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TOWARD AN ETHNOGRAPHIC MODEL OF DISABILITY IN THE ETHNOMUSICOLOGY OF AUTISM

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

—Mara Chasar

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

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

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

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

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

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

The Artism Ensemble, a neurodiverse group that features children on the autism spectrum performing original music together with their parents and professional musicians, is committed to such goals. The ensemble and the larger Artism Music Project of which it is a part have been central to my activities as a musician and ethnomusicologist.
for the past several years. Anthropologists Olga Solomon and Nancy Bagatell have called for “movement away from dominant biomedical discourses that focus largely on symptoms to a more phenomenological and ethnographic stance that addresses experiences of living with autism” (Solomon and Bagatell 2010, 1). Artism may be regarded as a musical and ethnomusicological response to that call. It belongs to a large and ever growing movement of advocacy and epistemological reconfiguration that encompasses intersecting streams flowing through the autistic self-advocacy movement, Disability Studies, the disability rights movement, the philosophy of disability, linguistic anthropology, cultural anthropology, comparative human development, and certain sectors and cohorts within music disciplines including historical musicology, music theory, music education, and music therapy. Artism draws on and cuts across much of this broadly interdisciplinary landscape while remaining primarily ethnomusicological in its foundations and orientation. To pinpoint its identity even more precisely, Artism is an applied ethnomusicology endeavor, in the sense that Jeff Todd Titon has defined applied ethnomusicology as “the process of putting ethnomusicological research to practical use” (Titon 2011).

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

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

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

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

You know, I like to make my songs funny. And NICKstr likes to make his songs really precise. E.S. liked to make her songs quiet. And Coffeebot likes to make his songs precise and sort of loud, and he really likes the steel drum. Me, I really like all their songs. They’re always so great. . . . And honestly, it’s really cool seeing all these kids come up with different songs and different styles of songs.

And of course the Autism Ensemble [sic] is not a cure. I don’t treat it like a cure, because it isn’t, and if you call it a cure I will disagree with you. It’s simply the kind of way you can calm down and, you know, help with the bad parts of autism without restricting the good parts. . . . What I [mean by that] is that Artism kind of helps with my anger issues without restricting my creativity. . . .

It’s the fact that I’m allowed to bang on drums for a while—and any instrument I want (as long as I don’t break it or it’s not meant to be banged)—without anybody telling me I’m supposed to do it this way, or I’m supposed to do it that way, or I’m supposed to put this there or that THERE, or I’m doing it wrong. . . . Because I’m told that every day. I want a break from it! . . . It’s just nice being there with other people without them telling me what to do, or just jabbering about all the things they can do that I can’t. . . .

We’re all just kids in the end. I mean, that’s the whole point. We’re all just kids in the end. Who friggin’ cares whether we’re autistic or not? Why does it matter?

ARTISM is an acronym for “Autism: Responding Together In Sound and Movement.” The Artism Ensemble is a neurodiverse, intergenerational, and intercultural creative music performance collective that features four to five children with autism spectrum conditions, their co-participating parents, and professional musicians of diverse multicultural background performing improvisation-driven music together on an E-WoMP, or Exploratory World Music Playground. The E-WoMP comprises a large array of percussion instruments that both the child and adult players are free to explore, as they wish to and on their own terms, individually or collectively; thus the “playground” identifier in the name. Most of the E-WoMP’s instruments were manufactured by the Remo percussion instrument company and are modeled after traditional drums and other percussion instruments originating in West Africa, Latin America, Native America, and other world regions. They include djembes, congas, bongos, ocean drums, thunder tubes, cuicas, a Native American–type gathering drum, tom-toms, egg shakers, and steelpans (steel drums), among many others. All instruments selected for the E-WoMP
must meet two basic requirements: high yield for low input (i.e., easy to produce pleasing/satisfying sounds without need of specialized training) and safety for use by the children in the program. Flexible rubber swimming pool dive sticks are the main types of mallets, and other mallets and sticks with padded or rubber ends are used to ensure optimal safety as well. The use of rubber and padded beaters also helps to prevent the production of excessively loud sounds and harsh timbres, which is important given that people on the autism spectrum often have sensory challenges including a high level of sensitivity to loud and abrasive sounds.

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

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

**Toward an Ethnographic Model of Disability**

In its on-the-ground and philosophical commitments to relying on the creative and agentive priorities of its child members for its musical identity and social life, the Artism Ensemble privileges autistic ability over disability, supportively responding to the creative initiatives and impulses of children with autism rather than trying to restrain, retrain, or redirect them. Moreover, the ensemble, through its concerts and other public
events, serves as a social model in its own right: a model of inclusive sociality, music making, and cultural coproduction that promotes public recognition of and appreciation for the abilities of people on the autism spectrum; that displays a productive and creative domain of musical praxis built on the elimination of conventional boundaries and barriers of identity and ability construction; and that in turn challenges conventional assumptions about musical expertise, musical value, and the ostensibly self-evident social hierarchies that exist within group music-making environments. Artism aspires through its musicultural practice and performances to contribute to the enablement and empowerment of people who have historically been disenabled, build culture and community in environments where “conventional logic” would seem to deny the very possibility, and publicly perform autistic ability and sociocultural inclusivity as public challenges and alternatives to autistic disability and exclusion.9

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

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

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

As an ethnomusicologist of autism, I operate from a different premise than most of my counterparts in the music therapy profession. I am not interested in changing the people whose lives and music I endeavor to understand. My goals are basically ethnographic, not therapeutic; and to the extent that a therapeutic aim may be said to exist at all, it is to cultivate a space in which the children in Artism get to be themselves as they
wish to be, a space devoid of the kinds of externally imposed pressures, expectations, assessments, and objectives that customarily go hand in hand with programs and activities rooted in symptomatological epistemologies of autism and autistic experience.

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

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

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

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

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

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

Individuals on the autism spectrum tend to gravitate toward preordered systems in which the relationship between parts can be predicted based on rules, and struggle to function within open-ended systems requiring flexibility, improvisation, and intuition. They thus gravitate toward and function best under a “stable symbolic and social order,” under conditions where social expectations and givens are consistent, explicit, systematic, and shared between interlocutors. (Fein 2012, 69–70)
Artism's open-ended approach, reliant as it is on flexibility, improvisation, and intuition, may be seen to push back against such logic to a considerable degree, even if other key features of the project—the regular weekly meeting time and location, its stable membership, the relatively predictable structure of the round-robin protocol described above—do offer frameworks of consistency and reliability within which the more fluid and improvisatory elements may unfold. There is no doubt that children in the group (and adults as well) often do struggle with the overall unpredictability and open-endedness of the process, and that in many respects their individual and collective decisions to create quasi-structured musical works and to take charge of the ensemble in a directorial way, rather than to maintain a more free-flowing improvisational environment, are commensurate with their desires for a certain measure of systematicity, control, and consistency. But there is likewise no doubt that over time they have come to revel in the open-ended possibilities for spontaneous invention and co-creation that the E-WoMP environment affords. Each in their way, they have come to find both the challenges and triumphs of contending with the inherent fluidity of Artism's musicultur al process to be empowering and rewarding.

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

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

**CRITIQUING ARTISM**

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

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

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

The future addition of neurotypical children to the ensemble would seem to be another logical extension of the neurodiversity ideal principle. The feedback received from members of the autistic community—within and outside of the ensemble’s membership—has increasingly convinced me that maintaining separate demographic profiles within age-set classes in the ensemble (autistic children, neurotypical adults) is counterproductive to our mission.
Richter and his fellow panelists offered other useful recommendations that we are in the process of incorporating as well. These include the following:

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

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

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

**Mara Spins**

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

"Spinning chairs! Spinning chairs make *everyone* happy!" she sings. Then, in a mock serious tone, "I get distracted easily," and after that, throwing back her hair and laughing wildly, "especially by things like this that are SPINNY CHAIRS!!"
“You know,” I say to Mara, laughing along with her as she continues to spin away, “the scientists and the doctors and therapists and people like that who specialize in autism . . . would say that what you’re doing now—spinning and spinning and spinning while we have this conversation—is an example of stimming, that it’s a ‘symptom’ of your Asperger’s or your autism or whatever.”

“Stim—what?” Mara asks, seemingly confused. “What is that?”

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

Mara’s laughter now escalates to a fever pitch.

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

ZOLABEAN STIMS

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

For Mara and a great many other people on the autism spectrum, though, there is nothing “dysfunctional” about stimming at all. In her ethnographic study of an autistic self-advocacy group to which she ascribes the pseudonym AACT (Autistic Adults Coming Together), Nancy Bagatell observes that actions viewed as “self-stimulatory” by the biomedical community, such as rocking and hand flapping, are reframed as a valued activity[,] not a meaningless action that should be “extinguished.” Many members told me that they enjoyed these activities tremendously and felt a sense of relief being in a place where they could, in fact, be themselves. (Bagatell 2010, 39)
Zolabean, a former member of the Artism Ensemble who played in the group for its first two seasons in 2011 and 2012, is a stimmer. Two years prior to joining, she had participated in Artism's predecessor program, the Music-Play Project. At that time, she was an adorable, petite eight-year-old with straight blonde hair, a charmingly wry pixie grin, and a diagnostic label of Asperger's syndrome. She was reserved yet articulate, highly intelligent, and possessed of considerable creative talents as a musical improviser from the start. When there was no music being played, she tended to be rather passive, even flat, in affect, but as soon as the music started up she became an engaged and intense participant. She almost never stirred, and on the rare occasions that she did (usually for a fleeting moment of hand-flapping) she would quickly check herself and stop.

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

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

MICHAEL (M): So, let's talk about Artism for a minute.
ZOLABEAN (Z): OK.
M: 'Cause you like that.
Z: Yes.
M: [During] the first couple of weeks, you . . . were participating in your way . . . but you weren't playing, you weren't playing instruments very much at all—sometimes I think you didn't play them at all. Do you remember in [the] Music-Play Project [in 2009]? There you used to play quite a bit, I seem to recall.
Z: Well, there was a reason why I played a lot in that. I was afraid that someone was going to tell me I had to play if I didn't . . . There were people with video cameras. It was just a lot of pressure and I felt like I had to play the instruments, like [that] was why I was there. [But] during the Artism project [Zolabean trails off mid-sentence, pauses thoughtfully, then shifts gears and resumes]—I have characters in my head. I think about them a ton, like probably more than I think about my own life. That's fine with me because they kind of relate to me. A lot of them have similar diagnoses [sic] . . . And what's happening was, they were all musicians, the people in my head, and so I was imagining them playing the instruments, like I had one on the zheng and one on the djembe, and everything . . .
M: [So] because you've got these characters in your head and then they were playing the instruments [you didn't feel the need to play yourself]?
Z (smiling glowingly): Yes!
M: But then, at a certain point, that changed, and then you became [involved] very actively [in] playing and composing and directing the band. [Why?]
Z: At the beginning I was a little nervous that I'd have to play like in the last one [MPP 2009]. But after a while I realized it was cool if I could just express myself in any way. And in the end I felt comfortable enough and my characters kind of merged with it. That's when I started playing more.
M: So the main thing, then, it sounds like, there were two things: the characters sort of merging [Z cuts M off mid-sentence to interject]
Z: And it was also just me getting more comfortable with it.

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

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

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

The "seemingly natural conflation" of Zolabea's particular brand of disability, the one labeled Asperger's syndrome, with "undesired vulnerability and ineptitude" (Titchkosky 2007, 10) has been not only disrupted, but fully overturned in this moment of revelation and discovery. Zolabea has shown that her decision to not play instruments early on in Artism, to instead stim or listen silently while jamming with the "band of brothers" in her head, was just that: a decision. It was not an action of retreat or regression determined by her autism, but rather a choice determined by her preference; not a symptom of isolationism and social impairment, but an expression of creative exploration and inventiveness. And when, later on, she did choose to connect in a more conventionally "musical" manner (at least some of the time)—playing instruments, interacting with the rest of us in readily tangible ways, leading the ensemble in some pieces and following her fellow players in others—this did not constitute a positive outcome of a successful therapeutic intervention. It merely made manifest a fluid progression between two different modes of productive musical engagement, one centered on stimming-based movement and adventurous flights of imagination, the other on performance and explicit social connection with the other music makers in the room. While a symptomatic reading
would show the latter of these modes to be “normative” and the former to be “autistic,” neither is in actuality any more normal or autistic than the other. They are just different—and they are, moreover, relational, dialectical, and organically in tandem with one another. They are alternate ways of being musical and being tuned in, which is a far cry from the contrasting view that they are oppositional ways of being musical versus being tuned out.

**CONCLUSION: TOWARD LIVING AND IMAGINING A LITTLE DIFFERENTLY**

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

**Notes**

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

I am autistic, non-speaking. I am also labeled “low-functioning.” This label is a 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)

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


4. Fein’s work is representative of a burgeoning literature on the anthropology of autism that aligns in many key respects with both the Disability Studies and ethnomusicological sensibilities foregrounded in this article. See also Ochs et al. 2001, 2004, and 2005; Kremer-Sadlik 2004; Solomon 2010a and 2010b; Sterponi and Fasulo 2010; Grinker 2010; and Brezis 2012.

5. The intersectionality of autistic and child identities that largely defines the demographic of the Artism Ensemble is not addressed explicitly in this essay on account of both space limitations and my endeavor to maintain a manageable scope of inquiry. Exploring such intersectionality is of potentially great significance, however. Ethnomusicologically oriented, ethnography-informed approaches to the study of children’s music making, as exemplified, for example, in publications by Campbell (2010), Marsh (2008), and Gaunt (2006), offer valuable models and possibilities relative to future projects and studies on the musical lives of autistic children.

6. Selected literature from these many areas and disciplines is cited and discussed throughout this chapter. Notable is the emergence of a body of relatively recent books, dedicated exclusively to autism, which approach their subject from positions that run contrary to the mainstream medical-scientific paradigm. Beyond the aforementioned Loud Hands volume (Bascom 2012a), these include Biklen 2005, Nadesan 2005, Grinker 2007, Murray 2008, and Osteen 2008.

7. For additional perspectives on applied ethnomusicology, see also Titon 1992; Sheehy 1992; Alviso 2003; Harrison, Pettan, and Mackinlay 2010; and Harrison 2012.

8. Participants were recruited through the client registry of the Center for Autism and Related Disabilities (CARD) at Florida State University. At all phases, the project has been
reviewed and approved by the Human Subjects Committee of the Institutional Review Board at Florida State University.

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


12. I am aware that this comparative analogy can only be taken so far. Whereas the gamelan-based musical activities of the bale banjar long predated my arrival in Bali as an ethnomusicologist, the E-WoMP is a built environment that was created as a cultural space for the creative musical activities of autistic children and their nonautistic adult interlocutors by myself and other neurotypical adults. Therefore, I may rightly be accused of having essentially created the ethnographic field site that I now visit and research. While recognizing that there is some irony in this situation ethnographically speaking, I hold to the conviction that a large measure of "ownership" of the E-WoMP space and of Artism's musical and social processes and priorities overall have been claimed and maintained by the children in the group.

References


