2005; Nagi, 1991). Her role might then lead to her totalization as only a person "with a developmental disability of unknown etiology" and block others from coming to be-with her in, through, or around music, thereby blocking her from manifesting in others' lifeworlds in ways that are true to her being.

[vi] *Music as "speaking to" and "speaking for" (e.g., Pate, 2012):* Sienna and Birdie spoke of the ways they came into contact with different voices and vibrations through music listening. Pate (2012), noted that during music listening, a person might find moments in which the music resonates deeply with their being in a way they feel that the music, or the music makers, speak to them. For Sienna and Birdie, music seems to allow new presences to enter their lifeworlds as people, perspectives, frequencies, and lines to take shape. These manifestations might "tear [them] out of [themselves] . . . throwing [them] beyond [themselves] into the dry dust of the world, on to the plain earth," to paraphrase Sartre (1947/1970, p. 4), to exist in their internal worlds and walk among the worlds of others who speak to them through the music. For Culann, the songs of his playlists may speak to him in a similar way to the experiences of Sienna and Birdie. Yet, his experiences seem more marked by ways that through music he finds a way to speak for himself. Culann encounters lyrics, ideas, specific musics, and people that resonate with his being and allow aspects of himself to become tangible through the music.

Pate (2012) notes that the "speak to"-"speak for" couplet is highly complex and not a simplistic binary in that things that speak for one appear to speak to them first, before these other voices and "things" become integrated into one's self-concept, which then affords speaking for. For example, the moment Culann heard Kurt Cobain's music, Cobain seemed to speak to him, to disclose his miserable state through music. This resonated with Culann's sense of self and being, providing him with an "other" who had similar characteristics that manifested in Culann's lifeworld.

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At the same time, Cobain provided Culann words and music he could use to create, affirm, and recreate himself—words through which he might come to manifest in the lives of others. Culann came into the presence of others and found ways to connect with others through music.

[vii] *Congruence and resonance through music:* Culann's notion of "congruence" and Birdie's discussion of feeling some things resonating with her could be interpreted from an intersectional perspective (e.g., Crenshaw, 1991; Erevelles & Minear, 2010; Moodley & Graham, 2015). Things that are congruent and that resonate with these participants may be things that connect with multiple aspects of their intersecting identities. For Culann, moody music, music that is epic and tells tragic stories, and lyrics and music that support a questioning of gender role norms all feel congruent for him. These musics intersect with his self-image and subjective experiences rooted in his diagnosis/disabled identity, interest in fantasy/geek identity, and feelings of not being typically "masculine" in his gender role. Birdie is drawn to music and artistic engagements that resonate with aspects of her being and identity. She finds abstract painting to be resonate with (but not triggering of) her seizures, which she also describes as abstract; music such as the Antler's song "Atrophy" deeply resonates with Birdie as do musics she judges to be "timeless" and "authentic." The song "Atrophy" also includes sections that Birdie described as mellow and "a wall of noise," descriptions of sound that might resonate with Birdie's experiences with disability. Beyond concerns of genre preferences, Birdie and many other participants in this study note the importance of finding music and musical activities that resonate with their personhood in an almost ineffable manner. In these ways, participants such as Culann and Birdie may find a reflection of their identities, and their disabilities, through music and, thus, be able to find themselves in the music.

[viii] *Control:* The importance of having "control of" aspects of one's life is prominent in many of the accounts of participants. Culann, Duke, Ice Queen, and Birdie noted the importance of having control over the musical activities in which they engage or the music they hear. Control over one's personal or social identity was also an important facet of accounts of Sienna, Daren, Erica, and Birdie. Birdie and Daren noted concerns over "playing the disability card" and/or otherwise being forced to disclose an attribute that might become a social identity that was stigmatized and might "spoil" their identity (e.g., Goffman, 1963), thus losing "maintenance of expressive control" of their social identities (e.g., Goffman, 1959, p. 33). Culann's attempted suicide in this teen years forced a disclosure but this led to his access to a youth hospital where he found people to connect with through and around music. Sienna's status of being blind gave them access to a residential school with a school-based, community music therapy program that they prized. Yet, neither of these disclosures were completely voluntary..

[ix] *Psychological or psychosocial aspects of disability:* Daren, and others, note the psychological and social aspects of disability experiences in, through, and around music as being of more concern than the diagnostic aspects of disability. These "hidden" psychological and psychosocial aspects of disability may not be observable to others and can easily be overlooked by others, especially if those others are focused on diagnostic criteria or stereotypical symptoms. There is a great deal of interplay between one's impairment, their psychosocial and psychosocial states, and their disability identity (e.g., Shakespeare, 2014; Lubet, 2011; Kuppers, 2011).

[x] *Music as therapeutic 2:* Similar to Birdie's experiences through music, which she found to be therapeutic, Daren uses music and movement therapeutically to shape his experience of disability in music. Not only this, but his experiences can be motivating to him. The choice to engage in something that is intrinsically motivating is a powerful one that many participants discussed as necessary for their experiences in, through, and around music. Lack of choice about the kind of

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music and the kinds or types of experiences in, through, or around music could be disabling, as in the case of Culann when forced to perform. Lacking choice or, more directly agency, could place a participant in a problematic subject position as a dependent other (e.g., Reindal, 1999).

[xi] *Solitary and exclusive musicking:* Daren articulates his enjoyment of solitary experiences in music. Rather than longing for social experiences or to be “included” in group activities, Daren enjoys engaging with music and breaking on his own, seeking social connections when they serve his interests. Culann noted a similar desire for solitary experiences through music. When they explored music as they wished, alone or with social engagement at their discretion, Daren and Culann were no longer bothered by the stress of controlling or masking their identities and/or behaviors that may be stigmatized in social groupings (e.g., Goffman, 1959, 1963). Choice of social engagement arose for other participants as well. Sienna, though a fan of inclusive social music experiences, enjoyed being a part of an exclusive music group for disabled musicians/musicians (i.e., the school-based, community music therapy bluegrass band)—a group of people who share similar music experiences and, possibly, experiences of disability. For some DP/PwD, contexts that are “exclusive” may be more welcoming/hospitable and, potentially, more preferred than mainstreamed contexts (e.g., Rathgeber, 2017). Potentially, exclusive settings or solitary settings may afford spaces where the need to mask or control disability-related identities and symbols can be relaxed. From an intersectional perspective, exclusive groups can provide DP/PwD with chances to interact with peoples whose identities and experiences might be congruent or resonant with the other social actors.

[xii] *Numerous types of independence:* Ice Queen characterized independence in three different ways when she said, “do things on your own or, well, for yourself . . . I used to do a lot of music things for only *me.*” “On your own,” ‘for yourself,” and “for only me” are three different expressions of independence in her experience. Thinking aligned with IFCD suggests that to be independent is to be some sort of completely autonomous agent who is a productive member of capitalist society (Reindal, 1999). Yet, here, Ice Queen defines independence as (a) choice, (b) self-determination, and (c) self-motivated and/or self-serving, the latter of which was not necessarily positive for her.

[xiii] *Social connections around music through experiences in music:* While Sienna spoke of listening and performing as a way to experience connection through music, Ice Queen notes how her experiences in music via performances and her experiences around music in ΣAI and after rehearsals provide ways to connect with others. Here, the connection is still facilitated by shared intersectional identities, such as being a female musician interested in service or being an alto saxophone player in a college marching band, yet the around music connections only arise, for Ice Queen, because of experiences in music via performance. She may not feel direct connections with individuals in music; although she feels a general sense of comradery and group unity in performance, experiences in music provide for opportunities to connect around music.

[xiv] *Music as social disconnector:* As much as many of the participants discuss how experiences in, through, and around music can allow for social connection, Culann and Birdie note that that certain experiences can manifest social disconnection. For Culann, if music, whether genre or activity, is not congruent with who he sees himself to be, then he can feel isolated or alienated. Birdie “dis-cludes” herself from certain settings (e.g., raves, loud music clubs, concerts), kinds of musics (e.g., music that has “flash beats” and music that seems inauthentic), and specific people who engage with these musics and/or in these settings. Similar to the social confluence of disability and inclusion/exclusion (Lubet, 2009a, 2011), solitary and social experiences in,

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through, and around music, for these participants, had to do with the music used, the musical activity engaged, the music itself, and the physical environments and the interactions of those elements with their disabilities as they experienced them.

[xv] *The disability-hyperability binary:* Culann was adamant in his belief about natural talent for specific skills and musical activities. He discussed talent as natural ability or potential that people possess which makes certain activities easier for them. He did not suggest that one cannot engage in an activity without talent for it, but he was concerned with how people might not consider talent in educational settings. Specifically, he felt that not all people had talent for singing, and so attempting to get all people to develop a similar level of skill in singing was an impossible task, to him, and one that might be over-stressed in music learning. He hoped that people would be encouraged to find their own talents. Culann also noted how having a learning disability can stand in the way of finding or realizing one's talent. Culann felt he had a talent for spatial reasoning and the imagination necessary to be an engineer, but his learning disability (dyscalculia) made it impossible for him to use this talent to connect with a career path. Lubet (2009a, 2009b, 2011) addressed the complex interplay of disability and "talent," which he refers to as an assumed hyperability. Lubet also describes the way in which the disability-hyperability binary is an artifact of an exclusionary and highly Western conception of music education as professional development rather than music education as the human musical development (Lubet, 2009b).

[xvi] *Finding oneself through music:* When Culann found "his" music, he began to find himself. The aspects of the music that were congruent with his feelings manifested into his lifeworld, providing a structure for himself to manifest in more clarity into his own lifeworld.

[xvii] *Disability as a means of accessing a "fluid structureless structure" and belonging:* Sienna notes here how their experiences of disability, specifically with a diagnosis, has given them access to a meaningful way to be in music and connect through music. Much like the participant in Bell's (2017) study, Sienna did not experience disability in a salient way in music via playing in bluegrass group. Unlike the participant in Bell's study, however, Sienna first had to experience disability around music by disclosing their impairment or having it disclosed for them, which then allowed access opportunities to be in and through music in the bluegrass band—something that she experienced as a "fluid structureless structure" provided by belonging in the group of people and by Sienna's assumption of the openness of bluegrass music. In this musical practice, Sienna is given space and time to connect with others through a shared interest in the practice and/or repertoire. In and through the music, Sienna finds a sense of belongingness (e.g., Anant, 1966), having a "'we' or 'us' feeling" (p. 22).

[xviii] *Presence and belonging:* Being with Erica means being present with her in music making, to be doing music, rather than talking about and thinking about music or music making. Although one might assume limited communication and connection due to her limited linguistic abilities, Erica uses singing and sharing music with others to find belonging in music. Through musical presence, Erica appears to feel some sense of her needs being met and meaningful participation with another person in a rather quick manner (e.g., Anant, 1966). Presence in music provides for belonging through music. Her experiences of disability manifest different means of communicating and connecting.

[xix] *Self-differentiation:* Ice Queen discusses the importance of being able to choose the level and intensity of her musical engagement. This aspect of choice has strong connections to the concept of "alternative zones of inclusion where people can assert their own versions of ability and

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normality" (Adkins et al., 2012, p. 513) and the power to make a choice concordant with their needs and desires. Rather than having one's path differentiated for them by music teachers, Ice Queen and other participants desire to have options that they can choose from, much like a someone playing a videogame can decide upon the difficulty level or, in open world or role playing games, the chance to literally tailor the adventure to fit their interests and personal situations.

Ice Queen appreciates the ability to self-differentiate or self-select the level of challenge of her experiences in music. Yet challenge and even repertoire are not the only dimensions that participants appreciated having choices and opportunities to self-differentiate. Culann and Daren indicated they appreciated being able to self-select their social immersion, their social "inclusion" in, through, and around music. Being able to engage in small groups, large groups, and alone was an aspect of self-differentiation prized by participants.

[xx] *Connecting around and through music at rock shows:* Attending rock shows and hanging out at concert venues afford Duke opportunities to connect with others around music. The venues attract Duke because of the music, and by attending he makes chances to connect to people by helping bands unload, supporting and making friends laugh, and playing. Being on stage and playing drums provides Duke with spaces for being in music and to connect through the music with others who might give him praise. Duke's performances also may challenge other concert-goers' assumptions about disability—if they read Duke's "stigma symbols" (e.g., Goffman, 1963)—and may open for concert-goers additional viable ways of doing music and being musical through engaging with Duke and his performance of disability (e.g., Laes & Westerlund, 2018).

[xxi] *Attention:* Erica, Ice Queen, and Duke enjoy how positive attention can manifest in their experiences in, through, and around music. Ice Queen noted a long-standing need for attention. The positive attention she receives through music may buck her own internal anxiety and worries about her own competency in other areas of her life. For Erica and Duke, positive attention manifests when they perform in contexts or in ways counter to other social actors' expectations; positive attention manifests when their mask/front (e.g., Goffman, 1959) disappears in ways that are not too disorientating for other social actors. Though this is only conjecture, I worry about whether Duke and Erica become "inspiration porn" (e.g., Grue, 2016) in these moments. The attention, while received in a positive manner, may occur because of low expectations and ableist assumptions audience members have. In these situations, do Erica and Duke manifest in their realness in audience members' lifeworlds, or do they manifest as "wondrous," "sentimental," or "exotic" (e.g., Garland-Thomson, 2002) specters? Regardless of intentions/assumptions of audience members, though, Duke and Erica feel empowered by positive attention.

[xxii] *Infantilization and desexualization of disabled persons - Ableism:* There were numerous times when I infantilized Erica in my mind, questioning the songs she listened to because of references to drugs and sex. These moments felt odd, even insulting to Erica, in reflection, because she is a teenager, she goes to public school, has friends, and access to YouTube and the internet. Why would her "disability" make me think of her as not a teenager? Not only had I infantilized her, I desexualized her, thinking of her unintentionally as a being without sexual feelings. Sienna often railed against the way nondisabled people think that disabled people cannot or do not have sex. As Sienna shared, "Persons with disabilities also have sex. They do, believe it or not . . . Well, some do, it is a personal choice . . . They're normal people with normal people desires . . . Who would have thought?" Both infantilizing and desexualizing, with their paternalistic subject positions and social actions neutralized in power relationships, demonstrate the elements of tacit ableism that circulate in social interactions (e.g., Campbell, 2008; Hahn, 1986; Strickling, 2002).

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[xxiii] *Performing self:* Participants commented directly and indirectly about the performativity of their senses of self. Some performances were true to their sense of self. Other performances involved purposeful fronting (e.g., Goffman, 1959) to mask their “self” for various reasons. Still other performances were forced and informed by the contours of ableism.

Duke’s performance of self is either unfettered by worries of masking because he performs his true self all the time or he happily performs a role created for him by discourse. Birdie performed her authentic self, storm-like and all, even when her performance was disruptive and/or had “violent repercussions” for other social actors who would have to adapt to her performance (e.g., Peers, Brittian, & McRuer, 2012, p. 301). She would dis-cluded herself when she perceived that she could not perform authentically, although this very well may be a masking performance (e.g., Goffman, 1959) through the front of absence from social space.

Sienna’s performances are interesting in that they purposefully mask their “self” to suit the role, literally when on stage, or the social position in which they find themself. Sienna is clear that they want to be seen as whatever performance they are giving. If they are performing as the Baker’s Wife in Into the Woods (Sondheim et al., 1999), they want to be seen as that. If they are performing as a social worker, a disabled advocate, or as a mixture of multiple roles/identities, that is what their self is in that moment. The performance of their self was not through repetition but was shaped and reshaped by context.

Culann’s performance of resistance was subversive and displaced the naturalized and reified notions of being through music (paraphrasing Butler, 1990) that were at work within the contexts in which he enacted his performance. He also masked (e.g., Goffman, 1959) in music when he was worried that aspects of his “mental illness” would become visible to a judgmental crowd (i.e., to avoid “looking crazy”). Daren masked throughout his experiences of disability in, through, and beyond music, including with his friends until he felt he owed them an unmasking, often because of the presence of numerous stigmas.

Erica performs her unique self in music, singing to be and to connect with others. Her performance, however, can be misrecognized, as it was by a past speech therapist and by educators. To understand Erica’s performance of her self, one must enter the music with her and/or find other ways to be present with her. Otherwise, one might impose a performance interpretation on Erica that reinforces ableism and obscures the reality of her as she is.Daren masked throughout his experiences of disability in, through, and beyond music, including with his friends until he felt he owed them an unmasking, often because of the presence of numerous stigmas.

[xxiv] *Disablement of oneself and one’s families:* Birdie’s conception of how epilepsy can be harder on her friends and family than herself provides an interesting extrapolation of the social dimensions of disability. Disability impacts Birdie’s friends and family and this, in turn, causes her anxiety. Birdie may be considered “socially disabled” in that she feels unable to advocate for herself or feels anxiety over the need for help, which she sees as a burden; the narrative of being an independent social actor who does not need others is a barrier for her and potentially an example of internalized ableism (e.g., Campbell, 2008). Yet, the extent to which her friends and family viewed her impairment as disabling to or for her seemed troubling to Birdie and may deserve greater attention by researchers. Birdie’s account articulates the need to consider disability from an interactional rhizomatic perspective (e.g., Kuppers, 2009, 2011)—to consider how disability is experienced by the “disabled person” as well as by their social support network. e-father made a passing reference to a similar complex interaction of disability when he interacts with music teachers, therapists, and other caregivers in Erica’s life. These recognitions by participants expand Shakespeare's notion that “people are disabled by society and by their bodies” (2014, p. 75); “people” in Shakespeare’s quote could include both DP/PwD and nondisabled people.

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[xxv] *Forced disclosure:* Daren specifically addresses the way in which he may feel forced to disclose his disability, specifically when he is unable to manage the visible physical signs of Tourette syndrome or stigmatized social interpretations of those signs of Tourette (e.g. Goffman, 1963). Other participants note experiences of or risks of forced disclosure. For Birdie, self-advocacy for her own safety is at risk when she is *around* specific kinds of music others choose because to ask for an alteration of the music or musical experience may require that she "play the epilepsy card" and, thus, be forced to disclose her disability to others. Sienna's account of how they can be treated differently due to the presences of stigma symbols, such as when they use their cane or wear thick glasses, may force some amount of disclosure. Yet, Sienna also felt able to use disclosure for personal empowerment, to yield disclosure in order to access social capital (e.g., Bourdieu, 1985) in specific situations.

[xxvi] *Being and being through disability:* In interviews, Duke did not go into too much detail about "disability" but he did suggest that his disability, Williams syndrome, may have helped him make friends *around* music. While I do not suggest a cause-and-effect relationship between Duke's diagnosis and his life, a cursory investigation of characteristics of persons diagnosed with Williams syndrome suggests that his impairment may play a greater role in his lived experiences and personal identity than he discusses: "Williams syndrome (WS) is a genetic condition that is present at birth and can affect anyone. It is characterized by medical problems, including cardiovascular disease, developmental delays, and learning challenges. These often occur side by side with striking verbal abilities, highly social personalities and an affinity for music" (Williams syndrome Association, 2018). Duke's being-in-the-world appears to be experienced through or highly shaped by WS. Yet, although many of these seemingly positive "symptoms" seem to resonate with Duke, assuming a negative IFCD risks the danger of losing Duke and blocking his concrete being and manifestations in the lifeworlds of others.

[xxvii] *Depression and anxiety as a background, as not manifest, or the newness of diagnosis:* For Ice Queen, "ADHD" was more salient in her experiences than depression and anxiety. Although she had lived with and through depression and anxiety since early childhood, she did not discuss these diagnoses much. In retrospect, I wondered whether her experiences in music are firmly grounded in or filtered through depression and anxiety to the extent that she cannot conceptualize them without the impairment or if the newness of her ADHD diagnosis made the more salient feature of her experiences. My reliance on participants sharing their stories and meanings with me and the limitation of only three interviews also limited getting to know Ice Queen and her lived experiences in a more substantial way.

[xxviii] *Different types of preferred disability terminology:* Disability terminology is highly contested. What is offensive to one person and what is preferred by another person may be one and the same. Disability and the labels one uses may play an important role in one's personal identity (Ladau, 2015), and how one chooses to identity oneself was a highly important issue for participants in this study. Bloggers and disability rights advocates such as Brown (2011), Monje (2012), and Sinclair (1999/2013) along with scholars such as Bickford (2004) and McRuer (2006b) advocate for empowering DP/PwD to make decisions about their preferred terminology rather than enforcing hegemonic norms articulated in policy and legislation.

[xxix] *Accommodation and inclusion:* Sienna's idea of "accommodating with [them] in mind" is rather similar to Buber's (1965) concept of inclusion in which a teacher acts with the student's existential being inhabiting their consciousness, rather than empty stereotypes guiding their practices. I found it interesting how infrequently participants spoke about "inclusion" as being structurally

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“included” in group (i.e., mainstreamed). Rather, they often spoke of a desire to be included in the lifeworlds of others as full and actualized social beings. They spoke of wants for meaningful relationships and belonging. I explore these issues in greater detail in Chapter Six.

[xxx] *The resilience of naturalized bias and internalized ableism:* In our imagined group conversation, Sienna shies away from saying “inspiration porn” in Erica’s presence, using an initialism. In our interviews for this study, Sienna specifically noted the problem of desexualization and paternalization of disabled persons, yet, they also demonstrated that although they were conscious of these biases, they were not outside of the reach of the highly embedded nature of them in their social life. I often found myself thinking paternalistically about participants, thinking that I should help them when no help was requested and conceiving of some of them in infantilizing ways. Regardless of Sienna’s consciousness of disability rights issues and my own reading and investigation about disability oppression, we both demonstrated paternalistic tendencies rooted in ableism (e.g., Hahn, 1986), specifically with regard to Erica, a person with a “cognitive impairment.” This paternalism extended by people “woke” to disability issues illustrates the resilience of biases and may be symptomatic of internalized ableism. Regarding internalized ableism, Campbell (2008) noted: “The experience of disablement can, arguably, be spoken of not in terms of individualized personal tragedy but in terms of communal trauma, where the legacies of ableism pervade both the conscious and unconscious realms” (p. 155). Perhaps, to draw on the parlance of the times: you can be “woke” to a source of oppression and still be “asleep” in your actions. For music educators who might be inclined toward social justice work, it is possible to work consciously to dismantle ableist structures while unconsiously perpetuating ableist structures.

[xxxi] *Self-differentiation 2 (accommodative freedom):* Participants noted a wish to be proactively accommodated for, yet to have the freedom to reject the accommodation—and to self-accommodate—either for no specific reason or because the accommodation was more oppressive than helpful. As Sienna noted, many participants would rather be offered accommodations than not, but they wished to have control in the decisions of whether and/or how to use the accommodations. Without control, accommodations become the kind of social barriers to inclusion and actualized personhood that Oliver (1983) articulated as a kind of harmful helping. In, through, and around music, Jellison (2012) advocated for something akin to self-differentiation urging for music classrooms and practices where DP/PwD could “experience autonomy, demonstrate competence, and make decisions about music, music making, and other music activities in their lives “(p. 67).

[xxxii] *Diagnoses and stereotypes blocking participants’ manifestation in the consciousness of others:* Participants shared that they wished people would meet them and know them, rather than assume things about them based on diagnostic criteria or stereotypes. Participants wished that others could encounter them in their concrete realness, to allow them to manifest in others’ lifeworlds through deep interaction. Unfortunately, participants implied that they had various experiences in which stigma symbols, bias, ignorance, and assumptions based on their diagnostic criteria and/or stereotypes seemed to manifest as a proxy for them in the lifeworlds of others. By not meeting the person but meeting the diagnosis or stereotype, nondisabled persons disallow concrete manifestations of nondisabled persons in the lifeworlds.

[xxxiii] *Universal treatment:* Participants make it clear that would rather not be treated differently because of their disability, but that they wish that all persons would be offered supportive and empathetic relationships that would help them flourish personally in a given setting or practice. Sienna, with their comment, gets to the heart of the “universal” in “universal design:” all are

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offered help and personalization, not just those "with a disability." Participants alluded to a way in which difference could become visible and normalized in social settings.

[xxxiv] *A reluctance to ask for help and forced disclosure:* Ice Queen, as with Culann and to some extent Erica, have noted a reluctance or inability to ask for help. For Erica, the issue, articulated by her parents, is that she communicates in a way that is not recognized by many. For Ice Queen and Culann, as with Daren and Birdie, the reluctance to ask for help and/or to be self-advocates may be rooted in a worry over forced disclosure and social stigma (e.g., Goffman, 1963). Perhaps, also, ableism informs narratives of self-sufficiency and independence as Swain and French (2000) describe. Once catalyzed in discourse, these narratives subject DP/PwD to internalize ableism (Campbell, 2008), blocking requests for assistance and pride in interdependence.

[xxxv] *Universal/unconditional inclusion:* While participants offered numerous examples of microaggression, the comment offered by Birdie illustrates the type of "universal" inclusion for which participants longed. This type of inclusion often manifested for participants in personalized and non-oppressive types of help that did not force disability disclosure or add to social stigmatization. This type of inclusion involved participants having a high level of choice and self-differentiation. Sienna discussed something akin to unconditional inclusion, acts/gestures extended to all regardless of one's identities, differences, or subject positions. There is danger in this, though, as "treat all the same" may result in whitewashing or able-washing, when the kind of help one expects to be useful is shaped by identities, differences, and subject positions.

[xxxvi] *Physical presence ≠ being included:* Bledsoe (2015) reminds us of the ways music teachers may "confuse presence with inclusion" (p. 22). Culann's comments indicate that people may confuse physical presences with real or relational presence (i.e., the presence of a person in their concrete realness). Perhaps, from a Buberian (1965) perspective, inclusion requires real presence, meeting of the "*I-Thou*" kind in which both *I* and *Thou* connect in a state of *being-with* one another fully without analyzing one another.

[xxxvii] *Microaggressions, inspiration porn, and nondisabled discomfort:* Keller and Galgay (2010) described the way that people may commit microaggressions by being self-serving in their help. Here, Sienna shared how narratives of disabled persons "overcoming" challenges are often celebrated by nondisabled people in a way that overemphasizes disability and normative success over difference and individual personhood. Here, "overcoming" means that DP/PwD are no longer bound by their impairment, which decreases the tension nondisabled social actors feel when faced with disability (Grue, 2016). The disabled person becomes "nondisabled" in the moment of performance of overcoming and nondisabled viewers force a kind of mystification (e.g., Goffman, 1959) upon disabled actors in order to manage nondisabled discomfort and angst in the presence of what they may interpret as a negative identity position. Inspiration porn, for Sienna, is self-serving for nondisabled persons. For more information on inspiration porn, see Stella Young's (2014) "Inspiration porn and the objectification of disability: Stella Young at TEDxSydney 2014."

[xxxviii] *Challenge as portal to becoming:* Culann noted that challenges allow people not only to become who they will become, but also to find out who they are. Numerous participants commented that, all too often, people thought that helping them meant removing all challenge from their path, which was not something they wished for. Rather than true affordances, they often were met with paternalistic and infantilizing "help" in the form of ableist microaggressions (Keller & Galgay, 2010) that got in their way.

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[xxxix] *Disability as central to self:* Birdie's comment, later reiterated by Sienna, indicates the way that disability can be central aspect of the lived experiences of DP/PwD. Since disability is part of Birdie's present, it is impossible for her to fully conceptualize a present without it. Disability shapes one's internal, external, individual, and social experiences. Disability may be so central to one's sense of self because it provides "unique ways of interacting with the human condition . . . showing that [disability] is not an add-on to the human condition, it's an active modifier of it that gives it depth" (Monje, 2012, n.p.).

[xl] *The social barriers of expectation.* Culann points out that social structures and expectations about ability and personality are barriers for him based on his impairment, echoing Cameron (2012), Oliver, Sapey, and Thomas (2012), and other advocates of SFCD. Through policy, social expectations, institutional edicts, and informal social structures, Culann, and all participants, is subjected to social marginalization (e.g., Finkelstein, 2001, Rioux & Valentine, 2006; Shakespeare, 2014). Yet, as Shakespeare (2014) noted, that marginalization feels, looks, and is very different for each participant. Culann and Birdie are clear about their experiences of marginalization, Daren addresses stigmatization, Ice Queen implies social pressures related to her disability, and e-father noted instances of ableism and worries over social isolation. Duke does not directly address social barriers or marginalization, although, at the time of writing this chapter, he has had to move out of his beloved town because his parents do not think he can care for himself—although he often cares for and has cared for his infant-now-toddler sister for long periods of time. Ice Queen does not equate her impairment with social isolation, although, as noted in "*Depression and anxiety as a background*" above, it may be that other impairments/differences ground her experience to the extent that she has internalized the barriers as being inside her and not socially situated.

[xli] *Is the unexamined intersectional life worth researching?:* Cho, Crenshaw, and McCall (2013) suggest the need for intersectional analysis to consider the ways that different identities and types of oppression connect and run in parallel to each other in order to reject "single-axis thinking [that] undermines legal thinking, disciplinary knowledge production, and struggles for social justice" (p. 787). Disability researchers such as Erevelles and Minear (2010) and Moodley and Graham (2015) advocate for intersectional inspections of the lived experiences of disabled persons in order to avoid approaching disability from a single axis. As the participants note in this imaged conversation, they were a rather homogenous group of people: mainly white, mainly cisgender, mainly straight, mainly middle class, all naturalized citizens of the United States, and all native English speakers. Additionally, some participants had similar diagnoses: neurological disorders (i.e., Birdie and Daren), ADHD and/or mood disorder (i.e., Ice Queen and Culann), developmental disabilities (i.e., Erica and Duke).

[xlii] *Partiality of given experiences and manifestations:* As Stein (1989) noted, one cannot be given the experiences and lifeworlds of others completely. All phenomenologies of others can only be partial and the manifestations found should always be seen as tentative (Vagle, 2014). Others cannot fully manifest in one's lifeworld, but additional interactions with others can make manifestations more and more concrete (e.g., Buber, 1965).

[xliii] *Longings for acceptance and belonging:* Participants noted desires to be accepted as who they are, in their complexity and concreteness, including in, through, and around music. Who they are does involve disability, but the what disability was and what manifested through their experiences with disability were always shifting, never stable or consistent. Participants noted that they wanted people to accept them and be with them, rather they trying to remediate them. They wanted people to see them as "real" (e.g., Garland-Thomson, 2002) and to recognize them as of

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equal worth (e.g., Anant, 1966). They wanted to belong, but to belong without the need to fit the needs, desires, and performances expected of them by other social actors.

[xliv] *The power to name:* Freire (1968/2000) noted that “To exist, humanly, is to name the world, to change it. Once named, the world in its turn reappears to the namers as a problem and requires of them a new naming. Human beings are not built in silence” (p. 88). Participants valued chances to name their worlds and their lives. They shared their ways of identifying and, through that, they share a great deal about their lives, their experiences of disability, and the patterns and relationships of their experience that are salient to them (e.g., Shakespeare, 2015, p. 3). How participants identify may speak much of how they conceive of disability (e.g., Cameron, 2014), their sense of belongings (e.g. Anant, 1966; McDermott & Varenne, 1995), and their intersectional situatedness (e.g., Crenshaw, 1991; Kuppers, 2014).