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The Oxford Handbook *of* MUSIC AND DISABILITY STUDIES

THE OXFORD HANDBOOK OF

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Edited by
BLAKE HOWE,
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This book was Suzanne Ryan's idea. She recognized that the emerging subfield of music and disability had begun to attract widespread attention and had reached sufficient maturity to merit an Oxford Handbook, and she committed the resources of Oxford University Press to the enterprise. After we assembled our dream team of contributors, scholars from every corner of our discipline and at every career stage, we convened an author's conference at the City University of New York Graduate Center in May 2013, generously underwritten by City University of New York administrators William Ebenstein and Christopher Rosa. At this conference, we exchanged early drafts and engaged in intense discussion and critique, forging an intellectual community and laying the groundwork for what has been a profoundly collaborative enterprise: every essay in this book is the product of communal effort. As the book neared completion, we benefited from the assistance of many people, including Inés Thiebault and Tom Johnson (who prepared some of the musical examples) and an outstanding editorial team at Oxford University Press. Above all, we are grateful to the authors in this collection whose intellectual and emotional commitment to our shared issues and ideals has been an inspiration to us.

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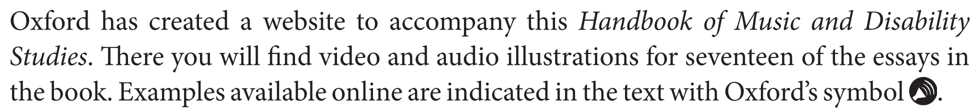

Oxford has created a website to accompany this *Handbook of Music and Disability Studies*. There you will find video and audio illustrations for seventeen of the essays in the book. Examples available online are indicated in the text with Oxford's symbol .

THE OXFORD HANDBOOK OF

MUSIC AND DISABILITY STUDIES

INTRODUCTION

Disability Studies in Music, Music in Disability Studies

BLAKE HOWE, STEPHANIE JENSEN-MOULTON, NEIL LERNER, AND JOSEPH STRAUS

Cultural Disability Studies

In recent years, disability has emerged as a category of cultural analysis in the humanities, tracking the earlier trajectories of gender, sexuality, and race/ethnicity. Emerging with the disability rights movement of the late 1980s (which led to the passage of the Americans with Disabilities Act of 1990), the new, interdisciplinary field of Disability Studies has offered a sociopolitical analysis of disability, focusing on its social construction and shifting attention from biology to culture.[1] The medical sciences consider disability a deficit with respect to normal standards of good health and seek diagnosis and cure. In contrast, Disability Studies explores the social, cultural, and political meanings of disability with the goal of understanding human variety and difference. At the core of this field is the contention that, although it may have a concrete, somatic basis, disability is endowed with meaning by elaborate interpretive networks that emerge within particular societies and cultures. Disability is simultaneously real, tangible, and physical and also an imaginative construct whose purpose is to make sense of the diversity of human morphology, capability, and behavior. While we may relegate the study of biological impairments to the medical establishment, this cultural study of disability has been energetically undertaken by humanists from a variety of disciplines.

The word *disability* forges a binary between what one can do (ability) and what one cannot do (dis-ability). Indeed, disability throughout history has often emerged as an antithesis to some other desirable standard. Before the nineteenth century, this standard was often imagined as an idealized body: the body of God, Adam before the Fall, the King, the cosmos, or some other perfection, from which all human bodies were poorly fractioned and morally compromised. This is the moral or religious model of

disability, in which bodily differences are stigmatized as deviant from some elusive ideal. Beginning in the nineteenth century, this "ideal body" was usurped by the "normal body." Normalcy, a concept popularized by the rise of statistics, imagines human morphology on a bell-shaped curve: most people are of average height, while some are too tall, and others are too short. This is the medical model of disability, in which disabled people are cast as outliers, requiring either rehabilitation by medical science or elimination by eugenics (Davis 1995).

More recently, the social model of disability, advocated in politics by the disability rights movement and in scholarship by Disability Studies, has argued for the value of bodily difference. Under this model, disability is not a fixed, medical condition; rather, it emerges from a society that chooses to accommodate some bodies and exclude others. As Davis 2002 explains, "An impairment involves a loss or diminution of sight, hearing, mobility, mental ability, and so on. But an impairment only becomes a disability when the ambient society creates environments with barriers" (41). Indeed, Straus 2006 defines disability as "any culturally stigmatized bodily difference" (119): bodies themselves are neutrally defined, accruing their stigma only through cultural reception. A wheelchair user is disabled by curbs, but not by sloped curbs. A deaf person is disabled by oral language, but not by sign language. Noting the ubiquity of accommodation that all bodies (disabled or nondisabled) receive, some scholars have recently sought to reconceive bodily difference without hierarchy. For example, Davis 2013 seeks "a new category [of identity] based on the partial, incomplete subject, whose realization is not autonomy and independence, but dependency and interdependence" (275).

As claimed in Sandahl and Auslander 2005, the social model casts disability not as a fixed physical or mental state, but as a process: "To think of disability not as a physical condition but as a way of interacting with a world that is frequently inhospitable is to think of disability in performative terms—as something one *does* rather than something one *is*" (10). This argument, linking disability with performance, is long-standing, as Davidson 2008 explains: "From nineteenth-century freak shows and carnival acts, through the photographic displays of eugenics textbooks to Jerry Lewis telethons, disability has been synonymous with the theatrical display of 'different' bodies" (18–19).[2] Much scholarship within Disability Studies has examined these and other "theatrical displays," drawing parallels between the social performance of disability and its similar performances on stage—whether within the dehumanizing frame of the freak show (Garland-Thomson 1996; Adams 2001), or in newly liberatory scripts associated with dance (Albright 1997) and performance art and theatre (Sandahl and Auslander 2005).

Marked against prevailing social norms, the disabled body has often served a rhetorical function within narrative. As Garland-Thomson 1997 argues, "A disability functions only as visual difference that signals meaning. Consequently, literary texts necessarily make disabled characters into freaks, stripped of normalizing contexts and engulfed by a single stigmatic trait" (10–11)—from Captain Ahab to Captain Hook. Many narratives, requiring tension before release, requiring a problem before its resolution, appropriate

disability as their obstacle of choice. Mitchell and Snyder (2000) have termed this appropriation of disability "narrative prosthesis." The narrative prosthesis (usually a disabled character within a story) has two main functions: it gives the story a problem to solve; and it defines by counterexample the desirability of the subsequent resolution.

Disability scholars have identified some familiar scenarios that narratives use when confronted with the apparent problem of disability. Most commonly, the disability may be rehabilitated, or the disabled character may be expelled. This is what one disability scholar terms the "cure or kill" paradigm, drawn from a "cultural logic of euthanasia" that "draws a sharp distinction between disabled bodies imagined as redeemable and others considered disposable. One approach would rehabilitate disabled bodies; the other would eliminate them" (Garland-Thomson 2004, 779). (Thus, Captain Ahab is swallowed by a whale and Captain Hook is swallowed by a crocodile.) Other common scenarios involve a disabled figure overcoming disability by acquiring superpowers that render his or her disability moot, or passing as able-bodied so that the disability is nearly undetectable; the film *Avatar* (2009) traffics in both tropes.

None of these narrative strategies appreciates disability as a valid and stable mode of embodiment; it is a disruptive abnormality, one that requires a compensatory solution (curing, killing, overcoming, or passing). In contrast, at the ethical core of Disability Studies is an argument for placing a positive value on formerly stigmatized bodily differences. When assessing disabled bodies and the activities of people with disabilities, Disability Studies is interested in what the disability has enabled and in what has been achieved not in spite of disability, or as an overcoming of disability, but rather by, through, and because of disability.

Brief History of Disability Studies in Relation to Music

Musicology (including ethnomusicology and music theory) has been a relatively recent arrival within Disability Studies, and has witnessed an impressive burst of scholarly activity since around 2005.[3] In the process, while musical scholars have found many different ways of applying the insights of Disability Studies to the study of music, they have also made a significant contribution from their musical vantage point to the study of disability.

Musical scholars began to take note of disability issues in 2004 with a panel discussion at a meeting of the American Musicological Society. Several of the participants in that panel later contributed to a published collection of essays coedited by Neil Lerner and Joseph Straus (2006), who return as two of the four coeditors of the present volume. That was the first published collection of essays to bring music and disability into a productive relationship. Several of its contributors (Stephanie Jensen-Moulton, Jennifer Iverson, Laurie Stras, and Marianne Kielian-Gilbert) have contributed to the present

collection—Jensen-Moulton as its third coeditor, and all four as authors. In the ensuing years, musical scholars, including many of the contributors to this Handbook, have shaped this new subfield and brought it to an early maturity.

The central theoretical categories of cultural Disability Studies have proven extraordinarily fruitful in the study of music. First, disability has been shown to be a core feature of the musical identity of music makers (especially composers and performers), often an identity that is affirmatively *claimed* in the face of widespread stigma (Linton 1998). For example, Blake Howe (the fourth of our four coeditors) has explored the ways that Paul Wittgenstein claimed the identity of a one-handed pianist through a series of prominent commissions, and saw the critical reception of his performances refracted through the lens of disability (Howe 2010b). Similarly, Honisch 2009 seeks to understand how physical disability can be "re-narrated" through musical performance, providing an aural medium for the self-expression of disability identity. Although disability has typically been interpreted as a defect or abnormality, these and other studies have sought to understand disability as an important and valuable component of identity, akin to gender, sexuality, and race; notably, this negotiation of identity can occur in the cultural domains of music.

Second, disability has inflected reception of the lives and work of composers and performers. If the composer or performer is identified as having a disability, the language that accretes around them tends to incorporate a rich (if predictable and stereotypical) network of disability-related metaphors. Thus Beethoven is understood as a Heroic Overcomer—someone whose music and life represents a triumph over deafness; Evelyn Glennie and Thomas Quasthoff are understood as Saintly Sages—their disabilities are understood to confer on them a higher, transcendent wisdom; Glenn Gould and Robert Schumann are Mad Geniuses—their work is both marred and ennobled by disability.[4]

In their reception these composers and performers are (to return to the terminology of Garland-Thomson 1997, cited earlier) "engulfed by a single stigmatic trait." Although Disability Studies argues for the cultural significance of disability, the process of "engulfment" results in its overdetermination: because of its marked status, disability is often treated as the most important (and perhaps only) governing feature of a person's life and career. As Lerner 2006 argues, "To claim the title *pianist*, one must have two functioning hands. With only one functioning hand, someone who wishes to play the piano becomes not a pianist but a one-handed pianist" (75). Against the norms of music composition and performance, "disabled music" composed by or for "disabled musicians" is almost always branded as such.

Third, although music is a famously nonrepresentational art form, scholars have shown that musical works represent disability in various ways. Through harmonic imbalance, melodic disfluency, or formal deformations, musical texts may be said to embody various disabled states; indeed, according to Straus 2006 and 2011, many theoretical traditions (including organicism, energetics, embodiment, the *Formenlehre*) commonly apply metaphors of disability to describe various states of musical dysfunction. These tools have helped some scholars seek to locate signs of a disabled

composer's identity within his or her musical language: for example, expressions of madness in Alkan's music (Burstein 2006), expressions of autism in "Blind Tom" Wiggins's music (Jensen-Moulton 2006), and expressions of aging in the "late styles" of Bartók, Schoenberg, and Copland (Straus 2008). Complementary texts, such as song lyrics, symphonic programs, opera librettos, and film, can further specify the presence of a disability within a musical work. These representations of disability tend to follow familiar cultural scripts and archetypes—for instance, the associations between disfigurement and derangement (*Rigoletto*), between stuttering and feeblemindedness (Vašek in *The Bartered Bride*), and between blindness and prophecy (Tiresias in *Oedipus Rex*). Of course, there is no medical basis for these associations; they are entirely cultural.

Beyond the direct representation of disability, music has also been shown to embody certain narrative trajectories that engage disability, most commonly through the "cure or kill" paradigm. For example, in *Lucia Di Lammermoor*, Lucia's madness presents Act III with an extreme problem, one that disrupts the normal social order: her subsequent death rehabilitates this chaos. In opera, we might think of the many mad characters in opera who regain their reason just before curtain call (Handel's Orlando or Paisiello's Nina). We might also think of the many mad characters who do not last that long (Wozzeck or Peter Grimes). The mechanism of the "cure" need not be strictly medical. For example, Grave 2008 examines narratives of recuperation, transformation, and transcendence in the string quartets of Haydn. Roughly contemporaneous with the rise of the medical model of disability, these and other musical narratives in the late eighteenth and early nineteenth centuries introduce rhythmic or tonal disruptions subsequently remediated over the course of the work (see also Straus 2011). These are enduring tropes: Singer 2010 identifies compensatory narratives about blindness in the songs and writings of Machaut and Landini.

Finally, and perhaps most important, music has proven a fertile ground for exploring the contention within Disability Studies that disability (like gender) can be understood as a performance: something you do rather than something you are. In particular, musical performers with disabilities have the dual task of performing their music and their disabilities, and these two sorts of performances are intertwined (Straus 2011). Recent studies of Glenn Gould (Maloney 2006), Paul Wittgenstein (Howe 2010b), and Thomas Quasthoff (Straus 2011) have developed this theme, examining how the reception of disabled musicians so often accounts for both performances—musical and social. In a related vein, Stras 2006 offers a compelling example of the cultural malleability of disability within a musical context: vocal trauma (such as hoarseness) is profoundly disabling for performers of opera, but not for performers of many popular genres like the blues, where such scratchy timbres are culturally valuable.[5] This is a provocative and important example of the cultural model of disability: impairments can be stigmatizing and enabling in different cultural contexts. What is interesting (and, for many disability scholars, ethical) about this model of disability is that it assigns stigma not to the imperfect person or to the abnormal person, but rather to the exclusionary societies that fail to accommodate bodily differences.

This Handbook

This Handbook is tangible evidence of a field that is mature enough to have spawned an impressive array of scholarship that shares a common point of departure, grounded within cultural Disability Studies, yet still young enough that a spirit of pioneering energy is felt in every essay, where virtually every topic represents a first encounter. The diversity of these essays is as impressive as their originality. The chronology of the subject matter ranges from the biblical (Howe), the medieval (Singer, Cuthbert), and the Elizabethan (Bassler, Leonard), through the canonical classics of the eighteenth and nineteenth centuries (Graves, Sisman, Quaglia, Deaville), up to modernist styles (Straus, Gimbel, Lee) and contemporary musical theatre and popular genres (Iverson, Maler, Jones, McKay, Fox, Knapp), with stops along the way in post–Civil War America (Accinno, Burke), Ghana and the South Pacific (Hogan, Schwarz), and many other interesting times and places. Disability is a broad, heterogeneous, and porous identity, and that diversity is reflected in the variety of bodily conditions under discussion here, including autism and intellectual disability (Bakan, Carlson, Straus), deafness (Maler, Jones), blindness (Fulton, Hogan, Sykes, Johnson, Honisch, Cuthbert, Lerner), and mobility impairment often coupled with bodily deformity (Accinno, Burke, Law, Lee, Leonard, Murray, Straus).

Cultural Disability Studies has, from its inception, been oriented toward physical and sensory disabilities, and has generally been less effective in dealing with cognitive and intellectual impairments and with the sorts of emotions and behaviors that in our era are often medicalized as "mental illness." In that context, it is notable that so many of these essays are centrally concerned with madness, that broad and ever-shifting cultural category (Bassler, Beckerman, Deaville, Howe, Jensen-Moulton, Keyes, Schwarz, Singer, Sisman). This is one of the areas in which musical scholars have their opportunity to make a significant contribution to Disability Studies—our nonverbal art form may make it easier for us to discuss the representation of affective states, without the distractions of narrative or dramatic language. There is also a perhaps surprising diversity of subject matter—it turns out that disability is everywhere when you start looking for it—including YouTube videos (Maler), Ghanaian drumming (Hogan), Cirque du Soleil (Jensen-Moulton), piano competitions (Honisch), castrati (Law), Hollywood films (Lerner), medieval smoking songs (Singer), and popular musicals (Knapp, Fox, Sternfeld).

Amid this diversity of time, place, style, medium, and topic, these essays share two core commitments. First, they are united in their theoretical and methodological connection to Disability Studies, especially its central idea that disability is a social and cultural construction. Disability both shapes and is shaped by culture, including musical culture. Second, these essays individually and collectively make the case that disability is not something at the periphery of culture and music, but something central to our art and to our humanity.

Beyond those central commitments, we note seven general themes that animate these essays:

1. **Normalcy**. Many of these essays probe the boundary between the *normal* and *disabled*, terms that have been defined historically in relation to each other (Iverson, Kielian-Gilbert). Traditionally, that process of definition unfolds within the prevailing medical model, with its orientation toward diagnosis and cure of perceived deficits. Medical models themselves, however, are historically contingent, and many of these essays explore and challenge medical explanations ranging from humors to modern psychiatry and neurology (Singer, Cuthbert, Sisman, Jensen-Moulton, Deaville, Straus). Disability and normality are both cultural constructions. They emerge in parallel, intertwined, mutually influential ways, and music plays a central role both in embodying and shaping them.
2. **Otherness**. In music, as in art, literature, and film, disability is often inflected by and intertwined with race/ethnicity, gender, and sexuality. It is not essential to agree with Mitchell and Snyder (2000) that "disability is the master trope of human disqualification" (2–3) to recognize that the stigmatizing and othering of personal identity takes similar forms in each of these domains. Some of these essays take race/ethnicity, gender, or sexuality as their principal topic (Maus, Kielian-Gilbert, Murray); many others weave these concerns into their narratives.
3. **Enfreakment**. In artistic representations, as in life, people with disabilities are often depicted in negative ways, confined to narrow and stigmatized roles. In film and in literature, these roles include Obsessive Avengers, Charity Cripples, and Mad Geniuses (Kriegel 1987; Norden 1996). Such stereotypes have the effect of othering these "starees," causing us to look down at them in pity for their deficits, or across a vast distance at them in amazement or horror at their exoticism or freakishness, or up at them in awe of their apparently superhuman difference.[6] Indeed, many of these essays invoke the tradition of the "freak show" as a paradigm for the stigmatizing perception of extraordinary bodies (Jensen-Moulton, Stras, Sternfeld, Accinno). In the process, many of these essays interrogate the most punishing complex of metaphors that have accreted around disability, metaphors that take disability as a sign of irreducible otherness, including moral evil (Bassler, Howe, Leonard, Hogan, Lee, Sternfeld). The explicit or implicit goal of virtually all of the essays is not to ignore disability or to pretend that it is irrelevant, but instead to find a realistic mode of looking at and thinking about disability.
4. **Commotion**. Many of these essays acknowledge the subversive potential of disability to undermine and disrupt normal, conventional ways of doing things, both in art and in life. When disability comes onto the scene, it creates a commotion (Sandahl and Auslander 2005). Within musical narratives, disability often enters as a disruptive problem, which the music may expel, overcome, accommodate, or perhaps embrace. In such works, disability functions as a narrative prosthesis, enacting a drama that simultaneously calls attention to and attempts to efface disability (Howe, Grave, Quaglia).

5. **Self-Representation**. One of the slogans of the disability rights movement is "nothing about us without us." In most times and places, people with disabilities have had their economic, social, and cultural lives significantly circumscribed by ambient political and cultural structures. Many of these essays chart and celebrate a countervailing trend toward disability communities formed, in part, around music making, which becomes an important mode of self-expression and self-representation (Santoro, Honisch, Bakan, Carlson, Jones, Maler, Sykes, Hogan, Johnson, Accinno, Schwarz).
6. **Performance**. Many of these essays deal directly with the onstage musical performances of performers with disabilities (Bakan, Jones, Hogan, Sykes, Maler, Howe, Honisch, Fulton, Law, Murray, Accinno, Knapp, Stras, Jensen-Moulton, Straus). Virtually all of them deal with disability as a performed identity. Onstage and off, people with disabilities construct their identity by making their disability visible (audible) in particular ways.
7. **Myths of Autonomy**. Many able-bodied people ("normates" in Garland-Thomson's [1997] useful formulation that calls attention to the constructed nature of the concept of normality), cling to an ideology of autonomy: every person is (or should be) independent and self-supporting. People with disabilities generally know better than that, and understand the networks of mutual dependence, care, and assistance that bind us all together. A critique of the ideology of autonomy and a related interest in subverting the boundary between normal ability and disability is a theme in many of these essays (Iverson, Fulton, Stras, Howe, Lerner).

Developing these and other themes, the essays in this volume examine familiar musical topics—and uncover new ones—from the fresh perspective of Disability Studies. They also address an important lacuna within a Disability Studies that has mostly overlooked (or underheard) the musical arts as a medium through which disability has been and continues to be constructed. Indeed, as much as a cultural understanding of disability can teach us about music, music also has much to teach us about the culture of disability.

Notes

1. Among the principal publications in Disability Studies in the humanities, sometimes referred to as "cultural disability studies," all from the past fifteen years, see Albrecht et al. 2001; Bauman 2008; Corker and French 1999; Corker and Shakespeare 2002; Couser 1997; Davidson 2008; Davis 1995, 2002, 2008, and 2013; Garland-Thomson, 1997 and 2009; Kuppers 2001; Linton 1998; Longmore 2003; Longmore and Umansky 2001; McRuer 2006; Mitchell and Snyder 1997 and 2000; Poore 2009; Sandahl and Auslander 2005; Scully 2008; Shakespeare 2006; Siebers 2008 and 2010; Smith and Hutchison 2004; and Wendell 1996.
2. The freak show is a common point of reference for cultural disability studies. See Adams 2001 and Garland-Thomson 1996.

3. The book-length literature on music and Disability Studies prior to the current volume includes Howe 2010a, Lerner and Straus 2006, Lubet 2011, McKay 2013, Rowden 2009, and Straus 2011. See also special issues of two journals: *Music Theory Online* 15 (3–4) (2009) and *Popular Music* 28 (3) (2009). For a complete bibliography of publications in this area, see http://musicdisabilitystudies.wordpress.com/reading-list-for-disability-and-music/.
4. For typologies of disability representations, see Kriegel 1987 and Norden 1996. This issue is explored in a musical context in Straus 2011.
5. For additional consideration of vocal disfluency as a contextually defined disability, see Goldmark 2006 and Oster 2006.
6. "Staree" is a coinage of Rosemarie Garland-Thomson (2009), as are the modes of staring described in the rest of this paragraph.

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PART 1

DISABILITY COMMUNITIES

CHAPTER 1

TOWARD AN ETHNOGRAPHIC MODEL OF DISABILITY IN THE ETHNOMUSICOLOGY OF AUTISM

MICHAEL B. BAKAN

> *Who says autism is a bad thing? . . . Autism isn't cholera; it isn't some disease you can just cure. . . . And there is no cure. There really isn't. It's just there, wound into your personality.*
>
> —Mara Chasar

The Centers for Disease Control and Prevention (CDC) estimates that approximately one out of every sixty-eight children in the United States is affected by an ASD, or autism spectrum disorder. The rate of prevalence is much higher among boys than girls, and the overall rate of ASD (aka ASC, or autism spectrum condition, a preferable though less widely used designation) has risen sharply in recent decades. For example, as recently as the year 2000 the CDC estimate of rate of incidence was just one in 150 (CDC 2015).

Medical sources describe autism as a neurodevelopmental disorder with an early childhood onset and a pervasive lifelong course; its scope of impact is both biological and social. Key criteria for the diagnosis of autism include "delays and atypicalities in reciprocal social interaction; impaired development of language and communication skills; and highly circumscribed, stereotypic behaviors and interests" (Sirota 2010, 94; see also American Psychiatric Association 2000, 2013).

Autism is conceptualized as "a spectrum disorder that includes a broad range of manifestations," and people diagnosed with autism disorder or with related spectrum conditions such as Asperger syndrome and PDD-NOS (pervasive developmental disorder—not otherwise specified)[1] "span a wide continuum and may demonstrate functional capacities that range from profoundly limited to extraordinarily gifted" (Sirota 2010, 94).[2]

Yet in spite of this heterogeneity, writes anthropologist Karen Sirota (2010, 94), people across the entire spectrum of autism "have often been portrayed in the professional literature and the popular media as asocial creatures bereft of words and subjective worldviews." In turn, they have been cast as suffering from "an inability to co-create culture" (Vinden and Astington 2000, 515). With the medicalization of their personhood framed against a triadic backdrop of "inability, lack, and loss" (Titchkosky 2007, 8), individuals diagnosed with ASD are customarily mapped onto a larger topography of disability that has become virtually inextricable from pervasive tropes of absence, negation, and abnormality. The "concept of disability," writes Rosemarie Garland-Thomson (1997, 24), "unites a highly marked, heterogeneous group whose only commonality is being considered abnormal." This leads to recognition of a "negating sort" for the disabled-labeled individual, to what Judith Butler has described as "a form of qualified recognition that does not lead to a viable life" and that is founded on an often unarticulated premise that certain individuals and classes of individuals are categorically recognized as less human than others (Butler 2004, 2; see also Titchkosky 2007, 8).

"Our Autism is called a 'tragedy' or even, by some parent groups, 'the enemy' to be fought at all costs," writes autistic self-advocate Penni Winter in the landmark 2012 volume *Loud Hands: Autistic People, Speaking*.[3] "We're said to 'ruin' our parents' lives and break up marriages, and we get discussed in terms of the 'burden' we are on our families, the 'difficulty' we cause others. What we might feel or think or want is hardly even asked—because, oh yeah, that's right, we don't *have* feelings or needs" (Winter 2012, 119).

But as Julia Bascom, in her Foreword to *Loud Hands*, asserts, this need not—and should not—be the status quo. "Autistic brains are different from non-autistic brains—not better or worse, just different," she explains. "Autistic voices, similarly, can take different forms or styles or express different things through different means than non-autistic voices. These facts are simple and neutral, but regularly obscured and overridden by cultural scripts and fallacies demanding broken, voiceless not-people stranded by huge chasms from the rest of the world in place of everyday autistics" (Bascom 2012a: 8, 10).

The better way forward, states Bascom, "starts with the basic, foundational idea that *there is nothing wrong with us*. We are fine. We are complete, complex, human beings leading rich and meaningful existences and deserving dignity, respect, human rights, and the primary voice in the conversation about us" (Bascom 2012a, 10). There is a pressing need to move toward the achievement of social and cultural environments wherein, to quote the anthropologist Elizabeth Fein, the "interaction between autistic individuals and their social surroundings is a bi-directional process of influence, in which social practices influence autistic individuals while the characteristic needs, behaviors, and communicative styles of those individuals also shape the communicative practice of their surroundings" (Fein 2012, 31).[4]

The Artism Ensemble, a neurodiverse group that features children on the autism spectrum performing original music together with their parents and professional musicians, is committed to such goals.[5] The ensemble and the larger Artism Music Project of which it is a part have been central to my activities as a musician and ethnomusicologist

for the past several years. Anthropologists Olga Solomon and Nancy Bagatell have called for "movement away from dominant biomedical discourses that focus largely on symptoms to a more phenomenological and ethnographic stance that addresses experiences of living with autism" (Solomon and Bagatell 2010, 1). Artism may be regarded as a musical and ethnomusicological response to that call. It belongs to a large and ever growing movement of advocacy and epistemological reconfiguration that encompasses intersecting streams flowing through the autistic self-advocacy movement, Disability Studies, the disability rights movement, the philosophy of disability, linguistic anthropology, cultural anthropology, comparative human development, and certain sectors and cohorts within music disciplines including historical musicology, music theory, music education, and music therapy.[6] Artism draws on and cuts across much of this broadly interdisciplinary landscape while remaining primarily ethnomusicological in its foundations and orientation. To pinpoint its identity even more precisely, Artism is an applied ethnomusicology endeavor, in the sense that Jeff Todd Titon has defined *applied ethnomusicology* as "the process of putting ethnomusicological research to practical use" (Titon 2011).[7]

In this essay, I explore Artism ethnomusicologically and use that exploration as a springboard for larger discussions relating to issues of autistic self-advocacy, Disability Studies and rights, the anthropology of autism, and epistemological and pragmatic debates and consequences of competing autism discourses and philosophies. I propose an ethnographic model of disability as a potential alternative and complement to the existing social and medical models, and I endeavor to create a polyvocal narrative that weaves together my own words and ideas with those of child members of the Artism Ensemble, autistic self-advocates, and scholars from a range of disciplines, most especially Disability Studies and the anthropology of autism.

My core argument is that musical projects like Artism hold the capacity to contribute productively and meaningfully to the causes of autistic self-advocacy and quality of life, modeling new horizons of possibility for the cultivation of neurodiverse environments of cultural co-creation and self-determination while transforming public perceptions of autism from the customary tropes of deficit, disorder, despair, hopelessness, and stigma to alternate visions of wholeness, ability, diversity, possibility, and acceptance. In this sense, such projects might be described as having a therapeutic potential, not by virtue of their capacity to correct or reduce the so-called symptoms of autism or other forms of neurodiversity, but conversely on account of their power to modulate public perceptions away from assumptions and paradigms of pathology while at the same time creating productive spaces in which neurodivergent people have freedom and agency to be themselves on their own terms.

I will additionally engage Artism from a more critical perspective. The need to do so is based on my realization that despite its mission to challenge and move beyond the limiting constraints and typologies of conventional autism-related discourse and practice it critiques, the project, at least as currently configured, remains entrapped in some of the very negating constructs it ostensibly defies, sometimes in ways that are remediable, other times in ways that are intractable.

The Artism Music Project: A Different Way of Doing Things

Twelve-year-old Mara moves back and forth between her preferred black "spinny chair" and the two filing cabinets against my office wall. As she paces, she talks about her own compositions and those of her three fellow ASD-diagnosed child members of the Artism Ensemble:

> You know, I like to make my songs funny. And NICKstr likes to make his songs really precise. E.S. liked to make her songs quiet. And Coffeebot likes to make his songs precise and sort of loud, and he really likes the steel drum. Me, I really like all their songs. They're always so great. . . . And honestly, it's really cool seeing all these kids come up with different songs and different styles of songs.
>
> And of course the Autism Ensemble [*sic*] is not a cure. I don't treat it like a cure, because it isn't, and if you call it a cure I will disagree with you. It's simply the kind of way you can calm down and, you know, help with the bad parts of autism without restricting the good parts. . . . What I [mean by that] is that Artism kind of helps with my anger issues without restricting my creativity. . . .
>
> It's the fact that I'm allowed to bang on drums for a while—and any instrument I want (as long as I don't break it or it's not meant to be banged)—without anybody telling me I'm supposed to do it this way, or I'm supposed to do it that way, or I'm supposed to put *this* there or that THERE, or I'm doing it wrong. . . . Because I'm told that every day. I want a break from it! . . . It's just nice being there with other people without them telling me what to do, or just jabbering about all the things they can do that I can't. . . .
>
> We're all just kids in the end. I mean, that's the whole point. We're all just kids in the end. Who friggin' cares whether we're autistic or not? Why does it matter?

ARTISM is an acronym for "Autism: Responding Together In Sound and Movement." The Artism Ensemble is a neurodiverse, intergenerational, and intercultural creative music performance collective that features four to five children with autism spectrum conditions,[8] their co-participating parents, and professional musicians of diverse musicultural background performing improvisation-driven music together on an E-WoMP, or Exploratory World Music Playground. The E-WoMP comprises a large array of percussion instruments that both the child and adult players are free to explore, as they wish to and on their own terms, individually or collectively; thus the "playground" identifier in the name. Most of the E-WoMP's instruments were manufactured by the Remo percussion instrument company and are modeled after traditional drums and other percussion instruments originating in West Africa, Latin America, Native America, and other world regions. They include *djembes*, congas, bongos, ocean drums, thunder tubes, *cuicas*, a Native American–type gathering drum, tom-toms, egg shakers, and steelpans (steel drums), among many others. All instruments selected for the E-WoMP

must meet two basic requirements: high yield for low input (i.e., easy to produce pleasing/satisfying sounds without need of specialized training) and safety for use by the children in the program. Flexible rubber swimming pool dive sticks are the main types of mallets, and other mallets and sticks with padded or rubber ends are used to ensure optimal safety as well. The use of rubber and padded beaters also helps to prevent the production of excessively loud sounds and harsh timbres, which is important given that people on the autism spectrum often have sensory challenges including a high level of sensitivity to loud and abrasive sounds.

Artism's staff musicians play both the E-WoMP percussion instruments and their own instruments, including guitar, bass, steelpan, flute, and clarinet. In previous years, other instruments, such as the *zheng* Chinese zither and the Aboriginal Australian *didgeridoo*, were also featured. The diverse backgrounds of the musicians on staff, which has included master musicians/ethnomusicologists from Peru, Trinidad, Bolivia, and China as well as Canada and different regions of the United States, contributes to the profusely intercultural palette of musical resources from which Artism's music springs. Compositions, arrangements, and directed improvisations by the children reflect this musicultural diversity, as elements of festejo, rumba, flamenco, calypso, raga, and gamelan combine with those of jazz, blues, funk, hip-hop, rock, classical, and other genres—as well as with ideas and concepts that are uniquely the children's own and bear no recognizable resemblance to any preexisting musical genre or tradition—to forge the distinctive sound and approach that define Artism's music. (Six brief videos of Artism performances are available on the Companion Website for this book.)

The Artism Ensemble was founded in Tallahassee, Florida, in January 2011. It represents an extension and outgrowth of its predecessor program, the Music-Play Project (Bakan et al. 2008a, 2008b; Bakan 2009; Koen et al. 2008), and has likewise been a product of collaboration between researchers, musicians, and clinicians associated with the College of Music, Center for Autism and Related Disabilities, Autism Institute, and College of Medicine at Florida State University. Since its creation, Artism has been jointly sponsored by the National Endowment for the Arts, the Florida Department of State's Division of Cultural Affairs, Remo Inc., and other supporting institutions.

Toward an Ethnographic Model of Disability

In its on-the-ground and philosophical commitments to relying on the creative and agentive priorities of its child members for its musical identity and social life, the Artism Ensemble privileges autistic ability over disability, supportively responding to the creative initiatives and impulses of children with autism rather than trying to restrain, retrain, or redirect them. Moreover, the ensemble, through its concerts and other public

events, serves as a social model in its own right: a model of inclusive sociality, music making, and cultural coproduction that promotes public recognition of and appreciation for the abilities of people on the autism spectrum; that displays a productive and creative domain of musical praxis built on the elimination of conventional boundaries and barriers of identity and ability construction; and that in turn challenges conventional assumptions about musical expertise, musical value, and the ostensibly self-evident social hierarchies that exist within group music-making environments. Artism aspires through its musicultural practice and performances to contribute to the enablement and empowerment of people who have historically been disenabled, build culture and community in environments where "conventional logic" would seem to deny the very possibility, and publicly perform autistic ability and sociocultural inclusivity as public challenges and alternatives to autistic disability and exclusion.[9]

Key to such aspirations is an epistemological stance that differs fundamentally from what is often described in Disability Studies discourses as the medical model of disability. In this medical model, the site of disability is the allegedly disabled individual him- or herself, who is affected by some form of physical, mental, or cognitive defect or flaw (disorder, disease, pathological condition, illness, impairment) in ways that create forms of difference demanding medical intervention—diagnosis, therapy, rehabilitation, and ideally cure (Straus 2013, 462).

Given such an epistemological position, it follows that proponents of the medical model, whether acting as researchers, physicians, or therapists, as teachers, aides, or even parents, operate from a fundamental position that there is a need to *change* the autistic or otherwise disabled person. They are effectively agents of change in search of solutions. Music therapists are a case in point, as we learn in the 2012 online article "Music Therapy as a Treatment Modality for Autism Spectrum Disorders," published by the American Music Therapy Association (AMTA) on its website:

> Music Therapy is the clinical and evidence-based use of music interventions to accomplish individualized goals within a therapeutic relationship by a credentialed professional who has completed an approved music therapy program. . . . Music therapy provides a unique variety of music experiences in an intentional and developmentally appropriate manner to effect changes in behavior and facilitate development of skills. . . . Music therapy can stimulate individuals [with ASD] to reduce negative and/or self-stimulatory responses and increase participation in more appropriate and socially acceptable ways. . . . Because music is processed in both hemispheres of the brain, it can stimulate cognitive functioning and may be used for remediation of some speech/language skills [in persons with ASD]. (American Music Therapy Association 2012)[10]

As an ethnomusicologist of autism, I operate from a different premise than most of my counterparts in the music therapy profession. I am not interested in changing the people whose lives and music I endeavor to understand. My goals are basically ethnographic, not therapeutic; and to the extent that a therapeutic aim may be said to exist at all, it is to cultivate a space in which the children in Artism get to be themselves as they

wish to be, a space devoid of the kinds of externally imposed pressures, expectations, assessments, and objectives that customarily go hand in hand with programs and activities rooted in symptomatological epistemologies of autism and autistic experience.

In contradistinction not only to the medical model of disability but also, to a lesser degree, to the social model of disability (which "opposes the medical model by defining disability relative to the social and built environment, arguing that disabling environments produce disability in bodies and require interventions at the level of social justice"—see Siebers 2008, 25),[11] the guiding model for an ethnomusicology of autism might be described as an ethnographic model of disability. Consistent with our ethnographic and musicianly leanings, ethnomusicologists are interested in understanding the subjects of our investigations—in the present case of my own work, children with autism—principally according to their terms and from their perspectives: learning from them, sharing experiences with them (including but not limited to musical ones), comprehending their conceptions and values of community, personhood, social experience, humor, work and play, pleasure and pain, joy and suffering, and of course music. To borrow an oft-quoted turn of phrase from Clifford Geertz, I am "seeking, in the widened sense of the term in which it encompasses very much more than talk, to converse with them, a matter a great deal more difficult, and not only with strangers, than is commonly recognized" (Geertz 1973, 13).

I am interested as an ethnomusicologist in the music, thoughts, lives, and musical communities of the autistic children with whom I currently work and play music in much the same way that I was interested in the music, thoughts, lives, and musical communities of Balinese musicians with whom I worked and played music in Indonesia in the 1980s and 1990s (Bakan 1999). I did not endeavor to remediate the performance practices of my Balinese fellow musicians, nor to cure them of their preference for paired tunings over equal tempered ones. I assumed that these Balinese musicians were competent practitioners of the Balinese musical arts with which they were associated, and that their distinctive clusters of behaviors, abilities, and attitudes in musical and social practice reflected individual manifestations of a broader Balinese worldview and ontology. I welcomed opportunities to learn from them through musical and social interactions, through performances and conversations that yielded ethnomusicological insights into Balinese ways of being and of being musical.

I assume similar things and welcome similar experiences and insights in my musical collaborations with the child members of the Artism Ensemble. Entering the E-WoMP, the principal site of Artism musical production, I approach matters much as I did when entering the *bale banjar*, the principal site of Balinese gamelan music production: as a learning musician, a curious and committed ethnographer, and a co-participant in the making of music and cultural community.[12] Here, though, the culture bearers are not musicians in Bali who play on a gamelan but American children on the autism spectrum who play on an E-WoMP. It is these children who direct Artism's musical proceedings, guiding the course of group improvisations, coming up with themes and variations that blossom into full-grown compositions, selecting preexisting materials—a melody from Liszt's *Hungarian Rhapsody No. 2*, a Bo Diddley beat under an extemporized rendition

of Dr. Seuss's *Green Eggs and Ham*—from which to create inspired arrangements that cleverly combine precomposed and improvised passages.

As for the adult members of the ensemble, the professional musicians and "nonmusician" parents alike, we are not there to teach or direct the children; rather, we are there to learn from and respond to them. We apply whatever skills and attributes we bring to the E-WoMP, individually and collectively, to nurture the children's creativity, agency, individual and social aspirations (musical and otherwise), and reciprocity. There are no preestablished repertoires, right or wrong notes, specific musical goals or demands, or defined expectations of any kind beyond ensuring that all participants contribute to maintaining a safe environment emphasizing mutual respect and support for one another.

Typically, rehearsals and concerts move in round-robin fashion from one piece to another, with each child taking charge of the composition/arrangement and ensemble direction duties for one or more of their own pieces per program. This protocol was not created or imposed by me or any of the other adult ensemble members. Rather, it was an organic and gradually forming outgrowth of the children's own desires for how Artism's musical process should work, one that was worked out collectively among them in rehearsals. The development of this protocol seemed to emerge as a direct response to the children's learning at the outset of the project in 2011 that the ensemble was not going to function exclusively in a "play lab" environment, as it had in the Music-Play Project, but would additionally be getting out in public and performing concerts. Once they realized that they were going to have an audience, they almost immediately became committed to the idea of fashioning a "high quality" musical product warranting public consumption, and in tandem with their specifically musical goals they became quite deeply invested in delivering the goods with showmanship and style, that is, with showmanship and style defined on *their* terms, which have often been deliciously and provocatively at odds with "conventional" musical tastes and sensibilities. It was fascinating to witness this strategic and aesthetic shift from a participatory to a presentational mode of performance (Turino 2008) and to both observe and be a participant in the making of the distinctive sound, look, feel, and identity that have come to define Artism's unique musicultural brand over time.

It is also important to mention that in both their broad outlines and specific characteristics, the generative processes of musical production and social engagement that define the Artism Ensemble's approach contrast in key regards with "best practices" positions regarding clinical, therapeutic, and educational approaches to working with people with autism:

> Individuals on the autism spectrum tend to gravitate toward preordered systems in which the relationship between parts can be predicted based on rules, and struggle to function within open-ended systems requiring flexibility, improvisation, and intuition. They thus gravitate toward and function best under a "stable symbolic and social order," under conditions where social expectations and givens are consistent, explicit, systematic, and shared between interlocutors. (Fein 2012, 69–70)

Artism's open-ended approach, reliant as it is on flexibility, improvisation, and intuition, may be seen to push back against such logic to a considerable degree, even if other key features of the project—the regular weekly meeting time and location, its stable membership, the relatively predictable structure of the round-robin protocol described above—do offer frameworks of consistency and reliability within which the more fluid and improvisatory elements may unfold. There is no doubt that children in the group (and adults as well) often *do* struggle with the overall unpredictability and open-endedness of the process, and that in many respects their individual and collective decisions to create quasi-structured musical works and to take charge of the ensemble in a directorial way, rather than to maintain a more free-flowing improvisational environment, are commensurate with their desires for a certain measure of systematicity, control, and consistency. But there is likewise no doubt that over time they have come to revel in the open-ended possibilities for spontaneous invention and co-creation that the E-WoMP environment affords. Each in their way, they have come to find both the challenges and triumphs of contending with the inherent fluidity of Artism's musicultural process to be empowering and rewarding.

On the basis of what I have observed relative to my work on the ethnomusicology of autism over the past decade, and also as a member of a family affected by autism for roughly the same period, I believe that people with autism are not necessarily any less spontaneous, intuitive, flexible, or improvisatory than other people are; rather, they appear to be that way because they are almost invariably forced to contend with life situations and settings in which their particular attributes and preferences for expressing spontaneity, intuition, flexibility, and improvisational ability are demeaned, or are patronized, or go unacknowledged or unrecognized altogether by their interlocutors. The evidence coming from the autism self-advocacy movement, as well as from Artism and similar types of projects (see, for example, Fein 2012, Bagatell 2010, Bascom 2012b), suggests that in situations where autistic people are given opportunities to have their talents enabled rather than disenabled, nurtured rather than quashed, and embraced for what they are rather than being subjected to therapeutic interventions aimed at their transformation or remediation, they can and will thrive in ways that people without autism would never think possible unless they witnessed it firsthand. A primary purpose of Artism is therefore to provide neurotypical people with precisely that opportunity: to witness, enjoy, appreciate, and celebrate autistic ability rather than identify, symptomatize, marginalize, and take pity on autistic disability.

The child stars of the Artism Ensemble, together with their supporting cast of parents and professional musicians, make good and innovative music, make good culture and community, and make change. They do this through their compositions and arrangements, their improvisatory explorations, their concert performances, and their public presentations of individual and collective selfhood. Change is achieved internally among the group's members through our joint musicultural ventures and all that they reveal. It is achieved externally as we reach out to audiences through concerts in which Artism's players, the children foremost of all, are *applied* to the cause of transforming public perceptions of autism from disability-centered to ability-centered

ones, from recognition of a negating sort to recognition of the more affirming and celebratory kind.

Critiquing Artism

Whatever its merits may be, it must be acknowledged that Artism, as a program that has received funding and sponsorship specifically because of its connection to autism, and that presents public performances in which the autistic identities of key players are either explicitly or implicitly acknowledged, highlights and benefits from the staging of autism and the performance of disability. In so doing it simultaneously and paradoxically resists and is co-opted by hegemonic stances that have long dominated both medical-scientific and mainstream public/media discourses in their positing of "autistic" in contradistinction to "normal."

Artism may thus be justifiably criticized for propagating the very constructs of exclusion and hierarchy it aims to overturn, at least in some measure. Such criticisms were raised by panelists on a June 28, 2013, session I attended at the twenty-sixth annual conference of the Society for Disability Studies in Orlando, Florida (see Grace et al. 2013). Several autistic members of the panel had attended the Artism concert performed at the meeting's Opening General Session two days prior. The concert seemed to have gone extremely well, an unqualified success in all respects as far as I could determine in its immediate aftermath, but the comments offered up by these panelists revealed significant issues in need of address and remediation.

The autistic scholar, author, and advocate Zach Richter served as the primary spokesperson. He and his colleagues provided constructive criticism and suggestions on how the approach of Artism could be revised to put the group in better compliance with the priorities of autistic people and the autistic rights movement (at least to the extent that the positions of organizations like the Autistic Self Advocacy Network and Autism Network International may be regarded as representative of the broader views of the autistic community). Key to their critique was the point that Artism featured autistic children performing together with their nonautistic parents and with professional musicians who likewise were not autistic. Thus, all of the children were autistic, while none of the adults were. It was strongly recommended that adult autistic musicians be recruited to either join the ensemble or serve as professional consultants. This is a suggestion we are now in the process of implementing, and one that will without doubt enrich the ensemble both musically and socially, as well as in terms of its capacity to work on behalf of effectively promoting autistic ability, self-determination, and acceptance.

The future addition of neurotypical children to the ensemble would seem to be another logical extension of the neurodiversity ideal principle. The feedback received from members of the autistic community—within and outside of the ensemble's membership—has increasingly convinced me that maintaining separate demographic profiles within age-set classes in the ensemble (autistic children, neurotypical adults) is counterproductive to our mission.

Richter and his fellow panelists offered other useful recommendations that we are in the process of incorporating as well. These include the following:

- Strive to decrease the loudness of the performance in accordance with the aforementioned sensory challenges of many autistic people, this for the benefit of both members of the ensemble and their audiences.
- Instruct audiences to show their appreciation not by clapping, which is disturbing to many sound-sensitive autistics, but rather by employing the customary forms of silent applause used at autistic community gatherings (e.g., "jazz hands"-style silent applause).
- Completely avoid reference to the phrase *autism awareness*, which we had unfortunately included on a concert evaluation questionnaire distributed to the audience; this phrase, closely associated with Autism Speaks and other organizations that are not run by autistic people, is considered to be offensive within the autistic self-advocacy movement, which instead promotes the principle of *autism acceptance*.

The tempered outlining of criticisms and suggestions above fails to capture the impassioned mode in which they were presented to me at the conference. Richter, in particular, found several elements of Artism's performance to be, in his words, "offensive" and "disturbing," and while these words stung at the time, I was and remain deeply grateful to him and his colleagues for helping me and my Artism collaborators to rethink our approaches and priorities and move toward a better way of doing what we do.

Like most manifestations of disability practice and discourse, Artism exists in a complexly contested space wherein empowerment and appropriation are dialectically intertwined. Abundant opportunities exist to make things worse rather than better, regardless of our intentions or our efforts to do otherwise, whether through the kinds of unwitting insensitivities that brought offense to Richter and others in the autistic cohort at the Society for Disability Studies meeting or by inadvertently contributing to regressive essentialisms about autism that we are endeavoring to combat (e.g., an audience member walking away from an Artism concert saying, "Oh, isn't that special; isn't it nice that those disabled kids get to do something fun with music since they surely couldn't play in a *real* band or orchestra"). It is all a rather risky venture, but ultimately a worthwhile one, for in promoting autistic personhood as "something different from undesired difference" (Titchkosky 2007, 9), Artism holds the capacity to use music to make a real and positive difference.

Mara Spins

Mara has been spinning round and round in my black office chair for some time now.

"Spinning chairs! Spinning chairs make *everyone* happy!" she sings. Then, in a mock serious tone, "I get distracted easily," and after that, throwing back her hair and laughing wildly, "*especially by things like this that are SPINNY CHAIRS!!*"

"You know," I say to Mara, laughing along with her as she continues to spin away, "the scientists and the doctors and therapists and people like that who specialize in autism . . . would say that what you're doing now—spinning and spinning and spinning while we have this conversation—is an example of *stimming*, that it's a 'symptom' of your Asperger's or your autism or whatever."

"Stim-*what*?" Mara asks, seemingly confused. "What *is* that?"

"Stimming," I repeat. "It's a word that they use to describe so-called 'self-stimulating behaviors' that autistic people do when they're, I don't know, feeling stressed or uncomfortable or whatever, or maybe the scientists don't know why they do those things but they know they do them and they say that's one of the things that makes them autistic."

Mara's laughter now escalates to a fever pitch.

"That's just *ridiculous*!" she states incredulously. "I mean, I bet that the president has a spinny chair and sometimes *he* spins around. . . . [He] probably [doesn't] laugh like I do because the president doesn't laugh, or at least lots of people think that, but that's just another stereotype—but still. Spinny chairs. I *like* spinny chairs."

Zolabean Stims

Self-stimulatory behavior, or "stimming," is identified as a classic symptom of "autistic stereotypy" (Bagatell 2010, 39). Common "stims" include hand flapping, covering of the ears, spinning and twirling, and rocking back and forth or from side to side. Autism researchers offer competing theories regarding the causality of stimming. Some suggest that sensory overstimulation (hypersensitivity) is the main causal factor; others contend that sensory understimulation (hyposensitivity) is the key issue. Either way, there is agreement that stimming is practiced by autistics due "to some dysfunctional system in the brain or periphery" (Edelson n.d.), and training people with ASD to control or eliminate their stimming behaviors is a goal of many therapeutic interventions, including some music therapy interventions which, as noted earlier, may be employed to "stimulate individuals to reduce negative and/or self-stimulatory responses and increase participation in more appropriate and socially acceptable ways" (American Music Therapy Association 2012).

For Mara and a great many other people on the autism spectrum, though, there is nothing "dysfunctional" about stimming at all. In her ethnographic study of an autistic self-advocacy group to which she ascribes the pseudonym AACT (Autistic Adults Coming Together), Nancy Bagatell observes that

> actions viewed as "self-stimulatory" by the biomedical community, such as rocking and hand flapping, are reframed as a valued activity[,] not a meaningless action that should be "extinguished." Many members told me that they enjoyed these activities tremendously and felt a sense of relief being in a place where they could, in fact, be themselves. (Bagatell 2010, 39)

Zolabean, a former member of the Artism Ensemble who played in the group for its first two seasons in 2011 and 2012, is a stimmer. Two years prior to joining, she had participated in Artism's predecessor program, the Music-Play Project. At that time, she was an adorable, petite eight-year-old with straight blonde hair, a charmingly wry pixie grin, and a diagnostic label of Asperger's syndrome. She was reserved yet articulate, highly intelligent, and possessed of considerable creative talents as a musical improviser from the start. When there was no music being played, she tended to be rather passive, even flat, in affect, but as soon as the music started up she became an engaged and intense participant. She almost never stimmed, and on the rare occasions that she did (usually for a fleeting moment of hand-flapping) she would quickly check herself and stop.

It was thus both surprising and disturbing for me to see Zolabean stimming profusely and barely participating at all musically during our opening session of the Artism Ensemble program in January 2011. She spent most of the gathering flapping her hands, incessantly straightening and bending her legs, and twisting her fingers together awkwardly. What had happened?

Several months later, in the aftermath of Artism's inaugural season, I finally got an answer to that question. In the interim, Zolabean had seemingly "come around" as a member of the group, taking on an active role as both a composer and performer from about the third session onward. But throughout the season, she had continued to stim frequently as well, often moving between periods of instrumental playing and intensive stimming with a kind of fluidity that acquired a logic and aesthetic all its own. During a conversation with her and her mother, Suzanne, she explained how this had all come to pass:

MICHAEL (M): So, let's talk about Artism for a minute.
ZOLABEAN (Z): OK.
M: 'Cause you like that.
Z: Yes.
M: [During] the first couple of weeks, you . . . were participating in your way . . . but you weren't playing, you weren't playing instruments very much at all—sometimes I think you didn't play them at all. Do you remember in [the] Music-Play Project [in 2009]? There you used to play quite a bit, I seem to recall.
Z: Well, there was a reason why I played a lot in that. I was afraid that someone was going to tell me I had to play if I didn't. . . . There were people with video cameras. It was just a lot of pressure and I felt like I had to play the instruments, like [that] was why I was there. [But] during the Artism project [Zolabean trails off mid-sentence, pauses thoughtfully, then shifts gears and resumes]—I have characters in my head. I think about them a *ton*, like probably more than I think about my own life. That's fine with me because they kind of relate to me. A lot of them have similar diagnosises [*sic*] . . . And what's happening was, they were all musicians, the people in my head, and so I was imagining them playing the instruments, like I had one on the *zheng* and one on the *djembe*, and everything. . . .
M: [So] because you've got these characters in your head and then they were playing the instruments [you didn't feel the need to play yourself]?

Z (smiling glowingly): Yes!

M: But then, at a certain point, that changed, and then you became [involved] very actively [in] playing and composing and directing the band. [Why?]

Z: At the beginning I was a little nervous that I'd have to play like in the last one [MPP 2009]. But after a while I realized it was cool if I could just express myself in any way. And in the end I felt comfortable enough and my characters kind of merged with it. That's when I started playing more.

M: So the main thing, then, it sounds like, there were two things: the characters sort of merging [Z cuts M off midsentence to interject]

Z: And it was also just me getting more comfortable with it.

"OK," I say to Zolabean. "So when you say the characters merged, did they become you?"

She pauses, considers the question thoughtfully, ponders it as she looks out the window. Then she turns back toward Suzanne and me, but as she answers my question, she looks not at me but deeply and intently into her mother's eyes. "Yes!" she exclaims, an affirming smile curling the corners of her lips upward as a look of resolute clarity spreads across her face.

A pregnant pause hangs in the air until Suzanne breaks through it. "Cool!" she exclaims in a moment of quiet fascination, and in that same moment Zolabean, poised and composed up to now, starts stimming intensely. She shakes her foot nervously, twirls her hair around her fingers momentarily, then chews on her t-shirt as she looks back and forth furtively between Suzanne and me, as though seeking reassurance that it's OK for her to have characters in her head, that it's OK for them to merge and become her, that it's OK for her to be who she is where she is and how she is. And while there is a touch of apprehension, even a tinge of anxiety, in her current state, there is a far stronger sense of excitement and hope. Zolabean has made the connection. Suzanne and I "get it" now.

The "seemingly natural conflation" of Zolabean's particular brand of disability, the one labeled Asperger's syndrome, with "undesired vulnerability and ineptitude" (Titchkosky 2007, 10) has been not only disrupted, but fully overturned in this moment of revelation and discovery. Zolabean has shown that her decision to not play instruments early on in Artism, to instead stim or listen silently while jamming with the "band of brothers" in her head, was just that: a decision. It was not an action of retreat or regression determined by her autism, but rather a choice determined by her preference; not a symptom of isolationism and social impairment, but an expression of creative exploration and inventiveness. And when, later on, she did choose to connect in a more conventionally "musical" manner (at least some of the time)—playing instruments, interacting with the rest of us in readily tangible ways, leading the ensemble in some pieces and following her fellow players in others—this did not constitute a positive outcome of a successful therapeutic intervention. It merely made manifest a fluid progression between two different modes of productive musical engagement, one centered on stimming-based movement and adventurous flights of imagination, the other on performance and explicit social connection with the other music makers in the room. While a symptomatic reading

would show the latter of these modes to be "normative" and the former to be "autistic," neither is in actuality any more normal or autistic than the other. They are just different—and they are, moreover, relational, dialectical, and organically in tandem with one another. They are alternate ways of being musical and being tuned in, which is a far cry from the contrasting view that they are oppositional ways of being musical versus being tuned out.

Conclusion: Toward Living and Imagining a Little Differently

My adult Artism Ensemble colleagues and I have had the pleasure of seeing Zolabean, Mara, and the other three children who are or have been members of the group—E.S., Coffebot, and NICKstr—grow as people and musicians, engage in meaningful relationships and form friendships, work through musical and behavioral challenges with strength and resolve, and become increasingly confident, agentive, and willing and able to connect and negotiate with each other and with us. But all such prospective indicators of the practical utility of the Artism Music Project are misunderstood if they are interpreted as measures of progress *away* from autism or as remediations of autistic symptoms. That is not the point. The adult participants—the parents and the professional musicians alike—have demonstrated similar albeit distinct patterns of growth and development in their musical and social abilities, as well as in agency, reciprocity, and self-confidence, through their participation in the project. To grow and learn in such ways within the type of musical environment that Artism cultivates is not an autistic thing; it's a human thing, and as such it is prone to the myriad shortcomings, limitations, missteps, and misunderstandings that define human endeavors generally. It is all worth the effort, though. We carry on. We do our best. We are all in this together.

Notes

1. In DSM-5 (American Psychiatric Association 2013), the various separate "disorders" of the autism spectrum have been collapsed into a single diagnostic category: ASD, or autism spectrum disorder. This encompasses the conditions that were formerly categorized (in DSM–IV) as autism, Asperger syndrome, and PDD-NOS. Two conditions that were previously (in DSM–IV) encompassed within the ASD rubric, childhood disintegrative disorder and Rett's syndrome, have been eliminated from the ASD category in DSM–5 (Kaufmann 2012).
2. The classificatory scheme of "low-functioning" versus "high-functioning" forms of autism/ASD is often used as a baseline for marking gradations along this identified continuum. This is a fraught area marked by contentious debate in contemporary ASD discourse and research, and it is one with which I have consciously chosen not to engage in this essay beyond the present note. There are several reasons for this decision, but rather

than detailing them I will defer to the expressed views of the autistic author and advocate Amy Sequenzia:

> I am autistic, non-speaking. I am also labeled "low-functioning." This label is a prejudgment based on what I cannot do. It makes people look at me with pity instead of trying to get to know me, to listen to my ideas. . . . All the labels given to us only help to make myths seem like the reality. By classifying a non-speaking autistic as low-functioning, one is lowering expectations for the autistic individual. He or she is not given a chance to express him/herself and maybe show hidden abilities. We, autistic, have tried hard and accepted the neurotypical way of doing things to make it easier for non-autistic people to understand us, interact with us. Despite some progress there is still very little reciprocity. (Sequenzia 2012, 159 and 161)

Suffice it to say that among the more than thirty children who have participated in the Artism Music Project and/or the Music-Play Project since 2005, a very large portion of the autism spectrum, as accounted for within the established "low-functioning" to "high-functioning" continuum, has been represented, although the majority representation has consistently leaned toward the "high-functioning" end.

3. Additional published works addressing issues of autism and living with ASD that have been authored or coauthored by autistic people include the following: Williams 1992, Lawson 2000, Shore 2003 (of additional interest on account of Shore's professional status as a musician and music educator), Miller 2003, Prince-Hughes 2004, Biklen 2005, Ariel and Naseef 2006, Tammet 2007, Robison 2007, Prince 2010, Mukhopadhyay 2011. Numerous documentary films, blogs, websites, and other media also contribute to the increasingly present and essential autistic voice of ASD discourses.
4. Fein's work is representative of a burgeoning literature on the anthropology of autism that aligns in many key respects with both the Disability Studies and ethnomusicological sensibilities foregrounded in this article. See also Ochs et al. 2001, 2004, and 2005; Kremer-Sadlik 2004; Solomon 2010a and 2010b; Sterponi and Fasulo 2010; Grinker 2010; and Brezis 2012.
5. The intersectionality of autistic and child identities that largely defines the demographic of the Artism Ensemble is not addressed explicitly in this essay on account of both space limitations and my endeavor to maintain a manageable scope of inquiry. Exploring such intersectionality is of potentially great significance, however. Ethnomusicologically oriented, ethnography-informed approaches to the study of children's music making, as exemplified, for example, in publications by Campbell (2010), Marsh (2008), and Gaunt (2006), offer valuable models and possibilities relative to future projects and studies on the musical lives of autistic children.
6. Selected literature from these many areas and disciplines is cited and discussed throughout this chapter. Notable is the emergence of a body of relatively recent books, dedicated exclusively to autism, which approach their subject from positions that run contrary to the mainstream medical-scientific paradigm. Beyond the aforementioned *Loud Hands* volume (Bascom 2012a), these include Biklen 2005, Nadesan 2005, Grinker 2007, Murray 2008, and Osteen 2008.
7. For additional perspectives on applied ethnomusicology, see also Titon 1992; Sheehy 1992; Alviso 2003; Harrison, Pettan, and Mackinlay 2010; and Harrison 2012.
8. Participants were recruited through the client registry of the Center for Autism and Related Disabilities (CARD) at Florida State University. At all phases, the project has been

reviewed and approved by the Human Subjects Committee of the Institutional Review Board at Florida State University.

9. Of related interest are a variety of sources that approach the subject of music and autism from a Disability Studies perspective. These include Straus 2011, Marrero 2012, Lubet 2011, and the chapters contributed by Headlam (2006), Jensen-Moulton (2006), and Maloney (2006) to the edited volume *Sounding Off: Theorizing Disability in Music* (Lerner and Straus 2006).
10. Music therapy is a highly diverse field. The positions set forth in this AMTA publication should not be seen as representative of the field as a whole, let alone of its individual practitioners. That said, I would maintain that the basic distinction between the therapeutic goals of music therapists and the ethnographic goals of ethnomusicologists constitutes a fundamental epistemological difference that impacts theories, practices, and values at a most fundamental level: therapists generally endeavor to effect changes in their clients, whereas ethnographers generally do not endeavor to effect changes in the subjects of their investigations. For a range of approaches in music therapy, see Nordoff and Robbins 1977, Bruscia 1987, Edgerton 1994, Clarkson 1998, Ruud 1998, Aigen 2002, Stige 2002, Kern 2004, Pavlicevic and Ansdell 2004, Whipple 2004, Walworth 2007, Gold 2011, Reschke-Hernández 2011, and Simpson and Keen 2011. For perspectives on music in special education relating to autism, see Hammel and Hourigan 2013.
11. *The Disability Studies Reader* (4th ed.), edited by Lennard J. Davis (2013a), explores social versus medical models of disability from multiple perspectives. In particular in that volume, see Davis 2013b and 2013c, Shakespeare 2013, Siebers 2013, Garland-Thomson 2013, and Straus 2013. For perspectives from the philosophy of disability, see Silvers 2010 and Carlson 2009.
12. I am aware that this comparative analogy can only be taken so far. Whereas the gamelan-based musical activities of the *bale banjar* long predated my arrival in Bali as an ethnomusicologist, the E-WoMP is a built environment that was created as a musicultural space for the creative musical activities of autistic children and their nonautistic adult interlocutors by myself and other neurotypical adults. Therefore, I may rightly be accused of having essentially created the ethnographic field site that I now visit and research. While recognizing that there is some irony in this situation ethnographically speaking, I hold to the conviction that a large measure of "ownership" of the E-WoMP space and of Artism's musical and social processes and priorities overall have been claimed and maintained by the children in the group.

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CHAPTER 2

MUSIC, INTELLECTUAL DISABILITY, AND HUMAN FLOURISHING

LICIA CARLSON

People with intellectual disabilities[1] have suffered multiple forms of marginalization: they have been housed on the margins of society in institutional settings, they have experienced isolation and exclusion from participation in community life because they have not conformed to society's blueprint of normalcy, and they have been relegated to the margins of personhood and defined as profoundly "other" by scholars working in a broad range of disciplines (Carlson 2010). Until recently, intellectual disability has also figured less prominently than other forms of disability in the field of Disability Studies. This is rapidly changing, as there is a burgeoning body of work that addresses this lacuna and problematizes the very meaning and nature of intellectual disability. This critical scholarship explores the experiences and perspectives of people who are labeled with a broad range of conditions that fall under the umbrella of "intellectual disability," exposes forms of oppression, and traces the powerful advocacy and self-advocacy movements that have been so central in articulating and celebrating a positive identity for people with intellectual disabilities. One question that lies at the heart of much of this work is, What does it mean for people with intellectual disabilities to flourish as human beings in a world with others? The significance of this question cannot be underestimated, as it resonates with some of the most important themes and challenges raised in Disability Studies: the concept of quality of life, the importance of acknowledging and valuing both independence and dependency, and the demand that individual, familial, social, and political conditions be met so that individuals can realize their full potential.

In this essay I explore the connections between musical experience and human flourishing. In doing so, I am interested in moving beyond a medical and therapeutic model of disability and music, beyond what Joseph Straus has termed the two "ghettos" wherein discussions of disability are typically found: abnormal psychology and music therapy (Straus 2011, 158). My interest here is not in music as a means of *curing*

or *normalizing* disability; rather, it is in the ethical significance that musical experience holds for people with intellectual disabilities and those around them. In this regard, this project is also a departure from certain standard approaches to the philosophy of music. In *The Music of Our Lives*, Kathleen Higgins writes that the tendency of Western aesthetics "to treat music as an autonomous structural object and to minimize concern with the holistic character of musical experience . . . has obscured the experiential bases for recognizing music's . . . roles with respect to ethical living" (Higgins 2011, 114). Adopting a more holistic approach to musical experience, as Higgins advocates, means broadening the scope of analysis and considering various sites and forms of engagement with music. I find Christopher Small's definition of *musicking* to be particularly useful here: "To musick is to take part, in any capacity, in a musical performance, whether by performing, by listening, by rehearsing or practicing, by providing material for performance (what is called composing), or by dancing" (Small 1998, 9). In addition to recognizing that musicking can take place anywhere and can be done by anyone, Small argues, "The fundamental nature and meaning of music lie not in objects, not in musical works at all, but in action, in what people do. It is only by understanding what people do as they take part in a musical act that we can hope to understand its nature and the function it fulfills in human life" (Small 1998, 8).

In this chapter, I explore *musicking* by people with intellectual disabilities, thereby challenging a number of problematic assumptions often made about "the intellectually disabled." Specifically, I explore the significance of music in the lives of people with intellectual disabilities in two ways. The first part focuses on the value that music has for the individual; the second part traces the ways that musical experience can establish and reshape relationships. I then conclude with a brief consideration of how the intersections between music and intellectual disability can contribute to the field of Disability Studies more broadly. This critical project of bringing philosophical questions to bear on music and intellectual disability is greatly indebted to the emerging scholarship on disability and music (Straus 2011; Lerner and Straus 2006; Lubet 2011) and disability aesthetics (Siebers 2010). I share with these authors and my fellow contributors to this volume the conviction that the fields of Disability Studies, aesthetics, and I would add philosophy, stand to gain from these new alliances. These disciplines will be mutually enriched by inviting the "figure of disability" into the concert hall, the academy, the conservatory, and into everyday spaces where music is shared (Siebers 2010; Carlson 2013).

Musical Lives

Associations between intellectual disability and music can be found in many disciplinary contexts. In neuroscience, for example, researchers are examining a wide range of questions regarding music, intellectual disability, and the brain. People with various forms of intellectual disability (autism, Williams syndrome, Down syndrome) have provided the occasion to pursue a number of questions: What is the relationship between

music and language? What parts of the brain are responsible for various dimensions of musical experience and performance? How does damage to one part of the brain (e.g., the left hemisphere) enhance potential or capacities in other parts of the brain? The field of music therapy has also been central in defining a new therapeutic space within which music can serve many functions for people with intellectual disabilities, including the development of motor skills, social skills, communication, cognitive skills, self-confidence, and a fuller sense of identity. Finally, "musical savants" continue to receive popular attention as, arguably, the prototypical case of music and intellectual disability, "enshrining them as a species of 'super-crip,' people whose unusual ability in one narrow area has enabled them to transcend their general disability" (Straus 2014).

Yet these approaches to music and intellectual disability, in addition to perpetuating a model of disability that considers "the intellectually disabled" as abnormal and/or as an exceptional curiosity, do not explicitly address ethical questions regarding how music shapes the lives of people with intellectual disability and how it may contribute to their flourishing and to the very possibility of a *good life*. As a philosopher, I am particularly interested in exploring these questions because the assumption that people with intellectual disabilities are incapable of living even "minimally satisfying lives" is so widespread in philosophical discourse (Carlson, 2010). Thus, by considering the ways that music "facilitates a sense of selfhood" and enables expression and the capacity for "musical joy" (Higgins 2011, 120), I hope to provide an antidote to these attenuated philosophical portraits of intellectual disability. Kathleen Higgins says that while music is often connected to the idea of self-*transcendence* (i.e., it allows us to transcend ourselves, to escape or move beyond ourselves), little attention has been paid to the relationship between music and self-*awareness*. In response to this, she identifies three aspects of selfhood that emerge through music: it reveals my existence as a temporal, embodied, and vital being (Higgins 2011, 120–121). If we consider the emergence of musical selfhood in the context of intellectual disability, a picture emerges that challenges assumptions that have been made about people with intellectual disabilities: that they do not have a meaningful sense of self, that intellectual disability is a static condition, and that having an intellectual disability necessarily means a diminished quality of life.

Crip Time, Musical Time

There are a number of ways that the experience of disability can affect one's temporal existence. Philosopher Susan Wendell has argued that, in addition to all of the other ways that our society is structured around the nondisabled "normal" body, time is structured according to norms as well. For example, many people with disabilities may not be able to complete tasks in what is considered an appropriate time, and this can impact their ability to work and partake in activities in ways that are expected (Wendell 1996).[2] Moreover, living with a disability may affect the experience of one's life course, of the broader trajectory on which one maps out the future. Depending on the nature of the

disability, the experience of time may be radically transformed by the treatments one may have to undergo, and the concept of "life expectancy" may be affected in distinct ways. Finally, the ways in which intellectual disability has been defined are temporally articulated according to developmental norms. The very term *mental retardation* suggests that the process of normal development has been slowed, and the practice of classifying people with intellectual disability according to "mental age" as opposed to chronological age is another example of how temporal norms intersect with definitions of disability.

An interesting example of the juxtaposition between normative, chronological time and musical time can be found in researchers' descriptions of the musicality and "rhythmicity" of people with Williams syndrome. Levitin and Bellugi observe that people with this relatively rare congenital condition "appear to be more engaged than normal subjects" and demonstrate a high degree of rhythmic engagement and musicality (Levitin and Bellugi 1998, 375). People with Williams syndrome exceed not only the expectations that researchers have of them given their cognitive "deficiencies" (often expressed in terms of their "mental age"), but they outperform the "normal" subjects. While I say more about the musical lives of people with Williams syndrome later, I introduce this particular study here because it provides a good example of how the "normal listener" (or in this case "normal participant") is constructed in the process of researching musical cognition (Straus 2011). This discourse, informed by the medical model, highlights the dissonance between normal/nondisabled and abnormal/disabled subject, and also between mental age/cognitive ability and musical ability.

While the experience of disability may be defined in negative terms when people fail to live according to what is considered to be *normal time*, the temporal dimensions of living with a disability can have powerful positive consequences as well. In her book *Feminist, Queer, Crip*, Alison Kafer asks, "What would it mean to explore disability in time or to articulate 'crip time'?", and devotes a chapter to mapping out a broad range of intersections between disability and temporality (Kafer 2013). What might happen if we transpose "crip time" into a musical key? If people with disabilities experience their lives temporally in distinct ways, how might this be relevant to Higgins's recognition that, "As a listener [of music] I am a temporal being?" (Higgins 2011, 120).

In some instances, terms that have a negative connotation in relation to disability may take on a new meaning in a musical context. Consider the term *retardation*. In analyzing Heinrich Schenker's discussion of the musical work through the lens of disability, Straus highlights the important roles that blockages and obstacles can play within the musical work. Here he quotes Schenker: "'In the art of music, as in life, motion toward the goal encounters obstacles, reverses, disappointments, and involves great distances, detours, expansions, interpolations, and, in short, retardations of all kinds'" (Straus 2011, 118). In recasting musical terms in the context of disability, and by repositioning terms often associated with disability in a musical setting, new linguistic and metaphorical possibilities may emerge that may provide a kind of "reverse discourse," a new musical lexicon for Disability Studies.

If we move from the discursive to the phenomenological, there are important ways in which music can also transform the *experience* of time. In his discussion of the phenomenology of music in "Musical Presence: Towards a New Philosophy of Music," Charles Ford explains what makes music distinctive, temporally, in comparison with the other arts:

> Music is the only art that forms time through sound, and then so much so that listeners' intentional time *becomes* that of music. In Hegel's words, music thereby "penetrates the self, grips it in its simplest being." . . But, this "gripping," rather than being inner and individual and "expressing feelings," frees us from the fragile limits of the individual ego, delivering us over to the collective anonymity of musical style, whilst perhaps also resounding the collective anonymity of the nonconceptual world. (Ford 2010)

In the act of listening, one marks the passage of musical time, taking up a new rhythm of existence and experiencing time in a way that is distinct from the temporal demands and markers that dictate daily activities and functions. This can be liberating for people with disabilities whose bodies and abilities may not conform to dominant temporal expectations.

Consider the example of Sesha, a woman with profound disabilities whose "mental age" does not correspond with her chronological age (she is now in her 40s). In speaking about his experience of listening to music by Beethoven with his daughter, Jeffrey Kittay writes: "To make a special occasion with Sesha is to put on one of her favorites and sit next to her to listen. She is rejoicing to the music, we are visibly rejoicing at her pleasure and our redoubled appreciation of the music as we listen to it through her, and she is elated as she sees her musical pleasure shared and validated by those closest to her, so that she is not alone in these feelings both deeply held and finely wrought." (Kittay 2008; Carlson 2013). This description resonates with my own musical introduction to intellectual disability. As an undergraduate in Poughkeepsie, New York, I volunteered in a classroom for children labeled "multiply handicapped," and we spent much of our time listening to music together. We not only were moved by the music but also moved with it in a shared temporal landscape, achieving a synchrony in our embodied responses that brought us together in ways that verbal communication could not. This was not a therapeutic endeavor with a set goal; rather than being directed at teaching, normalizing, or cultivating particular skills, this musical experience unfolded organically and was valuable and valued for its own sake.

Partaking in musical time together happens in musical performance as well. In playing in an ensemble, the individual's experience of marking time becomes a part of the rhythm and tempo of the piece, enveloping each participant into a greater temporal whole. In some cases it may be less rigid, allowing individual players to mark their own rhythmic time and move to a distinct, improvised musical beat. For individuals who may otherwise be assumed to lack such capabilities, or for whom normative demands don't allow them to realize these creative modes of expression, this experience can be

transformative. In his chapter in this volume, Michael Bakan describes the ways that musical performance through the ARTISM project enables performers with autism to move beyond normative expectations: "I believe that people with autism are not necessarily any less spontaneous, intuitive, flexible, or improvisatory than other people are; rather, they appear to be that way because they are almost invariably forced to contend with life situations and settings in which their particular attributes and preferences for expressing spontaneity, intuition, flexibility, and improvisational ability are demeaned, or are patronized, or go unacknowledged or unrecognized altogether by their interlocutors." Thus, in the act of performing music together, people can inhabit a *shared* temporal landscape. This may offer forms of connection and expression for individuals who, according to other normative measures, would not "share time" in this way.

"Music is my favorite way of thinking"

The capacity for engaging with music also raises questions about the adequacy of current models that measure cognitive ability. Rather than assuming that the experience of music by people with intellectual disability is a purely affective, emotional response, such experiences may, in fact, involve certain cognitive capacities that were otherwise assumed to be lacking in these individuals. As I indicated earlier, there has been considerable attention paid to individuals with Williams syndrome, as they seem to possess a striking collection of musical abilities and an appreciation for music. Williams syndrome is a congenital genetic condition that affects about 1 in 10,000 individuals. Though these individuals often exhibit significant intellectual disabilities (and relatively low IQ scores), they also have sophisticated linguistic and musical abilities that have become the focus of a number of researchers interested in music and the brain (Levitin and Bellugi 1998; Lenhoff et al. 1997; Sacks 2007). In their study of individuals with Williams syndrome, Levitin and Bellugi argue that the existence of musicality, rhythmic ability, perfect pitch, and other musical traits indicates that they possess a form of "musical intelligence," one of the eight kinds of intelligence proposed by psychologist Howard Gardner in his theory of multiple intelligences: "The profile of abilities we found in subjects with Williams syndrome supports Gardner's theory that musical ability constitutes a separate faculty and is to a large degree uncorrelated with other aspects of cognitive functioning" (Levitin and Bellugi 1998, 380–381; the reference is to Gardner 1999). Howard Lenhoff, a retired biologist whose study of music and Williams syndrome was inspired by his daughter Gloria, a talented singer who has received national attention, echoes this conviction that people with Williams syndrome possess cognitive abilities that would otherwise be obscured or untapped without the experience of music: "I don't call them retarded. I call them mentally asymmetric. Williams people have a real musical intelligence, often surpassing that of normal individuals. Many other mentally handicapped populations might have untapped potentials waiting to be discovered, if only researchers,

and society, would take the time and trouble to look for and cultivate them" (Sforza 2006, 255).

From the vantage point of Disability Studies, there are a number of critical questions that this research raises. First, the very notion of testing and measuring "intelligence" as a reified concept is problematic and has been critiqued by Disability Studies scholars (Carlson 2010).[3] Second, some of the attention that has been given to individuals like Gloria is consistent with the super-crip and savant narratives that run the risk of further *othering* people with disabilities and contributing to their "enfreakment" (Straus 2014; Sforza 2006).[4]

Yet in recognizing the significance of musical experience for people with Williams syndrome, one need not fall prey to either tendency (i.e., to reify yet another form of intelligence or to perpetuate the problematic figure of the "idiot savant"). To view music in the narrowest terms as simply a new kind of litmus test for a particular form of intelligence, exceptionality, or abnormality is to miss the greater sense in which musical experience is a form of flourishing for people with Williams syndrome. It is not only extremely talented individuals with Williams syndrome who possess a high degree of musicality; the fact that music is a source of joy, community, and engagement for so many is confirmed not just by scientists but also by family members, friends, and by the individuals themselves. In the words of one of the participants of "Music & Minds" summer music program, which has become the Berkshire Hills Music Academy, a post-secondary program devoted to cultivating music through an integrated curriculum for people with intellectual disability in Lenox, Massachusetts: "Music is my favorite way of thinking" (Levitin and Bellugi 1998).[5]

The language of music also affords people with intellectual disabilities new modes of expression though performance and composition. In speaking about his son, composer Hikari Oe, who was born with significant disabilities, Nobel prize–winning author Kenzaburo Oe writes,

> If Hikari had not composed, he would surely never have been able at any time in his life to convey the rich, profound, crystalline and radiant message contained in this music. For our part, had Hikari not composed, we would have never realized, nor would we have been able even to imagine, that he possessed this sensibility. The scope of what we might have gained from this world and understood of it would have been significantly narrowed. I feel we would have missed gaining an insight into some of the most important and humble aspects of the meaning of human life. (Oe 1994; see also Carlson 2013)

Hikari Oe is considered a musical savant by many, and so one might attribute his forms of musical expression to his talent. Yet there are many individuals with intellectual disabilities, who would not qualify as "savants," for whom music is a mode of communication and expression. In the documentary *Praying with Lior* (Trachtman 2007), Lior Liebling, a boy with Down syndrome who is preparing for his Bar Mitzvah, expresses

himself through singing and davening, a form of Jewish prayer. The power of the sung word is not only the basis for his deep connection with God but also a way of maintaining a connection with his beloved mother, who died when he was young. Through music, Lior's capacities for self-expression, memory, and spirituality flourish. Kevin Finn, whose daughter Meghan attended the camp in Lenox, Massachusetts, puts it this way: "It's like music is their language—the sound of music is their way of thinking and feeling" (Sforza 2006, 255). In Meghan's own words: "Music is a huge part of my life. To me music is like soup: music comes down your throat and feels so warm. So music is like soup. It tastes good" (Sforza 2006, 193).

Dynamism and Musical Joy

Music affords the possibility of recognizing oneself and others as temporal, embodied, creative, and expressive beings. And as Meghan's description earlier illustrates, musical experience confirms our own vitality as human beings: "Music, simultaneously engaging our physical, emotional, and intellectual receptivities, makes us feel fully alive. The dynamism of music, moreover, reminds us of our own dynamism" (Higgins 2011, 121). The animating power of music is reflected in a broad range of musical experiences that people with and without intellectual disabilities have. And this dynamism challenges certain assumptions and stereotypes about disability. Historically, a static portrait of intellectual disability has been perpetuated in multiple ways (including a broad range of scientific, psychological, and pedagogical incarnations.) This persistent view of people with intellectual disabilities as in a state of arrested development, of extreme passivity and incapacity, has contributed to their dehumanization and has justified many of the cruel and violent forms of treatment to which they have been subjected (Trent 1994; Carlson 2010).[6] Through musical experience, people with a broad range of intellectual disabilities have the opportunity, whether through listening or performing, to actively engage, to enact and simultaneously reveal dynamic modes of being. Describing the summer residential program Music & Minds for children with Williams syndrome, Reis et al., explain, "The majority of parents indicated that their son or daughter displayed an unusual affinity with and love for music and interpreted this joy in music as an important factor in the personal happiness that would be achieved in life. 'For my son, life without music is life without heart and joy,' one parent explained. Parents of eight other participants used language that echoed this sentiment." In the words of Charles, one of the participants, "Music is my life" (Reis et al. 2000).

Attending to the significance of music for people with intellectual disabilities, then, can reveal a number of important dimensions of their lives: music can "call forth the self" (Sacks 2007, 346) in ways that might otherwise have been left obscure or unnoticed and can foster the cultivation of particular capacities and forms of joy that may contribute to the individual's flourishing (Carlson 2013). This is evident in the profiles of band members of groups like interPLAY, Flame, and Heavy Load, all of which include

musicians with intellectual disabilities. Their performances embody the power that music has to harness freedom and creativity and are imbued with energy, engagement, and vitality.[7] As Roberta B. Hochberg, an interPLAY board member, says, "You cannot help but be profoundly affected by watching the joy on the faces of the band members when they play and then receive positive feedback from the audience" (Weeks 2010).

In demonstrating the ways they are able to connect with their fellow band members and audiences, these musicians highlight the social nature of musicking. This points to an equally important dimension of their musical lives: the fact that they are experienced in the presence of others. Higgins writes,

> Music's appeal to our physical nature gives us a very immediate sense of enjoyably sharing our world with others. This sense of sharing is ethically beneficial in that it makes it difficult to consider others' experience alien to our own. In fact, we feel that others' living experience is in this case actually our own. . . . We rejoice beyond ourselves in musical experience. I cannot think of a better basis for ethical concern" (Higgins 2011, 128)

It is to the nature of these relationships forged through music that I now turn.

Transposing Relationships between Selves and Others

Philosopher of disability Anita Silvers opens her article "From the Crooked Timber of Humanity, Beautiful Things Can be Made" with two images: in the foreground she sees her friend who was born with certain physical, visible disabilities; behind her friend, Picasso's painting of a face. She provides a lengthy description of the similarities between the cubist portrait and her friend's disfigured appearance, confessing: "I am drawn to dwell on the face in the painting, yet my eyes avert from the real face, even though it is closer to me. . . . By looking away rather than seeing my friend, I make her invisible. While doing so, I condemn myself for joining in a visual practice that sustains the stigma our culture imposes on impaired bodies" (Silvers 2000, 197).

The question that motivates her subsequent reflections is this: "Why do we see the corporeal anomalies configured into Picasso's rendition of the human face as being beautiful but perceive my friend's facial anomalies as an unfortunate disability?" (Silvers 2000, 205). Put another way, "Why does the normal hold so much less sway in art than in life? We see a painted face in cubist style as beautiful, but see a similarly configured fleshly face as deviant" (Silvers 2000, 216). In developing her answer to these questions, she argues for the transformative and ethical power of art: "Art has a positive transfigurative—almost a redemptive—effect on configurations we otherwise would apprehend as being ugly. . . . Art can make impairment powerful." Thus she considers the

possibility that enlarging "our aesthetic responsiveness to real people . . . would enlarge our moral capacities" (Silvers 2000, 206, 215).

Silvers's discussion prompts a number of responses. First, it is not certain that everyone *does* experience Picasso's paintings as beautiful, and art may not make impairment powerful, or beautiful for that matter, for all who experience it. Second, the question of how impairment functions in a work of art, as opposed to in a live exchange between two individuals, is worthy of further consideration and raises questions about disability, impairment, and forms of representation. Finally, there may well be numerous *dis*analogies between Silvers's discussion of beauty, impairment, and art and the connections I am drawing between music and intellectual disability. However, I think her questions can be applied in a musical context: How can musical experience "reform exclusionary practices" that currently contribute to the devaluation of intellectually disabled people? And how might music serve to expand the moral imagination and transform the relationship between self and other? I will first consider the relationship between people with intellectual disabilities and nondisabled others and then move beyond this binary to consider how music establishes certain kinds of relationships more generally.[8]

There are many musical relationships between individuals with and without disabilities, and music can function in distinct ways in each of these. One might think most immediately of the ways that music functions in a therapeutic context and serves as a basis for the interaction between client and therapist. Yet it can also play a part in other capacities that are not explicitly therapeutic but that are meant to enhance both the individual's quality of life and the relationships they have with others. For example, in the activity of caregiving, Jeffrey Kittay speaks about how music might serve as a means of structuring certain forms of care and shape the auditory environment in ways that are beneficial to individuals with profound disabilities (Kittay 2008; Carlson 2013).

Higgins argues that music also "trains our capacity for empathy." While empathy is clearly important in caregiving, Higgins considers it in a broader sense. First, she says it teaches us to adopt a nondefensive and noncompetitive stance toward others. Thus, the "enjoyment of music involves the experience of taking satisfaction in a state of mind in which one does not oppose oneself to other human beings" (Higgins 2011, 129). In the context of disability, this might mean the transgression of expected roles and boundaries, particularly in cases where an individual with a disability has been considered to be only the passive recipient of care rather than an active agent. In speaking about the transformative power of art, philosopher Amy Mullin explains, "Art can start an encounter with another, and it can destabilize our terms of reference governing that encounter. To this extent it may enhance the possibilities that we will emerge from that encounter with changed beliefs and attitudes—but we cannot predict where those changes will take us" (Mullin 2000, 132). Though Mullin is speaking about the visual arts, her point applies to music as well. Musical encounters can be transformative insofar as they can move beyond perceptions of alterity and establish the ground for a shared world wherein a new model of the relationship between self and other emerges: one that is reciprocal rather than one-sided. In the case of disabled performers and composers, the nondisabled listener becomes the recipient of their gifts; in the case of listening together, the

experience of hearing a piece may be transformed by listening to it *with* another; and in the case of playing and singing together, disabled and nondisabled individuals are equal participants in the creation of music (Carlson 2013).

Higgins says that music also "affords a ground for empathy with particular others" because it "creates intimacy" (Higgins 2011, 130). This idea is particularly intriguing in cases where barriers prevent individuals with disabilities from connecting with others. These barriers might include the perception of an individual with an intellectual disability as radically "other," various obstacles to communication (for example in persons who are nonverbal), and social and structural barriers that prevent such relationships from being forged. Musical relationships can be transformative in that they overcome such obstacles and provide the possibility of finding new grounds of commonality. Higgins states, "One listens to music, not as lover, lawyer, or mother, but as a human being, and one relates to other listeners as human beings like oneself. This kinship is not grounded on the relatively contingent fact of occupying roles that are similar to or linked with those of other individuals. Instead it is built on sharing the freedom of imagination that enables one to feel empathy with the movement of tones, the simultaneous bodily response to stimuli that one receives without inhibition" (Higgins 2011, 132). The notion that certain roles and identities fall away in musical experience is an intriguing one, particularly in cases where music provides the basis for participation in a shared activity between individuals who might lack other means of establishing a connection.

Yet I do not agree that we must necessarily check all dimensions of ourselves at the door when engaging in a musical encounter. In fact, part of the power of exploring music in the context of disability is to recognize ways in which music and disability are performed together by uniquely embodied individuals. Just as music can call forth the self as a dynamic, temporal being, musical experience can *enable* and enact disability in unique, interesting, and positive ways. This may be in the form of "disablist hearing," like autistic, blind, or deaf hearing (Straus 2011), or through the many examples of musically performing disability contained within the chapters of this volume. Musicking is fully a part of our embodied existence.

Musical experience and relationships can also provide the occasion to cultivate certain virtues like appreciation and reverence. While these can be directed at the performers, composer, or the music itself, Higgins recognizes that in the process of valuing and gaining joy from musical experience, the possibility of a deeper appreciation for *others* in general can be developed. She characterizes this reverence for music as a "contagious and expansive emotion" that has ethical value because of what it can generate: "One values another person more for being sensitive to aesthetic experience. One becomes momentarily attuned to the other person's inner life. One realizes that . . . he or she remains vulnerable to being moved. Such vulnerability is precious for its contribution to the person's own life, but it is also a precondition for openness toward others" (Higgins 2011, 135). The idea of an individual *vulnerable to being moved* radically shifts the conception of vulnerability that is so often associated with people with intellectual disabilities. Vulnerability has been typically linked to dependency, to a lack of autonomy and self-possession, and to the features of a more infantile and hence precarious existence.

Yet to say one is vulnerable to being moved is to recognize a responsive power, an active capacity within a person whose subjectivity is brought out in the act of being moved by a piece of music.

In his book *Receiving the Gift of Friendship*, theologian Hans Reinders argues that it is not enough to ensure that the rights of people with intellectual disabilities are recognized. In order for them to lead full lives, to flourish as human beings, they are in need of the "gift of friendship." He writes,

> Rights certainly create new opportunities by opening up institutional space, and they are extremely important in that capacity; in creating new opportunities, they affect our lives as citizens. But disabled people, just like other people, are human beings before they are citizens: to live a human life, properly so called, they must not merely be included in our institutions and have access to our public spaces; they must also be included in other people's lives, not only by natural familial necessity but by choice. . . . Friendship is special because it is freely chosen. Our friends want us as friends for our own sake. No other relationships, either professional or kinship, can give what friendship gives. (Reinders 2008, 5)

Is it possible to draw connections between the nature of friendship and the kinds of relationships that are established through musicking? And might these hold promise for people with intellectual disabilities?

Sharing music is one way to partake in community, to establish and engage in a particular form of *being-with*, and to enrich our human lives. This is especially significant for people with intellectual disabilities who have been excluded or marginalized within ableist society. Insofar as music provides a basis for connecting with others, it may have what Higgins has called a "humanizing" effect, a phenomenon worthy of attention in view of the multiple forms of dehumanization that people with intellectual disabilities have endured. This musical attunement to the "other" can come in a variety of forms: in the act of listening together, through joint participation in a musical performance, and in the relationship between audience and performer. What is significant about these moments is that they can disrupt the expected *asymmetry* in a relationship between the "nondisabled" and "disabled"; there is a shared experience that is centered on a third term, one in which the traditional binaries and imbalances may be erased.

Yet there is also value in moving beyond the designations of disabled/nondisabled altogether when considering music and intellectual disability. Almost all of the ensembles that I have referenced here are collaborative projects that include individuals with and without disabilities; thus it is equally important to explore the nature of their experience *as musicians* rather than remaining ensconced in the able/disabled binary. In theorizing about relationships between individuals, in reflecting on the power of *being-with* in a musical context, new roles and identities may emerge as rich models for Disability Studies scholarship. These might include the virtues of generosity, openness, respect, and tolerance that underlie the relationship between audience and performer; the distinct forms of knowledge necessary for musical improvisation and collaboration among

musicians; and the examples of nonverbal expression and communication that take place among cocreators of a musical performance.

Finally, in thinking about musical relationships in the context of disability, there is a parallel between what Reinders says about friendship and what I am arguing about musical experience. The examples I have examined speak to the value of music *in itself*, rather than as a means to some other end. When music is chosen freely and for its own sake, as Reinders says friends are chosen, it contributes to the depth and value of shared human experience, and allows both musical encounters and musical lives to flourish. This is why it is so important that people with intellectual disabilities be given a broad range of musical opportunities *beyond* the clinic and the research lab. And it is here that discussions of flourishing and art intersect with ethical questions of justice and access (Carlson 2013; Wong 2010).

Conclusion: Music, Intellectual Disability, and Disability Studies

The forms of marginalization that many people with intellectual disabilities experience are not limited to the social sphere; there are also ways in which these patterns of exclusion are repeated within Disability Studies itself. While there has been increasing attention paid to various forms of intellectual disabilities within the purview of Disability Studies, there is still room for this interdisciplinary field to continue to expand and make itself more inclusive. In this vein, inquiring further into the varied and complex intersections between music and intellectual disabilities may prove instructive and fruitful.

Taking music or the aesthetic as a starting point in addressing intellectual disabilities may generate new ways of talking about the experience of disability. For example, new metaphors, analogies, and models may be found in the complexities and mysteries of the musical work, and in the nature and range of musical relationships (e.g., the relation between performers and between performer and audience). Speaking differently about intellectual disability may in turn allow it to be reimagined in the way that Silvers says art can expand the moral imagination. Recognizing the significance of music can also point out the limitations of theoretical models currently in use. In the context of moral philosophy, Higgins writes, "Music's value to philosophical ethics is to remind it of aspects of our ethical experience that are forgotten in other models" (Higgins 2011, 163). This might be articulated in terms of Disability Studies as well, as one considers how the musical lives of people with intellectual disabilities may challenge, expand, and enrich the current models of disability.

Many of the issues I have explored in this chapter also introduce certain questions and tensions that disability scholars must address. First, when considering musical intelligence and explanations of musical cognition and perception, what place should studies on music and the brain have in Disability Studies? On the one hand, there are very good

reasons to resist the medical model of disability and approaches to music and disability that simply reify intelligence and perpetuate essentialist definitions of disability and problematic categories of the "normal" and "abnormal." However, there may be important ways in which scientific research on musical perception can also challenge existing assumptions about intellectual disability, replace older problematic definitions of intelligence with more capacious and varied models, and open up new and fruitful paths of inquiry. Second, there is a tension between eschewing the very categories of disabled/nondisabled in the process of recognizing the nature and value of shared musical experience and preserving these designations so that "disablist" forms of musical expression and listening may be defined, explored, and celebrated. Given the heterogeneity of the very category of "intellectual disability" (Carlson 2010), there is also the question of whether any generalizations specific to particular kinds of intellectual disability (e.g., autism, Williams syndrome, Down syndrome) can or should be made when making claims about music. What *does* seem certain is that there is far more work to be done to foster the development of musical lives, to learn from and celebrate these forms of musical experience, and to critically analyze the barriers that prevent them from being recognized and realized.

Finally, paying attention to musicking, to the varied ways and places in which music is performed, composed, and experienced, is a reminder that the lived experience of music is distinct from theorizing and philosophizing about it. The French existentialist philosopher Gabriel Marcel, in speaking about the significance that music had for him, said, "In conditions that can only remain mysterious, music has always been for me, in the course of this hectic philosophical quest I have pursued, a permanent guarantee of that reality that I was attempting to reach by the arid paths of pure reflection" (Marcel 2005, 17). There is always the danger that the fullness and complexity of lived musical lives will be diminished in the process of trying to give voice to them in theoretical works. This concern is particularly salient for people with intellectual disabilities, who have so often been *spoken about* and *spoken for* rather than being given the opportunity to speak for themselves. Just as the totality of the musical work cannot be reduced to the score or to any single performance of it (Ingarden 1989), the lived, embodied experience of people with disabilities cannot be contained within labels and categories. Attempts to explain, analyze, and define both music *and* disability often call attention to the limits of language and the inadequacy of conceptual models. Perhaps in bringing music and disability together, new dimensions of this challenge will be taken up by critical disability scholars, philosophers, and music theorists alike, and more inclusive musical spaces may be created.

Musical communities can be temporary or permanent, large and small, improvised or well defined, professional or casual, with permeable, dynamic, or fixed boundaries. The vast range of musical encounters and relationships that can be established may serve as a basis for rethinking the very nature of community and the meaning of access and inclusion. In speaking about the group interPLAY, the Scottish tympanist Evelyn Glennie, who is deaf, said that a band for people with cognitive disabilities is about inclusion not exclusion: "Society cannot continue to disable themselves

through their need to categorize people or make assumptions as to another individual's abilities. . . . The human body and mind are tremendous forces that are continually amazing scientists and society. Therefore, we have no choice but to keep an open mind as to what the human being can achieve" (Weeks 2010). For people with intellectual disabilities who have experienced stigmatized and isolated identities, the possibility of sharing their musical lives with others, in whatever form, may prove to be fertile ground in which friendships and social connections can grow and flourish. In this way, attention to music might "reform exclusionary practices" both within and beyond the field of Disability Studies, and generate new modes of solidarity, community, and flourishing.

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Notes

1. The category "intellectual disability" is, of course, a varied and complex one and by no means straightforward. In invoking it here, my focus is primarily on those individuals who have been diagnosed as having some form of cognitive and/or developmental impairment. However, I do not view the terms and categories that accompany a diagnosis of "intellectual disability" as essential, nor do I wish to reify "intelligence" in any way. I also want to acknowledge that, though I include examples of autism, many individuals with autism are not classified as "intellectually disabled."
2. Disability scholar Tanya Titchkosky examines this phenomenon in the context of university life in Titchkosky 2010.
3. It is worth noting that Gardner himself rejects any kind of essentialist account of intelligence (Gardner 1999).
4. Even the description on the front and back book jacket on *The Strangest Song*, a wonderfully rich book about Gloria, Williams syndrome, and music more broadly, states: "Since she can't read music, each note is stored in her brain, which is only 80 percent as large as yours or mine. . . . Williams syndrome . . . exacts an enormous toll on body, brain and personality. The result is an atypical body, a profoundly asymmetrical mind, and often an amazing talent for music" (Sforza 2006).
5. See http://www.berkshirehills.org/student-life/student-stories.html.
6. I cannot help but think of the images of institutions like Willowbrook, where inmates were deprived all forms of human contact and modes of expression or enjoyment that might have enabled forms of expression that would directly contradict and challenge the diagnoses they had been given.

7. See http://www.friendshipcircle.org/blog/2013/03/08/5-amazing-bands-who-look-beyond-their-disabilities/.
8. Two notes about my use of the "disabled"/"nondisabled" categories. First, I do not mean to attribute any essentialist meaning to them. Second, I have deliberately referred to the "nondisabled" individual as *other* here to reverse the more common designation of "the disabled as other."

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CHAPTER 3

IMAGINED HEARING

Music-Making in Deaf Culture

JEANNETTE DIBERNARDO JONES

HEARING is something many musicians take for granted. Few hearing musicians stop to consider what it might mean to hear deafly. As hearing musicians increasingly become aware of the physiological experience of deaf bodies, hearing deafly is something that all types of bodies can do. Yet musicians and listeners can also participate in hearing Deafly, with a capital D that signals the cultural minority of those with hearing loss, as we become more aware of the political implications of the history and language of Deaf culture.[1]

"DEAF PEOPLE CAN DO ANYTHING, EXCEPT HEAR"

In the spring of 1988, students, faculty, and alumni gathered on the lawn of Gallaudet University, the only Deaf liberal arts university in the United States, to protest the election of a hearing candidate to the university presidency. Beyond the campus, the Deaf community across the country rallied against not only the hearing president-elect but also hearing members of the Board of Trustees. With forceful cheers in American Sign Language, "Deaf President Now!" (DPN), the protest—sometimes referred to as the "Gallaudet Revolution"—was highly visible and achieved all of its demands. In what became a pivotal moment in Deaf history, protesters borrowed a banner from the civil rights movement: "We still have a dream!" (Barnartt and Scotch 2001, 199–201; Garey and Hott 2007). Jack R. Gannon (1989), who had observed the protest, writes, "The world deaf community looks to Gallaudet for leadership, for innovation, for hope, and inspiration. If there could not be a deaf president here, at Gallaudet, at this time, then where, and when? There was no turning back. As I listened and watched, I finally

understood what the world would come to understand—the Gallaudet students could not lose" (10).

Today the 1988 Gallaudet protest is a highlight in Deaf historical consciousness. For the Deaf community, the DPN movement came to symbolize its rejection of nearly two hundred years of paternalism perpetuated by hearing medical and educational professionals (Jankowski 1997, 132–135).[2] Most culturally Deaf people are familiar with the words of I. King Jordan, who became the first Deaf president of Gallaudet University in the aftermath of the protest: "Deaf people can do anything, except hear." The phrase has been a mantra of empowerment since the Gallaudet protest. Deaf Pride draws its rhetoric from the "can" language of this phrase with such statements as "Deaf can" or "can the can't syndrome" (Jankowski 1997, 135).

Bob Hiltermann, the drummer for the Deaf rock band Beethoven's Nightmare, challenges the Deaf community to reconsider Jordan's words—is it really the case that deaf people can do anything except hear? What about music? Playing drums in a rock band has been a lifelong dream and aspiration for Hiltermann. Growing up in a large family with hearing siblings who played music together, he asked his mother to let him play music. He recalls his parents' response: "No, you're deaf. It's hard for you. Don't bother. You can't, can't, can't."[3] When Hiltermann arrived at Gallaudet, he realized that he "can, can, can" (Scari 2010).

Walking around with Hiltermann at the 2012 meeting of the National Association of the Deaf (NAD), I saw him approach people in conversation: "What did I. King Jordan say?" "Deaf people can do anything, except hear." Hiltermann pressed on: "What about music? Can Deaf hear music? Do you like music? I love music! But I'm Deaf!"[4] In this small repartee, Hiltermann calls into question commonly held views about music as an exclusively aural mode of expression. As I spent the afternoon perusing the vendor booths with Hiltermann at the NAD meeting, his conversations revealed that many Deaf people love music. Yet I also heard many deaf people say that music seemed irrelevant, that it was not fun to try to lip-read bands, that it was an experience with which they could not connect. The Deaf rock band Beethoven's Nightmare is reaching out to both of these groups in the Deaf community. They are sharing their love for music in a uniquely Deaf way with those who already love music, and they are addressing those in the Deaf community who never thought they could experience music. For these musicians, Deaf people can do anything—including "hearing" music.

Using as case studies the creative works and performances of Deaf musicians, including Beethoven's Nightmare and rappers Sean Forbes and Signmark, I challenge the hearing world to think about the alternative modes of hearing that a deaf musical experience offers, calling for critical reflection on how many of the current assumptions about music are connected to how people hear with their ears. Examining the musicians' biographies, repertories, performance spaces, and audiences within a greater context of Deaf culture and history, I argue for a way of making and listening to music that is specifically Deaf, celebrating deafness in a way that situates the Deaf as a cultural minority within a hearing world. Musical practices that arise from this political identity create a Deaf musical culture that should encourage music scholars to acknowledge the

linguistic differences and histories that are present in the performance and reception of Deaf music.[5]

Deaf History and Culture

Deaf history is colored by the constant struggles of the deaf world against the dominance and control of the hearing world. Psychologist Harlan Lane (1992) draws parallels between colonialism and oppression of the Deaf community by the hearing world, using the term "audist" as one might use the term "racist."[6] Further exploring the postcolonial status of Deaf culture, Deaf scholar Paddy Ladd (2003) asserts that the cultural patterns of Deaf culture have been directly affected by both the acquiescence and resistance to the cultural domination of the hearing world (79).

The struggles of the Deaf community as a minority group, the shared experiences of a common Deaf history and Deaf customs, and the shared institutions of Deaf schools and Deaf clubs have helped to shape a strong sense of Deaf identity. All these experiences characterize Deaf culture, but its definitive feature is sign language (e.g., American Sign Language, British Sign Language), so that Deaf people describe themselves as a linguistic minority.[7] Deaf scholars Tom Humphries and Carol Padden (2006) note that the struggle to make sign language intelligible "underlies nearly every political act of the community" (142).

Since the nineteenth century, American deaf education has been polarized by proponents of the oralist and manualist methods of teaching. Oralism is the belief that deaf children should be mainstreamed into hearing environments and taught only to speak, with the agenda of actively preventing them from learning or communicating in sign language (Ladd 2003, 7). In the nineteenth century, oralists were keen to develop musical education in schools that privileged a typical (or "normal") hearing experience. This motivated the development of hearing technologies, the goal of which was to "normalize" deaf people, so that their experiences matched those of a hearing person's as closely as possible.

Music was also part of manualist deaf education (that is, education in which sign language is the main form of communication). In this practice, musical activity is articulated as a bodily experience that privileges felt vibrations and observed visual cues.[8] Music education in manualist circles was also fraught with the undesirable possibility of "passing" as hearing. Ben Bahan (2006, 34–37) describes two traditional modes of musical expression in manualist, sign-based Deaf culture: translated songs and percussion signing, both derived from the rich heritage of ASL poetry and storytelling. Translated songs are those in which the lyrics of songs written in a spoken language have been translated into ASL for performance, such as the national anthem before a sporting event. Percussion signing is a type of performance that assigns signs to certain beats, sometimes accompanied with a drummer. According to Bahan 2006, percussion

signing is no longer extensively practiced, save for a few examples (including Gallaudet University's football song, the "Bison Song").[9]

Tensions between the oralist and manualist camps climaxed in 1880, when the oralists won a major victory at the Milan Congress, an international symposium of educators of the deaf to which no deaf people were invited. The resolutions of the Congress stated that oralism was the preferred method for deaf education, ensuring the subjugation of sign language (Ladd 2003, 120). Deaf culture was already flourishing in Deaf schools, where Deaf adults taught and mentored deaf students, and in Deaf clubs, where groups of Deaf adults could socialize and find community and advocacy. The Milan Congress threatened Deaf culture to its core by separating Deaf people from each other (Ladd 2003, 126). Edward Gallaudet became a dissenter of oralism and declared that Gallaudet College (later University) would remain a haven for sign language (Gallaudet 1881). The National Association for the Deaf in the United States was also founded in response to the Milan Congress to cherish, support, and promote sign language and Deaf culture. The tension between oralism and manualism is central to Deaf cultural practice in all contexts and media.

Deaf Musical Culture

It is necessary for sign language to be at the heart of an argument for a cultural practice within the culturally Deaf community—a Deaf musical practice, in our case. When George Veditz, then president of the National Association of the Deaf, remarked in 1912 that deaf people were "first, last, and for all time, people of the eye," he could not yet articulate the cultural implications that would follow from this idea in the twentieth century (quoted in Humphries and Padden 2006, 2). While sign language had been used among deaf people in the United States since before the nineteenth century, it was not until the 1970s that this lay, communal language practice was recognized by linguists as a legitimate language, American Sign Language. The recognition of native sign languages throughout the world has dramatically affected the international Deaf community. Deaf scholars Carol Padden and Tom Humphries (1990) were able to articulate, for the first time, the world of the "people of the eye" as a distinct Deaf culture with its own native language, practice, and customs. The Deaf community argues that sign language is the most natural language for those who are born deaf or become deaf when they are young—it is their native language.

The use of sign language is a strong artistic and political statement for Deaf musicians. Beethoven's Nightmare makes ASL a key part of their performance practice; Signmark (2010) and Sean Forbes (2012) rap in ASL and have created DVDs of music videos to accompany their albums. Not only is their live performance practice a visual experience, so is their recorded music. These musicians make music that is culturally Deaf: their lyrics speak to their unique experience as Deaf people, and they are communicated using

the language of Deaf culture, sign language. The politics of the culturally Deaf community would challenge the hearing world to recognize that they not only can speak on their own terms but also hear and perform on their own terms.

There are two modes of deafness within a deaf musical culture: the cultural-linguistic model that politically identifies itself as capital-D Deaf culture, and the physical model that takes into account all deaf bodies, not just those who identify with the culture of sign language users. Deaf musical culture might also prompt us to consider implications beyond the cultural/linguistic model on how both hearing and deaf individuals experience sound and music.

We generally focus on hearing as the complex process of sound entering the ears, passing across the tympanum (the ear drum) of the middle ear, stimulating hundreds of hair cells in our inner ear, and sending signals to the brain via the auditory nerve. The brain organizes the sounds and assigns meaning to them. For a deaf person the auditory process is shifted. Deafness is hearing loss that takes place in the ear. The many different types of hearing loss include middle ear or inner ear, congenital or later onset, and temporary or permanent. The degrees of hearing loss range across a spectrum from hard-of-hearing to mild, moderate, severe, or profound. Sometimes a person's hearing loss affects certain frequencies more than others. Perhaps there is noise in their heads that only they can hear, such as is the case with tinnitus.

Hearing people learn to think of the actuation of a thin membrane in the side of the head as the necessary precondition for what one can experience as music, but the membrane is incidental. In a deaf musical experience, the whole body becomes the membrane. Both deaf and hearing people can feel sound vibrations, but hearing people tend to focus only on the auditory perception of these sound vibrations. Without that distraction, deaf people tend to use their whole body to perceive sound vibrations. The physical characteristics of a deaf bodily experience of sound waves can be mediated through a culturally Deaf understanding of the significance of that experience. In addition to the politics and culture of sign language within the Deaf community, these visual and kinesthetic components of "deaf hearing" (Straus 2011, 167–170) contribute to the Deaf cultural expression of music.

Beethoven's Nightmare

The members of the Deaf rock band Beethoven's Nightmare found each other at Gallaudet University.[10] Bob Hiltermann, the drummer of Beethoven's Nightmare (2004), recalls his experience arriving as a student on the campus of Gallaudet University in the 1970s: "I got to the dorm. I was on the way to my room. Then all of a sudden I felt vibrations. . . . So I touched the wall. Ah, vibrations. What was that?" After Hiltermann met guitarist Steve Longo and bass player Ed Chevy, together they formed Beethoven's Nightmare while still at Gallaudet (Scari 2010). While they were students, they performed regularly on the campus, entertaining the Deaf student body. Their

rock'n'roll style was inspired by the Beatles, Led Zeppelin, and Jimi Hendrix, but often accompanied with ASL storytelling.

For many of the late-1970s Gallaudet alumni, including the band members, these performances were their first experience with Deaf music-making. Chevy reflects:

> As Deaf people, we have a rhythm inside our bodies, and we're famous for being storytellers. It's a huge, important part of Deaf culture. If you can see a beautiful storyteller, telling a story in ASL, it's just fantastic. And to pair it with that beat, the creativity that it elicits, is wonderful. It can really be paired with any story you want. ASL is a beautiful language, and we don't want to lose the language. (Garey and Hott 2007)

Chevy's comments indicate the integral roles that felt rhythm and sign language play in musical expression, rooted in long-standing traditions and practices within Deaf culture.

Since their days at Gallaudet, the band members have settled on the West Coast and Hawaii. Throughout their postcollege life, they have met regularly to play music together. In 2002, the band returned to its roots at Gallaudet University to participate in the international Deaf conference and festival, Deaf Way II.[11] Since Deaf Way II, they have been performing more frequently around the United States and Europe. In 2004, they released their CD, *Turn It Up Louder!* The album proudly declares itself "The Crossover Masterpiece of the Century," and the liner notes describe the group's music as "retro rock and roll infused with American Sign Language" (Beethoven's Nightmare 2004).[12]

The audience for Beethoven's Nightmare is primarily a Deaf audience, though they perform for the hearing world as well. Beethoven's Nightmare's use of ASL is at the heart of what makes their show distinctive. Hiltermann explains, "This is a whole new concept—this kind of performance. It's never been done before. With sign language. Not interpreting the song, no. Perform the song. There's a difference. Interpreting, yeah, you get the story. But performing, you get the picture" (Scari 2010). In this explanation, Hiltermann calls on listeners to consider ASL as an integral part of the music—not just an independent text, nor a translation of preexisting English lyrics.

Beethoven's Nightmare writes their own music and lyrics, and uses dance, mime, and sign language in their performances. Chevy, who composes most of the songs, describes his process as usually driven by an idea or a vision; then the music comes next, and he writes the lyrics in the last stages of the process.[13] This initial visual inspiration is a key part of their music, from conception to performance.

Working with ASL specialists has always been a central aspect of Beethoven Nightmare's concerts. From 2011 to 2013, they partnered with two hearing signers—Juanita Chase and Joshua Lamont, both trained as actors—who toured with the band and prepared a signed interpretation of the music. During instrumental passages, the signers may act out the idea of the song or simply dance, gesturing the pulse of the musical beat. Lyrics are sung in English by Chevy, who is Deaf. At the end of 2013 the band expanded their members to include Paul Raci, a hearing vocalist who also signs. Raci is

an award-winning singer and actor; he is also CODA ([hearing] Child of Deaf Adults) and has been immersed in Deaf culture and sign language for his whole life. His role in the band is to take over the vocals and the signing (Knowles 2013). The array of people involved with Beethoven's Nightmare is indicative of the spectrum of people who are part of Deaf culture—signing hearing people, signing deaf people who also voice, and a hearing person born into a Deaf family.

The stage is set up in such a way that all members of the band have visual access to each other. Hiltermann is in the center, his drum set positioned toward the back of the stage, with bassist Ed Chevy on his right and lead guitarist Steve Longo on his left. In addition to the monitor speakers in front of the musicians, additional monitor speakers are placed behind them. During the sound check they adjust their rear speakers to optimal bass levels to feel the music. They communicate with each other visually, connecting what they see with what they feel. During the concert at the NAD festival, Lamont and Chase signed for the band; they performed at the front part of the stage, thus foregrounding the visual aspects of their performance, including signing, dancing, and gesture. Paul Raci, positioned on stage in the place of a traditional vocalist, has his own microphone and sings and signs simultaneously, interacting with the band through visual contact, body language, and sign language.

Beethoven's Nightmare's repertoire can be broadly divided into two main categories. The first includes songs with very few lyrics that convey mostly abstract ideas, presumably stemming from Chevy's initial vision or concept; these ideas, dramatized by the signer(s), describe their experience as Deaf musicians. For example, the songs "Crash It Out" and "Angel of Darkness" each have only one line of text. Chevy's vision of the songs is pantomimed by the onstage signers, accompanied by long instrumental interludes. The liner notes explain that the song "Crash It Out" is an "attempt to break the deaf sound barrier with a heavy steady beat," while "Angel of Darkness" is about "a mythical deaf goddess of rock music [evoked] as a muse to give energy to the beat and sound to the silence." The song "Black Magnet" explores how Chevy perceives music: "To more fully feel his music, a deaf guitarist invents the most powerful planetary guitar using a strange magical black magnet" (Beethoven's Nightmare 2004, 2). The lyrics to "Black Magnet" (which appear in the CD booklet) seem to be a description of the dramatic performance of the signer:

> Turning into Black Magnet, it's getting better over time. It's becoming irresistible, super power all mine! Black Magnet comes alive recharging and testing amplifying and attracting rare earth.
>
> Now is the time. Turn on the power! It's alive! Now I've got the Black Magnet, the special force of music. The most powerful I can play. The living power!
>
> Amplifying and attracting rare earth. Now is the time. Turn on the power! It's alive! Now I've got the Black Magnet, the special force of music. The most powerful I can play. The living power!

Dramatically enacting the song's ideas, the signer also moves his body to provide a visual representation of the musical beat, sometimes fist-pumping the air or manipulating the signs to occur in rhythm with the song.[14]

The second type of song replaces dramatic pantomimes with more clearly articulated English translations of ASL signs. These songs often speak more directly about Deaf culture. The lyrics to "It's Just a Deaf Thing!" include colloquial signs that are central to Deaf expression: they include the handwave, or Deaf applause made famous at the Gallaudet protest; ILY, or the ASL sign for "I love you," also used to express camaraderie among the Deaf; and "pah!"—an expression that means "finally!" in a victorious sense.[15] The lyrics in English are simple: "It's just a Deaf thing! You wouldn't understand!" with interjections of handwaving, ILY, and pah! In a performance, the audience is encouraged to join these choruses of signs, the song creating a space for this communal Deaf experience. The signer offers visual representation of the beat, punctuated by clear ASL signs, encouraging the audience to join in.

"Turn It Up Louder!" (the title track of their CD) explains how deaf people experience music: by turning it up louder. The third verse describes the importance of rhythm, specifically the beat that rock'n'roll provides: "We need a real fast song, to sing real loud with a rock'n'roll rhythm to stay on time. We're gonna play a rock song to please the crowd. We're gonna turn it up louder let you unwind." The playful chorus cries "Turn it up Louder! We want it Louder! Make it louder! Louder! Turn it up Louder!—Hey, what are you?! Deaf?" As Chevy describes, the purpose of "Turn it Up Louder!" is to explain to Deaf people that just because they do not listen with their ears (ASL sign = LISTEN-EARS; see Track 3.1 on the Companion Website) like hearing people do, they can still enjoy music. Chevy maintains that they need to feel the rhythm or the beat of the music in their bodies, and often this is achieved by "turning it up louder," increasing the volume or the bass so that vibrations are felt or certain frequencies can be heard.

Feeling vibration is a key part of the deaf experience of music. Hiltermann explains, "The way I play, I depend on a lot of vibrations, so we play really, really loud, enough for us to hear and feel it" (Garey and Hott 2007). He describes hearing music through his whole body: "People still can't believe; they think it's hearing that makes the music. I said, 'No, it's your heart. It's your body. It's your rhythm inside of you that makes the music, not [the ear]" (Scari 2010). Reaching out to the Deaf community with music is one of the key artistic goals of Beethoven's Nightmare. According to Chevy, the band needs to explain to Deaf people that music is something that they can appreciate. In their album liner notes, Hiltermann explains, "When we started, we had to fight the misconception that being deaf meant we couldn't play or enjoy music" (Beethoven's Nightmare 2004, 3). Chevy explains that in Deaf culture there is a rich tradition of storytelling and mime, but not much of a musical culture. In an effort to open the door to the possibility of a musical experience, Beethoven's Nightmare clarifies that they must first separate the listener from the expectation that this experience is going to be LISTEN-EARS, like it is for a hearing person. Instead, their Deaf musical experience involves feeling vibrations (including the beat) and communicating expression through sign language and movement. In collaboration with interpreters, who gesture the pulse of the beat while signing the lyrics, the band has been able to show their Deaf audience how to "see" and "feel" music. In fact, one of the attendees at the 2012 NAD meeting exclaimed, "Once you connect

what you're feeling with what's going on onstage, it's amazing!" This was a sentiment I heard repeatedly.

Beyond their interest in facilitating the perception of music within the Deaf community, Beethoven's Nightmare also articulates their own experiences living as deaf minorities in a hearing majority culture; almost all of their songs contain lyrics that deal with these themes. When the band members were college students in the early 1970s, the genre of rock'n'roll provided much of what they looked for in a musical experience—loud music with a steady beat. But rock'n'roll has also had a long association with political and cultural nonconformity. Hiltermann identifies rock'n'roll as a safe place to convey thoughts, dreams, and protests without fear of reprisal, tapping into the history of rock'n'roll as a platform for protest and change in civil rights movements (Beethoven's Nightmare 2004). This connection resonates with the Deaf community's history of struggle for its own political and social voice. Beethoven's Nightmare's use of ASL is significant in this greater historical and political context, because historically the repression of Deaf culture has been largely carried out through the repression of sign language.

Beethoven's Nightmare is the first musical group to achieve any level of fame within the American Deaf community. But much of the band's musical practices are extensions of Deaf cultural traditional practices, including ASL storytelling and poetry; by signing on the beat, they perhaps even allude to the earlier tradition of percussion signing. But their musical style is also an extension of a hearing culture—the rock'n'roll of the 1960s and '70s. Synthesizing these influences, Beethoven's Nightmare has broken ground for a new Deaf musical culture, one that fuses hearing music (rock'n'roll) with deaf music (physical and visual experiences of music).

Sean Forbes

Sean Forbes, a Deaf rapper from Detroit, figures prominently in contemporary American Deaf culture. Since 2008, he has performed all over the United States in live venues and schools and university campuses. Before this, he enjoyed making ASL translations of many of his favorite popular songs, including some by Eminem, with whom he had a chance meeting in a studio in Detroit. When Forbes showed Joel Martin (the manager of the Detroit production studio that produces Eminem's work) his own video of his first song "I'm Deaf!" Martin agreed to work with Forbes to produce his first album *Perfect Imperfection* (2012), a CD/DVD set (Damico 2013).

Forbes is the only deaf person in his hearing family. His father is a guitarist in an award-winning country band, Forbes Bros, and from an early age, Sean Forbes loved music and wanted to play music. Although his early life was mostly oralist, he went to a high school with a large deaf and hard-of-hearing population. He met many students who were culturally Deaf and began learning ASL in order to communicate and have relationships with these friends. He attended the National Technical Institute for the

Deaf (NTID), a professional, technologically oriented program for deaf and hard-of-hearing students.

Because of his background in oralism, Forbes speaks English quite well; he voices all his raps, which are simultaneously in ASL and in English. Music videos are also an integral part of his work. For each audio track of his new album, a video track is included, with performances in English. Some of the videos include ASL performances of the songs, while others feature images or scenes that narrate Forbes's lyrics.

In all of his videos, lyrics are presented in interesting fonts and typographical effects; they are timed with the music to visually reinforce the underlying rhythms.[16] Forbes, who is enthusiastic about the potential of word videos, states, "Now I can go on YouTube and type in the name of the video, and lyrics videos just show up if it's a popular song. There's so much more accessibility today than there ever was before." The concept works well for making recordings that can be enjoyed by both deaf and hearing audiences.

Creating a bridge between deaf and hearing worlds is a driving motivation in Forbes's work. He has a growing and enthusiastic following among American Deaf youth, who sport his "I'm Deaf!" T-shirt quoting his most popular song. Forbes's work makes visible to Deaf youth an artistic world that does not exclude them. When Forbes performed at the Deafestival in the summer of 2012, Deaf teens and college-aged youth flocked around the stage, screaming and cheering, enthusiastically waving their hands and pounding the air with the beat.

Forbes's first hit, "I'm Deaf," loudly proclaims his Deaf identity, which he frames in terms of ability rather than disability. In a pun on the word "Def," which has long been used in hip-hop as a term to connote superlative qualities, the chorus to the song candidly declares, "Deafer than Def Jam/I'm so so Deaf" (Track 3.2 on the Companion Website). In the first verse he introduces himself, acknowledging the seeming oxymoron of "deaf musician": "My Name is Sean/But they call me Seen/Got a message here,/I'm delivering/Look I understand,/You might be leery/Getting music beats/From the hard-of-hearing." The second verse asserts his ability to overcome these potential obstacles: "Now there's people out there/Telling you what you can't do/'You can't overcome,/You got too much to prove[.]'/ I never listened,/How ironic." And in the third verse he places himself in the good company of others who were not held back by their physical differences: one-handed pitcher Jimmy Abbot, blind musician Stevie Wonder, and blind-deaf Helen Keller. He ends by affirming his own Deaf identity, arguing that his deafness will not prohibit him from doing anything he desires, including music: "I'd rather not hear/Rather not listen[.]/I'm the perfect imperfection/Never restricted."[17]

Forbes uses music to reach out to hearing students, showing them that deafness is nothing to fear. In a recent tour (Spring 2013), he performed not only in Deaf venues but also in many hearing venues, especially schools. Lamenting the limited interaction between deaf and hearing communities, Forbes observes, "There really hasn't been anything—other than, now, the TV show *Switched at Birth*—something that hearing and deaf can watch together. I would go see Deaf schools play basketball against hearing kids. It would always be hearing against deaf, hearing against deaf, hearing against deaf.

There was never a situation where both of them were together, and I feel like with my music we're doing that. Bringing the two communities together to enjoy something."[18]

Forbes is also a cofounder of the Deaf Performing Arts Network (D-PAN), which, among other activities, produces high-quality music videos of popular mainstream songs translated into ASL for deaf audiences. Under the motto "It's everybody's music," D-PAN provides the deaf access to popular music, breaking down the cultural barriers that have separated the deaf from mainstream arts while simultaneously raising mainstream hearing culture's exposure to ASL and Deaf culture.[19]

Signmark

What Sean Forbes is accomplishing on a national level in the United States is being achieved on a global level by Signmark. A Deaf rapper from Finland, Signmark (Marko Vuoriheimo) is from a deaf family, and he grew up signing; Finnish Sign language is his first and native language. He was empowered early on by his family to be proud of his deafness, his language, and his Deaf culture. Signmark's earliest musical endeavors included translating Christmas songs into sign language so that his deaf family and his hearing grandparents could all enjoy them together. Later, he began to translate popular songs from MTV into sign language and perform them with his deaf friends on the dance floors of clubs. Signmark was challenged by a friend to move beyond translating and instead to write his own lyrics.

His debut album *Signmark* was released in 2006, with a CD and a DVD of signed music videos. The album, in spoken Finnish and Finnish Sign Language, features many songs that describe aspects of Finnish Deaf history and culture, resonating with the experiences of other Deaf communities in the Western world after the Milan Congress—most notably, the repression of sign language in favor of oralist deaf school. After coming in second place in the final qualifying round to represent Finland at the 2009 Eurovision Song Content, Signmark became the first deaf artist to sign with an international record label, Warner Music.[20] In 2010, he released his second album, *Breaking the Rules*, also as a CD/DVD set. In order to reach a more international community, this album is performed in spoken English and American Sign Language. (Finnish Sign Language is its own language, as distinctive from American Sign Languages as the spoken language English is from Finnish.)[21] Signmark signs without using his voice (VOICE-OFF in ASL; Track 3.3 on the Companion Website). Signmark always signs VOICE-OFF, whether in casual conversation or in performance. He works closely with his partner, vocalist Brandon Bauer (who is Finnish-American and performs the English spoken translation of Signmark's signed raps) to create a bilingual ASL/English performance.

In February 2013, Signmark performed at the Kennedy Center in Washington, DC, representing Finland as one of the featured performers of the month-long Scandinavian festival at the Center. The audience rippled with the signing hands of Deaf and hearing people, communicating together or simply waving their hands in applause. Signmark signed from the stage, "Rhythm isn't something we hear, but also see and feel," as he

encouraged the audience to move their hands and bodies along with the music, reinforcing the multimodality of hearing deafly.

Through the performance in a spoken language and a sign language, Signmark creates a musical experience that is accessible to both hearing and Deaf cultures. Signmark states, "Through my music I want to break prejudice and fight for equality between cultures. I want to show to people that being different can be an asset. My message is that nothing is impossible for the deaf; we can do all the same things."[22] His song "Smells Like Victory" poignantly demonstrates his desire to bring together not only deaf and hearing cultures, but also other opposing groups. The video models a newscast, and as the chorus sounds ("I can feel it in the air, smells like victory; and I let it stick to me. You haters ain't shit to me"), images of groups of people who have traditionally opposed each other find reconciliation: a black man and a white man embrace, an Israeli and a Palestinian, and opposing teams in a soccer match (Track 3.4 on the Companion Website).[23] In this video, Signmark appears to suggest that social victory lies in the reconciliation between opposing forces rather than the triumph of one over the other. Distancing himself from what some might consider the medical aspect of deafness, he shifts his focus to the cultural and political implications of Deafness, by superimposing images of cultural and political tensions that are well recognized in the global community. Speaking from his experience, Signmark thus highlights the social, linguistic struggle that the Deaf community faces.

Many of Signmark's songs comment on his deafness, explaining that it is not something that keeps him from his dreams (including his dream of music performance). In the song "Talk 2 the Hand," he plays on the name Mos Def, the famous American hip-hop artist:

> Naw, this ain't Mos Def
> but if you ask me, in this rap biz I'm the most def
> ain't nobody else done it . . .
> Def Jam ain't heard of me I'm makin' the deaf jam
> you lookin at me funny like I committed a 3rd degree
> hah, like I can't rhyme?
> Well homie read my hands, oh, you can't sign? . . .
> Some walls got ears, well my ears got walls
> they say the higher you climb the higher you fall. . . .
> You still lookin' at me strange
> I'm the first deaf rapper and the industry ain't the same. (Signmark 2010)

Signmark is aware that by becoming a musician he has broken the boundaries of people's assumptions about what deaf people can or cannot do, a theme that he often addresses. He raps: "They wanna know how do I answer the phone/and can I drive a car, how I get chicks in the bar? . . . Can't be President, the army won't accept me/I can't be a pilot, could be a doctor if they let me" (Signmark 2010). He also speaks out against the paternalism that many deaf people face, and asks that the hearing majority join him in his deaf place and truly understand his culture, a desire that the Deaf community has held since the Milan Congress:

> Not asking for no favors, don't want your friendly deeds
> don't try to be my Savior. I bite the hand that feeds
> Nothing changes without the first step
> stay still but not to advance is to regress
> I'm knocking at your front door, demanding you to come out
> u need to get on my level to know what I'm about
> cause we're falling, hitting rock bottom
> gotta step up, now tell me wassup!

Signmark has taught the chorus for this song, "Against the Wall," to hundreds of hearing people all over the world in staged flash mobs that he calls, "silent shout"; he teaches the signs for the chorus and then performs the song having the audience join in.[24] By doing this, he vividly invites his audience to join his space, enacting in a small sense what he hopes to accomplish in a larger sense—bringing deaf and hearing people into a shared cultural space.

In the bridge of "Against the Wall," Signmark raps, "Without a fight you won't see me fall down/Since I'm doing this for my people/for all my people." By "his people," Signmark refers not just to the deaf of Finland, but rather to the Deaf community that transcends geographical boundaries. Another one of his songs, "The Letter," is a tribute to a young deaf woman who was tragically murdered in Christchurch, New Zealand in late 2007 (Booker 2007). Her death was mourned by the global Deaf community; tributes were expressed in blog posts and tweets from around the world. Signmark summarizes the feelings of what many Deaf people expressed: "I live in a community so tight, worldwide/in one blink of an eye we lost one of us/a life taken. At an age so young. So wrong/Our world was shaken." This song illustrates the global communality of Deaf culture, arguing that Deaf identity is not limited to national identity.

There is an ASL sign, DEAF-WORLD (Track 3.5 on the Companion Website), that describes what it means to participate in this culture—one based on shared social behaviors, customs, traditions, values, and institutions of the community and, perhaps most definitively, based on the traditions of signed language. The Deaf community is relatively small, thus there is always a search for connectedness to the others in this community. DEAF-WORLD is a picture of a community reaching for a connection beyond the borders of the maps that the hearing world has drawn. Signmark invokes this concept of DEAF-WORLD when he talks about his "community so tight." He is talking about the Deaf community across the globe.

Conclusion

The 1988 Gallaudet protest and DPN movement was an empowering moment for the Deaf community, playing a pivotal role in the disability rights movement that led to the passage of the Americans with Disabilities Act (ADA) in 1990. In recent decades, many Deaf artists in their twenties and thirties—coming of age in a post-DPN, post-ADA

era—are turning to music as a form of Deaf self-expression, using their native sign language. For these Deaf artists, music is no longer "out of bounds," only for the hearing. While Beethoven's Nightmare turned to rock'n'roll, using its heavy beats and its platform of protest, Sean Forbes and Signmark have turned to hip-hop, rapping in ASL. These new musical styles exploit digital and social media, which allows for the easy recording and sharing of multimedia performances, fusing the visual with the sonic.

In his book *Extraordinary Measures*, Joseph Straus (2011, 167–170) identifies four aspects of deaf hearing: feeling, seeing, moving, and inner, silent hearing. As we have already seen, felt sound vibrations are a key part of how deaf people experience music, on a continuum of experience from how a stage is set up for a public performance to individual, casual listening. The visual experience of music is tied closely to the kinesthetic experience through the use of sign language, inviting the audience into a spatial experience of song as lyrics are painted in the air. Both Sean Forbes and Signmark will often encourage their audiences to wave their hands back and forth with the beat. The signers working with Beethoven's Nightmare will often pulse the beat or otherwise visually demonstrate what is happening musically during instrumental passages.

If listening is more than what happens with the ears, what does it entail? Phenomenologist Don Ihde (2007) has questioned the strict separation of the realms of sound and sight. These two dimensions exist in a complementary relationship: "Silence is the horizon of sound, yet the mute object is silently *present*. Silence seems revealed at first through a visual category. . . . Listening makes the invisible *present* in a way similar to the presence of the mute in vision" (50–51). Ihde proposes a dimension in which listening is a mode of seeing, in which the invisible is translated into the visible (54). Perhaps this can help explain how it is that the visual is such an essential part of Deaf music-making. In ASL there are signs to describe how a person listens. Typically, a hearing person will LISTEN-EARS; the ears are the primary mode of receiving communication. To create this sign, the Bent-3 handshape is placed by the ears along with a motion that indicates the receiving of sound. By contrast, a Deaf person will LISTEN-EYES, using the same handshape placed by the eyes. This handshape indicates the reception of information; the position of the handshape will indicate the part of the body through which the communication is received. (Compare Track 3.1 and Track 3.6 on the Companion Website).

Perhaps more difficult to define is the idea of inner, silent hearing. The literary scholar Lennard Davis (1995) uses the term "the deafened moment" to describe a moment in which the distinctive categories of "hearing" and "deaf" become moot, because they are part of a process that does not involve speaking or hearing—for example, in the silent perception of a printed text (101). Davis states that "so many of our assumptions about writing, about language, are based on the premise that language is in fact sonic, audible, vocalized," such that even the words we use to describe various discursive practices are embedded with assumptions about the physical experience of language (100). For example, to say "I speak of this or that" in a written context is not entirely correct. As Davis argues, we are not actually speaking, we are writing. But our usual mode of linguistic communication is speaking, so we freely borrow the word as a metaphor for

communication. By highlighting "the deafened moment," Davis claims that we are pausing in a moment that transcends "hearing" and "deaf" in such a way as to "acknowledge the political oppression involved in denying that this major form of language interaction has in fact implied the ostracism of those who are differently abled linguistically" (101).

Applying Davis's argument about language to music, we are forced to consider how many of our assumptions about music are connected to how we hear with our ears. If language suppositions are connected to an idea of something that is "sonic, audible, and vocalized," how much more so are our assumptions about music? Even to use the phrase "deaf hearing," a seeming oxymoron, demonstrates that we cannot even talk about music without using ear words, such as "hear" or "listen." Is there an "implied ostracism" for those who perceive the sonic vibrations in their bodies rather than their auditory nerves?

Situating ourselves in the "deafened moment," we also realize that, inasmuch as there is not one way to be d/Deaf, there is not one way to be hearing. As a hearing person attending concerts performed by many of the musicians I have talked about here, I step into DEAF-WORLD. I feel the bass pounding deep in my core. I see the music and the lyrics, and I move my hands with the beat, performing signs with the chorus as Signmark invites his audience to join in. When I step away from DEAF-WORLD, I am challenged to reevaluate how I listen to all the music around me. Perhaps this is part of what Ihde means when he describes listening as the translation of the invisible to the visible. My intersection with deaf hearing, or hearing deafly, has made visible certain aspects of my own hearing that often go unmentioned, and I believe that the binary of the categories of deaf and hearing becomes blurred. By taking into account the multisensory musical experience of these Deaf musicians that I have examined here, I believe that music scholars can begin to understand the broad spectrum on which musical experiences can lie, somewhere between the ears, the eyes, and the body.

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Notes

1. It is conventional to use the term *Deaf* (with an uppercase "D") in reference to culture, community, and identity, and to use the term *deaf* (with a lowercase "d") to refer to the physical condition of deafness or the larger group of people with hearing loss who do not associate with Deaf culture. To use the term "hearing impaired" is problematic, because it

is viewed as offensive by the Deaf community. See Humphries and Padden 2006, 1–2 and 159; Davis 1995, xiv–xx; and Lane 1992, 89.

2. See Adelman 2006 and Shapiro and Valentine 2006 for interviews with I. King Jordan in which he reflects on the impact that his presidency had on Deaf culture and disability rights.
3. Throughout the essay, all quotes originally in American Sign Language have been translated into idiomatic English. As is customary, words transliterated from ASL are written in all capital letters.
4. Unless otherwise noted, all direct quotes from Beethoven's Nightmare or other Deaf individuals come from my fieldwork at the biennial meeting of the National Association for the Deaf, specifically Deafestival—the arts and music festival that finished the week's events in Louisville, Kentucky (July 7, 2012).
5. While this essay focuses on these particular musicians, who identify with Deaf culture and use a sign language as their primary language, I do not want to ignore the many other d/Deaf musicians. The percussionist Evelyn Glennie is deaf and talks about her deafness and her experience of music, but does not find an identity in a signing Deaf culture. Other musicians who do identify with the Deaf community include hard-of-hearing rock singer, TL Forsberg; the amateur hip-hop artist Wawa Snipes, who advocates for a new genre, "dip-hop" (deaf hip-hop); and the sound artist Christine Sun Kim, who plays with boundaries of sound and visual experiences. Also of note is the contemporary German avant-garde composer Helmut Oehring, who is a hearing child of Deaf adults (CODA); he grew up using German Sign Language and has incorporated signers into some of his chamber works.
6. As Lane 1992 explains, "Audism is the corporate institution for dealing with deaf people, dealing with them by making statements about them, governing where they go to school and, in some cases, where they live; in short, audism is the hearing way of dominating, restructuring, and exercising authority over the deaf community" (31–49). Originally coined by Deaf scholar Tom Humphries, "audism/ist" is now a term in common parlance in Deaf culture. Humphries (2012) has been working with the American Heritage Dictionary since 2012 on its official definition.
7. Humphries and Padden 2006, 1–2. Lennard Davis (2008, 320) has also observed that the definition of Deaf culture as a linguistic minority excludes non-ASL users who identify as a deaf "other." The linguistic minority model also includes hearing children of ASL-using Deaf adults for whom ASL is a first language in the home (children of Deaf adults, or CODA), yet they are not physically deaf. For the purposes of this essay, I am focusing on the section of Deaf culture that does identify itself around the linguistic model.
8. Because the history of music in deaf education and culture is still underdeveloped, I am grateful to Anabel Maler, who has shared with me an unpublished paper on deaf musical education in the nineteenth century.
9. Russell Harvard, "Galladuet [*sic*] University's Bison Song Team 2005–2006," YouTube video, 4:34 (August 6, 2010), http://youtu.be/4CVbUfuqXuk/.
10. Unless otherwise noted, information about the band and its history comes from my fieldwork at the NAD conference in July 2012 and at their concert at Kansas State University, Manhattan, on April 3, 2012.
11. Deaf Way II was attended by over nine thousand people from over one hundred countries. It was a follow-up to Deaf Way I in 1989, which I. King Jordan organized as a celebration

of international Deaf culture, with representatives coming from around the world. See Shettle 2002 and Brown and Goodstein 2004.

12. The album is only available on audio compact disc. With the exception of "Turn It Up Louder!" released on YouTube, the band has not recorded music videos. Steve Longo, "Beethoven's Nightmare—Turn It Up Louder in Sign Language and Captions," YouTube video, 3:43 (March 8, 2012), http://youtu.be/2WkfI9GH_AI.
13. Beethoven's Nightmare, interview with the author, April 3, 2012.
14. For a more detailed analysis on the range of sign language expression in song between deaf and hearing performers, consult Anabel Maler's essay in this volume.
15. "Pah!" is a standard English transliteration based on the mouth shape that is part of the sign.
16. Lyric videos are a rising trend in popular music (Blankenship 2012).
17. In a National Public Radio interview Sean Forbes explains that he likes to experience music by turning up the bass and prefers hip-hop because he can really feel the bass and drums and is able to follow the percussive lyrics (Moe and Sanchez 2008). Forbes also describes a device originally used for videogaming called the ButtKicker (a low-frequency audio transducer that allows the user to feel powerful bass without excessive volume); if held or attached to a table or chair, it can amplify vibrations and enhance the deaf musical experience.
18. Sean Forbes, interview with the author, February 28, 2013.
19. See, for example, D-PAN's production of the White Stripes's "We're Gonna be Friends" and Christina Aguillera's "Beautiful." Dpanvideos, "D-PAN ASL Music Video 'We're Going To Be Friends' by the White Stripes," YouTube video, 3:16 (October 24, 2011), http://youtu.be/IbLz9-riRGM; and Dpanvideos, "D-PAN ASL Music Video 'Beautiful' by Christina Aguilera," YouTube video, 4:32 (March 28, 2008), http://youtu.be/C6zVFGpGNJQ.
20. Signmark: The Official Site, http://signmark.biz/site/en/bio. For his Eurovision performance, see jarnova75, "signmark in eurovisio "Speakerbox," YouTube video, 5:17 (January 31, 2009), http://youtu.be/tIyjewBNiFA.
21. I am grateful to Keri Ogrizovich, certified deaf interpreter, for her input on different sign languages.
22. Signmark, "Signmark-Biography," Vimeo video, 6:24, http://vimeo.com/10254226.
23. Signmarkprod, "Signmark—Smells Like Victory," YouTube video, 4:42 (October 31, 2009), http://youtu.be/oUtM8_DOVUI.
24. Marcel de Araujo Coelho, "Signmark, Silent Shout," YouTube video, 4:46 (October 4, 2010), http://youtu.be/FloNPWU50X8. Also see dnainfo, "signmark.mov," YouTube video, 1:06 (September 23, 2010), Silent Shout in New York City, http://youtu.be/MCQeukjlfeQ.

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CHAPTER 4

MUSICAL EXPRESSION AMONG DEAF AND HEARING SONG SIGNERS

ANABEL MALER

Introduction

Musicians and composers are generally presumed to possess "normal hearing," as a deficiency in the sense of hearing is "understood as particularly problematic for musicians" (Straus 2011, 26). The assumption of normal hearing has led music scholars to imagine deafness as "the deepest imaginable antithesis to music." To the hearing majority, it seems unquestionable that music is "the one thing that a deaf person can never possess, a form of discourse unthinkable and unattainable" (Abbate 1991, 130). In this hearing-centric view of music, deaf people live in a world of silence, cut off both from musical expression and from receiving pleasure from musical works. The model of deafness as musically disabling agrees with the predominant view of disability as disqualifying or excluding the disabled person "from access to the benefits and status of the properly human" (Garland-Thomson 2012, 340).

As recent work by Rosemarie Garland-Thomson suggests, however, disability can be viewed as a resource, rather than as a burden that should be eliminated. Garland-Thomson (2012) proposes several "countereugenic" arguments for conserving disability. Following Garland-Thomson, in this chapter I put forward my own arguments for conserving the deaf experience of music. I propose that deafness, rather than being disabling in the context of musical experience, actually enables distinctive musical performances that are potentially less accessible to those who possess a "normal" sense of hearing. Deafness, I argue, is not a deficit for musical experience; rather, it is a source of musical ability.

Musical expression takes many forms within Deaf culture.[1] The concept of music comprises a variety of visual and auditory experiences, ranging from those that are