Neurodiversity and the Ethnomusicology of Autism

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Abstract

In this article, I explore how musical experience and an emergent ethnomusicology of autism can provide both people with autism and their neurotypical counterparts with opportunities to collectively live, model, and promote an epistemology of autism acceptance, in turn challenging and subverting the dominant paradigm of autism as tragedy, disease, disability, disorder, and impairment. I demonstrate how musical performance, ethnographic method, and cultural relativism, the epistemological cornerstones of ethnomusicological endeavor, may be combined toward efficacious ends in the struggle for autistic rights, agency, empowerment, and self-determination. My principal argument is that ethnomusicologically grounded ways of knowing autism, and of knowing about autism, have great potential to expand and enlighten autism-related discourses, as well as foster better self-regard, relationships, and levels of mutual understanding between autistic people and their non-autistic Others. Building from my own ethnomusicological work with the Artism Ensemble, a music performance collective featuring children on the autism spectrum, their co-participating parents, and professional musicians of diverse musical and cultural background, I interact with quoted passages from College Music Society publications of the past half century to stimulate new avenues of thought and action concerning how engagement with music can motivate advocacy, activism, and progressive social change. I am interested in making music make a difference, and I want to motivate others to take on that challenge as well.

When the...actual performance is seen to be unlike that suggested by the label, initial biases have been shown to be overcome.


Introduction

This is an article about epistemologies, about ways of knowing and knowing about. It is, beyond that, an article about the intellectual, musical, musicological, sociocultural, practical, and ethical implications and ramifications of epistemologies, especially ones that articulate at the crosshairs of ethnomusicological inquiry, public conceptions and perceptions of autism, and the theoretical and methodological contentions and convergences of autism science, disability studies, the anthropology of autism, and the autistic self-advocacy and neurodiversity movements. Neurodiversity has been defined by Nick Walker as “the understanding of neurological variation as a natural form of human diversity, subject to the same societal dynamics as other forms of diversity,” such as race, gender, ethnicity, and sexual orientation (Walker 2012, 233). The premise of neurodiversity is central to this article, relating to both conceptualizations of autism and possibilities for the advancement of progressive social change in this arena.

Cutting to the chase, my principal position is to assert that ethnomusicological, ethnographically grounded ways of knowing autism, and of knowing about autism, have great potential to expand and enlighten autism-related discourses and, in turn, to foster new and better self-regard, relationships, and levels of mutual understanding between autistic people and their non-autistic Others. I suggest that music making and musical performance
within an applied ethnomusicology context can help to subvert, radicalize, and debunk a host of destructive myths and assumptions about autistic people and autistic experience that have metastasized in the annals of medical-scientific research publications on autism and spread outward from there during the seven decades since the term autism was first introduced in published form in the early 1940s by Leo Kanner (1943).

An often dehumanizing and objectifying epistemology through which to perceive autistic people has been promulgated and granted scientific authority historically. Central to this epistemology is a pervasive fixation on negations: on deficit, disability, disorder, and impairment. For one of a myriad of possible examples, we might turn to the “Autism Fact Sheet” of the U.S. National Institutes of Health’s National Institute of Neurological Disorders and Stroke (NINDS) website, which opens with the statement that “Autism spectrum disorder (ASD) is a range of complex neurodevelopmental disorders, characterized by social impairments, communication difficulties, and restricted, repetitive, and stereotyped patterns of behavior” (NINDS 2013 [accessed 25 July 2013]).

Immediately, we have been cast into the realm of negation through this ostensibly neutral and factual listing of the ubiquitous “triad of impairments” in autism: impaired social interaction, impaired communication, and impaired behavior. In this triadic rubric, people with ASD are defined not by what they can do but by what they cannot. They are officially characterized in terms of their deficits, by what they are not rather than by who they are.

This foundational point of epistemological departure spans outward and then back inward to anywhere and to everywhere, from ASD medical treatment programs and therapeutic interventions to legislative policy and social justice debates. It is ubiquitous, but it is also deeply problematic and in need of fundamental change.

“I’m certainly not saying we should lose sight of the need to work on deficits,” states the autistic author, advocate, celebrity, and livestock scientist Temple Grandin. “But ... the focus on deficits is so intense and so automatic that people lose sight of the strengths [of autistic people] .... If even the experts can’t stop thinking about what’s wrong instead of what could be better, how can anyone expect the families who are dealing with autism on a daily basis to think any differently?” (Grandin and Panek 2013, 180-181).

Grandin’s remarks point to how a negation-driven epistemology of autism reaches from the medical-scientific establishment outward toward people with autism, their families and loved ones, and society at large. They affirm anthropologist Olga Solomon’s contention that there has been “a remarkable silence, an absence of discourse about hope in biomedicine’s views on autism ....” (Solomon 2010a, 253). This hope-deprived landscape cannot help but have deleterious effects on quality of life and opportunities for autistic people. Penni Winter, a contributor to the landmark volume Loud Hands: Autistic People, Speaking (Bascom 2012a), which was co-authored principally by autistic authors associated with the autistic self-advocacy movement (as represented by organizations such as the Autistic Self Advocacy Network and Autism Network International), offers an incisive critique of the rhetoric of tragedy and hopelessness that dominates autism discourses:

"Our Autism is called a 'tragedy' or even, by some parent groups, 'the enemy' to be fought at all costs, and the [apparent] increase in our numbers is referred to as an 'epidemic,' as if Autism were some dread disease. We're said to 'ruin' our parents' lives and break up marriages, and we get discussed in terms of the 'burden' we are on our families, the 'difficulty' we cause others. What we might feel or think or want is hardly even asked—because, oh yeah, that's right, we don't have feelings or needs. It's the parents and families who are focused on, because they are deemed to be the ones that 'matter', not the individuals with Autism. (Winter 2012, 119—square brackets in original)

Twelve-year old Maya C. (a pseudonym), with whom I have been performing music for the past several years as a fellow member of the Artism Ensemble, has an ASD diagnosis. As she said to me during a July 2013 interview
in Tallahassee, Florida:

Who says autism is a bad thing? ... Autism isn’t cholera; it isn’t some disease you can just cure. It’s just there. You don’t need to be aware of it; you just have to accept that it’s there .... And there is no cure. There really isn’t. It’s just there, wound into your personality.

For Maya C. and Penni Winter, as for an ever growing number of autistic people who are speaking out and demanding to be heard regarding what they want, need, and value, the call for an alternative epistemology of autism and ASD that promotes autism acceptance rather than autism awareness is ringing out loud and clear. This is a call for ways of knowing and knowing about autism that grants honor and respect to the integrity of autistic personhood rather than reifying autistic people in terms of their purported deficits and the resultant “tragedies” of their lives.

“It starts with the basic, foundational idea that there is nothing wrong with us,” Julia Bascom asserts in her foreword to Loud Hands. “We are fine. We are complete, complex, human beings leading rich and meaningful existences and deserving dignity, respect, human rights, and the primary voice in the conversation about us” (Bascom 2012b, 10).

In this article, I explore how musical experience and an emergent ethnomusicology of autism can contribute to fostering an epistemology of autism acceptance, in turn challenging and subverting the dominant paradigm of autism as tragedy, disease, disability, disorder, and impairment. I will show how musical performance, ethnographic method, and cultural relativism, the epistemological cornerstones of ethnomusicological endeavor, may be combined toward efficacious ends in the struggle for autistic rights, agency, empowerment, and self-determination. Ethnomusicology, through its theoretical groundings, its methods and aspirations, its historical triumphs and failures, has value beyond itself in the broader lessons it can teach about comprehending and engaging with human diversity in all its forms.

Joseph Straus, among others, has made the claim that autism is a culture, not a disease or disorder. “The term autism,” Straus writes, “is a medical term with a strongly stigmatizing impact” (Straus 2013, 467). Yet when engaged from a cultural rather than a medical perspective, that stigmatizing impact is largely thwarted, so that autism may be seen alternatively as something “constructed by autistic people themselves through the culture they produce (including writing, art, and music) ....” (Straus 2013, 466). This affirming, cultural epistemology of autism, in contrast to its largely negating medical counterpart, offers the opportunity “to reclaim autism as a term of cultural identification and pride” and “to have autism suggest not a defect but a distinctive and valuable style of thinking and imagining—a vibrant and interesting way of being in the world” (Straus 2013, 467).

An autism-as-culture framework places autism firmly within the purview of cultural analysis fields such as anthropology, disability studies, and ethnomusicology. Here, with particular reference to my own work in the area of the ethnomusicology of autism over the past decade, and especially my involvement with the aforementioned Artism Ensemble since 2011, I address some of the ways in which an ethnomusicology of autism has the potential to expand the scope of its host discipline while using the foundations of that discipline to inspire widespread change in societal attitudes toward autism and autistic people. In structuring the essay, I frame my discussion around a series of quotations drawn from College Music Society publications of roughly the past half century, which specifically date from the years 1962, 1972, 1982, 1992, 2002, and 2013, respectively. It is my hope that this article will stimulate new avenues of thought and action concerning how making, studying, thinking about, researching, and drawing inspiration from music can motivate advocacy, activism, and progressive social change. I am interested in making music make a difference, and I want to motivate others to take on that challenge as well.
Alternate Tunings

In 1962, College Music Symposium published its first snapshot-of-the-discipline piece on the field of ethnomusicology, an article by Paul Revitt in Volume 2 of the journal entitled "The Institute of Ethnomusicology at UCLA." This evocative and affirming essay, a kind of travelogue in which we are invited to follow along with Revitt as he explores the microcosm of world music diversity that was the UCLA Institute in the early 1960s, paints a vivid and rather Utopian portrait of the Institute's mélange of sounds, sights, and colorful characters (Institute founder and director Mantle Hood most of all), replete with the tone of exoticism fascination that was the tenor of the age where accounts of matters ethnomusicological and world musical were concerned.

In describing the process of training undertaken by graduate students at the Institute, Revitt precisely captures the integral connection between the epistemological priorities of cultural relativism and the methodological challenges and requirements of ethnomusicological practice at this time, all of which had come to be encompassed by Hood's concept of "bi-musicality" (Hood 1960). While not invoking that term specifically, Revitt implicitly characterizes one of the key challenges of acquiring bi-musical competence: "unlearning." He writes:

Accomplished in [Western] musicianship (especially ear training), in basic research methods, and in techniques of transcription, a student is equipped with the basic skills needed to comprehend a foreign musical idiom. Yet, a thoroughly trained musician in the western tradition has some "unlearning" to do .... it is too easy to repeat the mistake of many nineteenth-century analysts who used the diatonic and chromatic systems as the basis of comparison and criticized the rest of the world as being out of tune. (Revitt 1962, 40-41)

Ethnomusicologists have indeed learned not to make that mistake anymore, thanks not just to Hood and his contemporaries, but to some of the very 19th-century analysts to whom Revitt alludes, most notably Alexander J. Ellis. It may be suggested that Ellis's seminal article "On the Musical Scales of Various Nations" (Ellis 1885; see also Stock 2007) went farther than any publication before it or since in employing the diatonic/chromatic system as a basis of comparison against which to measure the rest of the world, not so much to criticize it for being out of tune as to objectively and scientifically validate the widely bought-into theory that Western European musical culture sat atop the hierarchy of evolutionary development where music was concerned (and, by extension, as far as most everything else was concerned as well). All other cultures fell at various rungs below on the evolutionary ladder of being: Chinese, Indian, and Japanese on the higher rungs, for example, African and Native American far down below.

Ellis's experiment in Social Darwinist comparative musicology was thorough and methodical. It was good science aimed at supporting his hypothesis that the relative measurable degrees of similarity between specific "exotic" and "primitive" pitch systems of other music traditions (measured using the cents system) and their perfect, natural, Western equal-tempered system counterpart should logically reveal evolutionary stages from the most primitive to the most advanced: the closer a foreign pitch system was to the standard Western one, the more advanced the culture; the more distant it was, the more primitive the culture.

A simple and elegant theory, albeit a totally wrongheaded one. But Ellis's saving grace as a scientist of considerable integrity was that he acknowledged that fact. He admitted he was wrong. As he writes in the final paragraph of the article, following forty-two meticulously wrought pages of scalar analysis reproduced in the smallest of print, "The final conclusion is that the Musical Scale is not one, not 'natural,' nor even founded necessarily on the laws of the constitution of musical sound, so beautifully worked out by Helmholtz, but very diverse, very artificial, and very capricious" (Ellis 1885, 526). And from this implicit admission of the error of his original hypothesis, of the disjunction between his theory and his scientifically deduced findings, was paradoxically born the cornerstone epistemological foundation of ethnomusicology: cultural relativism with regards
to music.

The implicit musical relativism pointed to by Ellis’s article established that no system of pitch organization—or anything else musical or musicultural (Bakan 2012, 10)—determines the superiority or inferiority of one musical system, culture, or tradition over another. Rather, each is uniquely suited and respondent to the specific contextual and ecological conditions of its emergence, sustenance, and transformation. Wherever in the world music is made and listened to—and that is everywhere—it reflects, embodies, and informs the making and living of culture. And in every case, sound and culture intersect through music (whether it is known by such a term) at the level of meaning: music makes meaning, and meaning makes music.

The entire history of ethnomusicology, right up to the present moment, could be written from the perspective of this epistemological perspective, notwithstanding the plethora of economic, ideological, advocacy-driven, postmodern, race/class/gender-based, neo-Marxist, reflexive, and even neo-evolutionist and neo-comparative vantage points that have been levied along the way, since all of these, and many more as well, may ultimately be said to have their grounding in at least a rudimentary adherence to relativism. We have moved beyond claims that certain groups of people are musically or culturally superior or inferior to others, or that certain groups of people are inherently more primitive or more advanced than others. This is an achievement of ethnomusicology, hard won and of which we can rightly be proud despite our past and present failings and shortcomings as a discipline. It is also an achievement that we might hold up as a model suited for epistemological emulation by the denizens of other disciplines, perhaps most urgently to those in medical and behavioral science fields who engage in research and clinical practice related to neurodevelopmental and cognitive conditions of difference such as autism.

**Autism**

The Centers for Disease Control and Prevention (CDC) estimates that approximately one out of every 68 children in the United States is affected by an ASD, or autism spectrum disorder. The rate of prevalence is much higher among boys than girls, and the overall rate of ASD (aka ASC, or autism spectrum condition, a preferable though less widely used designation) has risen sharply in recent decades. For example, as recently as the year 2000 the CDC estimate of rate of incidence was just one in 150 (CDC 2014).

Autism is classified medically as a neurodevelopmental disorder with an early childhood onset and a pervasive lifelong course; its scope of impact is both biological and social. Key criteria for diagnosis include “delays and atypicalities in reciprocal social interaction; impaired development of language and communication skills; and highly circumscribed, stereotypic behaviors and interests” (Sirota 2010, 94; cf. American Psychiatric Association 2000 and 2013).

Autism is conceptualized as “a spectrum disorder that includes a broad range of manifestations,” and people diagnosed with autism disorder or with related spectrum conditions such as Asperger’s syndrome (Asperger’s disorder) and PDD-NOS (pervasive developmental disorder—not otherwise specified) “span a wide continuum and may demonstrate functional capacities that range from profoundly limited to extraordinarily gifted,” with the result that rather than “conforming to a narrowly typecast profile, individuals diagnosed with autism exhibit a cline of expressive and receptive language and communicative skills” (Sirota 2010, 94).

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

Such negating, qualified recognition both fuels and feeds off of the suppositions of a “biomedical community that views disability as a deficit and people with disabilities as individuals who need to be ‘fixed’ (Riouxf 1994)” (Bagatell 2010, 33). This deficit-premised, medical-scientific epistemology of disability largely replicates the out-of-tune vs. in-tune dichotomy advanced by early comparative musicologists and critiqued by Revitt. Here, though, normative conceptions of personhood—physical, cognitive, developmental, social—substitute for the diatonic and chromatic pitch systems as epistemological reifications of the acceptable, the desirable, or the good. The “rest of the world”—that is, the people diagnosed and labeled as being somehow deficient in their physical attributes, their cognitive faculties, their meeting of ostensibly essential developmental milestones—are here either criticized as being out of tune or, worse, dismissed as so hopefully out of tune as to be beyond remediation altogether.

In the former case, regard for and attention to the disabled individual is reduced almost exclusively to fostering and measuring “improvements,” be these in areas of behavioral, social, intellectual, or physical movement toward the normative (and assumed superior) standards. As for the most deplorably disabled, the most “out of tune” (Revitt) and most “categorically ... less human than others” (Butler) among us, medical, clinical, and therapeutic efforts essentially become a form of palliative care, with neither expectations nor openness to possibilities of creativity, agency, meaningful cultural contribution, or a viable life granted to the “severely disabled” person.

From such an epistemological position, then, it is, again, inability, lack, and loss, not ability, endowment, and gain, which are imposed from without as the cornerstones of a disability identity: it is not who you are, but what you are not, that makes you the way people think you to be. While the particulars and contingencies of autism are distinct from those of any other so-called disorder or disability, and while it is those particulars and contingencies that are my primary concern here, pushing back against this larger template of disability as absence rather than presence, deficit rather than diversity, is central to the argument of the present essay. For this reason, I draw extensively on scholarly positions and activist priorities of the field of disability studies at large in order to engage critically with the discursive and ideological tenets of “autism.”

**Concept Formation, Categorization, and Mental Mischief**

Following from the foregoing discussion, one may draw a historiographical parallel between “non-Western music” and “dis-abled people”: epistemologically speaking, both have been cyphers in the absence of the negating prefixes used historically to categorize and marginalize them. By extension, autistic people, in this context understood as a neurodevelopmental subcategory of the dis-abled population, have been defined mainly in terms of what they lack, what and who they are not relative to their neurotypical counterparts. More specifically, the perceived ontological condition of people with autism, at least since the 1970s, has been anchored to the aforementioned autistic triad of impairments: social, communicative, and behavioral (NINDS 2013; Rutter 2013, 1750-51).  

Notwithstanding the fact that people on the autism spectrum often do have distinctive (and, it should be added, highly diverse) interests, modes of behavior, and interactional and communicative styles and preferences, to
calcify these alternate modes of cognition, behavior, and affect under the repressive and constricting banner of "impairments" is largely inaccurate, if not egregiously inhumane. The term impairment connotes "a state of being diminished, weakened, or damaged, especially mentally or physically" (dictionary.com). Most autistic self-advocates do not regard their autism as a form of impairment. It is, instead, an integral part of who they are, of their core identity. Being autistic brings challenges and obstacles, certainly, but it also brings special qualities of intelligence, empathy, compassion, and creativity. To the extent that they accept the designation of "disabled" that is linked to them, they propose, in the words of Autistic Self Advocacy Network (ASAN) founder and president Ari Ne’eman, that “we should in every instance consider the fact that it is often the social barriers rather than disability itself that pose the problems we face” (Ne’eman 2012, 93-94) and contend that “we should target our efforts toward the real challenges we face, rather than towards a broader, nebulous concept of ‘curing’ autism that is offensive to many of the people that it aims to benefit” (Ne’eman 2012, 93).

Fundamentally, Ne’eman and other autistic self-advocates call for autism acceptance, as opposed to “autism awareness” (the latter construct, associated with organizations like Autism Speaks, is actually regarded as offensive by most autistic self-advocates). They decry neurotypical intolerance, bigotry, ignorance, fear, and essentialism, as well as autism normalization/cure/eradication-directed initiatives, as the root causes of the overwhelming majority of impairing or disabling conditions they face. As Jim Sinclair, the founder and president of Autism Network International, famously wrote in his seminal autistic self-advocacy essay “Don’t Mourn for Us,” which was originally published in 1993,

> Autism isn’t something a person has, or a “shell” that a person is trapped inside. There’s no normal child [or adult] hidden behind the autism. Autism is a way of being. It is pervasive; it colors every experience, every sensation, perception, thought, emotion, and encounter, every aspect of existence. It is not possible to separate the autism from the person—and if it were possible, the person you’d have left would not be the same person you started with.

This is important, so take a moment to consider it: Autism is a way of being. It is not possible to separate the person from the autism.
Therefore, when parents say,

I wish my child did not have autism,
What they’re really saying is,
I wish the autistic child I have did not exist, and I had a different (non-autistic) child instead.

Read that again. This is what we hear when you mourn over our existence. This is what we hear when you pray for a cure. This is what we know, when you tell us of your fondest hopes and dreams for us: that your greatest wish is that one day we will cease to be, and strangers you can love will move in behind our faces. (Sinclair 2012[1993], 16-17)

Autism, as concept, has formed historically in ways that have become essentially inseparable from tropes of autism as tragedy, autism as impairment, autism as disorder, autism as a “mask” revealing the “real” (aka “normal”) person behind it, autism as an enemy to be driven out, cured, eradicated. And all of this has happened largely devoid of input from autistic people: “we who are the targets of this discussion have not been consulted,” writes Ne’eman. “Sadly, the traditional autism community has been driven by a set of priorities different from our own. Led almost exclusively by those not on the autism spectrum, it has made harmful decisions without our input” (Ne’eman 2012, 88).

This problematic situation speaks to generic issues involved in the formation, appropriation, and representation of concepts generally. Writing on the emergent discipline of sociomusicology in an article published by the College
Music Symposium in 1982, Barbara Lundquist astutely observed that

The categorization involved in concept formation is a necessary cognitive operation. However, categorization becomes inaccurate to the extent that values are placed on the categories as if the values were indigenous to them. Values applied to categories or concepts are, in fact, affect "leaks" in a cognitive process. The valuing is appropriate. The mental mischief caused as a result of treating the values as if they were indigenous to the concept is inappropriate. (Lundquist 1982)

The concept of "autism" is a case in point. The categorization of people as "autistic" is inaccurate to the extent that it projects neurotypical values such as normalization, cure, and eradication of autism as self-evident and implicitly indigenous to the category of autism itself. The result: inappropriate "mental mischief" by means of which, according to Julia Bascom, autistic difference is cast by others, and ultimately by many autistic people themselves as well, "in terms of an absence of neurotypicality, not as the presence of another equally valid way of being. We wind up internalizing a lot of hateful, damaging, and inaccurate things about ourselves, and that makes it harder to know who we really are or what we really can and cannot do ... autism, for all its diversity, isn't complicated or scary or hard—it just is .... Autistic brains are different from non-autistic brains—not better or worse, just different. Autistic voices, similarly, can take different forms or styles or express different things through different means than non-autistic voices. These facts are simple and neutral, but regularly obscured and overridden by cultural scripts and fallacies demanding broken, voiceless not-people stranded by huge chasms from the rest of the world in place of everyday autistics" (Bascom 2012b, 8 and 10).

Not Non-Western

The autistic triad of impairments, which forms such a foundational component of most scientific conceptions and public perceptions of autism and the autism spectrum, offers a good example of the on-the-ground effects of epistemological hegemony. In musical metaphoric terms, a triad of impairments suggests an extreme form of dissonance, an abject and chronic state of being out of tune with the rest of the world, an absence of capacity for harmonious relations with one's interlocutors that prefigures the impossibility of satisfactory resolution and the inevitability of anything but negating constructs of identity: non-communicative, asocial, deficient in imagination, limited by restricted interests and repetitive patterns of behavior. To presume such dissonance and discord in endeavoring to know autistic people and to know about autism is a fraught endeavor, neither accurate nor in the end productive.

Defining things in terms of what they are not and what they lack, rather than in terms of what they are and what they have, has been a dominant trope of ethnomusicology's troubled history as well. For decades, musics and musicians of foreign cultures were assigned a priori inferior status positions relative to their Western counterparts by early ethnomusicologists and their comparative musicologist forebears. The hallmark features of Western music—harmony, counterpoint, compositional development, polyphonic stratification, "complexity" in general—were put forward as the quintessential exemplars of advanced music and musical culture, against which all others were to be judged and against which all others were almost inevitably found wanting. In comparative terms, the musics of other cultures were defined largely by their lacunae: for all its melodic and rhythmic richness and complexity, Indian music lacked harmony; for all its polyrhythmic intricacy and vitality, West African music lacked counterpoint and development; for all its polyphonic layering, Javanese gamelan music lacked both harmonic organization and contrapuntal coherence.

The ability to move beyond this type of unilateral, limited thinking and to embrace the more relativistic views of musical diversity that are for the most part ubiquitous among contemporary ethnomusicologists has been a positive mark of distinction on the journey forward. This reformed view relies on two underlying epistemological premises: first, that there are many ways to be musically advanced and complex, not just those that are defined
by the traditional Western canon; and second, that complexity, development, and the like are not the sole measures of value through which musical systems make sense and acquire cultural meaning and usefulness anyhow: why would a nomadic hunter-gatherer society have been inspired to develop an institution like the symphony orchestra or an instrument like the pipe organ? That would not have made sense and would have been entirely impractical, after all.

As our epistemologies of musicultural value have been transformed in ethnomusicology, so too have our discursive strategies of accounting for them. We have largely transformed our lexicon from a deficit-centric, comparative one to an attribute-focused, ethnographic one. We look at what there is, we describe what we find, and we attempt to make sense of the meaning and value of it all in a contextually informed and context-sensitive way. The emphasis on what is over what is not is of crucial importance and has become a point of critical reflection and theory-building for ethnomusicologists. The following passage from an article by Dale Olsen in the May 1992 issue of the College Music Society Newsletter offers an example:

Many Music Departments and Schools of Music in the United States have increasingly been expanding their curricula by developing ensembles, courses, and even programs that emphasize non-Western musics. Thankfully, to my knowledge no such emphases have been officially termed “non-Western”—to do so would be to divide the world into two unequally-proportioned parts meaning, essentially, “us” and “them.” (Olsen 1992).

A similar recognition of the need for progress away from divisive, hierarchical dichotomies is sorely needed relative to autism, where deficit rather than attribute, absence rather than presence, still rules the day in mainstream scientific and public discourses. Implicit in Olsen’s comments is the realization that in us/them dyadic formulations, the “us” unit is typically assumed to be superior, more advanced, more normal, more important and essential, than the “them” unit, which is deemed inferior and marginal by comparison. Recognition of difference is a fine thing, and indeed a necessary one, but as soon as difference is equated with deficit—be that musical, social, intellectual, or of any other type—the epistemological stakes attendant to the basic human rights and dignities of classified individuals and groups on all sides of the divide, and to those deemed to be at the short end of the stick especially, are potentially devastating.

Aided by the core tenet of a relativistic purview, ethnomusicology has for the most part achieved extrication from the limiting and distorted forms of thinking that historically cast certain individuals, groups, and peoples as more or less “advanced” and “primitive” than others. It also has extricated itself from equally twisted epistemological constructs that historically relegated the entire range of global musicultural diversity beyond a small canonical strip of Euro-American “art music” to the margins of “non-ness,” instead of more appropriately recognizing and appreciating each tradition of music in the world for being what it is mainly from the vantage point of its makers and experiencers (e.g., listeners, consumers, and patrons).

It would be egregiously naïve to suggest that such epistemological ruptures and re-castings have been fully successful in ethnomusicology, or that each does not open its own proverbial can of worms (What is a tradition? Which music makers? Which consumers? What constitutes music making and music consumption?). Yet in relative terms, the core regard for individual and cultural creativity, personal and social agency, and attention to life as experienced by those who live it that ethnographic relativism has rendered normative in fields like ethnomusicology puts us in a good position to feel pressed not to emulate methodologies and value systems centered in scientific reductionism, but rather to motivate our peers and colleagues in the medical and behavioral science fields to perhaps learn a thing or two from us instead.

Choosing Diversity
"The traditional misunderstanding of people with autism as somehow fundamentally asocial, in their own world and locked away from culture and interaction," is just that, a misunderstanding, asserts the anthropologist and comparative human development scholar Elizabeth Fein (2012, 31). Supporting this claim with references to a range of recent research studies that collectively paint a very different and more affirmative portrait of autistic personhood, Fein explains that “autism in no way precludes a rich and complex engagement with the social and interpersonal world, though the nature of this engagement may often be confusing and unpredictable [to non-autistics].” She continues, “The interaction between autistic individuals and their social surroundings is a bi-directional process of influence, in which social practices influence autistic individuals while the characteristic needs, behaviors, and communicative styles of those individuals also shape the communicative practice of their surroundings” (Fein 2012, 31).

But achievement of that bi-directional process of influence and communication demands support, tolerance, and acceptance of autistic people and their ways of being on the part of the non-autistic majority as necessary but not sufficient conditions of progress. As individuals and as a society, we need to choose to embrace autism as an integral and valuable aspect of human neurodiversity. Moreover, we need to commit to making bi-directional processes of influence and communication—truly reciprocal and dialectical ones—our realities, and we need to actively work at ensuring the establishment and sustainability of these realities.

Robert Labaree, writing in Volume 53 of College Music Symposium in 2013, hits on precisely this point in his article “The Global DJ Project and the Blank Canvas: World Music, Memory and Meaning,” not in relation to autism or neurodiversity, but rather to the efficacious bridging of historical and cultural difference that inevitably attends to encounters with unfamiliar musics in the panoply of world music diversity. Diversity, writes Labaree, “is not simply something which happens to us, it is also increasingly something we choose on our own ... working across historical and cultural distances to parse the networks of meaning imbedded in any human creation is a reflexive process, a two-way street where there are no all-powerful agents of influence and no passive recipients.”

The same is true for working across the neurophysiological and cognitive distances that have too often stood as barriers blocking the communicative, social, imaginative, and cultural pathways of people with and without autism. Music can serve as an important pathway toward such bridging of distance and removal of barriers. The Artism Music Project is a case in point.

Artism and Autism, Ethnomusicology and Epistemology

Paralleling new epistemological directions in the anthropology of autism described by Olga Solomon and Nancy Bagatell, but from within a specifically musical context, the Artism Music Project constitutes a form of “movement away from dominant biomedical discourses that focus largely on symptoms to a more phenomenological and ethnographic stance that addresses experiences of living with autism” (Solomon and Bagatell 2010, 1). This is a stance that assumes autistic ability and competence rather than symptomatizing autistic disability and inability; that interprets autistic modes of communicating, socializing, and musicking as inherently in tune rather than out of tune; and that looks at and nurtures what is already present and right rather than seeking to establish what is missing and wrong. Such a stance effects an epistemological shift from autism awareness to autism acceptance, and from thinking of autistic people as “abnormal” to thinking of them as perfectly human, just differently so.

ARTISM is an acronym for “Autism: Responding Together In Sound and Movement.” The Artism Music Project was launched in Tallahassee, Florida, in January 2011, and remains active currently. It represents an extension and outgrowth of its predecessor, the Music-Play Project (Bakan et al. 2008a, 2008b; Koen et al. 2008; Bakan 2009), which emerged and developed out of collaboration between researchers, musicians, and clinicians associated with the College of Music, Center for Autism and Related Disabilities, Autism Institute, and College of
Medicine at Florida State University. Since its founding, Artism has been jointly sponsored by the National Endowment for the Arts, the Florida Department of State's Division of Cultural Affairs, the Remo percussion instrument manufacturing company, the Council on Culture and Arts for Tallahassee/Leon County (COCA), the Tallahassee Youth Orchestras, and other supporting institutions.

The Artism Ensemble, centerpiece of the project, is an intergenerational, intercultural, intermusical, and neurodiverse creative music performance collective that features four to five children with autism spectrum conditions, their co-participating parents, and professional musicians of diverse musically background performing improvisation-driven music together on an E-WoMP, or Exploratory World Music Playground.

The E-WoMP comprises a large array of percussion instruments that both the children and the adult players are free to explore, as they wish to and on their own terms, individually or collectively; thus the “playground” identifier in the name. Most of the E-WoMP’s instruments were manufactured by project sponsor Remo, and are modeled after traditional drums and other percussion instruments originating in West Africa, Latin America, Native America, and other world regions. They include djembes, congas, bongos, ocean drums, thunder tubes, cuicas, a Native American-type gathering drum, tom-toms, egg shakers, and steelpans (steel drums). All instruments selected for the E-WoMP must meet two basic requirements: they need to be high yield for low input (i.e., easy to produce pleasing/satisfying sounds without need of specialized training) and safe for use by the children in the program. Flexible rubber swimming pool dive sticks are the main types of mallets, and other mallets and sticks with padded or rubber ends are used to ensure optimal safety as well. The use of rubber and padded beaters also helps to prevent the production of excessively loud sounds and harsh timbres, which is important given that autistic conditions are often associated with sensory challenges including a high level of sensitivity to loud and abrasive sounds.

Artism’s staff musicians play both the E-WoMP percussion instruments and their own instruments: guitar, bass, steelpan, flute, clarinet; in earlier incarnations of the group the Chinese zheng zither and the Aboriginal Australian didgeridoo were part of the instrumentarium as well. The staff’s diverse backgrounds—the current lineup features master performers and improvisers from Peru, Trinidad, Bolivia, and several different geographical and cultural regions of North America—contribute to the profusely intercultural palette of musical resources from which Artism’s music springs. Compositions, arrangements, and directed improvisations by the children reflect this musically cultural diversity, as elements of festejo, rumba, flamenco, calypso, raga, reggae, and gamelan combine with those of jazz, blues, funk, hip-hop, rock, classical, and other genres—as well as with ideas and concepts that are uniquely the children’s own and bear no recognizable resemblance to any pre-existing musical genre or tradition—to forge the unique sound and approach that define Artism’s music.

Ethnography, Artism, and the Ethnomusicology of Autism

With an abiding practical and philosophical commitment to growing its musical culture and its social norms and priorities directly from the preferences, directives, and agency of its child members, the Artism Ensemble privileges autistic ability over disability and is oriented toward supportively responding to the creative initiatives and impulses of children with autism rather than trying to restrain, retrain, or redirect them. Moreover, the ensemble, through its concerts and other public events, serves as a social model in its own right: a model of inclusive sociality, music making, and cultural co-production that promotes public recognition of and appreciation for the abilities of people on the autism spectrum; that displays a productive and creative domain of musical praxis built upon the elimination of conventional boundaries and barriers of identity and ability/disability construction; and that in turn challenges conventional assumptions about musical expertise, musical value, and the ostensibly self-evident social hierarchies that exist within group music-making environments. In its aspirations toward fostering an atmosphere that is enabling rather than disenabling, building culture and
community from groups of people to whom “conventional logic” would deny such a possibility, and publicly performing autistic ability and sociocultural inclusivity as challenges and alternatives to autistic disability and exclusion, Artism endeavors to enrich quality of life for its autistic and non-autistic participants alike while positively transforming public perceptions of what autism and autistic people are like.

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

Those who think and work in accordance with the medical model, whether acting as researchers, physicians, or therapists, as teachers, aides, or even parents, operate from a fundamental position that there is a need to change the autistic person, to identify and locate “the problem” of his or her autism and work towards “fixing” it. They are effectively agents of change in search of solutions. Music therapists are a case in point. As we learn in the 2012 online article “Music Therapy as a Treatment Modality for Autism Spectrum Disorders,” which is published on the website of the American Music Therapy Association (AMTA),

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

As an ethnomusicologist of autism, I operate from a different premise than my counterparts in the music therapy profession. I am basically not interested in changing the people whose lives and music I endeavor to understand. My goals are ethnomusicological, not therapeutic, and consistent with my ethnomusicological leanings, I am interested in understanding the subjects of my investigations—in the present case, children with autism—principal according to their terms and from their perspectives: learning from them, sharing experiences with them, comprehending their conceptions and values of community, personhood, social experience, humor, work and play, pleasure and pain, joy and suffering, and of course music. To borrow an oft-quoted turn of phrase from the late anthropologist Clifford Geertz, I am “seeking, in the widened sense of the term in which it encompasses very much more than talk, to converse with them, a matter a great deal more difficult, and not only with strangers, than is commonly recognized” (Geertz 1973, 13).

I am ultimately interested in the music, thoughts, lives, and musical communities of the autistic children with whom I currently work and play music in much the same way that I was interested in the music, thoughts, lives, and musical communities of Balinese musicians with whom I worked and played music in Indonesia in the 1980s and 1990s (Bakan 1999). I did not endeavor to remediate the performance practices of my Balinese fellow musicians, nor to cure them of their preference for paired tunings over equal tempered ones. I assumed that these Balinese musicians were competent practitioners of the Balinese musical arts they practiced, and that their competencies in these musics, both on purely musical and more broadly cultural levels, could never be fully matched by an “outsider” like me. My situation, in common with those of a great many ethnomusicologists, essentially paralleled that described by Terry Miller in the following passage excerpted from an article of his that
My success in becoming a Thai musician has been limited because it has been so difficult to overcome my Western classical mindset, my presumptions of how music is organized, and the usual habits of learning that music. ... overall I have struggled to learn how to learn Thai music properly and admit that however Thai my performance appears, fundamentally it remains rather Western in process. (Miller 2002)

Like Miller with his Thai musical associates, I privileged the knowledge of Balinese musicians regarding their own music over my own, and at the broader cultural level, I assumed that their distinctive clusters of behaviors, abilities, and attitudes in musical and social practice reflected individual manifestations of a broader Balinese worldview and ontology. I welcomed opportunities to learn from them through musical and social interactions, through performances and conversations that yielded ethnomusicological insights into Balinese ways of being, and of being musical.

I assume similar levels of emic expertise and mastery on the part of the children with whom I play music in the Artism Ensemble. Entering the E-WoM, the principal site of Artism musical production, I approach matters much as I did when entering the bale banjar, the principal site of Balinese gamelan music production: as a learning musician, a curious and committed ethnographer, and a co-participant in the making of music and cultural community. Here, though, the cultural bearers are not musicians in Bali who play on a gamelan but American children on the autism spectrum who play on an E-WoM.16

As for myself and the other adult members of the group, professional musicians and “non-musician” parents alike, we are there not to teach or direct the children but rather to learn from and respond to them. We apply whatever skills and attributes we bring to the E-WoM, individually and collectively, to nurture the children’s creativity and agency, their personal and social aspirations, their musical explorations, and their sense of what it feels like to experience reciprocity and success. There are no pre-established repertoires, right or wrong notes, specific musical goals or demands, or defined expectations of any kind beyond ensuring that all participants contribute to maintaining a safe environment emphasizing mutual respect and support for one another.

The child stars of the Artism Ensemble, together with their supporting cast of parents and professional musicians, make good and innovative music, make good culture and community, and make change. They do this through their compositions and arrangements, their improvisatory explorations, their concert performances, and their public presentations of individual and collective selfhood. Change is achieved internally among the group’s members through our joint musicultural ventures and all that they reveal. It is achieved externally as we reach out to audiences through concerts in which Artism’s players, the children foremost of all, are applied to the cause of transforming public perceptions of autism from disability-centered to ability-centered ones, from recognition of a negating sort to recognition of the more affirming and celebratory kind.17

Critiquing Artism: Perspectives from within the Autistic Self-Advocacy Movement

Whatever its merits may be, it must be acknowledged that the Artism Ensemble has received federal funding specifically because of its identification with autism, presents public performances that either explicitly or implicitly acknowledge the autistic identities of key members, and both highlights and benefits from the staging and “performance” of autism. It is therefore reasonable to suggest that Artism is a cultural institution which is in key respects co-opted by the very hegemonic institutions it opposes, creating a paradoxical situation in which the ubiquitous and problematic positioning of “autistic” in contradistinction to “normal” is at once critiqued and reinforced. One is reminded of the Dale Olsen quote cited earlier, in which Olsen invokes the phrase “non-Western musics” only to debunk it.
From a critical perspective, then, Artism may justifiably be accused of propagating the constructs of exclusion, hierarchy, and essentialism it aims to overturn, at least in some measure. This issue and others were brought starkly to light during a June 28, 2013, panel I attended at the 26th annual conference of the Society for Disability Studies in Orlando, Florida (see Grace et al. 2013). Members of this panel, all but one of whom were autistic and all of whom identified strongly with the autistic self-advocacy movement, had attended the conference’s Opening General Session concert by the Artism Ensemble two evenings prior. The concert had come off extremely well, an unqualified success in all regards as far as I could tell in its immediate aftermath. But the critical response of this sector of the autistic community, at least, suggested a rather different assessment, one pointing to the need for change in the ensemble’s approach and performance protocol on multiple levels.

The autistic scholar, author, and advocate Zach Richter served as the main spokesperson for the panel on these issues. He and his collaborators, including the panel moderator, Dr. Elizabeth J. Grace, offered incisive but constructive criticisms of the concert, followed by useful suggestions on how the Artism Ensemble’s approach could be revised to put the group in better compliance with the priorities of autistic people and the autistic self-advocacy movement. Key to the critique was the point that Artism, in its current configuration, is made up of autistic children performing together with their non-autistic parents and with professional musicians who are likewise not autistic. Thus, all of the children are autistic, while none of the adults are. It was strongly suggested that adult musicians with autism be recruited to either join the ensemble or at least to serve as professional consultants. This is a suggestion that we plan to incorporate. It will without doubt enrich the ensemble both musically and socially, as well as in terms of its capacity to work on behalf of effectively promoting autistic ability, self-determination, and acceptance. The future addition of non-autistic children to the ensemble would seem to be another logical extension of the neurodiversity principle. The feedback I have received from members of the autistic community—both within and beyond the ensemble’s membership—has increasingly convinced me that maintaining separate demographic profiles within age-set classes (i.e., autistic children and neurotypical adults) is ultimately counterproductive to Artism’s mission.

Several other valuable criticisms and recommendations were provided by Richter and his co-panelists as well. We are currently working to retool the ensemble and its operations in accordance with these suggestions:

* Strive to decrease the loudness of the performance to better accommodate the sound sensitivity challenges experienced by many autistic people.

* Instruct audiences to show their appreciation for performances not by clapping, which is disturbing to many sound-sensitive autistics, but rather by employing the customary forms of silent applause used at autistic community gatherings, for example, raising the hands and silently touching thumbs to fingers or waving hands in the air overhead.

* Completely avoid reference to the phrase *autism awareness* (which, unfortunately, we had included in one of the questions on a concert evaluation questionnaire distributed to the audience); this phrase, closely associated with Autism Speaks and other organizations that are not run by autistic people, is regarded as offensive by most within the autistic self-advocacy movement, who instead promote the principle of *autism acceptance*.

The tempered outlining of criticisms and suggestions above fails to capture the impassioned mode in which they were presented to me during the conference. Richter, in particular, found several elements of Artism’s performance to be, in his words, “offensive” and “disturbing,” and while those words stung at the time, I was and remain deeply grateful to him and his fellow panelists for their honesty and candor, which are helping to enable me and my Artism collaborators to rethink our approaches and priorities and move toward a better way of doing what we do.
Like so much else in the practical and discursive realms of autism and autistic experience, Artism exists in a complexly contested space wherein empowerment and appropriation are dialectically intertwined. It is all a rather risky venture, but ultimately a worthwhile one, for in promoting autistic personhood as “something different than undesired difference” (Titchkosky 2007, 9), Artism holds the capacity to use music to make a difference, to enable autistic people not just to step to the music they hear but also to set the beat for music they themselves make, getting the people they play with and play for to move and groove with them along the way.

The road is always a bumpy one, though. In his prescient article “Music, the Public Interest, and the Practice of Ethnomusicology,” which was published in the journal Ethnomusicology in 1992 and is today recognized as one of the seminal texts of applied ethnomusicology, Jeff Todd Titon remarks that in this kind of work, “No one would claim perfection; action is risky, and sometimes one makes mistakes; but consider the alternative, non-action” (Titon 1992, 320). We have made mistakes in Artism and we will make more. We can only hope for the further good fortune of having these mistakes pointed out to us by people like Zach Richter, and for their forthright and constructive engagement with us as we continue to move forward together.

Maya Speaks

Twelve-year old Maya C. is seated in a black desk chair in my office. She calls it the spinny chair, and as she speaks eloquently to me of her experiences as a member of the Artism Ensemble, she spins around and around on it continuously.

“You know,” I say to her, “the scientists and the doctors and therapists and people like that who specialize in autism … would say that what you’re doing now—spinning and spinning and spinning while we have this conversation—is an example of stimming, that it’s a ‘symptom’ of your Asperger’s or your autism or whatever.” “Stim-what?” she asks, seemingly confused. “What is that?”

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

Maya laughs incredulously.

“That’s just ridiculous!” she exclaims. “I mean, I bet that the President has a spinny chair and sometimes he spins around. … [And] I like to talk a lot, but the President likes to talk a lot too. And he gives all those speeches, so why don’t they say that the President needs to be ‘cured,’ because the President talks a lot too. If he’s like me in any way, he needs to be ‘cured,’ doesn’t he?”

I chuckle. Maya stops spinning, leans forward, and points to the spot on my computer monitor where I have just transcribed her last remark.

“Just say that I said that sarcastically,” she insists. “I don’t want to offend the President.” She also tells me to be sure to place scary quote marks in both spots where she used the word “cured,” which I do.

Maya resumes her spinning before returning to the subject of Artism.

“And of course the Autism Ensemble [sic] is not a cure,” she insists. “I don’t treat it like a cure, because it isn’t, and if you call it a cure I will disagree with you. It’s simply the kind of way you can calm down and, you know, help with the bad parts of autism without restricting the good parts. Yeah. … Mom tells me that a lot of people
who have autism and Asperger’s can be more creative and insightful than other people, insightful in a way, you know, where they’ve experienced a lot of the emotions that they’re either writing about in stories, or plays, or poems; because a lot of people who have autism can swing between different emotions really quickly. I’m like that. Someone will just say one word and I become like a stereotyped emo (... if you haven’t heard it before, an emo is one of those really sad, dark people. I just go around telling people ‘Life is pointless’ when I’m like that). Of course, the bad parts in my situation are that when I get angry, I get ANGRY!! I mean, like, yelling, slamming-door angry. Of course, I never get physical angry. I don’t punch or hit or bite, though I have bitten someone, but that was in third grade.”

Maya rolls over to the office filing cabinets and back on her spiny chair.

“What I mean by helping with the bad parts but not restricting the good parts [of autism],” she continues, “is that Artism kind of helps with my anger issues without restricting my creativity. ... It’s the fact that I’m allowed to bang on drums for a while—and any instrument I want (as long as I don’t break it or it’s not meant to be banged)—without anybody telling me I’m supposed to do it this way, or I’m supposed to do it that way, or I’m supposed to put this there or that there, or I’m doing it wrong. ... Because I’m told that everyday. I want a break from it! ... It’s just nice being there with other people without them telling me what to do, or just jabbering about all the things they can do that I can’t. ... We’re all just kids in the end. I mean, that’s the whole point. We’re all just kids in the end. Who friggin’ cares whether we’re autistic or not? Why does it matter?”

**Conclusion: Toward Participation in the Social Struggle of the Current Moment**

The “modern music educator,” Meyer M. Cahn proclaimed in his 1972 *College Music Symposium* article “Bach Is Not Enough” (Volume 12), must go beyond merely teaching and teaching about music to “participate in some way or another in the social struggle of the current moment, and must help us to understand the basic elements of that struggle.” This may be an overstatement—social activism is not for everyone, nor need it be—but Cahn’s call for action should not go unheeded by any among us who feel the impulse or the responsibility to make music make a difference, or to make music to make a difference. Our words and deeds, our scholarship and activism, our musical participation and advocacy, the things we know and the ways we know them—all of these have the potential to make a positive impact on the world, sometimes in places we never dreamed they would and through means we could never have even imagined.

In this article I have tried to evoke and describe some of the places that autistic people and autistic musicians with whom I have worked and played have taken me as a musician, an ethnomusicologist, and a proponent of autistic culture, advocacy, agency, and self-determination. I used to be someone who knew almost nothing about autism, I then became someone who feared it, later someone motivated to “cure” it, and now someone who embraces and accepts it as an integral and valuable dimension of human neurodiversity. Autism has taught me to rethink what music is and what it can do in the world; music has taught me to better understand autism and has helped me to meet and get to know some really interesting people who are described, by themselves and/or by others, as autistic. Ultimately, music has also helped me to gain the trust of some of those same people, the candid and productive critique of others. It has also, I hope, earned me the right to work in collaboration with all of them toward the advancement of their causes and priorities, which have become my own, too, and should be all of ours as a society as well.

Whether the social struggle of the current moment involves working out a process to determine who gets to lead the next guided improvisation in an Artism Ensemble rehearsal or overcoming biases and working toward the achievement of a society that ensures social justice and equal rights and opportunities for all its members, including those living with other forms of difference, we all have a potential stake in the outcome, and we all have an opportunity to help make that outcome be the best it can possibly be. As musicians, educators,
and scholars, we have a powerful tool at our disposal in music. We should make music make a difference, and we should do so with as much compassion, commitment, and conviction as we can muster.

Notes

1Autistic self-advocates have argued against “person-first” language constructions such as “person with autism” and “child with autism” and in favor of constructions such as “autistic” and “autistics” (often capitalized as “Autistic” or “Autistics” to emphasize a cultural identity) (see, for example, Sinclair 2012a, Walker 2012). Thus, “He is autistic” is preferred over “He is a person with autism.” The rationale for this position is that person-first language implies something detachable from personhood, an appendage, and suggests that whatever the person is “with” is negative. Therefore, “autistic children” is more appropriate than “children with autism” because it implies acceptance and embrace of the autism as integral to the person. The child members of the Artism Ensemble, however, do not necessarily self-identify as autistics, so in this article I move between identifiers like “autistic” and person-first constructions like “child with autism,” depending on context. When I asked one child member of the ensemble, Maya C., “Are you an autistic kid or a kid with autism?” her reply was as follows: “It doesn’t matter. It’s like asking a zebra, ‘Are you black with white stripes or white with black stripes?’”

2Additional published works addressing issues of autism and living with ASD that have been authored or co-authored by autistic people include the following: Williams 1992, Lawson 2000, Shore 2003 (of additional interest on account of Shore’s professional status as a musician and music educator), Miller 2003, Prince-Hughes 2004, Biklen 2005, Ariel and Naseef 2006, Tammet 2007, Robison 2007, Mukhopadhyay 2011[2008]. Numerous documentary films, blogs, websites, and other media also contribute to the increasingly present and essential autistic voice of ASD discourses.

3In the quoted passage from Straus, and admittedly in the present essay as well, the complex dynamics inherent to the heterogeneity of the autism spectrum itself are essentially not accounted for. The proposed cultural, as opposed to medical, model of autism/ASD does not solve the problem of determining who ought rightly be considered “culturally representative” across the span of so-called (and problematic) low- to high-functioning autistic individuals and conditions. This is an area fraught with difficulties—pragmatic, ethical, political—that go well beyond the scope of the present discussion (see Fein 2012). That said, the following passage from Amy Sequenzia’s important contribution to the Loud Hands anthology, “Non-Speaking, ‘Low-Functioning’,” is instructive:

I am autistic, non-speaking. I am also labeled ‘low-functioning.’ This label is a pre-judgment based on what I cannot do. It makes people look at me with pity instead of trying to get to know me, to listen to my ideas .... All the labels given to us only help to make myths seem like the reality. By classifying a non-speaking autistic as low-functioning, one is lowering expectations for the autistic individual. He or she is not given a chance to express him/herself and maybe show hidden abilities.

We, autistic, have tried hard and accepted the neurotypical way of doing things to make it easier for non-autistic people to understand us, interact with us. Despite some progress there is still very little reciprocity. (Sequenzia 2012, 159 and 161)

Among the five children who have participated in the Artism Ensemble since its founding in 2011, four, at least (including Maya C.), would be described as “high-functioning” according to this problematic rubric, while among the more than thirty children who participated in Artism’s predecessor program, the Music-Play Project, between 2005 and 2009, the distribution was quite wide, though with the majority of participants still falling toward the “high-functioning” end of the continuum.
The term *musicultural* is one that I introduced in the book *World Music: Traditions and Transformations*, wherein I posit that ethnomusicologists “are interested in understanding music as a musicultural phenomenon, that is, as a phenomenon where *music as sound* and *music as culture* are mutually reinforcing, and where the two are essentially inseparable from one another” (Bakan 2012, 10). This is by no means a novel concept; employing the compound word “musicultural,” however, offers advantages (at least to me) in its capacity to crystallize this core epistemological premise while avoiding wordy or awkward constructions like “musical-cultural,” “music-cultural,” “musical/cultural,” or “musical and cultural.”

In the most recently published edition of the *Diagnostic and Statistical Manual of Mental Disorders*, DSM-5 (American Psychiatric Association 2013), the various separate “disorders” of the autism spectrum have been collapsed into a single diagnostic category: ASD, or Autism Spectrum Disorder. This encompasses the conditions that were formerly categorized as Autism, Asperger Syndrome, and PDD-NOS. Two conditions that were previously (in DSM-IV) encompassed within the ASD rubric, Childhood Disintegrative Disorder and Rett’s Syndrome, have been eliminated from the ASD category in DSM-5 (Kaufman 2012).

Rutter’s article, “Changing Concepts and Findings on Autism” (2013), provides an excellent overview of current research issues and debates in this field. Of particular note regarding the triad of impairments discussed here is his review of recent research suggesting that the three elements of the triad are now viewed as “genetically separable and therefore better studied independently rather than as part of an overall cohesive syndrome” (2013, 1751).

It is important to note, however, that there is much diversity of view and opinion regarding such matters even among different individuals aligned with the autistic self-advocacy movement itself, and that neither the movement as a whole nor its individual spokespersons may be said to speak for all, or even necessarily the majority of, autistic people. Indeed, many autistic people openly oppose the positions of autistic self-advocates, claiming, for example, that the emphases on “cure” and “normalization” inherent to much research and activism in the autism arena are well-founded. There is, additionally, the issue of who, if anyone, is best equipped to speak for and on behalf of the large number of autistic people who are non-verbal. For further perspectives on this contentious area of autism discourse and policy, see Fein (2012) and Bascom (2012a).


Both the Music-Play Project and the Artism Music Project were instituted and have been continually developed, annually reviewed, and annually renewed by the Human Subjects Committee of the Institutional Review Board at Florida State University.

The participating children were originally recruited through the client registry of the Center for Autism and Related Disabilities (CARD) at Florida State University.

Video footage from Artism Ensemble concerts or rehearsals featuring compositions by some of its child members include the following: “Purple Eggs and Ham,” by Maya C., at http://www.youtube.com/watch?v=ClN8gvA96-E; “Joobai,” by E. S., at http://www.youtube.com/watch?v=2DZHiD9JLCo; and “Steel Percussion,” by NICKstr, at http://www.youtube.com/watch?v=SjkrjHf_cSl
Intersectionalities between autistic and child identities are central to Artism’s demographic, but my focus here is limited to the autistic side of this dialectic. This is for reasons of space and maintaining a manageable scope for the article. Exploring such intersectionalities is of potentially great significance, however. Ethnomusicologically oriented, ethnography-informed approaches to the study of children’s musical lives, as exemplified, for example, in publications by Campbell (2010), Marsh (2008), and Gaunt (2006), offer valuable models and possibilities relative to future projects and studies on the musical lives of autistic children.

Of related interest are a variety of sources that approach the subject of music and autism from a disability studies perspective. These include Straus 2011, Lubet 2011, Marrero 2012, and the chapters contributed by Headlam, Jensen-Moulton, and Maloney to the edited volume Sounding Off: Theorizing Disability in Music (Lemer and Straus 2006).

For critical discussion of the medical model of disability, as well as of the social model of disability to which it is usually contrasted in disability studies literature, consult The Disability Studies Reader (4th ed.), edited by Lennard J. Davis (2013a). Especially recommended in that volume relative to this subject are the following essays: Davis 2013b and 2013c, Shakespeare 2013, Siebers 2013, Garland-Thomson 2013, and Straus 2013. For perspectives from the philosophy of disability, see Silvers 2010 and Carlson 2009.


That there are limits to this analogy is likely self-evident. Whereas the gamelan-based musical activities of the bale banjar long predated my arrival in Bali as an ethnomusicologist, the E-WoMP is a built environment created by myself and other non-autistic adults prior to its establishment as a musicultural space for the creative musical activities of autistic children and their adult (neurotypical) interlocutors. Therefore, I may rightly be accused of having essentially created the ethnographic field site that I now visit and research. I recognize the irony of this situation, but I do so notwithstanding an abiding conviction that the children in the Artism Ensemble have indeed claimed a large measure of “ownership” of the E-WoMP space and of Artism’s musical and social processes and priorities overall.

This concept of application is closely tied to basic tenets of the sub-discipline of applied ethnomusicology, which has been defined by one of its leading proponents, Jeff Todd Titon (2011), as “the process of putting ethnomusicological research to practical use.” For additional perspectives on applied ethnomusicology, see also Titon 1992; Sheehy 1992; Alviso 2003; Harrison, Pettan, and Mackinlay (eds.) 2010; and Harrison 2012.

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