Discovering Diffability: Musical Experiences and Perspectives of Individuals with Williams Syndrome at Whispering Trails

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DISCOVERING DIFFABILITY: MUSICAL EXPERIENCES AND PERSPECTIVES OF
INDIVIDUALS WITH WILLIAMS SYNDROME AT WHISPERING TRAILS

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For the Williams Syndrome Association- the change we wish to see in the world.
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In this thesis, I explore musical experiences of people with Williams Syndrome (WS) to examine how music not only shapes personal identity and worldview, but can also serve as a path to citizenship for these individuals. WS has historically been examined within a deficit-centric and medicalized model of disability by the scientific and medical community; researchers have characterized WS as a congenital developmental disorder that is manifested in cardiovascular disease, low IQ, unique facial features, hypersociability, and in some cases, high degrees of musical aptitude. In contrast to this medical paradigm that tends to stress disability and disorder, I approach the study of WS musically and ethnographically with an emphasis on the abilities, creativity, and agency of these individuals. I examine my time at the Williams Syndrome Association-sponsored summer camps for children, teenagers, and young adults at the Whispering Trails Camp in Grand Rapids, Michigan. During this three-week period I immersed myself in the camp community and engaged in musical ethnography through participant-observation and interviews with campers, parents, and staff members. In this thesis I will demonstrate the ways in which the musical experiences of the campers transform notions of WS from a dis-ability into a difference of ability, or diffability. Though society has often viewed individuals with WS as being dis-abled, the personal narratives presented in this thesis, along with my own experiences of shared musicking, will serve to illuminate the disconnect between how our culture constructs and imputes notions of disability to individuals with WS and the ways these people conceptualize their own identities. A central concern of this work is to ensure the presence of my interlocutors’ voices and to allow them to articulate their feelings about what it means to be an individual with WS, especially with regard to how music and musical experiences impact and affect their worldviews.
INTRODUCTION

Thesis Statement

This thesis is an ethnomusicological study of the musical experiences of individuals with Williams Syndrome within The Whispering Trails Camp environment in Grand Rapids, Michigan. While many studies have focused on the impairments and deficits associated with WS (Brown and Percy 2007; Dykens et al. 2005; Martínez-Castilla, Sotillo, and Campos 2001, 2008), I take an alternative approach that centers on the abilities, creativity, and agency of individuals with WS, especially in regard to their musical lives and experiences. In other words, I engage with WS as a diffability, rather than a disability (Kennedy 2012). Considerable attention has been paid to the musical proclivities and talents of people with WS, though most have examined WS within a deficit-centric model that views musicality as either “symptomatic of” or “in spite of” the disability. Instead, I take an ethnographic approach, in which the campers are “experts” of their own musical culture, and explore how an ethnomusicological epistemology of Williams Syndrome reveals a rich and complete musical world of capable musicians.

Purpose and Significance

The purpose of this thesis is to demonstrate that Williams Syndrome is a form of human diversity and difference of ability through an exploration of the role of music in the lives and experiences of individuals with WS who attended the Whispering Trails Camp. In addition to investigating WS as a diffability, I also illustrate how music can serve as a path to citizenship for these individuals through demonstrations of sometimes-extraordinary musical ability and musicality, and through moments of meaningful shared communication, personal expression, and the creation of community.
This thesis is significant in its emphasis on engendering an understanding of people with WS from a cultural, ethnographic perspective within a musical framework. The tendency of neurotypical majorities to dismiss people with disabilities or to try to “fix” them through medicalized models of rehabilitation is pervasive and insidious (Byrom 2001: 133). In modeling an alternative approach, this work exhibits a contrasting portrait of people with WS, who have historically been stigmatized and disenfranchised as a result of their differing from the standards of typicality established by society (Davis 2006: xv; Garland-Thomson 1997: 6). The lens through which I have come to see individuals with Williams Syndrome is one of ability that privileges what they can do over that which they find challenging. My hope is that this thesis will generate different modes of response and action towards people with WS that replace the “problem” of disability with the embrace of diffability. Only through such a model of accommodation and acceptance can society benefit from the talents and gifts that people with WS have to contribute.

On other levels, this thesis is significant both as a contribution to the growing literature on music and disability and as the first ethnomusicological study to examine the musical worlds of people with WS. Moreover, it adds to studies of “cognitive impairments” and “intellectual disabilities” within the disability studies arena. This is notable since the field of disability studies has historically given greater attention to the physical side of disability than to its cognitive and intellectual dimensions (see “Survey of Literature” for further discussion).

**Background**

Williams Syndrome was first diagnosed by John Cyprian Phipps Williams in 1961. Due to the rarity of this condition, Williams Syndrome has only recently gained more widespread
attention from educators, medical professionals, and researchers. Early literature about Williams Syndrome reflects the cultural and social notions surrounding disability at that time, which were founded upon views of the disabled as “other” (Goffman 1963). This perception of “disability” as deficiency is still evident today within medical descriptions of Williams Syndrome. According to the National Institute of Neurological Disorders and Stroke (NINDS):

Williams Syndrome (WS) is a rare genetic disorder characterized by mild to moderate mental retardation or learning difficulties, a distinctive facial appearance, and a unique personality that combines over-friendliness and high levels of empathy with anxiety. The most significant medical problem associated with WS is cardiovascular disease caused by narrowed arteries. Within language, the strongest skills are typically in concrete practical vocabulary, which in many cases is in the low average to average range for the general population. Abstract or conceptual-relational vocabulary is much more limited. Most older children and adults with WS speak fluently and use good grammar. More than 50% of children with WS have attention deficit disorders (ADD or ADHD), and about 50% have specific phobias, such as a fear of loud noises. The majority of individuals with WS worry excessively. (NINDS 2008; accessed September 29, 2013)

This depiction has led those working within this medical and scientific model to conceptualize the experience of individuals with WS in terms of deficits and non-ability. Despite the remaining presence of this disability-centric approach, the rise of the disability rights movement over the past fifty years has created a shift towards a more humanizing and inclusive paradigm (Albrecht, Seelman, and Bury 2001: ix). This change in attitude is most noticeable within the arts, where disability is viewed as a form of human variation, rather than as a defect (Siebers 2010: 3). Such new conceptions have led researchers to explore the creative abilities of differently abled individuals and to recognize their proclivity for artistic capability, as well as opportunities for musical enjoyment and personal expression within these populations (Siebers 2010: 15; Christian 1990). The contrast between challenges in spatial-motor skills and musical aptitude within the Williams community has led several neuroscientists to conduct studies.

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1 Williams Syndrome affects approximately 1 in 10,000 people worldwide (Williams Syndrome Association 2013).
examining the cerebral organization of these individuals (Bellugi 2000; Järvinen et al. 2012; Levitin 2004; ibid. 2005; Martens et al. 2011; Sacks et al. 1995; Sacks 2007). Music therapists, educators, and journalists have all been similarly interested in people with WS and have explored the effects of music on behavior and communication (Claussen and Hanser 2000; Deruelle et al. 2005; Dykens et al. 2005; Hopyan et al. 2001; Mackenzie 2005; Stambaugh 1996).

The Williams Syndrome Association (WSA) has been an invaluable resource for this project and for individuals with WS and their families. This non-profit organization, formed in 1982, “strives to enrich the lives of individuals and families affected by Williams Syndrome and similar conditions through support, research and education” (WSA 2013). The WSA provides information and emotional support to individuals with WS and their families, develops programs and services for individuals from childhood to adulthood, increases public awareness of WS, and encourages research in a wide variety of areas. The organization holds national conventions every two years and offers yearly summer camps in Michigan, Illinois, and California. The research for this thesis was conducted over three weeks at the Whispering Trails Camp in Grand Rapids, Michigan.

My interest in Williams Syndrome began after viewing the 20/20 television special “Friendly to the Extreme: Meet Kids and Adults with Williams Syndrome,” a piece that was primarily filmed at Whispering Trails. I was immediately enchanted by these people’s outgoing personalities, unreserved verbal communication, and musical enthusiasm and creativity. However, when searching for further information about WS and music in academic journals and other scholarly publications, I found a significant amount of research that focused on the disability aspect of Williams Syndrome, rather than emphasizing the considerable strengths of these individuals. This lacuna inspired me to explore the role of music in creating experience,
shaping worldview, and informing personal identity in individuals with Williams Syndrome as articulated through their own narratives.

Two years after viewing the 20/20 special, I obtained permission from Terry Monkaba, the Executive Director of the WSA and former Director of the WSA Whispering Trails Camp, to conduct research during the Therapeutic Camp Experience for children and their parents, the Music and Enrichment Camp for teens, and the Adult Reunion Week sessions. Monkaba and other parents of children with WS founded the WSA summer camp twenty years ago. It began as a music therapy camp located in Massachusetts, but after ten years moved to its current location at Whispering Trails. Over the years the camp has evolved from being solely music therapy-based to incorporating other forms of therapy as well as traditional camp activities. In addition to diversifying the activities offered, the sessions have undergone multiple reconstructions during which the campers have been regrouped by age, and policies have been adjusted to reflect these changes. This has resulted in what Terry Monkaba refers to as “Camp 4.0.”

Survey of Literature

This thesis will build upon existing musical studies conducted within the Williams Syndrome community in the areas of neuroscientific (Maher 2001; Sacks 2007), quantitative (Jones et al. 2000; Lenhoff et al. 2001; Levitin and Bellugi 1998; Levitin 2005), and qualitative research (Mackenzie 2005; Stambaugh 1996). Much of the literature that informs my theoretical approach stems from the field of disability studies. Though to date there has been no research conducted on Williams Syndrome within the field of ethnomusicology, Michael Bakan’s work

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2 This field grew out of the advocacy movement of the 1950s and 1960s that fought for deinstitutionalization and independent living for people with physical disabilities (Fleischer and Zames 2001: 33). However, in recent years this discipline and the disability rights movement has expanded to include people with so-called “intellectual disabilities.”
on the ethnomusicology of autism is closely aligned with my own theoretical views and ethnographic approaches to the study of music and WS. Due to the breadth of research that informs this study, I will examine these publications in terms of existing literature pertaining to Williams Syndrome (and specifically to musical studies), disability studies literature, and ethnographically based research within the field of ethnomusicology.

**Extant literature on Williams Syndrome**

There are numerous medical and scientific guides, handbooks, and organizations that have been responsible for defining Williams Syndrome. Within *A Comprehensive Guide to Intellectual & Developmental Disabilities* Ivan Brown and Maire Percy briefly depict WS as “a genetic syndrome associated with a distinct behavior phenotype, caused by an abnormality on chromosome 7. People with Williams syndrome tend to be loquacious and unusually musical” (Brown and Percy 2007: 726). This cursory explanation of WS is further embellished by the National Institute of Neurological Disorders and Stroke, which describes WS as being characterized by “mild to moderate mental retardation,” “learning difficulties,” and “concrete, practical vocabulary, which in many cases is in the low average to average range for the general population” (NINDS 2008; accessed 2013). Though these medicalized and disability-centric depictions are diametrically opposed to my own theoretical conceptions of and experiences with individuals with WS, they are useful in their demonstration of the need for further and more comprehensive research.

Over the past two decades numerous neuroscientific studies have been conducted to examine the genetics, brain functions, and behaviors of individuals with WS, particularly in regard to their perceived “hypersociability” and musical ability (Jones et al. 2000; Lenhoff et al.
These studies reveal a strong connection between verbal expression, music, and memory within the Williams community (ibid. 2000; ibid. 2001; Martens 2011). However, one limitation of quantitative research is the focus on objective traits. Since much of the musical strength of those with WS lies in their musical innovation, quantitative studies tend to present a two-dimensional rather than holistic view of these individuals. This lack of focus on more subjective musical traits has at times contributed to an overall focus on disability over capability; however, some researchers, such as Daniel Levitin and Ursula Bellugi, have focused on the musical strengths of people with WS. In their article “Musical Abilities in Individuals with Williams Syndrome,” Levitin and Bellugi attempted to measure the rhythmic processing abilities of eight individuals with WS by examining both accuracy and musical innovation. This emphasis on the musical creativity and strengths of these individuals over their “disability” is a trend that is continued in Levitin’s later work on musical behavior, hyperacusis, and musical phenotype in people with WS (Levitin et al. 2004, 2005).

Music therapists have similarly engaged in quantitative studies of Williams Syndrome, often in collaboration with neuroscientists. Such investigations include explorations of perception and responses to music by individuals with WS, as well as examinations of music’s effect on language skills and anxiety levels within these populations (Claussen and Hanser 2000; Deruelle et al. 2005; Dykens et al. 2005; Hopyan et al. 2001). Though I approach the study of music and WS from an ethnographic and ethnomusicological, rather than a quantitative and therapeutic standpoint, these studies contribute to my understanding of methods employed by music therapists, particularly those of my colleagues working within the Whispering Trails environment.
Neuroscientist Oliver Sacks has bridged the gap between strictly quantitative and qualitative study. In his book *Musicophilia: Tales of Music and the Brain*, Sacks examines the connection between music and neuroscience through a series of case studies. He emphasizes the narrative, musical, and social strengths of the WS population, which he argues is a result of the individuals’ unique neural organization (Sacks 2007: 330). Additionally, Sacks includes narratives from people of all ages, including renowned singer and performer Gloria Lenhoff. These stories and testimonies serve to reinforce the “who,” rather than the “what,” of Williams Syndrome and give the work an overall ability-centered emphasis that parallels that of this thesis.

Many of the campers I met during my fieldwork attend the Berkshire Hills Music Academy (BHMA) during the school year. In addition to functioning as a small educational community for young adults with WS (as well as other people labeled as having developmental disabilities), the BHMA is the sight of previous research conducted on music and WS, as can be seen from Lauren Benotti Mackenzie’s dissertation, “‘When words fail, music speaks’: How communication transforms identity through performance at the Berkshire Hills Music Academy” (Mackenzie 2005). In this work, Mackenzie examines the ways in which people with Williams Syndrome are portrayed through academic writing and medical literature in contrast to how individuals with WS define their condition. Similar to my own methodologies, Mackenzie utilizes interviews and participant-observation to explore how music is used in the classroom to facilitate communication and personal expression. Mackenzie’s technique of representing her informants through their own stories and agency has influenced the approach I employ in this work.
Disability studies literature

Since the enactment of the Americans with Disabilities Act in 1990, the field of disability studies (DS) has emerged and grown exponentially (Davis 2006; Fleischer and Zames 2001). This expansion is especially evident in the proliferation of DS literature over the past twenty years. Central to disability studies’ theoretical orientation is the rejection of the historically established medical model of disability in favor of the social and cultural construction paradigm. Beyond participation in research and publications that critique stigmatizing images and perceptions of individuals with disabilities, many disability studies scholars are also involved with the disability rights movement as social activists. This combined scholarly/activist profile is evident in works such as The Handbook of Disability Studies, which, in addition to examining disability, culture, and personal identity, also emphasizes activist agendas (Albrecht et al. 2001). Such blending of academic scholarship with advocacy is a pervasive element of this thesis as well.

Two texts that have been significant in shaping my understanding of the history of disability and the disability rights movement are The New Disability History: American Perspectives (Longmore and Umansky 2001) and The Disability Rights Movement: From Charity to Confrontation (Fleischer and Zames 2001). These works explore the historical disenfranchisement of those branded with the label “disability” and examine the efforts made by the so-called “disabled” to overturn these prejudices (Longmore and Umansky 2001: 34). Though disability studies only emerged as an academic discipline in the last fifty years, the disability rights movement has worked to secure equal rights for differently abled individuals since the early nineteenth century. While many different models for conceptualizing disability have circulated throughout the history of the movement, the current model is that of acceptance.
and accommodation. Disability is no longer seen as a label of deficit, but rather as a cultural marker and a form of social identity.

One scholar and activist who has been influential within the field of disability studies is Tobin Siebers. In his 2008 book *Disability Theory*, Siebers contrasts our ableist society’s perception of the disabled with a new model for conceptualizing disability as a form of human variation rather than as a medical defect. This is reinforced by his assertions that though disability may have biological realities, much of society’s understanding of disability is socially constructed (Siebers 2001: 738; see also Garland-Thomson 1997). Though negative notions of disability have been established throughout history and are seemingly entrenched, I posit that if ableist society has used socially constructed notions of disability to marginalize those labeled as “disabled,” then personal testimonies and musical narratives can be employed as modes of representation to deconstruct these disenfranchising conceptions. As stated by Siebers, disability is “the form of physical and mental diversity with the greatest potential for artistic representation” (Siebers 2010: 139). This view of people with disabilities as valued and creative contributors to society emphasizes the abilities of these individuals and overturns the historical perception of disability as degeneracy.

Bridging the gap between disability studies and music theory, Joseph Straus explores the effect of disability on musical discourse in his work *Extraordinary Measures: Disability in Music* (Straus 2011). In the text, Straus discusses the musical reception of works by composers with disabilities and the concept of musical accommodation and acceptance versus overcoming disability. Straus’s concept that music is one aspect of culture in which disability is reflected and constructed is particularly useful to my research, which aims to examine how notions of disability (particularly WS) constructed by society compare to the conceptions created by the
individuals themselves.

Much of the early literature in disability studies focused primarily on physical disability (Garland Thomson 1997; Wendell 1996). Though Rosemarie Garland Thomson’s work *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature* and Susan Wendell’s *The Rejected Body: Feminist Philosophical Reflections on Disability* have been invaluable to the field of disability studies, particularly in terms of their focus on the intersections of feminist discourse and social constructionism, their discussions of disability and its relationship to the body tend to emphasize physical disability to the exclusion of intellectual disability. Though its earlier editions reflect this emphasis on physical disability, *The Disability Studies Reader: Fourth Edition* (Davis 2013) has been expanded to include articles that discuss mental illness as well as intellectual disability (Price 2013: 298; Straus 2013: 460).

This more comprehensive exploration of “disability” within disability studies is evident from the recent publications coming from the fields of musicology, music theory, philosophy, and psychology. Neil Lerner and Joseph Straus’s edited volume *Sounding Off: Theorizing Disability in Music* is notable for “its focus on mental, cognitive, and developmental disability, in contrast to the more typical focus within disability studies on physical impairments, particularly deafness, blindness, mobility impairments, and body dismorphisms” (Lerner and Straus 2006: 2). This work does not address Williams Syndrome specifically, however, it does examine the previously ignored subject of developmental disabilities. While still addressing the subject of intellectual disabilities, Licia Carlson’s philosophical orientation in her work *The Faces of Intellectual Disability: Philosophical Reflections* represents a departure from Lerner and Straus’s musical and socially constructed view of disability. Carlson examines multiple approaches and models for understanding intellectual disability, while operating within a critical
disability stance that asks the questions, “Why is having a disability considered to be objectively bad and why are disabled lives devalued?” (Carlson 2010: 12). This use of philosophical inquiry has led me to pose my own questions of “How are musical experiences of individuals with WS manifested as a difference of ability and how can demonstrations of this diffability be used to alter established conceptions of disability?”

Terminology is fundamental to the way humans construct meaning and assign values within society. One work that has greatly influenced my understanding of the importance of language in conceptualizing disability is Erving Goffman’s publication, *Stigma: Notes on the Management of Spoiled Identity* (Goffman 1963). Within this work, Goffman examines the concept of stigma and how various types of stigma (bodily stigma, character stigma, and stigma of group identity) are humanly constructed to rationalize difference and justify discrimination by “normals” against others based on these distinctions. Though Goffman’s language is outdated and sometimes even offensive by today’s standards, particularly in his use of the term “cripple” as a foil to “normals,” this work has informed my understanding of the power of words to reflect, reinforce, or alter established cultural conventions. While I do not consider Goffman’s vocabulary appropriate for discussing the concept of “disability,” his work on stigma and the “Other” has inspired me to utilize language that accurately reflects my theoretical conceptions about those labeled as having a “dis-ability.”

Two scholars who I believe employ innovative terminology in their descriptions of so-called intellectual disability are Nick Walker and Lyndel Kennedy. Walker’s adoption of the

3 Goffman’s concept of humanly constructed notions of stigma directly relate to Peter L. Berger and Thomas Luckmann’s work *The Social Construction of Reality: A Treatise in the Sociology of Knowledge* (1966). Within this work, Berger and Luckmann examine how society constructs notions of knowledge, reality, and knowledge about reality; they then explore how these subjective ideas are crystallized into objective realities and then institutionalized through language.
term “neurodiversity” refutes the pathology paradigm by replacing the term “disability” with the more accurate and innovative appellation of neurodiversity. Likewise, Lyndel Kennedy’s book *Hidden Diffability: Discovering Asperger’s* promotes the notion that autism does not constitute a “dis-ability” so much as a difference of ability, or *diffability* (Kennedy 2012). Though both Kennedy’s and Walker’s research focuses specifically on people with autism, their approach to theorizing what have traditionally been considered intellectual disabilities as forms of diffability and neurodiversity are directly applicable to this thesis.

**Ethnomusicology**

Though sometimes referred to as the “opposite of Williams Syndrome,” many of the methodologies and theoretical approaches used in ethnomusicological studies on autism have informed this thesis. Michael Bakan has made great strides in generating a new model for understanding music and disability through methods that are rooted in ethnographic research but in some instances have incorporated other qualitative and quantitative measures as well (see Bakan 2009). In his collaborative article, “Following Frank: Response–Ability and the Co-Creation of Culture in a Medical Ethnomusicology Program for Children on the Autism Spectrum,” Bakan examines the experience of Frank (a child with Autism Spectrum Disorder) within the Music-Play Project. As is the case with Williams Syndrome, much of the existing literature about Autism Spectrum Disorder (ASD) takes a “deficit-centric” approach, which emphases the *child with autism* instead of the *child with autism* (Bakan 2008).

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4 The Music-Play Project was an interdisciplinary medical ethnomusicology program conducted in the exploratory world music playground (E-WoMP) at the Florida State University. According to the authors of the article, “This project was created for the purpose of facilitating growth in response-ability and social agency of its child participants, and also with the goal of developing new tools and methods for improving applied- and research-based understandings of their special abilities, challenges, likes and dislikes, and modes of communication and interaction.” (164).
This person-centered approach and focus on ability is fundamental to my understanding of the personal experience and worldview of individuals with Williams Syndrome.

In recent years Bakan’s research has moved away from quantitative studies towards a strictly ethnographic and applied approach. Within his forthcoming articles for publications such as *The Oxford Handbook of Applied Ethnomusicology* and *The Oxford Handbook of Music and Disability Studies*, Bakan discusses his applied work with the Artism Ensemble, a neurodiverse group that consists of children on the autism spectrum who perform original music together with their parents and professional musicians. These works frame the exploration of autism through autistic self-advocate Nick Walker’s articulation of a “neurodiversity paradigm” (Walker 2012, cited in Bakan 2013).

**Theoretical Approach**

This thesis approaches the subjects of music and Williams Syndrome through an exploration of diffability in the Whispering Trails Camp community and examines how this difference of ability is expressed through musical interactions. My theoretical orientation draws heavily from disability studies approaches in which populations traditionally defined in terms of their disabilities (e.g. deafness, autism) are instead viewed in cultural terms. Within this literature, a fundamental point of departure is the conception that “disability” is socially constructed and culturally contingent (Garland Thomson 1997: 5; ibid. 2006: xiii; Lerner and Straus 2006: 1; Siebers 2001: 738; ibid. 2008: 73). Tobin Siebers explains this concept in his assertion that “The social model challenges the idea of defective citizenship by situating
disability in the environment, not in the body. Disability seen from this point of view requires not individual medical treatment but changes in society” (Siebers 2008: 73). While the medical model tends to reinforce skepticism about the ability of those with disabilities to contribute to society, the social model refutes this idea by removing the label of dis-ability from the individual and examining it as “a product of social injustice” (ibid.: 3).5

Closely aligned with this dichotomy between the medical and social models of disability (with a specific focus on cognitive impairments) is Nick Walker’s discussion of the pathology paradigm versus the neurodiversity paradigm (Walker 2013). In his forthcoming article “Being Applied in the Ethnomusicology of Autism,” Bakan elaborates on Walker’s work and describes the pathology paradigm as a “belief in a ‘right,’ ‘normal,’ or ‘healthy’ way for human brains and minds to be configured and to function” (25). The pathology paradigm is very similar to the medicalized model in its marginalization of those who deviate from the societal standard of “neurotypicality.” In contrast, the neurodiversity paradigm views the “diversity in the configuration and functioning of human brains and minds…as ‘a natural, healthy, and valuable form of human diversity’” (ibid.). This differs in focus from that of social constructionism in that the social model situates disability within the environment rather than within the individual, while neurodiversity does not even discuss “disability.” Rather, “neurodiversity” expresses the concept that “There is no ‘normal’ or ‘right’ style of human brain or human mind, any more than there is one ‘normal’ or ‘right’ ethnicity, gender, or culture” (Walker 2013). Walker advocates for the neurodiversity paradigm as a lens through which to view, appreciate, and embrace

5 This is not to say that the medical model is not valuable. It is simply a different perspective that is specific to an audience comprised of doctors and researchers. It is not the nature of the medical model to take positive attributes into account, as the goal is to identify an issue and remedy it in order to improve the health of an individual. While these medical goals are understandable, from a social constructionist view, disability is not a sickness to be remedied, but rather a form of human diversity to be accommodated.
different forms of humanity. Thus, my theoretical approach examines WS as a form of neurodiversity and diffability, and explores how this altered view can be used to negate existing conceptualizations of dis-ability within society.

My use of the term diffability is closely aligned with what disability studies scholars call “disability.” Like many DS scholars, I acknowledge the notion that “disability” and diffability are socially constructed, and I seek to overturn existing conceptions that “disability” is synonymous with non-ability. While I consider my goals to be consistent with that of disability studies scholars, I am choosing to use the term diffability over “disability,” not to be overly fastidious, but rather to attempt to shed the ingrained and negative connotations that our society has equated with disability. In support of this decision, I offer Nick Walker’s commentary on Audre Lorde’s speech, “The Master’s Tools Will Never Dismantle the Master’s House,” delivered at the 1979 Second Sex Conference in New York:

*The master’s tools will never dismantle the master’s house.* To work within a system, to play by its rules, inevitably reinforces that system, whether or not that’s what you intend. Not only do the master’s tools never serve to dismantle the master’s house, but any time you try to use the master’s tools for anything, you somehow end up building another extension of that darned house. (Walker 2013)

Thus I am choosing to put down the “master’s tools” and to avoid the language of non-ability as it is antithetical to my research objectives, beliefs, and personal experiences with this incredibly able group of people.

Bakan’s work, which takes an ethnomusicological approach grounded in a disability studies perspective, is especially germane to the present investigation. In common with Bakan relative to autism, my orientation relative to WS is likewise to view music as a medium by which neurodiverse individuals can co-create a culture founded upon ability and acceptance. Additionally, Bakan’s focus on purely ethnographic and experiential methods of inquiry has
provided a model for operating outside of the realm of therapeutic practices traditionally
campioned by music therapists. According to the American Music Therapy Association’s
article “Williams Syndrome (WS): Recent Research on Music and Sound,“

Music Therapy (MT) is the clinical and evidence-based use of music intervention to
accomplish individualized goals within a therapeutic relationship by a credentialed
professional who has completed an approved music therapy program…The aim of
therapy is to help people with WS to optimize their talents and musical affinity in order to
address multiple potential outcomes. (AMTA 2013)

Though I frequently interacted with music therapists at Whispering Trails and participated in
music therapy activities, my method of examining music and WS remained strictly ethnographic.
While I support my colleagues in music therapy and admire their applications of educational
music therapy techniques, my ethnomusicological approach differs from that of music therapists.
As explained by Bakan in his article “Towards an Ethnographic Model of Disability in the
Ethnomusicology of Autism,” “Ethnomusicologists of autism operate from a different premise
than their counterparts in the music therapy profession in that we are typically not interested in
changing the people whose lives and music we endeavor to understand. Our goals are
ethnographic, not therapeutic” (15). In other words, Bakan’s assertion is that the ethnographic
lens privileges cultural interlocutors, in this case people with WS, as normative, whereas the
therapeutic model considers the disability in question as non-normative and subject to change
through therapeutic intervention.6 Though music therapy and ethnomusicology vary
epistemologically, one is not superior to the other; like Williams Syndrome ontology and
neurotypical ontology, they merely represent different ways of viewing and operating within the
world.

6 Within the Whispering Trails Therapeutic Camp Experience, the goals of my music therapy
colleagues were often educational and therapeutic. The techniques employed by these therapists
did not seek to “change” the campers in any way, but rather utilized adaptive music education
Methodology

The principal period of fieldwork for this thesis was July-August 2013. During these months, I spent a total of three weeks in residence at the Williams Syndrome Association-sponsored Whispering Trails Camp in Grand Rapids, Michigan (July 14th-20th, August 4th-17th). The primary research method for this thesis is musical ethnography utilizing the tools of participant-observation and informal and formal interviews. I actively participated in the camp community and at times took on the role of an honorary staff member. Through this participation in the community, I became involved in the co-creation of the musical and social camp culture.

As established in the discussion of my theoretical approach, the centrality of ethnography is key to my methodology. The primary purpose of ethnography is to engender understanding of one’s subjects, whereas that of therapy is to facilitate change. As an ethnographer, I do not approach this work with the intention of altering the campers in any way. I am an ethnomusicologist and, as such, am concerned with how humans create music and culture. The nature of ethnomusicology is not to change people, but rather to figure out their culture and who they are on their own terms, using their own vocabularies of identity. My goal in conducting this research is to gain an understanding of the intersection between individual and group identity, musical experience, and personal expression within the camp environment and to share this understanding with the world. Though I am a music ethnographer, through my experiences with these people I have become an advocate for this community of differently abled individuals.

The Whispering Trails Therapeutic Camp Experience was held July 14th-20th for children ages 6-12 and their parents. Despite the variety of therapies offered during this week, music therapy was a dominant focus of the camp and music itself was often integrated into the physical, strategies to teach and develop important life skills (math, manners, respectful communication, and personal expression).
occupational, and speech therapy sessions. The campers were divided into groups on the basis of age and attended morning and afternoon sessions with their peers. Though the activities were similar for all groups, modifications, focus, and overall goals set by the therapists were determined by the age, developmental level, and maturity of the group members.

Following this initial session, The Whispering Trails Music and Enrichment Camp was held August 4th-10th for campers ages 13-20. Though in the past this session has focused almost entirely on music, in recent years it has been altered to create an even split between musical and traditional camp activities. Campers had the option of taking private applied music lessons, joining the camp chorus, taking dance, eurhythmic, or improvisation classes, or playing instruments in the camp rock band. Additionally, campers participated in other camp events, such as canoeing, archery, rock climbing, art, slip-n-slide, a shaving cream fight, and swimming. The session culminated in a final Friday night movie-themed showcase attended by parents that was replete with choral and band performances of songs from well-known films, choreographed dances, and improvised sketches.

The Adult Reunion Week for young adults ages 21-35 was held August 11th-17th. This year Robin Pegg, Camp Director, and Terry Monkaba, Executive Director of the WSA, restructured the week to reflect the age and independence of the young adults. Instead of being called “campers” the young adults were referred to as such and viewed the week not as a camp, but rather as a time to reconnect with old friends, meet new people, and enjoy a vacation. Though the young adults signed up for daily activities, they were free to exercise their agency and were not required to participate in events. The counselors became mentors, whose primary responsibility was to “hang out” with the young adults, be their friends, and provide support if and when they asked for it. In addition to having fun and building community, this session
focused on the importance of exercising independence and agency, two objectives highly valued by both the WSA and the young adults with WS themselves.

Though each session was different due to the various foci and ages of the campers, music was a prevalent and integral aspect of each week. In addition to being a part of planned music lessons and activities, random outbursts of musical expression throughout the day were a common occurrence. These displays of musicality were continually used to build community based on inclusion and mutual respect, as well as to demonstrate the wealth of ability within this community. In this way, music is a lens through which Williams Syndrome can be viewed as capability, possibility, and diffability, rather than as dis-ability.

**Agency and Musicality**

In addition to examining the musical identities of individuals with Williams Syndrome, this thesis also explores the interests, challenges, and experiences of the different age classes within the Whispering Trails environment. Each camp session had a distinct focus and was geared toward a specific age range: the Therapeutic Camp Experience was for children age 6-12, the Music and Enrichment camp was for teenagers age 13-20, and the Adult Reunion Camp was for young adults age 21-35. This variety of personalities and age groups greatly enriched my ethnographic understanding of the campers’ musical lives and narratives. Within each camp notions of what constituted agency shifted to correspond to the age and maturity level of the campers. For instance, the young adults exercised greater agency than the children, who were given the opportunity to make decisions within a structured framework created by their parents and the camp staff members. These various experiences and levels of autonomy are reflected in this thesis, in which each section addresses different themes of camp sessions and age classes.
Rather than presenting a global portrait of the experience of people with WS, this work instead features snapshots of the musical lives of individual children and adults within this highly diverse group of campers.

It is important to make a distinction between musical “talent” and musicality as I have experienced it within the Williams community. While not all individuals with Williams Syndrome are musically talented, they all seem to innately understand and enjoy music. When discussing this concept with John Wallace, whose daughter Kate is an accomplished singer and performer, he asserted that children who have WS are not necessarily more musically gifted than neurotypical children:

I think that as far as their talent in making music, I think they perform pretty much in accordance with their siblings. So if they’re a musically talented family I think you have a musically talented kid with WS. On the other hand, they all seem to respond very, very strongly to music. So from a receptive standpoint music is very important. From a standpoint of making music, they all like to make music; some of them are good at it and some of them are not. I don’t know that there is any additional talent that they get, but they certainly do get additional love from making music. You’ll hear that when you hear them make music. Some of them will be quite talented and some of them will not. But they all love it and they love to perform.

More important than the numerous instances of musical aptitude I witnessed within this group of people is this love of performance that contributes to their ability to create culture and build community through musical activity. This is something I observed from almost all members of the community, both the musically gifted and those who were less skilled. Time and again I participated in spontaneous jam sessions, musical rehearsals, and Open Mic nights where everyone enthusiastically participated regardless of his or her musical “talent.” In this arena, “talent” is trumped by participation; there is a sense that everyone has something to contribute which allows these individuals to create such a strong community based on a shared and collaborative musical culture. As articulated by Thomas Turino in his book *Music as Social Life*:
The Politics of Participation,

The performing arts are frequently fulcrums of identity, allowing people to intimately feel themselves as part of the community through the realization of shared cultural knowledge and style and through the very act of participating together in performance. Music and dance are key to identity formation because they are often public presentations of the deepest feelings and qualities that make a group unique. (Turino 2008: 2)

These displays of musicality that serve to build community, articulate identity, and demonstrate ability will be evident throughout this thesis.

Thesis Structure

In Chapter One, I focus on the presence of music therapy within the Whispering Trails environment and its use in teaching important life skills to the child campers. I draw distinctions between the field of music therapy and ethnomusicology, and examine the ways in which music is inherently therapeutic for the campers. In this chapter, I reference Victor Turner’s work on *communitas* and posit that instances of shared musicking\(^7\) during all-camp events, such as evening campfire, are instrumental in creating community bonds. Additionally, I explore the importance of the camp community in providing a support system for parents and their children.

In Chapter Two, I investigate the use of music in facilitating personal expression for the campers and examine the overall significance of performance as an affirmation of individual and collective ability. Within the chapter, I reference publications such as Thomas Turino’s *Music As Social Life: The Politics of Participation* (2008) and Tobin Siebers’ *Disability Theory* (2008) to illustrate the importance of music in identity formation and enacting social change through

\(^7\) Musicking is a term that was coined by Christopher Small in his book *Musicking* (1998). Gary Ansdell describes this term in his book *How Music Helps in Music Therapy and Everyday Life* (2014). According to Ansdell, musicking refers to “music as an activity rather than a product.” When engaged in musicking one is “creating a system of relationships between sounds, people, and places in order to enhance personal, social, and cultural needs” (Small 2014: xiii; cf. Small 1998).
displays of musicality.

Chapter Three examines the shifts in agency that the campers experience from adolescence to young adulthood. In this chapter, I discuss the ways in which music informs the young adults’ participation in society, and how music often serves as a path to citizenship for these individuals. While I demonstrate that displays of musical talent often increase the young adults’ visibility, I argue that it is their humanity, not their musicality, which justifies their inclusion in and acceptance by mainstream society.

Finally, in Chapter Four I problematize the term “disability” and examine how it provides systems of support while simultaneously disenfranchising individuals branded with labels of disability. Central to this chapter are the narratives from campers, young adults, parents, and staff members that demonstrate the diversity of viewpoints regarding this terminology. Though I view Williams Syndrome as a diffability, rather than as a dis-ability, and advocate for use of such ability-centered language, I acknowledge that social change will not be achieved by simply exchanging one term for another. Ultimately, I posit that we will only create a more just, tolerant, and accommodating society by listening to the stories of diverse voices.
CHAPTER ONE

THERAPEUTIC CAMP EXPERIENCE

Music Therapy Interventions

In this chapter, I explore two very important aspects of the Therapeutic Camp Experience: music therapy (MT) and the parental camp experience. As an ethnographer I was less interested in the goals and outcomes set forth by the therapists than in the actual moments of individual and shared musicking experienced by the campers; however, music therapy was the principle mode that defined the interactions between the therapists and campers, therapists and parents, and therapists and other staff. Thus, this chapter closely examines the role of music therapy in communicating educational concepts, developing life skills, and facilitating personal expression. Additionally, the presence of various therapies exposed parents to early intervention techniques that could be used to enrich their child’s education and to enhance the prospect of allowing their child to live independently in the future. This access to information and resources, combined with frequent instances of community musicking and social bonding, provided the basis for the creation of a supportive community rooted in the shared experience of having a child with WS.

Over the past twenty years, the Whispering Trails camp has undergone many changes and has expanded to include multiple sessions featuring a variety of activities for individuals of all ages with WS (i.e., up to 35). However, one element that has remained constant within the July session is the focus on music therapy. The summer of my fieldwork (2013) marked the first year that other therapies, such as physical, occupational, and speech, were incorporated into the weeklong Therapeutic Camp Experience. Though the staff’s interdisciplinary team of specialists utilized a variety of different techniques based upon their specific goals, all of the therapists
incorporated music into their sessions. For instance, many of the physical therapy classes used music and dance activities to help the campers refine gross motor skills, while in the speech therapy sessions campers simultaneously sang and signed songs. Through sign singing, campers worked on developing fine and gross motor skills, while also learning Sign Language. Despite the incorporation of other disciplines, music therapy (MT) still provided the primary foundation for kid’s camp. The dominance of MT was evident in the staff demographic, which was mainly comprised of certified music therapists and counselors earning degrees in music therapy, as well as in the organization of classes, in which three of the six daily therapy sessions were dedicated to music.

Each music therapy session featured different activities that reflected the focus and goals of a particular therapist based on the needs of the campers. Since people with WS generally have difficulty with mathematics, one session was dedicated to counting by numerical intervals. The therapist would accompany the campers on guitar and together they would practice count singing by 2s, 3s, 5s, 10s, and 25s. Though this session was similar for all groups, the therapist modified activities to fit the age, developmental level, and maturity of the group members. For example, while the 8-9 year-olds were asked to count by 3s to 30, the eldest group was expected to count by 3s to 60. Within the older groups there was also a greater focus on counting by 25s and then applying this concept to calculating money. This exercise is considered particularly important by both therapists and parents because it reinforces monetary concepts that are crucial for the campers’ independence.

Other music sessions emphasized the development of social skills. Concepts of manners, sharing, and dialogue exchange were explored through singing songs and conducting musical conversations via instrumental jam sessions. One song that was particularly popular focused on
asking permission before taking things and then accepting a possible answer of “no” in a positive way: “When I see something I want/ do I just reach and grab it? /No, no! I should ask/ ‘Can I play with that?’” These songs were not only fun for the campers to sing, but were also effective in reinforcing the concepts that they encompassed. Counselors and therapists would draw upon these resources outside of sessions to remind the campers of the lessons they had learned in class. Instead of having to verbally correct a camper by saying, “No, don’t just grab things without asking,” the staff member could musically reinforce the lessons by singing, “When I see something I want…” In most instances, the camper would stop what he or she was doing and begin singing along. This musical intervention positively reinforced social skills and prevented the camper from feeling as though he or she was being chastised.

Instrumental conversations were another popular activity among the campers. In these sessions, the therapist would allow each camper to choose an instrument and select someone to be the leader. This camper would then lead the rest of his or her peers by dictating dynamics, pauses, and articulation through his or her playing. Occasionally, the leader and the rest of the ad hoc ensemble would switch off playing or fall into a call-and-response pattern. The purpose of this activity was to encourage the campers to exercise impulse control by waiting their turn to play and to engage in a productive and respectful musical exchange with their peers. Additionally, this activity provided each camper with the opportunity for freedom of musical expression and artistic validation during their turn as the leader.

During the extended kid’s camp (in which the older children participated in activities similar to those they would experience the following year at teen camp), many of the campers took private music lessons with staff members. These sessions were diverse in nature and varied from voice and instrumental lessons to using programs such as Ableton Live and MIDI
controllers to create improvised dance pieces. In addition to honing musical skills, these lessons also facilitated musical expression and opportunities for decision-making. This was evident in Cameron’s lesson with Izzy Branch, counselor and music therapy student at Western Michigan University.

**Izzy and Cameron Make a “Robin Song”**

During their lesson conducted in the camp library, Cameron was drawn to a book about robins. He took it off the shelf and began reading it. Izzy, seeing this as an opportunity, encouraged Cameron to incorporate the book into their music lesson. Izzy recalls,

> He was not attentive and ran across the room and grabbed a book. I said “We aren’t at reading camp, we are at music camp; so if you want to look at this book you have to sing it to me.” I know Cameron has innate pitch and ability and loves to sing. I was just playing four chords and he would go through and if he didn’t get the words right you can hear on the recording where I would say, “Please wait. Go back. I know you can read that.” Because I knew he could do it. His dad, Lance, said that was his favorite part of the song, because he knew he could do it.

Through this compromise, the lesson was transformed from a purely musical activity to an interdisciplinary opportunity for Cameron to demonstrate his musicality and reading abilities. Cameron greatly enjoyed this lesson and the next day asked if he could sing the song at the Fifteen Minutes of Fame performance that evening. Izzy, who had recorded their session the day before, agreed and suggested adding additional instruments to the recording. Through the use of Garage Band and auxiliary percussion instruments, Cameron, his dad Lance, and Izzy worked together to create a musical arrangement. Izzy recalls,

> His dad happened to come to that session and so we got to each add a layer together and Lance got to make music with his son; we got to manipulate it on the computer. Cameron specifically added rhythm sticks, maraca, claps, and electric piano facilitated through musical typing in Garage Band; his dad added tambourine, and I added dumbek and we all clapped. It’s not like Top 40 music, but it’s a finished project that he finished in an hour, and it was completely improvised, and he got to make all the choice procedures.
In talking with Izzy, choice and decision-making were the main focal points of her lessons with Cameron. Though Cameron made all of the decisions about instrumentation and form, Izzy facilitated these choices by giving him options to make the process more manageable.

It’s very hard for him to pay attention and so I set him up for success by giving him options—do you want to do this or this, but I would sing, “Please pick one.” So that’s what I did with him. He got to make all the decisions on what instruments he wanted to play, I would play, and his dad would play. So it was facilitated through all of us, but it was definitely his project.

Izzy and the other staff members frequently emphasized the importance of independence and ownership both within and outside of lessons. One of the goals of camp and the WSA is to promote independent living and to create adaptations that make independence possible.

According to Izzy,

I had no doubt in my mind that [Cameron] could do it. That is the thing with people with special needs—I feel like so many people just put them on this “they can't do that; they need help with this.” No, they can accomplish so many things independently. People just don’t give them the chance…They need to make active decisions on their own; that is independent living. We need to set them up so that they can live independently as quickly as possible just like any other typically functioning person. They can do it—I have no doubt in my mind.

Rather than doing difficult tasks for the campers, the staff adapted the situation to insure that the campers were successful in completing challenges autonomously. This is one aspect in which the staff approached the campers as being differently abled, rather than dis-abled.

The Medical Model?

Through my interactions with music therapists I not only learned that the field of MT is highly diverse, but also observed that MT as it is represented in scholarly literature has a loose relationship with MT as it is practiced intuitively by individual therapists. The success of each MT session was not measured by quantitative data, but rather determined by the engagement and
positive response of the campers. The role of music therapists at camp was to facilitate opportunities for campers to successfully perform their abilities as well as to provide them with tools for building important life skills. Though my ethnographic goal of understanding the campers’ culture through their musical experiences was entirely separate from the therapeutic goals of my colleagues, through participant-observation I did engage in these activities with the campers and noticed their effectiveness. As stated by Terry Monkaba, “Music therapy helps all the kids whether they are musical or not; there is just a piece of them that responds to music…At this stage it’s a wonderful way for them to learn a lot of skills that they don’t have.” The music therapy sessions were successful in teaching and reinforcing important life skills (mathematics, social etiquette, and independent decision-making) through the incorporation of musical performance and interaction.

In disability studies literature the medical model of disability has been responsible for depicting people with diffabilities as being dis-abled and in need of rehabilitation (Longmore and Umansky 2001: 133). Though some scholars believe that music therapy falls within this medical paradigm, as is evident from the descriptions of MT sessions above, none of the music therapists I met at the Therapeutic Camp Experience week subscribed to or practiced this model. According to the American Music Therapy Association, “The aim of therapy is to help people with WS to optimize their talents and musical affinity in order to address multiple potential outcomes” (AMTA 2013). This is an apt description of what I experienced at camp. While the therapists engaged the campers in certain activities designed to produce intended outcomes (i.e. increasing the likelihood of asking permission before taking something), they did not view the campers as a problem to be “fixed.” The medical model is ultimately about change, and thus the practices of the music therapists could be described as fitting into this category. However, the
behavior of the therapists at Whispering Trails was not clinical. On the contrary, the therapists were invested in the campers as people, and treated them as valued individuals with different abilities that could be enhanced through a model of acceptance tempered with tools for accommodating challenges. The therapists did not implement practices as a way of “overcoming” problems, but rather used music to adapt situations to insure the campers’ success.

**Effectiveness of Music Therapy**

The music therapy techniques were effective in developing important life skills for the campers, such as turn taking, sharing, respectful modes of communication, and simple mathematics. These skills are routinely cultivated in all children and, arguably, musical interventions could be an equally effective tool in teaching valuable life lessons to neurotypical children. However, neuroscientific studies suggest that there is a special connection between music and the neurological organization of individuals with WS. Many studies have examined the musical talents of individuals with WS in relation to rhythmic and melodic replicative abilities and incidence of absolute and relative pitch (Hopyan et al. 2001; Lenhoff, Perales, and Hickok 2001; Levitin and Bellugi 1998; Levitin et al. 2004; ibid. 2005; Sacks 2007). While these studies set out to quantify the participants’ ability to accurately replicate rhythms and melodies, researchers have found that creativity comprises a large part of the individuals’ musical abilities. As stated in Daniel Levitin and Ursula Bellugi’s article “Musical Abilities in Individuals with Williams Syndrome,”

Most interestingly, when the subjects with Williams syndrome made errors in rhythmic production, their errors were far more likely than comparison subjects’ errors to form rhythmically compatible musical elaborations to the test items; that is, responses of subjects with Williams syndrome, when incorrect, tended to be creative extensions of the reference rhythm. (Levitin and Bellugi 1998: 357)
In addition to examining musical abilities of individuals with WS, other neuroscientific studies have explored the connection between WS, music, and hypersociability and the strong emotional responses that many individuals with WS display when listening to or performing music (Claussen and Hanser 2000; Jones et al. 2000; Maher 2001). More recently, neuroscientists have been interested in the effect of musical experience on verbal memory in individuals with WS. In their article “Musical Experience on Verbal Memory in Williams Syndrome: Evidence from a Novel Word Learning Task” Marilee Martens, Melissa Jungers, and Anita Steele found that music enhanced verbal memory in those participants who had previous musical training and had little to no effect on those who did not have musical training. According to the authors, “These compelling findings provide the first evidence that musical experience may enhance verbal memory in individuals with WS and shed more light on the complex relationship between aspects of cognition and altered neurodevelopment in this unique disorder” (Martens, Jungers, Steele 2011: 3093). While further studies are required to fully understand the connection between music and WS and, more specifically, the effectiveness of music in the education of individuals with WS, the MT activities I witnessed aided campers in developing important life skills.

Music Therapy Outside of Camp

Camp is a unique experience in many ways, one of which is the focus on music therapy. In speaking with parents I learned that while they find music therapy to be very beneficial, many do not have access to music therapists in their daily lives. When asked if she and her son participate in music therapy outside of camp one mother answered, “We don’t because we don’t have it available in our area. There’s not really anywhere to take him.” The lack of available
music therapists was a recurrent theme in my conversations with parents. Though a few families were able to secure music therapy services through their schools, many times these opportunities were short-lived. According to Darien Packard, mother of Joelle, “In kindergarten she was in public school and we talked to the school about bringing in a music therapist, which they did for a semester and then they didn’t have her come back the next semester and didn’t even talk to us about it.”

Due to the limited availability of music therapy services, families that have seen the benefits of music in their child’s life and education often try to implement musical interventions on their own. Kim Serre commented that she frequently makes up songs to help her daughter Kendal carry out daily tasks, such as brushing her teeth and getting dressed. Likewise, Joseph Raschke has begun setting mathematical concepts to music that his son, William, finds challenging. Raschke recalls,

> It’s [music] how he learned to count money. He’ll sing the value of coins in a song… He can rattle off the song, I don’t know what it is, but he always sings the value of the coins. So to me, that was the big thing that got him over that hump. He could not figure out pennies, quarters, nickels, and dimes until he had that. He has been having trouble with time on the clock so now they are using music to try and work him through that.

Many parents commented that music was an effective learning tool and increased their child’s ability to retain information. According to Heather Hansen, mother of Hope, “We have tried to do lots of learning to music, like math facts or state capitals, and if it’s to music she totally remembers. I think she could learn anything if it’s put to music.” This sentiment has been echoed by researchers such as Sally Reis, Robin Schader, Harry Milne, and Robert Stephens, who in their study of an alternative talent-based educational model found that individuals with WS had greater success with difficult academic concepts when music was incorporated into the learning process: “By engaging the love and appreciation for music in persons with WS, their
confidence and performance levels increased in both math and music” (Reis et al. 2003: 310). In this way, music therapy can be used to help bridge the gap between musical activities, which the campers consider enjoyable, and academic concepts they find challenging.

Beyond its use as a learning tool for academics and life skills, music is also an important part of everyday life for the campers, both within and outside of camp. Music is often an outlet for personal expression and facilitates catharsis. Even when music therapy techniques are not being directly implemented, many of the campers find music making to be therapeutic. When asked, “How do you feel when you make music?” the campers almost always responded with replies like “happy,” “good,” or “great!” Sometimes these positive feelings are physically manifested, as is the case with Leah Carruthers. In an interview, Leah’s mother, Karen, recalls, “Remember the day when we were listening to the music and you asked me if it made me feel the same way as you? Because she said she could feel it in her muscles. It made her feel so happy she could feel it right into her muscles.”

Figure 1.1: Leah Carruthers (left) and Joelle Packard (right) dancing during jam session
In addition to inciting feelings of joy and excitement, numerous campers and parents also commented that music has a calming effect. Many people who have WS are prone to high anxiety and music is one way that campers counteract these feelings. Angie Calhoun remarked that music is “really calming” for her daughter Zoe and that musical interventions help to prevent meltdowns that occur during difficult tasks, such as transitioning from one activity to another. Similarly, Jackie Hahn revealed that her son, Tiernan, often plays their electric keyboard when he is aggravated:

When he gets frustrated or angry he will go to [the keyboard] and I think that is a calming thing for him...at times when he is frustrated on the electric keyboard he often plays the same chords. It might be two weeks in between when he has one of these difficult times but he will go back and play the same chords.

Outside of the therapy model, musical activities provide campers with opportunities for personal expression and emotional release; thus, for the campers, the act of making music is inherently therapeutic.

**Fifteen Minutes of Fame**

At Whispering Trails the use of music as a personal and emotional outlet was most evident during the nightly performances at Fifteen Minutes of Fame. Each night after dinner, campers participated in Fifteen Minutes of Fame, a sanctioned time during which campers were free to “let off steam” and perform for one another by singing, dancing, drumming, or telling jokes. Campers often recruited parents and camp staff members to assist them with their acts thus making this hour a time when the entire camp community was gathered together in a fully integrated setting. It seemed to be everyone’s favorite time of day (campers, parents, staff members) and within two minutes of the very first act I understood why.
The first session of this year’s Fifteen Minutes of Fame began with a performance of “New York, New York” sung by 8-year-old Kendal Serre. The lodge was packed with parents seated in the semi-orderly rows of chairs while the campers squeezed into non-existent spaces on the couches and sat squished together with their friends on the floor. Due to the limited space, I situated myself near the back of the room where I could clearly see the “stage.” After being introduced, Kendal made her way up to the front of the room, took the microphone from its stand, and waited for a counselor to start the recording. As soon as the introduction began, Kendal became animated and started singing along with Sinatra. Her voice was clear and strong, and what I expected to be a simple karaoke rendition of the popular song instead took on the trappings of a Broadway revue. Kendal threw in occasional dance moves amidst theatrical hand gestures while she sang her heart out. By the time the song had reached its climax I found that I had inadvertently inched my way towards the front of the room (with my mouth hanging open) to get a better look at this tiny girl who had the entire audience spellbound. She ended the song with a dramatic finish, and as we all jumped into a standing ovation, Kendal burst into tears. She was so overcome with emotion, both her own and that of the audience, that she began sobbing uncontrollably. I too began to tear up and in looking around at the rest of the parents and campers saw that some of them had also begun to cry. One of the staff members, noticing my awestruck expression and the stray tears streaming down my cheeks, approached me smiling and said, “Just wait til teen camp.”

The next day I had the opportunity to interview Kendal’s mother, Kim Serre, and ask her about Kendal’s performance. What follows is a partial transcription of that conversation.

Alex (A): It was so amazing to see her perform and then…

Kim (K): Burst into tears. She does that a lot.
A: Was than an excitement thing?

K: Yeah, excitement that she did it. When I heard about the 15 minutes I signed her up and I told her, and then she burst into tears when I told her because she was so happy that I did it. And then she took her name off the board because she couldn’t do it. And then by the end of the day she said, “OK, put me back on the board; I can do it.” So I put her back on the board. I knew that once she started seeing it, she would want to do it. I think it was just the emotion of the day and thinking about it and preparing for it. Once she gets up there, there is so much more emotion when she is in front of people.

Fifteen Minutes of Fame is not only an arena in which the campers are able to showcase their abilities, but it is also a vital component in the creation of camp community. No matter the outcome or quality of the performance, the campers are encouraged and celebrated by their peers. As Monkaba explains,

Whether they play Beethoven or “Twinkle, Twinkle Little Star,” they get a standing ovation…They aren’t all great musicians, but they don’t all have to be—they still have a basis of how it makes them feel and they want to be together. So it definitely builds community. The kids who come together here for the teen camp are drawn together and everything they do is based in that music, even when we have some who don’t have a musical bone in their body; it doesn’t matter…And again, they feel community like most of us don’t. It’s very important to them and they just naturally know how to do it like most of us don’t.

This talent for creating a supportive and welcoming environment is a prevalent feature of individuals with WS and demonstrates their special ability to create community. For the campers, the Fifteen Minutes of Fame environment offers a safe place in which to relax, express themselves through performance, explore their abundant potential, and let the struggles of the day become a distant memory.

**Around the Campfire: The Parental Camp Experience**

Though the therapy camp is a rejuvenating, affirming, and fun time for the campers, it is an equally invaluable experience for the parents. In addition to having the opportunity to attend workshops on behavior modification techniques and planning Individualized Education
Programs (IEPs), parents are also able to engage with therapists, counselors, and other parents. Since Williams Syndrome affects one in every ten thousand people, the Williams community is very diffuse. This can be isolating for parents and their children who often find themselves as the only Williams family in their local community. Thus, camp presents a time for parents to form lasting friendships, exchange ideas, and gain a sense that they are not alone in their parenting challenges.

A particularly important and cherished time for the parents occurs nightly when they put their children to bed and then gather around the campfire. While enjoying an adult beverage and coating themselves in bug spray to prevent being attacked by the ferocious Michigan mosquitoes, parents have the opportunity to speak with music therapists one-on-one about their child’s education, exchange parenting strategies with one another, hold fearsome leg wrestling competitions, and simply be in the company of friends who understand what it’s like to have a child with WS.

Throughout the week I noticed that there were two therapy camps occurring simultaneously: a music therapy camp for the kids and a community therapy camp for the parents. This observation was confirmed through an interview with Joseph Raschke, father of William, who commented:

To me, as the parent here this week it’s the two things that I think are the biggest part of this—his absolutely pure enjoyment of being here; it’s his perfect world—and me being able to sit here and talk to all the other parents and go over, “Look, this is what I’ve noticed. Did you deal with this? How did you help him get through this?” And if this community wasn’t able to do that, I would be lost and I think he would be worse off for it.

Through this week of fellowship and sharing parents not only gain a sense of belonging that comes from being a part of the community, but also cultivate deep and lasting friendships.

When I asked Camp Director Robin Pegg about this phenomenon she smiled and explained,
The parents bond; they form friendships. They form friendships here that have led to joint vacations. We have people who will go on vacation every year and they started here as friends. My original rec dad crew, they get together every year. It’s an indescribable resource for the parents. It lets them know they are going to be OK.

During an interview, Melissa Baer, mother of Ashlyn, explained that the ties formed at camp often extend beyond friendship and become familial. This sense of family is not only cultivated among the parents, but also between staff members, parents, and campers:

It’s great to come here and see friends that you get to see once a year, which makes you kind of sad. All of these wonderful people who have come into our life who we never would have met from all over the country—we have friends in all states and they aren’t just friends, they are like family because we have such a bond that I just don’t share with my friends back home. It’s very spiritual; it’s very uplifting… It’s not just the parents that you bond with but people like you and the counselors that really are complete strangers when you walk into camp. You see the way they love our children and would do anything for our children. I have family and friends who don’t really put that much effort. They don’t have a reason to do it other than they just love our kids and they are great people. It’s incredible to have that much love.

Though many of the parents have been coming to camp for years and have a firmly established network of friends, the community eagerly welcomes newcomers. Several first time-attendees commented that they felt immediate acceptance and support from the WSA camp community. Jackie Hahn, mother of Tiernan, describes her first year at Whispering Trails thusly: “As far as the community, it is very supportive and they have opened us to so many resources. It’s amazing to have that support…You realize that we all have similar children. We all have the understanding.”

As an ethnographer, a cultural outsider, I could not have found a more welcoming, kind, and knowledgeable group of people to teach me about the Williams community. Over the course of the week I had the opportunity to speak with almost all of the parents, who sacrificed hours of their cherished vacation to tell me about their experiences. I was deeply moved by the generosity
and openness with which the parents shared their lives, and by their efforts to make me feel like a part of the community. When I commented on this many parents attributed it to their children.

In interviews I frequently asked parents what it meant to them to have a child with WS and to be apart of the Williams community. Many parents shared the difficult realities that they and their child face on a daily basis, however, most parents also spoke of the joy that comes from being a parent in this community. During an interview with Theresa Potts she shared these thoughts about her daughter Madison:

Madison is a challenge and a joy all wrapped up in one cute little package. I’ve said things that I never thought would come out of my mouth like, “Don’t lick the refrigerator door.” But they did…For my husband, he is very much an introvert. I think God gave us Madison to get him out…I think he’s experienced things he never would have thought of or experienced.

Several parents echoed this sentiment and commented that having a child with WS, while challenging, has positively altered the way they live their lives and view the world. In a conversation about her daughter, Zoe, Angie Calhoun stated that “Zoe has completely changed me as a person and opened me up to so much beauty.”

Therapy camp not only provides parents with resources to help their children face daily challenges, but also affords them the opportunity to celebrate their child’s strengths and abilities. According to Heather Hanson, mother of Hope, “The whole reason we go to camp is because it makes her feel like she’s good at something and she’s not different from other people. Like, there are other people just like her…It’s how we make it through the school years.” Many parents agree that camp is the highlight of their family’s year. Beyond the opportunity to access resources and to reunite with friends, camp provides parents and their children with a sense of support, community, and belonging.
“Bugaloo”: Creating Communitas

Camp is an affirming experience for both parents and their children; it allows them to co-create a culture based on the commonality of Williams Syndrome, while also celebrating individual personalities and experiences. The campers’ diversity is expressed through various music therapy exercises, general camp activities, and random outbursts of music making. Though parents are sometimes slow to join in the musicking, they are often persuaded to participate through their child’s enthusiasm and gentle cajoling from the counselors. Each evening the entire camp gathers around the campfire to roast marshmallows, talk, and, most importantly, to sing and dance. Counselors take turns leading the festivities by playing instruments and singing popular top 40 hits and camp songs. While some songs receive more attention than others, “Bugaloo” is the unanimous favorite and is thus performed on a nightly basis. During this song everyone sings the chorus, which is then followed by a counselor choosing an individual to perform his or her own version of the dance.

The song follows a call-and-response format:

Everyone: Bug-a-loo, bug, bug-a-loo/bug-a-loo, bug, bug-a-loo

Counselor: Hey, Sarah!

Sarah: Hey, what?

Counselor: Hey, Sarah!

Sarah: Hey, what?

Counselor: Show us the way that you BUG-A-LOO!

*Drum solo coinciding with a brief freestyle dance

This song may last for up to fifteen minutes if the counselor calls everyone’s name individually. Though repetitive and often wearing on the leading counselor’s vocal cords, “Bugaloo” is not
only an essential component of each campfire, but is also vital to the overall cohesion of the camp community. Through the calling of their name each camper is individually recognized and free to express him or herself through improvised body movement. As each camper “bugaloos,” their peers offer cheers and shouts of encouragement.

Figure 1.2: Evening campfire

This is their time to shine and to musically and physically express themselves without fear of judgment. Parents and counselors are also included in this community-building ritual. While many parents merely observe the majority of the campfire activities, all are called to fully participate in the “Bugaloo.” In these moments of musical expression, hierarchical structures of parent-child and adult-minor dissolve. As each person’s name is called, he or she enters a liminal space created by music and dance. This state of liminality is then followed by what the symbolic anthropologist Victor Turner described in his book, *The Ritual Process* (1969) as *communitas*. According to Thomas Turino, *communitas* is “a possible collective state achieved through rituals where all personal differences of class, status, age, gender, and other personal distinctions are
stripped away allowing people to temporarily merge through their basic humanity” (Turino 2008: 18). This transition from a state of individuality to being one with the community can be seen in the camp ritual of “Bugaloo.” In the process of shedding inhibitions and engaging in a dance that is entirely one’s own, each person crosses the threshold separating the individual from the collective and is initiated into the camp community. This musical ritual serves to affirm the individual and to construct a supportive community that is free of judgment. Once you bugaloo, you belong.

![Image](image.png)

**Figure 1.3: Sarah Keegan striking a dramatic pose at the conclusion of her dance solo**

The sense of belonging and the close-knit community that it produces are paramount to the experience of the campers, parents, and staff. Within the camp environment, Williams Syndrome is not treated as a deficit, but rather as a marker of difference that is appreciated, nurtured, and accommodated. While the parents, staff, and campers are initially drawn together by the shared experience of WS, over the course of the week they create a community and culture based on mutual support, understanding, and possibility for the future that is crafted through musical experience.
CHAPTER TWO
MUSIC AND ENRICHMENT CAMP

Teen Camp: Affirmation through Performance

The Music and Enrichment Camp for teens (aged 13-20) differs from the Therapeutic Camp Experience in several ways. Firstly, parents do not stay on camp property, though many accompany their children on the first day and stay in a nearby house or cabin rented for the week with other parent friends. Free from parental supervision, the teens are given greater agency to explore their independence while still adhering to the structured rules and regulations upheld by the camp staff members. Secondly, though many of the certified music therapists and music therapy students remain on staff as counselors, music therapy is not explicitly practiced during this week. The current model of The Music and Enrichment Camp is the result of years of work to develop a program that caters to the diverse interests of the teens. Though many of the classes revolve around preparing music that is performed at the final showcase, a comparable number of activities are nonmusical. These events afford campers the opportunity to try things one might experience at a typical summer camp including swimming, canoeing, playing games, rock climbing, archery, and arts and crafts. In an interview, Robin Pegg described the importance of teen camp’s accessible blend of musical and traditional camp activities:

The mission of the teen camp is to provide a typical camp experience in a fashion that individuals with WS can be successful. Many times when kids go to a camp for kids with disabilities, they will do similar things to what you maybe did at summer camp when you were younger, but a lot of times they are very watered down versions. And sometimes there are things that they just don’t do because people decide that maybe it’s just too dangerous. So we are no holds barred. We take all the crazy experiences: shaving cream fights, the giant slip and slide, the rock wall, the canoeing, the fishing, the water balloon fights, the water hose fights, and baseball. And yes, we throw in garage band [rock band], and chorus, and do a big show. And we have an art teacher helping the kids make props and backdrops. There is all of that because we do this big show at the end of it, which is really great. So it’s kind of a combination of typical summer camp and band camp
smashed together, but all have been adapted so the kids are 100% successful. It’s not all about the music. In fact, that camp has really morphed into being very 50/50.

As stated by Pegg, the primary objective of the Music and Enrichment Camp is to insure that the campers experience success while trying new things. Though traditional camp activities were well represented (and greatly enjoyed by campers and staff alike), the dominant presence of music was evident from the many applied music lessons offered to campers, as well as by the emphasis on boy band, girl band, and chorus, which were featured in the final showcase.

While music therapy and the construction of a supportive community were the focal points of the Therapeutic Camp Experience, individual and personal expression through performance became the primary focus of the Music and Enrichment Camp. The teens quickly cultivated a tight-knit sense of community through musical interactions and shared experiences, yet the community itself took on a supporting role and served to confirm individual capability. From a musical and ethnographic perspective, I witnessed two important and mutually reinforcing themes that emerged throughout the week: music consistently served as a vehicle for personal expression through performance, and performance functioned as an affirmation of personal ability and identity. This was most evident during applied music lesson and performances at Open Mic Night.

**Applied Music Lessons**

The teens signed up for activities and classes based on their interest in music, dance, and recreation. Those taking applied music lessons were assigned to a counselor who specialized in the camper’s instrument of choice. In these one-on-one musical sessions the campers decided what they would like to learn, how they would like to participate in the lesson, and whether or not they wanted to perform what they learned at Open Mic Night. The counselors were often
accomplished musicians and teachers, yet in the context of the lesson they assumed the role of facilitator. While they would offer suggestions for how to improve technique, ultimately their role was to assist the individual teen in his or her own musical process. In these lessons the status hierarchy of counselor-camper became negotiable as both teacher and student worked together towards a mutual musical goal.

As established in the Introduction, while not all people who have WS are musically talented per se, the majority of campers I met seemed to innately understand and enjoy music. Those who had previous musical training and took lessons outside of camp tended to be more musically accomplished than their peers who did not cultivate musical skills through regular lessons (Martens, Jungers, Steele 2011; 3093). However, all lessons served as opportunities for campers to demonstrate their abilities regardless of previous training or degree of musical skill. Counselors adjusted lessons to fit the camper’s level of musical prowess and allowed the camper to dictate how he or she wanted to perform.

This model of diversity and accommodation became apparent after I observed Carol Malerich’s piano lesson followed by Mike Healey’s drum controller jam session. Carol has been playing the piano for fourteen years and, though she does not read music, can play anything by ear. In her lessons, counselor and prodigy musician Peter Littlejohn continuously gave her musical challenges to help expand her technique and repertoire. Peter would play a pattern on the piano and ask Carol to replicate it. After playing it back perfectly, Peter would challenge her by asking her to repeat the exercise but with a slightly more complex pattern. In every instance, Carol met the task with ease and transformed the concept of a “challenge” into a display of her capability as a musician and student. By the end of the lesson, Peter had taught Carol several new chord patterns which she then began integrating into her own improvised compositions.
While Carol is a practiced pianist who used these lessons to hone her skills, other campers, such as Michael Healey, approached applied lessons as an opportunity for personal expression and musical experimentation. Mike does not regularly study music outside of camp and his lessons consisted of using MIDI controllers to create improvised electronic compositions with certified music therapist Brad Hatfield. Mike is a veritable expert on all things Godzilla related, and thus he and Brad decided to create a musical soundscape for this fearsome dinosaur. Over the course of several lessons, Mike and Brad composed the “Roar Song,” an improvised, musical conversation, in which Brad laid down a beat over which Mike interspersed sound effects from various Godzilla movies. Though Mike is naturally shy and more introverted than most of the other campers⁸, he and Brad performed their composition during Open Mic Night one evening. This allowed Mike to express his enthusiasm for Godzilla through a musical medium and to have his expertise acknowledged and celebrated by the rest of the community.

In the Music and Enrichment Camp, and applied lessons specifically, musical talent was always secondary in import to the joy the campers received from performing. Music was not

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⁸ In addition to being born with Williams Syndrome, Mike also has autism.
used to establish a pecking order of aptitude, but rather served as a vehicle for personal expression. Applied lessons allowed campers to demonstrate their strengths and to be valued for their individual abilities without being compared to other campers. The variety of musical talent and forms of expression not only reinforced the great diversity that exists within the camp community, and the Williams community in general, but also illustrated the wealth of ability and many strengths of the individual campers.

**Open Mic Night**

During teen camp the nightly Fifteen Minutes of Fame event that took place at the Therapeutic Camp Experience was transformed into a biweekly, all-camp event called Open Mic Night. All campers were free to signup and by the end of the week the majority had participated either through solo performance or collaboration with counselors or other campers. Many of the “acts” performed during these events were the result of music learned or compositions created in applied music lessons. This gave campers the opportunity to demonstrate what they had learned and to share their musical creativity with the rest of the camp community. As in applied lessons, performances varied based on the musical prowess and interest of the camper.

For example, Kagen Gibson, who is an experienced drum set player, chose to perform the entire unaccompanied drum part from the Rush song “YYZ” at the first Open Mic Night. I had witnessed him practice this technically challenging piece in lessons with instructor and musician Lisa Taylor, who encouraged him to perform for the camp. Kagen was the final act of the night and seemed completely at ease as he approached the microphone in his flame-streaked bandana and a navy T-shirt displaying the words “Pure Texan.” He raised his drumsticks and said, “I have one question only: are there any fans of the band Rush in the building?” As his fellow campers
cheered and threw their hands in the air in response to his question, Kagen made his way to the
drum set. He wasted no time, and as soon as he sat down he began playing the introductory riff
on the cymbals. After two bars he added snare, tom-toms, and hi-hat to the texture. The rhythmic
tension built as Kagen added more excitement to his playing, culminating in a four bar fill before
finally settling into a basic rock beat pattern. I looked around the lodge and saw several campers
in the back standing to get a better look while others emitted shouts of encouragement as Kagen
interspersed varying drum fills throughout the main rhythmic pattern. As I watched, what
amazed me just as much as Kagen’s technical skill was the fact that he was playing the entire
song unaccompanied, yet had the main track been playing his rhythms would have aligned
perfectly with the melodic components. Kagen’s final drum fill was followed by uproarious
applause, yells of congratulations, and many hands raised in rock salutes.

Figure 2.3: Kagen practicing “YYZ” in a drum lesson
In an interview the following day I was surprised to learn that Kagen had developed his great technical skills on drum set in only four years. When I asked him how he felt about the performance he confided that although he was initially a little nervous, he greatly enjoyed performing for his friends. He also shared his thoughts on the role of music in his life and in the Williams community: “I think that music is kind of a way that we are sponsored. It’s kind of a way to be a leader. I think that music helps us to become more the people that we are cause a lot of people don’t know that there is more to us than meets the eye.” For Kagen music is not only a form of personal expression and a vehicle for demonstrating his exceptional musical abilities, but it is also a way for him to be an advocate for his community.

In addition to being an opportunity for campers to demonstrate their musical virtuosity, Open Mic Night is also a space in which campers are free to be themselves and express their identity in their own unique way. This side of Open Mic Night was evident from Elliot Deiters’ performance of his free-style rap composition “Cat Daddy, Mac Daddy.” Around camp Elliot was famous for his “Cat Daddy” dance move, which he frequently shared with other campers and staff members. With the help of counselor and music therapist Brad Hatfield, Elliot created a rap song that integrated his signature dance move with improvised lyrics. He even added a section that he dedicated to his counselor, Bill Bentley, who was infamous among his cabin for frequently wearing his baseball cap backwards. In this section Elliot turned his hat backwards, gestured to Bill, and changed the lyrics “Cat Daddy, Mac Daddy, Mac Daddy, Cat Daddy, meow, meow, meow” to “I got my Bill back, Bill back, wow, wow, wow.” During his performance the rest of the campers stood up and proceeded to dance around, cheer, and sing along. When I asked Elliot the following day how he felt when performing, he responded, I feel unstoppable. Definitely. Two thumbs up for unstoppable…I felt good inside and felt like I was singing and I did what I was supposed to do and I did good. When I was
singing it was good because I could sing and I haven’t been singing a lot, but I went on stage by myself and did my song and it was good. Being with Brad is great; he’s so much fun. He’s my home diggity dog. He’s a good guy.

Figure 2.4: Elliot performing “Cat Daddy, Mac Daddy” at Open Mic Night

Open Mic Night was an opportunity for Elliot to musically express his identity as the “Cat Daddy,” a persona that his WSA camp comrades greatly enjoy.

Open Mic Night is the primary arena in which campers perform their abilities for their peers. In this context the campers’ “performance” is not charged with a value judgment, nor is it compared to the performance of any other camper. This is reflective of the way that the campers naturally interact with one another. Everyone is valued as an individual and everyone is treated as an equal, regardless of musical talent. During Open Mic Night, what one performs is secondary to the fact that one performs. This type of sequential participatory performance⁹ can be seen in many different cultural contexts from Prespa Albanian weddings to American contra

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⁹ According to Thomas Turino, sequential participatory music occurs when “everyone takes a turn alone or smaller groups perform for the other people in the event” (Turino 2008: 48).
dancing (see Sugarman 1997; Turino 2008). These participatory settings provide the opportunity for self-expression while simultaneously involving the individual in a collective social ritual that engenders feelings of belonging. As stated by Thomas Turino, “Participatory sound style actually functions to inspire people to join in, and this type of music making serves a deeper function of creating a special sense of social synchrony, bonding, and identity” (ibid., 48). In the case of Open Mic Night, the campers appreciated when their peers shared their talents by performing for them and they demonstrated this gratitude by affirming the individual. This acknowledgement of each camper’s contribution strengthened the community as a whole and created a deeper sense of belonging and acceptance both between the individual and the collective group.

Final Showcase

While Open Mic Night provided an opportunity for individual campers to perform their strengths for their peers, the final showcase functioned as an occasion for the entire camp community to perform its abilities for the parents. All week long the campers worked on music, improvisational acts, and props for the final movie-themed showcase. Whereas applied music lessons cultivated individual acts performed by campers at the Open Mic Nights, the final show featured collective performances by the camp chorus, girl rock band, and boy rock band. Interspersed between the musical numbers, campers also performed group-choreographed dances as well as comical sketches based on popular movies that they developed in the improvisation class. Though most campers participated in some aspect of the performance, other campers expressed their talents by creating props and decorations for the show.

In the midst of having fun, engaging in new and exciting activities, and spending time with friends, the campers worked hard in rehearsals and classes to put on what numerous parents
described as “the best showcase ever.” This final evening served as a time for the parents to see what their child had learned during the course of the week. To an outsider it may appear as though the showcase was primarily put on for the benefit of the parents, and to an extent this was true; however, the showcase was also a celebration of the entire camp community and an opportunity for the campers to not only perform their abilities, but also their identities. Each camper had different strengths and talents, and the showcase provided a space for each to contribute and to be valued for that contribution. In this way, the final show built and fortified community ties while reinforcing individual feelings of belonging.

Figure 2.5: Final showcase prop featuring musical selections

Decked out in their camp tie-dye, the campers presented a variety show in which the boy band and chorus performed songs such as “Pretty Woman,” which they dedicated to Grandma Susie (mother-in-law of Robin, camp sous chef, and beloved surrogate grandmother to all the campers). The all-boy songs were then juxtaposed against the girl band and chorus’ rendition of numbers such as “Girls Just Wanna Have Fun” and “Independent Woman” (similarly featuring
Grandma Susie). These musical numbers were punctuated by group-choreographed dances to the songs “Ghostbusters” and “Fame” and by creative interpretations of scenes from classic movies such as *Benny and Joon*, *Dirty Dancing*, and *The Princess Bride*. For the final number the whole camp performed “Time of My Life.”

Towards the end, all the campers and staff joined hands and began singing as much to one another and to themselves as to the audience. The collaborative efforts of the staff, chorus and band members, dancers, and actors resulted in an exciting show that not only greatly entertained the audience, but also provided campers with a feeling of accomplishment and pride.

**Being the Change**

As the showcase came to a close, Camp Director Robin Pegg thanked all the parents for coming and graciously acknowledged the hard work and dedication of both the staff and campers. After introducing each staff member to the audience, Robin once again thanked the parents for sharing their children with us. She concluded her speech with these words: “Here at camp we like the saying ‘Be the change you wish to see in the world.’ And they [the campers] are the change we wish to see in the world.” Much of the way people understand and conceptualize the world is based on human constructions. The construction that I most closely examine in this thesis is that of “disability” as it is understood within the Williams community. According to disability studies scholar and advocate Tobin Siebers,

Disability is not a physical or mental defect but a cultural and minority identity. To call disability an identity is to recognize that it is not a biological or natural property but an elastic social category both subject to social control and capable of effecting social change. (Siebers 2008: 4)

While what I witnessed during the Music and Enrichment Camp was not a demonstration of dis-ability, but rather of a difference of ability, the campers with whom I interacted displayed
the potential to effect social change. This was evident not only through their capacity to perform their own musical abilities and to contribute to the camp community, but also in their aptitude for identifying and appreciating the strengths and contributions of others. Over the course of the week, music was the main medium through which the campers created a community based on cooperation, appreciation of diversity, and understanding of difference. While this community only exists for a short time each year and may seem like a utopian ideal, it consists of a diverse group of individuals that views the world through a lens of ability and the possibility of a change that is worth pursuing.

Figure 2.6: Robin’s speech following the final showcase performance
CHAPTER THREE

ADULT REUNION WEEK

Being a Young Adult

This year’s Adult Reunion Week differed greatly from past sessions in several important ways. Much like the Music and Enrichment Camp for the teens, in past years Adult Camp was dominated by musical activity in the form of applied lessons, rock band, chorus, and a final showcase at the end of the week. However, this year camp was completely restructured to provide campers with a variety of activities and opportunities for self-exploration and development. The week was organized into a collection of thematic days: Monday focused on self-determination and life skills; Tuesday featured numerous opportunities for volunteering within the local community; Wednesday centered around musical activity in the form of applied lessons, drum workshops, and social dance classes; Thursday gave adults the chance to go off campus on trips to a museum, horse ranch, or winery; and Friday was dedicated to arts and crafts in the morning followed by a trip to the beach house.

In addition to offering a greater assortment of activities, this year the camp was altered to provide the young adults with greater agency. The participants of this week’s session were between the ages of 21 and 35 and thus no longer felt it was appropriate that they be called “campers.” They are young adults and expected to be treated as such. Their status as adults was reflected in multiple changes in camp policy; for instance, they were not given a set bedtime, could access their phones at all times of the day, and could choose whether or not to attend a scheduled camp activity. As the overall structure of the camp shifted, so too did the position of counselors who took on the role of peer-mentors, friends, and, when requested, advisors. According to Terry Monkaba, the goal of this shift in mentality was to foster a greater sense of
independence within the young adults and to “make sure we are respecting their freedom while encouraging them to participate [in activities].”

The purpose of Adult Reunion Week was twofold. Firstly, it was a time for the young adults to reunite with their friends, catch up, have fun, and relax. Most of the adults do not live close to one another and during the year are able to sustain close friendships through social media such as Facebook and Skype. This week gave them a chance to make their virtual communities a physical reality, renew relationships, meet new people, and gain a sense of belonging created by the shared sense of what it means to be an individual with Williams Syndrome. For many young adults, this week is the highlight of their year. Secondly, it was an opportunity for the young adults to learn more about self-determination and independent living. This was accomplished through classes, workshops, and activities that raised important questions such as “What are my strengths?” “What do I want from life?” “How can I achieve the goals I set for myself?” and “How can I best contribute to society?” Throughout the week, music was integrated into these activities and played an important role in building community, facilitating self-expression, and generating a response to these big questions.

“Give Back Tuesday”: Performance at the Retirement Community

Volunteering is an important way that the young adults contribute to their local communities while not at camp. In order to allow the adults to continue this work and to expose them to new opportunities Tuesday was entirely dedicated to conducting community service projects within the local community. The young adults were divided into groups that each performed different service projects. These included cleaning up a section of the beach along Lake Michigan, feeding animals at the Grand Rapids Zoo, volunteering with Habitat for
Humanity on their landscaping and beautification program, and performing a music program for a local retirement community. To say the young adults were enthusiastic about these projects would be an understatement. One of them described his experience with Habitat for Humanity as follows: “I got to dig holes for planting trees and moved piles of rocks! It’s probably one of the coolest things I’ve ever done!” Likewise, 28-year-old Marin Lock expressed that she greatly enjoyed the opportunity to give back to the community and maintained that her love for helping others, like many of her peers, was part of her personality:

...what I love about this camp is finding new volunteer opportunities and Habitat for Humanity was amazing! I felt super good, but super tired [laughs]. That’s something I want to do when I get back home...I’m doing it because you aren’t worried about yourself; you are worried about someone else. I love that feeling. I love not worrying about me and worrying about someone else. That’s in my nature.

Many of the young adults volunteer outside of camp through their churches, weekly classes,\textsuperscript{10} or clubs. This not only provides them with an opportunity to give back to their local communities, but also demonstrates their ability to be contributing members of society.

Like many of the children and teenagers I encountered, the majority of the adults greatly enjoyed music and some were exceptionally talented. Their musicality, combined with a natural ability to easily interact with new people, made a musical concert at the local retirement community the perfect opportunity for them to share their gifts. The group began the morning rehearsal session with a rousing rendition of “Surfer Girl” led by Ben Monkaba, expert drummer and Beach Boy aficionado. It served as an excellent warm-up number, even though they didn’t end up performing it in the afternoon concert. The band members were already energetic and excited to begin rehearsal, though the mentors were slower to warm up as it appeared they were

\textsuperscript{10} Several of the young adults participate in day programs during the week. For instance, 25-year-old Ashley Brownstein attends a day program three days a week that offers physical activity classes such as jazzercise, basketball, and hockey.
still waiting for the caffeine from their coffee to kick in. “Surfer Girl” helped set the day in motion.

After the warm-up number, the mentors joined the rest of the band in a time of group stretching and vocalizing. The set list for the upcoming performance consisted of many popular tunes that would be familiar to the audience of retirees including “Don’t Sit Under the Apple Tree,” “Fly Me to the Moon,” “I Can’t Help Falling in Love With You,” “Hound Dog,” and “Hit the Road Jack.” Each song featured one or two adult song leaders accompanied by a group of mentors singing and playing the guitars, mandolin, and drums. As the rehearsal progressed the young adults began to take active ownership of the music. Scott, 34, an accomplished pianist who plays exclusively by ear, stepped up to provide piano accompaniment, while others volunteered to lead songs or sing solo sections and joined the mentors and musical directors in making artistic decisions. The rehearsal became a collaborative endeavor and was quickly transformed from a highly structured practice session into a free-flowing and somewhat improvisatory jam session. This was most evident in “Hit the Road, Jack,” which was substantially extended to include 23-year-old David Jaeger’s spontaneous and highly amusing interjections of “Adios!” “See ya!” “Be gone!” and “Get out of here!” between each choral reiteration of “Hit the road Jack!”

After lunch the group piled into several cars and made their way over to the retirement community. Upon arrival we discovered that the room scheduled for our concert was occupied by a small group of people conducting a church service. We filed quietly into the back of the room just as the chaplain was encouraging the residents to join her in a concluding hymn. Her invitation was met with a lukewarm response from the congregation, many of whom did not even bother to open their hymnals. What began as a lonely solo rendition of “When I Survey the
Wondrous Cross” featuring the chaplain soon grew into a strong choral number as many of the young adults joined in. Following suit, the mentors chimed in and began passing out spare hymnals to those less familiar with the words. The adults milled around the room and sat down next to the retirees, sharing their hymnals, smiling, and encouraging them to sing along. Several of the congregation members eyed the adults dubiously, but over the course of several verses (we sang them all) eventually began to sing. This intervention by the young adults softened the initially rigid atmosphere of the small service, causing the chaplain to beam as we finished the hymn and to suggest that we come back every week.

As the service ended, more residents shuffled into the room, some offering us friendly words of welcome while others silently took their seats. The chorus members sat among tables of residents and introduced themselves to some of the more chatty retirees. Throughout the concert the adults continued to engage the residents in conversation and encouraged them to sing with them. Much like those attending the church service, several of the residents were initially reserved and slow to join in the singing; however, the young adults were undeterred by the retirees’ reticence and within ten minutes had transformed the room with their contagious enthusiasm. The informal concert concluded with a soulful medley of “I Can’t Help Falling in Love with You” and “What A Wonderful World.” By the end of the medley the young adults had managed to coax most of the residents into singing and dancing around the room with them. As we prepared to depart, the residents thanked the adults profusely for coming and sharing their music with them and requested that they come back again soon.

Unbeknownst to most of the young adults, a news crew had been present during the beach cleanup and surfing session. That evening the local news channel, WZZM 13, featured a
news story entitled “William Syndrome Adults Incapable of Prejudice.” After a brief introduction overviewing the medical aspects of WS the newscaster stated,

Tuesday, adults with Williams Syndrome learned to surf, but this group also teaches compassion…Despite developmental delays, scientists found Williams Syndrome adults are so loving they are incapable of prejudice. In fact, we found this group doing a beach cleanup while waiting their turn. Once it is their turn they prove that they’re capable of anything. While these friends only meet once a year, they teach the world a true lesson in caring for others without boundaries. (Barwacz 2013)

While this broadcast only gave a snapshot of young adults who have WS, it did increase their visibility as a community and reinforced the message that they are a highly compassionate and capable group of people. Seen through this lens, people with WS are not only able, but also willing, to give of their time and talents in order to engender positive change within society; this portrait turns the entire notion of “developmental delays” on its head and challenges neurotypical conceptions of “what constitutes a capable citizen” (Kudlick 2013: 766).

“Give Back Tuesday” contributed to my growing understanding that “dis-ability” has little to do with who the young adults are as individuals and as a community. They are different from one another and from the neurotypical majority. However, this difference—in talents, worldview, expression, and personality—directly correlates to their ability to make a positive difference within society. “Give Back Tuesday” gave the adults the opportunity to share their different abilities with the community and, perhaps more importantly, reinforced their own sense of agency, ability, and power to effect change within society.

Mojo’s Piano Bar: Increasing Visibility

In addition to community services projects, ventures outside of Whispering Trails during day trips and evening activities allowed adults to participate in and contribute to the local community. The most memorable of these events took place on Thursday evening when I
traveled with a large group of the young adults to Mojo’s, the local piano bar in downtown Grand Rapids. Mojo’s was a large, dimly lit space equipped with an extensive bar in the back and a multitude of different sized tables situated close to the stage. The stage itself was small and crowded with two faux grand pianos positioned in front of a drum kit. Above the stage was a small black sign illuminated with neon writing entitled “Word of the night.” It was later explained that the message on the sign would change throughout the night as people paid to have various messages written on it.

Soon after ordering drinks and food, the musicians began taking song requests. I was sitting next to Scott, who had provided the piano accompaniment for our performance at the retirement home a couple days earlier. I turned and asked him, “Are you having a good time?” He nodded his head while still grooving to the music and replied, “Oh yeah.”

“How have you ever done this before?”

“No.”

“Is this something that you would be interested in doing?”

“Yes. That’d be fun.”

I began considering if and when during the course of the evening Scott might be able to perform onstage. An hour later I posed this question to our music director, who responded by finding Scott and pushing him onstage towards the vacant piano. The pianist on the far side of the stage exchanged a nervous look with the drummer, whose eyes grew wide as Scott took a seat at the adjacent piano, calmly adjusted his ball cap, and placed his hands on the keyboard. Their worried expressions soon turned to full grins as they watched Scott fill in chords and add the occasional ornamentation to the other pianist’s melody. Scott concluded the song with a
jazzy tremolo, head thrown back, eyes closed, and smiling. As he headed back to his seat, the drummer approached him and, after a brief word of admiration, the two shared a high-five.

By stepping foot onstage, Scott transformed the musical atmosphere from a presentational arena defined by artist-audience distinctions into a participatory and socially interactive space (Turino 2008: 29). Scott’s impromptu participation, combined with the non-stop dancing and singing from his young adult peers, solidified this shift from a presentational to a participatory atmosphere; this was evident both from the interest and involvement of the local audience members at Mojo’s (most of whom had no idea what they were getting themselves into when they decided to attend the piano bar on a presumably quiet Thursday evening), and from the resident musicians, who continued to invite the young adults onstage to perform throughout the evening. The neon “Word of the night” sign, first sporting the message “Quilters from Wisconsin,” was soon glowing bright blue with the words “Williams Syndrome.” This message, combined with the exuberant participation from the young adults, increased their visibility and sparked questions from audience members such as “Where are you all from?” and “What is Williams Syndrome?”

Figure 3.1: “Word of the night” sign at Mojo’s
Towards the end of the night, 29-year-old Eric Pape was slated to come onstage and play drums on “Sweet Home Alabama.” Eric had just returned from getting some water when he was waylaid by one of the mentors informing him that, “It was time.” The resident musicians beckoned him towards the stage and Eric, looking both bewildered and excited, squeezed behind the piano, sat down at the drum set, and picked up the spare drumsticks. Several of the local audience members seemed to be observing this new musical line-up with interest and directed their full attention towards the stage. After briefly conferring about the upcoming song, the musicians counted off the tempo and began playing. Eric immediately fell into the groove with the other musicians, comfortably playing fills and exchanging frequent smiles and head nods with the pianists. At one point, the other musicians made meaningful eye contact, first with one another, and then with Eric in a gesture that clearly conveyed the message, “take it away!” Eric then proceeded to play an intense and long drum solo that elicited wild shouts of encouragement from the crowd. Towards the end of his solo, Eric again made eye contact with the two pianists, and with a nod of his head the three of them joined together once again to conclude the song. The crowd erupted in applause and, looking around, I noticed that most of the audience was focused on the stage, eyes filled with admiration for what I heard many people describe as a “rockin’” rendition of this popular song. Though Eric was the final person from the group to perform onstage, the young adults spent the rest of the evening singing, dancing, and generally enjoying the music. As we closed our tabs and prepared to leave, the resident musicians approached our group and with words of thanks and admiration presented several of the young adults with drumsticks as a memento of the evening.

The next day, when speaking with Eric about his experience performing at the piano bar, he remarked: “It was totally unexpected...I almost cried because I was just so happy. It was an
amazing great time. I didn’t expect it.” Though Eric is a skilled drummer and has taken lessons in the past, he does not frequently perform in public. When I asked him how he feels when playing the drums, and particularly how he felt while performing at the piano bar, he responded,

Great. I mean, it’s kind of freeing. Last night I didn’t know what the direction was going to be—if we were playing some song I never heard of or some song I don’t like—I just got up there. It was something I’ll probably never forget...I did not get this gift thing or whatever you want to call it for no reason. I believe that it is a gift…I just thank God that I didn’t see it coming; it just came to me.

Eric lamented the fact that many people form opinions about others before getting to know them and make judgments solely based on outward appearances. However, he believes that music functions as a way for people to look past superficial labels of disability and to gain a deeper understanding of who he is as a person.

In a later conversation with Eric he again reflected on his performance at Mojo’s, saying, “Sometimes I feel like people don’t really care about me, like they don’t really see me. But last night, they saw me.” While Eric’s narrative is deeply moving, as were many of the stories that were shared with me by individuals within the Williams community, his triumph does not stem from gaining acceptance or attention from neurotypical members of society for his musical ability. Eric is indeed a talented musician; however, this should not serve as justification for why he should be recognized or accepted. Eric, like many of his young adult peers, is insightful, kind, and empathetic, and is skilled at putting others at ease. Additionally, like his many of his peers, he is not only an excellent musician, but also has the innate ability to create a sense of community through instances of shared musicking. This co-creation of musical culture that engenders feelings of collaboration, belonging, and mutual understanding is valuable and necessary for the creation of a healthy society. However, it is equally important for the well-being of the individual. Whether or not Eric’s performance at Mojo’s altered the neurotypical
audience’s perception of his ability is secondary to the self-actualization he gained from the experience.

Figure 3.2: Eric Pape performing “Sweet Home Alabama”

Eric’s performance was an opportunity to express his agency through music and to demonstrate his competence as a musician, as much to himself as to the audience. In this way, his drumming was not only an indication of musicality, but also an act of self-advocacy and empowerment.

Music as a Path to Citizenship

Citizenship is an important topic of conversation for young adults with Williams Syndrome. While they have amazing strengths in some areas, unfortunately these abilities are
often obscured by the label of disability assigned to them by neurotypical society, as well as by the distinct challenges that they face on a daily basis as a result of having WS. However, as can be seen from the previous narratives, their capacity to contribute to society is often made visible through musical and social interactions. When I asked Robin Pegg what she considered the importance of music to be in the campers’ and young adults’ lives she responded:

I think that music for kids with Williams Syndrome, it’s their universal language. Music for a child with WS is their ticket to independence; it’s their ticket to being seen as valuable. Let me explain. Typically people with disabilities…have an appearance [and] you are judged. You are judged on your appearance. And WS has, people with WS have issue with their elastin gene so they typically have an imbalance of tone…People pass judgment on these kids. So you have this kid who looks like they have a disability—they can’t really write; they don’t do math so hot; unless you are teaching phonics they are struggling to read. Most people don’t understand it’s the teacher problem, not the student problem; you are just teaching them the wrong way. And they pass judgment on their capacity as human beings. And then you give them a mic, or a pair of drumsticks, or a keyboard, and all a sudden, Emerson, who also has a little bit of autism, looks really capable. She can memorize all the words to “Single Ladies” and sing it back on pitch and on beat. She can do that; I wonder if she can do other things. Curtis can tell you absolutely everything you need to know about Phantom of the Opera and Broadway. Ben Monkaba can’t tie his shoes, but he plays drums like Buddy Rich. Colin is almost 30; he writes like a first grader, but he plays Tchaikovsky by ear and mostly Metallica because that’s what he likes, on the piano...All of a sudden people look at the kids different...Because of their affinity for music, it has the capacity to level the learning field for them. Joelle can spell “biology” and “character” and “government” and “senate” because she taps her leg while she spells. Most of our kids can learn just about anything when you put it to rhyme, rhythm, and cadence. So music is a doorway; it’s a path to citizenship for them.

As can be seen from the young adults’ involvement in community service projects and their participation at the local piano bar, music and social interaction through music increase their visibility within the dominant neurotypical society. While these displays of musical talent and musicality are advantageous in helping neurotypical people see beyond external labels of disability, they should not be a requisite for inclusion within society. People with Williams Syndrome should not be acknowledged by society solely because they are musical, or social, or because they inherently understand and care about others; they should be accepted because they
are human beings and, as such, deserve a voice within their society. This full inclusion and integration into the community is the ultimate goal for people who are often stigmatized as the “Other” (Goffman 1963). In her book *The Rejected Body*, Susan Wendell reflects on the difficulty of achieving this acceptance:

> the exclusion of people with disabilities from many aspects of life in a society prevents non-disabled people from getting to know them, and also prevents people with disabilities from making their mark on culture, both of which contribute to their remaining the symbolic ‘Other’ to non-disabled people. (Wendell 1996: 64)

For people who have Williams Syndrome, music both facilitates interaction across neurotypical-neurodiverse boundaries\(^{11}\) and allows them to simultaneously leave “their mark on culture,” as well as to create their own. Such shared musical experiences remove socially constructed masks of disability and engender an understanding that, in the end, we are all different versions of the same thing. As stated by 18-year-old Kagen Gibson,

> I think that people need to understand that although people have special needs it doesn’t mean they can just judge a book by the cover. It means they have to accept the person for who they are even if they are a little bit different. You still need to go with the flow of it and you also need to learn how you can reason with the person who has different problems… I am just saying, from the bottom of my heart and from all the people at the WSA, do not judge us, for although we might be different, we are the same and there is more to us than meets the eye.

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\(^{11}\) Music also promotes interaction and conversation that transcends religious, ethnic, and sexual boundaries.
CHAPTER FOUR

DEFINING DISABILITY, DEFYING DIS-ABILITY

Disability, Diffability, and Social Constructionism

Central to this thesis is the examination of what it means to be an individual with Williams Syndrome and how music informs this identity. An equally important aspect of this work is the terminology that is used by campers, young adults, staff, and parents to describe their experiences and formations of individual selfhood and collective culture. I came to Whispering Trails for the ethnographic purpose of listening to these individuals’ stories and learning what these knowledgeable people have to teach about their own culture and way of being in the world. Bakan clarifies this ethnographic perspective in his forthcoming article “Don’t Go Changing to Try and Please Me: Combating Essentialism through Ethnography in the Ethnomusicology of Autism,” in which he asserts that regardless of whether the subjects of our musical ethnographies are Balinese gamelan musicians or Autistic children, Akan master drummers or young adults with WS, we work from the same assumption that they are in every case “experts at being who they are, whether as individuals, as musicians, or as exponents of the cultural worlds and lifeways they reflect, embody, and inform” (Bakan, 2013). I was the student of culture at Whispering Trails and I viewed my teachers, principal among them children and adults with WS, not only as knowledgeable, but also as incredibly capable. This experience helped me to understand Williams Syndrome as a diffability rather than a dis-ability.

Disability studies scholars have long maintained that disability is a social construction rather than a physical reality. This perspective “un-Others” those labeled as having a disability by examining the concept of disability as a creation of society. In this context, people are not defined by their disability, but rather are viewed as citizens entitled to acceptance and
accommodation: “The social model challenges the idea of defective citizenship by situating disability in the environment, not in the body. Disability seen from this point of view requires not individual medical treatment but changes in society” (Siebers 2008: 73). This model not only informed my understanding of disability and disability studies, but was also consistent with my role as an applied ethnomusicologist whose goal is to bring about social change by sharing the stories and experiences of my teachers within the Williams community.

Throughout my time at camp, I had countless conversations about music, WS, and disability that were woven into the fabric of personal narratives. As I believe language is vital to how we conceptualize the world and our place within it, I frequently asked my interlocutors what they thought about the word “disability.” The responses I received were as varied as the diverse individuals that comprise this community and reinforced the fact that identity is complex, multifaceted, and highly individual. These conversations also revealed that terminology is complicated and that a single word can be simultaneously beneficial and detrimental to the people to whom it is ascribed.

**Arguments for “Disability”**

“Disability” is an established term that is recognized by governmental structures that provide services and accommodations to those who need them. In this way, the label of disability is advantageous and essential for fuller participation in society. According to Susan Wendell, Definitions of disability officially accepted by government bureaucracies and social service agencies determine people’s legal and practical entitlement to many forms of assistance, where assistance is available. This may include economic help for such purposes as: education, training, and retraining; obtaining equipment, such as wheelchairs for basic mobility or computers for basic communications; modifying a home or vehicle to enable a person with a disability to use it; hiring assistants to help with bodily maintenance and household tasks; even obtaining medical supplies such as medications
and bandages. For people with disabilities who are unemployed, it includes the basic support to buy food and shelter. (Wendell 1996: 11)

The function of “disability” used in this way was recognized by many of the campers and parents. Melissa Napoli described the inevitability of the term disability during an interview with her and her daughter Sofia. Below is a partial transcription of the conversation:

Melissa (M): I mean, it’s just a word. But unfortunately it has a negative…

S: Of course it’s just a word. All words mean something really different, right? Like mad means angry, and sad means blue, and happy means you’re excited!

M: Of course it’s better than some other words also used to describe that category of individuals. So I mean, it’s just a necessary evil. It has its benefits because it can provide some additional supports for Sofia when she is categorized with that word and it can provide some not so great benefits because it is telling the individual that they are unable to keep up or do things that the general population can do. So it’s kind of a catch-22.

Within this context, “disability” becomes a double-edged sword where necessity is bound to designations of inadequacy.

Figure 4.1: Sofia Napoli playing the djembe during an evening jam session
While many parents and campers viewed the word “disability” as inescapable and misrepresentative, others were unconcerned with the term. For many, the word “disability” is not offensive, but merely describes the challenges that are a part of their everyday lives. According to Joseph Raschke, father of William,

My son, for his age is not where he should be. He has a genetic disorder and it affects him in ways that are noticeable and will have lasting effects of the rest of his life. The bottom line is, I don’t know that my son will ever move out of my house and live on his own. There are certainly derogatory words I won’t stand to have anyone use around me, but disability is not one of those. I consider it a fact of our situation.

I encountered several campers who shared this pragmatic viewpoint and even more who found the word “disability” preferable to more derogatory terms. When I asked 24-year-old Becky Kleinman how she felt about this designation, she responded, “I’m used to saying that word because it’s not offensive when you do… That’s better than saying the ‘r’ word.” It goes without saying that the “r” word, this lowest common denominator for self-identification, is offensive and inappropriate and, consequently, many of the campers, young adults, and parents view “disability” as a welcome alternative.

Perhaps more importantly, the majority of my interlocutors who supported the term “disability” did not find it offensive, because they did not feel as though it defined them. Twenty-four year-old Maegen Miller articulated this concept during our discussion about her experience in an integrated school system. She indicated that she liked the mainstream model

12 Here the “r” word references the outdated term “mental retardation” and the less formal, but equally offensive designation “retard.”
13 The term “integrated” refers to school programs in which people with intellectual difficulties have some classes in the special education or resource center and other classes with their mainstream neurotypical peers. The level of mainstreaming is determined by the comfort and developmental level of the individual student. For instance, while some of the campers I met participated in a few mainstream classes, such as art, gym, and social studies, other campers, like Maegen Miller and Darian Morneau, conducted all of their learning in the mainstream classroom with the help of a paraprofessional educator.
and when I asked her why, she answered,

I am proud of that because I showed people how smart I really am, and not to let my disability define who I am and who I want to be. It’s just a little part of me; there is so much more to me that people should know or could know if they ever talked to me or met me.

Maegen’s words reinforce the person-first paradigm that privileges the person who has Williams Syndrome over a Williams Syndrome person.\textsuperscript{14} Within this model, which was ubiquitous in the camp environment, the emphasis is placed upon the person over the “disability.” Viewed in this way, the term “disability” is not offensive because it is not the dominant characteristic defining the individual.

\textsuperscript{14} The variation in font used to emphasis the importance of person-first language is a technique that is used by Tom Kitwood in his book \textit{Dementia Reconsidered: The Person Comes First}, as well as by Michael Bakan in his article “Following Frank: Response–Ability and the Co-Creation of Culture in a Medical Ethnomusicology Program for Children on the Autism Spectrum.”

Figure 4.2: Maegen Miller and David Jaeger sharing a moment during a jam session
The sense of self-assurance that Maegen expressed was shared by many campers, and may have contributed to the sense that, as a term, “disability” is innocuous. This self-acceptance was most clearly expressed by 10-year-old Anja Kaneski during an interview with her and her mother Lisa. When I asked Lisa “What does it mean having a child like Anja and be a part of the Williams community?” and “What do you think about the term disability?” Anja asked if she could share her thoughts. What follows is a partial transcription of Anja and Lisa’s conversation:

Anja (A): Can I say it, mom?
Lisa (L): Sure.

A: I love being me. And I think that when I’m in the WS community, I love it... Someday I would love to be a normal kid, but I like this life. What? I’m just saying.

L: I think that’s awesome. And I think that is a very intriguing statement. When Anja got diagnosed she was still a baby—six weeks old. It is a learning experience as a parent to see how they affect everybody and to see how wonderful they are. Because, what is normal? They have these crazy abilities to do things that your average person can’t do.

A: And you know what? Guess what I can do? I can ride a bike with two wheels! No training wheels!

Disability: “It should be thrown out the window!”

While many people did not find the term disability offensive, a roughly equal number of parents, campers, young adults, and staff members felt that “dis-ability” was an inaccurate label for their experience with Williams Syndrome. These individuals maintained that the term masked their many abilities and instead preferred descriptors such as “differently abled,” “different attribute,” and “special needs.” Terry Monkaba expressed her view on the subject of terminology thusly:

I like “differently abled” better because they do have abilities, wonderful abilities in many areas. They are gifted in the way that they can approach people and make them feel at ease, but they struggle carrying that conversation to the next level. Things that would make perfect sense don’t make sense. To use my own son as an example, Benjamin has
been hit very hard in the fine motor area. [He] literally has never been able to learn how
to tie his shoes, has trouble buttoning shirts as a 20-year-old—these are real tough issues.
But he was able to sit down at a drum set and play it when he was 7—not bang it; he sat
down and rhythmically played it and just intuitively knew how to do it. That’s a
strength…Many of our kids have that, and it might not be playing the drums; it might be
public speaking or music of some sort, whether it’s piano, or drums, or voice. But those
strengths are strong enough that they are not disabled; they have plenty of abilities. So I
think that “differently abled” is a good way to talk about it.

Darian Packard, mother of Joelle, shares this viewpoint, and is outspoken about the importance
of replacing “disability” with a more ability-centered and accurate term:

I am definitely a parent who wants to change that. I believe that we aren’t born with a
disability; we’re born with different abilities, each and every one of us. And it’s not about
what we can’t do, but what we can do and to accentuate the strengths and support the
challenges…This one national speaker on inclusive education uses the word “attribute”; I
love that so much I use it. So whenever I refer to WS or I say “Joelle’s attribute is WS.” I
use that because it doesn’t define her, but it’s just a part of her. I also use the term
“different ability” [or] “intellectual difference”; just because a person is born with WS, or
Downs Syndrome, or autism doesn’t mean they can’t learn—they can. You just have to
lay out support tools that will work for them to access the curriculum.

Like many disability scholars who subscribe to the social model of disability, as a parent-
advocate, Darian believes that this shift in terminology will bring about changes in societal
perceptions of “disability” and, hopefully, lead to greater acceptance and accommodation.

Perhaps the strongest reaction I received to the term “disability” came from 28-year-old
Marin Lock. During our conversation, we began talking about “normalcy,” to which Marin
responded, “There is no normal; there never has been; there never will be.” I saw this as an
appropriate segue into a discussion about terminology and posed what had become the frequently
asked question, “What do you think about the term ‘disability’”?

“It should be thrown out the window,” she answered matter-of-factly.

“What would you prefer?” I asked.

“Ability. Cause ‘dis-’ means you can’t and ‘ability’ means you can. So ‘dis-’ should be
thrown out the window and ‘ability’ should stay as it is.”
“So you don’t think of Williams Syndrome as a disability?”

“Shoot, I think of Williams Syndrome as new adventures. You can adventure out and even though you’re scared you have so many people who have got your back. It’s crazy.”

Marin’s opinion was shared by other campers and parents, many of whom did not consider WS to be a “dis-ability” at all. As stated by Eric Pape, “Well, it’s not called ‘Williams disability.’”

**Learning to Listen**

As can be seen from the variety of perspectives offered throughout this chapter, perceptions of identity are complex and diverse. Though all of the campers and young adults I encountered had WS, and many of them shared similar attributes, they were all unique individuals. They did not all have the same experiences and thus did not all share the same values and viewpoints. Despite the variety of opinions regarding appropriate terminology, the members of the camp community unanimously privileged the campers’ abilities over that which they found challenging. This approach supports the age-old cliché, “Actions speak louder than words.”

However, words should not be dismissed so quickly. In addition to forming the way we conceptualize the world we live in, language turns mere phonemes and morphemes into actions; words influence behavior and activity; words are imbued with value judgments that directly correlate to how we view others and ourselves and, ultimately, to how we operate as individuals and as communities. Language is a human construction that is established through the humanly constructed institution of society. According to John Searle, philosopher of language and author of *The Construction of Social Reality*,

The solution to our puzzle is to see that language is precisely designed to be a self-identifying category of institutional facts. The child is brought up in a culture where she
learns to treat the sounds that come out of her own and others’ mouths as standing for, or meaning something, or representing something. (Searle 1995: 73)

The meaning of a word becomes a physical reality as it is spoken into existence. That is why disability, so often synonymous with non-ability, has also become associated with experiences of discrimination and disenfranchisement. That is why, throughout this thesis, I have chosen to view the Williams community as a neurodiverse group of individuals with diffabilities, rather than as an impaired class of people with disabilities.

It goes without saying that the solution to gaining equal rights, access to resources, and acceptance and accommodation from society is not as simple as exchanging one word for another. This kind of change requires a shift in perspective and a willingness to make room for those who are different. In the Preface to the English translation of Henri-Jacques Stiker’s book *A History of Disability*, David T. Mitchell quotes Stiker, stating, “The love of difference or the passion of similarity. The former—especially if it becomes socially contagious (through education, cultural action, political action)—leads to human life. The latter leads, in full-blown or latent form, to exploitation, repression, sacrifice, rejection” (Stiker 1999: viii). Building a more inclusive and accommodating society can only be accomplished if we are willing to view others through a lens of capability and to acknowledge that, if given the chance and proper tools, everyone has something to contribute. Solely shifting to a more accepting terminology will not guarantee all of these changes; however, language will be instrumental in providing a medium through which different voices can tell their stories and enrich our understanding of what it means to be human. These narratives will engender feelings of compassion, tolerance, and knowledge that we are all bound by the same thread of humanity. We therefore need to listen, and carefully. Listening alone is not enough, but it is an imperative first step towards the realization of a paradigm of social justice and inclusiveness to which all societies should aspire.
CONCLUSION

Throughout my time at Whispering Trails, parents, campers, and staff members repeatedly referred to camp as “the happiest place on Earth,” and the majority agreed that their time spent at Whispering Trails was the highlight of the entire year. Camp provides campers and parents with a pressure-free week of fun and new experiences and, more importantly, is essential to the health of the Williams community. While social media such as Facebook and Twitter and virtual interactions via Skype and FaceTime allow campers to stay connected over the course of the year, these technological tools are no replacement for the sense of understanding and belonging that is fostered through the creation of a physical community.

For campers, parents, and young adults, camp is far more than a support system; it is a family. According to another young adult, “I have friends here. I have no other way to explain it. Whenever I’m here, I’m home, and when I’m home, I feel safe cause I have all these WS brothers and sisters around me. Nobody in my life has ever given me that.” Thirty-four year-old Andrew Cobb echoed this sentiment, saying, “Being here is like being with family—home.” These feelings of belonging and family are not exclusive to the campers and parents, but are also shared by the camp staff members. Counselor and music therapy student Izzy Branch stated matter-of-factly,

It is the best place in the world because these people with Williams Syndrome are the most sharing, caring, comfortable…beautiful people I’ve ever met in my life… It’s indescribable. You feel so loved and accepted. With people with WS anything goes; they love you no matter what. It’s unconditional from the moment you meet them…The campers, parents, and friends you make here become your family.

Even as an ethnographer, a cultural outsider, I found this to be true. Though the subject of music dominated many of my conversations within the Williams community, camp members also shared stories of family, education, and personal experiences from within and outside of
camp. One day, while discussing the topic of family with Marin Lock, I expressed that I had always wanted lots of brothers and sisters. She simply smiled and responded, “Well, now you’ve got, like, 50 of them.”

Camp is a wonderful place; however, it is not representative of the everyday experience of individuals who have WS. Sadly, they are not constantly surrounded by people who share their experience, nor are they immersed in a safe environment built on the principles of accommodation and acceptance. The challenges that campers, parents, and young adults face on a daily basis are invisible at camp, yet that does not mean that they do not exist. While I have primarily focused on the positive elements and abilities of people who have WS, I do not wish to misrepresent the experiences of my interlocutors. Like all people, they undergo frequent hardships, and they encounter difficulties that many neurotypical individuals do not. Though most individuals with WS are, as Terry Monkaba described, “glass half-full” people, just like everyone else, their lives are a mixture of positive and negative moments.

Camp is not indicative of the majority of their lived experiences; however, that does not make it any less valuable. On the contrary, the positive, rejuvenating, and supportive atmosphere is vital for the sustenance of both the individuals and the Williams community. It is a place where musical expression is appreciated for its own sake, and not judged by neurotypical standards of musical excellence. Here, disability is seen through the lens of possibility and capability, and thus transformed into diffability. At camp, neurodiversity is cherished, accommodated, and celebrated. The support and respect given to every individual in the camp community is contingent not upon designed labels of ability or its absence, but upon humanity. Camp is a place where social change is cultivated through actions of acceptance and equality providing a model for the creation of a healthier, more diverse, and stable society.
APPENDIX A

HUMAN SUBJECTS APPROVAL

Office of the Vice President For Research
Human Subjects Committee
Tallahassee, Florida 32306-2742
(850) 644-8673 · FAX (850) 644-4392

APPROVAL MEMORANDUM

Date: 05/29/2013
To: [Redacted]
Address: [Redacted]
Dept.: MUSIC SCHOOL
From: Thomas L. Jacobson, Chair
Re: Use of Human Subjects in Research
   Making Music at Camp: Experience and Perspectives of Individuals with Williams Syndrome

The application that you submitted to this office in regard to the use of human subjects in the research proposal referenced above has been reviewed by the Human Subjects Committee at its meeting on 04/19/2013. Your project was approved by the Committee.

The Human Subjects Committee has not evaluated your proposal for scientific merit, except to weigh the risk to the human participants and the aspects of the proposal related to potential risk and benefit. This approval does not replace any departmental or other approvals which may be required.

If you submitted a proposed consent form with your application, the approved stamped consent form is attached to this approval notice. Only the stamped version of the consent form may be used in recruiting research subjects.

If the project has not been completed by 04/09/2014 you must request a renewal of approval for continuation of the project. As a courtesy, a renewal notice will be sent to you prior to your expiration date; however, it is your responsibility as the Principal Investigator to timely request renewal of your approval from the Committee.

You are advised that any change in protocol for this project must be reviewed and approved by the Committee prior to implementation of the proposed change in the protocol. A protocol change/amendment form is required to be submitted for approval by the Committee. In addition, federal regulations require that the Principal Investigator promptly report, in writing, any unanticipated problems or adverse events involving risks to research subjects or others.

By copy of this memorandum, the chairman of your department and/or your major professor is reminded that he/she is responsible for being informed concerning research projects involving human subjects in the department, and should review protocols as often as needed to insure that the project is being conducted in compliance with our institution and with DHHS regulations.

This institution has an Assurance on file with the Office for Human Research Protection. The Assurance Number is IRB00000446.

Cc: Michael Balkan <mbalkan@fsu.edu>, Advisor
   HSC No. 2013 10163
APPENDIX B

CONSENT FORMS

Verbal Child Assent Form (6-11)

Making Music at Camp: Experiences and Perspectives of Individuals with Williams Syndrome

To be read to by the researcher: Script for Child Assent (ages 6-11)

I am writing a report about how you and other campers make music and listen to music while at camp. I would like to watch you play music and talk to you about what you think about different kinds of music, what your favorite kind of music is, and how you feel about making music. Can I do that? If you say yes but then change your mind later, that is O.K., and that won’t have any effect on your other activities here at the camp. Your parents have said that it is O.K. with them if you do this.

I would also like to record the music you make and write down and record the talks we have about music and your activities here at camp. I may include the things you say in my final written report. You can tell me at any time if you do not want me to write something down that you say, or if you do not want me to include it in the final report.

Would you like to participate in this project?

I have been told that my parents (mom or dad) or guardian (the person who takes care of me) have said it’s okay for me to participate, if I want to, in a project about music at camp.

I know that I can stop any time I want to and it will be okay if I want to stop.

Name: _______________________________________________________

Verbal Child Assent Form (12-17)

Making Music at Camp: Experiences and Perspectives of Individuals with Williams Syndrome

To be read to by the researcher: Script for Child Assent (ages 12-17)

I would like you to participate in a project about making music at camp. I am writing a report about how you and other campers make music and listen to music while at camp. I would like to observe you and your friends making music and then talk to you about what you think about different kinds of music, including the types of music that you play and listen to.

I would also like to record you making music and write down and record the conversations we have about your experiences with music. I may want to include these conversations in my final written report. You can tell me at any time if you do not want me to include the things you say in my final report.

Would you like to participate in this project?

I have been told that my parents or guardian have said it’s okay for me to participate, if I want to, in this project about music at camp.

I know that I can stop any time I want to and it will be okay if I want to stop.

Name: _______________________________________________________

Name: _______________________________________________________
Adult Consent Form

You have been asked to participate in the ethnographic research study entitled “Making Music at Camp: Experience and Perspectives of Individuals with Williams Syndrome” conducted by Alex Carrico, a Master’s student at the College of Music at the Florida State University. By signing this form you are acknowledging that your participation in this project is voluntary and that you have the right to withdrawal from the study at any time.

The purpose of this research project is to observe the role of music at camps for individuals with Williams Syndrome and to better understand how individual campers experience this music. Additionally, this study is concerned with recognizing and emphasizing the musical and experiential abilities of the campers and is designed to allow campers to describe their experience and generate their own testimonies about what it means to be an individual with Williams Syndrome.

You are asked to participate in a thirty minute to one-hour video or audio-recorded interview in which you will be asked about your background, musical experience within the camp, and perceptions about music and personal identity. You are encouraged to give honest and thorough answers, but may refuse to respond to any questions with which you are uncomfortable. Above all, this study is designed to benefit you and the larger Williams Syndrome community; your protection and emotional health is the primary concern of the researcher.

There are no risks involved with this study and you will not be exposed to any potentially harmful physical or psychological situations. Though there are no foreseeable concrete benefits for you as a result of your participation in this project, there is a possibility that you will benefit from co-participation in musical activities with a trained musician from beyond your residential environment (i.e., the researcher) and also from experiencing the validation of your music making which comes from being the subject of the study.

By signing this form you are acknowledging that, in addition to an individual interview, your participation in musical and camp activities may be observed by the researcher at any time from August 4-16th, 2013. You or your family may request a copy of the notes made by the researcher during these activities or a copy of your interview, which will be available by June 1, 2014.

This study is being conducted with the permission and support of the Williams Syndrome Association and is intended to provide insight into the musical experience and worldview of individuals with Williams Syndrome. The results of this project will be shared with you and your family, with the Williams Syndrome Association, and with the larger academic community. You have the option of disclosing your identity or remaining anonymous. If you choose to remain anonymous, your participation in this project will remain confidential to the extent of the law.

If you have any questions or concerns about this research project or your rights as a participant, please contact the Institutional Review Board (IRB) at Florida State University, through the Human Subject’s Office (850) 644-8633.

Option 1
I have read and understand this consent form. My questions have been answered to my satisfaction, and I agree to participate in this study with full disclosure of my identity.

______________________________  ______________________
(Printed Name of Subject)          (Signature of Subject, or legal guardian if applicable)

______________________________  ______________________
(Signature of Researcher)          (Date)

Option 2

I have read and understand this consent form. My questions have been answered to my satisfaction, and I agree to participate in this study, but wish to remain anonymous. I understand that my information will remain confidential (available to the researcher only) to the extent of the law.

______________________________
(Printed Name of Subject)

______________________________
(Signature of Subject or legal guardian if applicable)

______________________________  (Date)
(Signature of Researcher)
Recording Consent

I hereby agree to have these conversations and musical activities recorded and made available to future researchers.

______________________________
(Printed Name of Subject)

______________________________
(Signature of Subject or legal guardian if applicable)

______________________________ (Date)
(Signature of Researcher)

I hereby agree to have these conversations and musical activities recorded, but never made available to future researchers.

______________________________
(Printed Name of Subject)

______________________________
(Signature of Subject or legal guardian if applicable)

______________________________ (Date)
(Signature of Researcher)
I hereby request that a copy of these recorded conversations and musical activities be made available for my personal/family use.

(Printed Name of Subject)

(Signature of Subject or legal guardian if applicable)

(Signature of Researcher)       (Date)
Parental Consent Form

My name is Alex Carrico and I am a Master's student in ethnomusicology at the Florida State University. I am in the process of beginning my Master's thesis work and am conducting research to explore the musical experience of individuals with Williams Syndrome within the summer camp environment. The purpose of this project is to examine how the musical and social experiences taking place within the Whispering Trails Camp shape your child’s personal development and worldview and how music-making contributes to his or her sense of individual and group identity.

During the session, I would like to observe your child’s participation in camp activities (both musical and non-musical) and to conduct a brief interview with your child in which I will ask about his or her favorite camp activities, musical interests and experiences, and the overall importance of music in his or her life. All interviews will be recorded with either an audio or video device unless otherwise specified by the interviewee. You are welcome and encouraged to be present during this time, but in the event that you are unable to observe your child’s interview, a camp staff member will be present to ensure the comfort and safety of your child. For campers ages six to eleven the interviews will be fifteen to thirty minutes in length, while I will ask campers ages twelve to seventeen to speak with me for thirty to sixty minutes.

There are no risks involved with this study and your child will not be exposed to any potentially harmful physical or psychological situations. Though there are no foreseeable concrete benefits for your child as a result of his or her participation in this project, there is a possibility that he or she will benefit from co-participation in musical activities with a trained musician from beyond his or her residential environments (i.e., the researcher) and also from experiencing the validation of his or her music making which comes from being the subject of the study. My primary goal is to gain individual perspectives about the role of music as an outlet for personal, social, and creative expression in your child’s life while ensuring that my presence does not detract from your child’s enjoyment of or participation in other camp activities.

This study is being conducted with the permission and support of the Williams Syndrome Association and is intended to provide insight into the musical experience and worldview of individuals with Williams Syndrome. The results of this project will be shared with you, your child, and your family, with the Williams Syndrome Association, and with the larger academic community. You have the option of requesting that your child remain anonymous, in which case his or her participation in this project will remain confidential to the extent of the law.

If you have any questions or concerns about this research project or your rights as a participant, please contact the Institutional Review Board (IRB) at Florida State University, through the Human Subject’s Office (850) 644-8633.

Option 1
I have read and understand this consent form. My questions have been answered to my satisfaction, and I agree to allow my child ______________________________ to participate in this study with full disclosure or his/her identity.

__________________________________________________  
(Printed Name of Guardian)

__________________________________________________  
(Signature of Guardian)

__________________________________________________  
(Signature of Researcher)  __________________
(Date)

Option 2

I have read and understand this consent form. My questions have been answered to my satisfaction, and I agree to allow my child ______________________________ to participate in this study, but request that he/she remain anonymous. I understand that his/her information will remain confidential (available to me and the researcher only) to the extent of the law.

__________________________________________________  
(Printed Name of Guardian)

__________________________________________________  
(Signature of Guardian)

__________________________________________________  
(Signature of Researcher)  __________________
(Date)
Recording Consent

I hereby agree to have my child’s conversations and musical activities recorded and made available to future researchers.

__________________________________________________
(Printed Name of Guardian)

__________________________________________________
(Signature of Guardian)

__________________________________________________
(Signature of Researcher)       (Date)

I hereby agree to have my child’s conversations and musical activities recorded, but never made available to future researchers.

__________________________________________________
(Printed Name of Guardian)

__________________________________________________
(Signature of Guardian)

__________________________________________________
(Signature of Researcher)       (Date)
I hereby request that a copy of my child’s recorded conversations and musical activities be made available for my personal/family use.

__________________________________________________
(Printed Name of Guardian)

__________________________________________________
(Signature of Guardian)

__________________________________________________    __________________
(Signature of Researcher)    (Date)
Parent/Guardian Participant Consent Form

My name is Alex Carrico and I am a Master's student in ethnomusicology at the Florida State University. I am in the process of beginning my Master's thesis work and am conducting research to explore the musical experience of individuals with Williams Syndrome within the summer camp environment. The purpose of this project is to examine how the musical and social experiences taking place within the Whispering Trails Camp shape your child’s personal development and worldview and how music-making contributes to his or her sense of individual and group identity.

In addition to observing your child’s participation in camp activities (both musical and non-musical) and conducting a brief interview with your child, I would like to interview you regarding your experiences within the Whispering Trails Camp and your perceptions about the role of music in your child’s development. The interview will be thirty to sixty minutes in length and will be recorded with either an audio or video device unless otherwise specified by you. Your participation in this study is entirely voluntary and if you agree to participate you are free to withdraw at any time with no repercussions for either you or your child.

There are no risks involved with this study and you will not be exposed to any potentially harmful physical or psychological situations. Though there are no foreseeable concrete benefits for you as a result of your participation in this project, sharing your perceptions and stories about your and your child’s musical experience may prove beneficial and affirming to your overall camp experience. My primary goal is to gain individual perspectives about the role of music as an outlet for personal, social, and creative expression in your and your child’s life while ensuring that my presence does not detract from your or your child’s enjoyment of or participation in other camp activities.

This study is being conducted with the permission and support of the Williams Syndrome Association and is intended to provide insight into the musical experience and worldview of individuals with Williams Syndrome. The results of this project will be shared with you, with the Williams Syndrome Association, and with the larger academic community. You have the option of remaining anonymous, in which case your participation in this project will remain confidential to the extent of the law.

If you have any questions or concerns about this research project or your rights as a participant, please contact the Institutional Review Board (IRB) at Florida State University, through the Human Subject’s Office (850) 644-8633.

Option 1
I have read and understand this consent form. My questions have been answered to my satisfaction, and I agree to participate in this study with full disclosure of my identity.

(Printed Name of Subject)

(Signature of Subject)

(Signature of Researcher) (Date)

Option 2

I have read and understand this consent form. My questions have been answered to my satisfaction, and I agree to participate in this study, but wish to remain anonymous. I understand that my information will remain confidential (available to the researcher only) to the extent of the law.

(Printed Name of Subject)

(Signature of Subject)

(Signature of Researcher) (Date)
Recording Consent

I hereby agree to have these conversations and musical activities recorded and made available to future researchers.

__________________________________________________
(Printed Name of Subject)

__________________________________________________
(Signature of Subject) ___________________________

__________________________________________________
(Signature of Researcher) ________________________
(Date)

I hereby agree to have these conversations and musical activities recorded, but never made available to future researchers.

__________________________________________________
(Printed Name of Subject)

__________________________________________________
(Signature of Subject) ___________________________

__________________________________________________
(Signature of Researcher) ________________________
(Date)
I hereby request that a copy of these recorded conversations and musical activities be made available for my personal/family use.

__________________________________________________
(Printed Name of Subject)

__________________________________________________
(Signature of Subject)

__________________________________________________ __________________
(Signature of Researcher)       (Date)
BIBLIOGRAPHY


BIOGRAPHICAL SKETCH

Alexandria H. Carrico was born in Middletown, Ohio and raised in Morganton, North Carolina. She studied music at Furman University, graduating Summa Cum Laude in 2008 with a B.M. in Vocal Performance. Honors awarded to her include being on the Dean’s List throughout her undergraduate career and acceptance into the honor societies Phi Eta Sigma, Pi Kappa Lambda, and Phi Beta Kappa. Her research interests include music and disability, traditional Irish music, the folksong tradition of Southern Appalachia, and gender studies. She enjoys singing with the Tallahassee Irish band, Sligo Line, playing soccer, and hiking.