
[Special Issue on Music Therapy and Disability Studies]

Ethnomusicological Perspectives on Autism, Neurodiversity, and Music Therapy

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Abstract

In this article, I suggest that a provisional paradigm shift from disability as pathology to disability as neurodiversity has the potential to productively resituate the epistemological orientations of music therapy, both as a field of inquiry and a domain of practice. I draw from my own work on the ethnomusicology of autism, as well as from research and writings in disability studies and autistic self-advocacy, in proposing that the relativistic foundations of ethnomusicology offer a potentially useful alternative and complement to the principally treatment-directed foundations of music therapy.

Keywords: Autism, autism spectrum, Asperger's syndrome, neurodiversity, autistic self-advocacy, ethnomusicology, Artism Ensemble, E-WoMP, ethnography, disability studies, Balinese gamelan, relativism

[Editors note: Upon publication on November 1, 2014 two details have been changed in this manuscript. A note #14 has been added. Further in note #4 the reference Brezis (2011) [ Social and Non-Social Memory in Children and Adolescents with Autism Spectrum Disorders. Ph.D. dissertation, University of Chicago] has been replaced with Brezis (2012).]

When I first received Susan Hadley’s call for contributions to this special issue on music therapy and disability studies, I was pleased to see that she had included in the document several definitions of music therapy in order to provide “a framework from which to begin” this rich and potentially important interdisciplinary exchange. The first, from Kenneth Bruscia (1998), stated that music therapy “is a systematic process of intervention wherein the therapist helps the client to promote health, using music experiences and the relationships that develop through them as dynamic forces of change.” The second, from the American Music Therapy Association (AMTA, n.d.),
described the field as being grounded in “the clinical and evidence-based use of music interventions to accomplish individualized goals within a therapeutic relationship,” in particular, a relationship geared toward the address of “physical, emotional, cognitive, and social needs of individuals” through music-centered modes of treatment that strengthen clients’ abilities in target areas of deficit, and that transfer those gains to other life domains as well. The third, issuing from the British Association for Music Therapy (BAMT, n.d.), positioned music therapy as “an established clinical discipline which is widely used to help people whose lives have been affected by injury, illness or disability.”

In their varied nuances, points of emphasis, and epistemological orientations, these three definitions cover a diverse range of answers to the questions of what music therapy is and what music therapists do. For all their diversity, however, they collectively exhibit a clear unity on at least one key point: the job of a music therapist, and in turn the charge of music therapy at large, is to effect change through programs of intervention and treatment; and more specifically, the locus at which change is expected to happen is the individual client, whose course of treatment should optimally be beneficial in terms of measurable gains in ability, functionality, health, wellness, or other areas of diagnosed need. It is certainly the case that three isolated definitions of a discipline, especially when presented devoid of their larger contexts of publication and surrounding discourse as they are here, cannot be said to represent the epistemological foundations—let alone the full scope and diversity—of that discipline. There are alternative discourse and praxis orientations in contemporary music therapy that depart from and contest the paradigmatic assumptions that the Bruscia, AMTA, and BAMT definitions above inscribe, whether one considers those definitions individually or across the expanse of their collective paradigmatic breadth. Feminist music therapists, community music therapists, and music therapists working from disability studies-informed perspectives are challenging the established treatment-centered models of music therapy on multiple levels (see, for example, Pavlicevic & Andsell, 2004; Rolvsjord, 2004; Hadley, 2006; Edwards & Hadley, 2007; Stige et al., 2010; Aigen, 2012; Hayes, in press).

Notable exceptions aside, however, I would maintain that the vast majority of music therapists may be described as agents of change who endeavor to help the people with whom they work to be better, to do things better, and to feel better. To characterize a field and its practitioners in such positive terms may seem a strange point from which to embark upon a critical consideration of it, but that is precisely what I plan to do in this essay. My method of argumentation is epistemological. I propose that adopting an at least partial paradigm shift with respect to where disability resides, and what disability is, has the potential to productively resituate the epistemological orientations of music therapy, both as a field of inquiry and a domain of practice. This proposed paradigm shift is from pathology to neurodiversity. It relies on a definition of neurodiversity advanced by the Autistic self-advocate and scholar Nick Walker: “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, or sexual orientation (Walker, 2012, p. 233). Drawing from my own work on the ethnomusicology of autism,[1] as well as from research and writings in disability studies and autistic self-advocacy, I suggest that the relativistic foundations of ethnomusicology offer a useful alternative to the treatment-directed foundations of most music therapy, and that this could be useful in
terms of helping to advance neurodiverse perspectives in the music therapy field.

My focus is on autism and the autism spectrum, with what are widely known as autism spectrum disorders, or ASDs, but may more appropriately be classified as autism spectrum conditions, or ASCs. According to a 2012 article entitled “Music Therapy as a Treatment Modality for Autism Spectrum Disorders,” which was published on the AMTA’s website, “music therapy can stimulate individuals to reduce negative and/or self-stimulatory responses and increase participation in more appropriate and socially acceptable ways.” Moreover, the article states, “[b]ecause 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” (American Music Therapy Association, 2012, pp. 2-3). The epistemological emphasis of music therapy in the treatment of autism thus conceived rests squarely in the corner of facilitating symptomatic reduction and remediation, as well as in promoting behavioral and functional normalization. Granted, the same AMTA publication does state elsewhere that “music therapy focuses on strengths, which in turn may be utilized to address each individual’s areas of need,” and it also stresses that many on the autism spectrum “have innate musical talents; thus, music therapy provides an opportunity for successful experiences” (American Music Therapy Association, 2012, pp. 2-3.). Yet even with this highlighting of autistic strengths and emphasis on success-directed orientations, the goal of the enterprise remains essentially unaffected: solve problems, reduce symptoms, increase functionality.

Autism is a serious issue. It is one of the defining phenomena of our age (Solomon, 2010; Fein, 2012), and it is undeniable that music therapy is, and has long been, an invaluable asset to a great many Autistic individuals.[2] as well as to the people and communities encompassed within their respective circles of influence and concern.[3] My purpose here is not to deny or trivialize the disenabling impacts of autism, nor in any way to discredit the extraordinary contributions of music therapy—and music therapists—in this domain, but it does involve trying to move the compass in a different direction: away from perceptions of autistic pathology and “autism awareness” and toward an ethnographic perspective on autism and Autistic people that is grounded in autism acceptance.[4] As Steve Silberman asserts in his contribution to the landmark anthology Loud Hands: Autistic People, Speaking:[5]

Autism is a part of who we are. As sure as skin color or sexual orientation, we cannot change being Autistic...we are not broken, defective, or diseased. We do not need to be fixed or cured....Yes, autism is a disability, and yes, some Autistic people are very severely disabled. Accepting autism does not mean ignoring or denying disability; it means accepting us for who we are, as we are....we have valid, legitimate, and important things to say about our lives and about the issues that affect us collectively. Like any group of people, we are not homogeneous in opinion or ideology, and this diversity is part of the Autistic community. Yet we must be included in any conversation about us, because decisions made by policymakers, school administrators, and grant reviewers often impact our daily lives and future outlook. We can speak (or write or sign or type) for ourselves, and it’s time to listen. (Silberman, 2012, p. 364-65)

Silberman’s perspective has its limitations. There are many Autistic people who at
present can neither speak, write, nor sign, and who either do not have or have not yet found any alternative mode of “voice” to communicate their thoughts, needs, and wants. There is also contentious debate over whether Autistic self-advocates, neurodiversity proponents, or disability studies scholars or rights activists are better qualified, or indeed are qualified at all, to articulate and address the broad range of issues faced by Autistic people across the spectrum of their diversity, and there are those who propound that other constituencies—parents, siblings, doctors, therapists, medical and scientific researchers, teachers—are indeed better positioned to do so (Fein, 2012). Moreover, many people on the autism spectrum who are both capable of and inclined toward expressing their views on such matters are openly averse to the claims and positions of autistic self-advocacy and neurodiversity spokespersons, stating, for example, that they are much more interested in having their autism cured or reduced in severity than they are in having it “accepted.”

In short, there are a great many stakeholders, a plethora of views and agendas; most if not all warrant our serious consideration and critical engagement. Ultimately, however the preponderance of pathologizing and negating discourse about autism is so great that if nothing else, there is a need to redress it and put it in better balance with the more ability-centered, affirming, and agentive perspectives of autistic self-advocacy, neurodiversity, and disability studies.[6] As Temple Grandin explains, “I’m certainly not saying we should lose sight of the need to work on deficits. But...the focus on deficits is so intense and so automatic that people lose sight of the strengths [of Autistic people]....” (Grandin & Panek 2013, pp. 180-81).

I would add to Grandin’s assertion that along with losing sight comes a loss of hearing: our pervasive deficit-centrism yields a certain kind of tone-deafness when it comes to being able to really listen to Autistic voices. Whatever else might be worth doing, be that therapeutically, medically, or in public policy, through social activism or legislative reform, we will never go wrong by making it a priority to first listen closely, attentively, and with deep engagement, flexibility, and creativity to what Autistic people have to say and the ways they choose to play, whether via verbal conversations, shared musical experiences, or any other means. These are good places from which to start moving in the right direction, and the methodological and theoretical orientations of ethnomusicology can provide good locations from which to begin, as I will endeavor to illustrate.

Ethnomusicology and Relativism

My primary area of specialization as an ethnomusicologist in the earlier years of my career was the gamelan music of Bali, Indonesia. In particular, my research focused on the music and cultural world of a specific type of gamelan, the gamelan beleganjur, a processional ensemble consisting of gongs and melodic gong-chimes of many sizes and functions, multiple pairs of crash cymbals (cengceng kopyak), and a pair of kendang drums—each played by a separate player—that leads the ensemble (see Bakan, 1999).

As a field researcher in Bali, I worked closely with a number of Balinese gamelan musicians and groups. I took lessons, conducted interviews, developed language
competence in Bahasa Indonesia (the Indonesian national language), participated regularly in gamelan rehearsals, hung out and got to know people, attended and took part in many communal and ritual events, and performed frequently with gamelan groups on different parts of the island in a variety of contexts, from temple ceremonies and cremation processions to high-stakes beleganjur contests.\[7\]

In other words, I did what ethnomusicologists typically do: ethnographic fieldwork based on intensive, music-centered participant-observation. I did not look to identify impairments or deficits among my Balinese field consultants; nor did I endeavor to “fix” or “improve” their music, their behavior, or their values in any way. It never occurred to me to try to remedy their predilection for paired tunings, in which the simultaneous sounding of often strikingly different “male” and “female” versions of the same pitch can prove jarring to Western ears, at least initially. I did not see it as my place to suggest that they consider enlisting the services of a non-playing conductor to direct their ensembles either.

To take any such action or propose any such form of remediation would have been ludicrous within the epistemological parameters of an ethnomusicological worldview. My assumption was and remains that the Balinese musicians with whom I have worked, studied, and played are experts at being who they are, whether musically, culturally, socially, or in any other way. My job is not to endeavor to change them, but rather to try to understand and relate to them, to the greatest extent possible (and at the risk of invoking a tired ethnographic cliché “on their own terms.” I define ethnomusicology as the study of how people make and experience music, and of why it matters to them that they do. This is the kind of knowledge that I have always sought to gain and to communicate to others in my work on Balinese music and other musicultural traditions I have researched (Bakan, 2012).

The Artism Ensemble

It is precisely this same kind of knowledge—knowledge about how people who are experts at being who they are make, experience, and find meaning in music—that I aspire to develop and share in my current endeavors as an ethnomusicologist of autism. This work is defined mainly by my activities as a member (and also the founder and coordinator) of the Artism Ensemble.

The Artism Ensemble was founded in January 2011 under the aegis of a grant funded by the National Endowment for the Arts (United States), which served as the project’s main financial sponsor for a three year period from 2011 to 2013.\[8\] Throughout that entire period and up to the present, the Artism Music Project has been vetted, approved, and overseen by the Human Subjects Committee of the Institutional Review Board at Florida State University. “ARTISM” is an acronym for “Autism: Responding Together In Sound and Movement.” The group is an intergenerational, intercultural, intermusical, and neurodiverse creative music performance collective that features four to five children with autism spectrum conditions,\[9\] their co-participating parents, and professional musicians of diverse musicultural background performing improvisation-driven music together on an E-WoMP, or Exploratory World Music Playground. It should be noted that while all of
Artism’s music is improvisatory to some degree, the overall evolution of the group’s repertoire—inspired by the agency of its child members specifically—has moved increasingly toward compositional forms and structures that are quite precisely ordered and controlled. Each child has emerged as a composer in her or his own right, and each demonstrates a unique blend of predilections regarding the balance of “controlled” and “free” elements in their respective original musical works.

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, toms-toms, egg shakers, and steelpans (steel drums). All instruments selected for the E-WoMP must meet two basic requirements: they must 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 musicultural 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.[10]

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. It 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.[11] 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 both enrich quality of life for its participants and positively transform public perceptions of autism and Autistic people.

Autism and Neurodiversity, Ethnomusicology and Music Therapy

I suspect that many music therapists reading the above paragraphs will identify a great deal of overlap between their own methods and theoretical orientations and those we are applying in the Artism Ensemble project. Indeed, I am the first to admit—and with enthusiastic gratitude—that much of what we have done in Artism has issued directly from music therapy influences, whether from literature review or direct collaboration and consultation with therapists. But where I would maintain that there is a fundamental distinction between doing work of this kind ethnomusicologically versus doing it within a music therapy framework is epistemological. The best way to illustrate this point is through the use of an example.

Entering the E-WoMP, which is both the principal site of Artism musical production and the primary field site for my current ethnomusicological research, I approach matters much as I did when entering the bale banjar, the principal site of Balinese gamelan music production and the primary site of my Indonesian field research: 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-WoMP.[12]

Yet whereas in my gamelan research such methods were deemed normative and expected, in the arena of autism studies they have been regarded as atypical, if not idiosyncratic. This is because autism, unlike gamelan, has traditionally been a construct of the medical/scientific rather than the ethnographic/ethnomusicological imagination. It “goes without saying” that autism is a disorder, but that being Balinese is not; that the behaviors associated with being autistic are symptoms, while those associated with being Balinese are integral and inalienable expressions of cultural identity; and that diagnosing, treating, and even eradicating autism are desirable goals, though even the thought of diagnosing or treating, let alone eradicating, Balineseness is unconscionable.

The problem, as I see it, is precisely that such things do so habitually go without saying. Steeped as they are in the paradigmatic thinking of what disability studies scholars have called the medical model of disability, they have the potential to cause great harm and, just as significantly, to stand in the way of great progress. “Medical culture—what has
been described and vigorously critiqued within Disability Studies as the *medical model,* writes Joseph Straus in his essay “Autism as Culture,” “has certain defining attributes. First, medical culture treats disability as pathology, either a deficit or an excess with respect to some normative standard. Second, the pathology resides inside the individual body in a determinate, concrete location. Third, the goals of the enterprise are diagnosis and cure” (Straus 2013, p. 462).[13] Far from being neutral standpoints for value-free modes of inquiry and action, these “defining attributes,” according to Straus and others writing from a disability studies perspective, yield trenchant essentialisms with far-reaching implications. They objectify so-called disabilities and thus the people who “have” them, depriving these individuals of agency and reifying their personhood in potentially damaging ways.

To counter these effects, a different perspective—an alternative paradigm from which to build from the ground up—is needed. The view of many in disability studies, as well as in the contemporary social and academic movements associated with disability rights activism, neurodiversity, and autistic self-advocacy, is that the epistemological orientation of neurodiversity provides such an alternative. In Nick Walker’s *neurodiversity paradigm,* variation in the configuration and functioning of human brains and minds, for example, as in autism and ASC, is regarded as “a natural, healthy, and valuable form of human diversity,” and “all of the diversity dynamics (e.g., dynamics of power, privilege, and marginalization) that manifest in society in relation to other forms of human diversity . . . also manifest in relation to neurodiversity” (Walker, 2012, pp. 227-28). The neurodiversity paradigm’s opposite is to be found in what Walker refers to as the *pathology paradigm,* which rests on the notion that there is a “right,” “normal,” or “healthy” way for human brains and minds to be configured and to function, and that substantial divergence from this dominant “normal” standard equates with the blanket assessment that there is “Something Wrong With You” (Walker, 2012, p. 227; caps in original).

Straus suggests that with respect to autism in particular, it is efficacious to take “the concept of ‘neurodiversity’ as a point of departure—a belief that autism is not a defect or pathology, but rather an aspect of naturally occurring and inherently desirable human variability.” He proposes a goal of seeking “to understand autism as a way of being in the world, a world-view enshrined in a culture...a difference, not a deficit” (2013, p. 467). Ethnomusicology, founded as it is on the premises of cultural relativism, offers powerful tools from which to pursue this goal. In its essentially exclusive focus of on how Autistic people make and experience music, and of why it matters to them that they do, the ethnomusical approach to autism resists complicity with medical model-based priorities in what amounts to a suspension of engagement with the entire complex of diagnosis, treatment, and cure.

The therapeutic goals of an ethnomusically informed approach to music therapy within this radicalized epistemological framework would come to reside not in treating Autistic people, but rather in cultivating venues and facilitating outlets for their own agency on their own terms. Such agency is empowering in and of itself, and its public expression—for example, in Artism-like music performance contexts—could have the capacity to make manifest social models, and more particularly *social-musical models,*
of neurodiversity that could positively transform public perceptions of autism and Autistic people from disenabling to enabling. Therapy, in this manifestation, would be achieved not by targeting Autistic ways of being for change, but rather by targeting change through the embrace of Autistic ways of being.

Words about Music, Words about Autism

I recall the late Mantle Hood, one of the founders of modern ethnomusicology, proclaiming the following during a lecture of his that I attended at Florida State University in 1997: “If you’ve learned to play it, to sing it, to dance it, then you’ve earned the right to talk about it.” Reflecting on my relationships with the children in the Artism Ensemble over the past several years, I find Hood’s words modulating into a somewhat different key, to the effect of If you’ve learned to play with them, to sing with them, to dance with them, they may decide you’ve earned the right to really talk with them as well. Making music together has helped me establish rapport and trust with these children, in the process opening other channels and modes of communication and interaction that did not formerly exist between us. I regard this musical bridge to conversational and social connection as a key methodological feature of this work as ethnomusicology.

In some cases, the expansion and enrichment of interactional possibility has remained mainly in the domain of musical connection per se. One child member of Artism in particular, a girl named E.S., has to this day only very rarely exchanged words with me or other members of the group, restricting anything beyond the most cursory verbal communications to her conversations with her mother. In other cases, however, the trust and familiarity built at first through shared musical experiences has ultimately paved the way toward conversational exchanges of the more conventional kind, and these conversations have been profoundly revealing in some instances. This has been especially true of my relationship with one of the other girls in the group, Mara, who in the following dialogue transcript offers an enlightening, experience-near perspective on music, autism, and disability from which music therapists and ethnomusicologists alike stand to learn a great deal.

Mara Speaks

“Come in,” I say, inviting Mara, twelve years old at the time, into my office on a sweltering hot August afternoon in 2013.[14] She enters with eyes downcast and sporting a mild frown. This is the first time we have seen each other since performing together in an Artism Ensemble concert for the Society for Disability Studies (SDS) annual conference in Orlando, Florida, six weeks prior; and it is the first time we have ever met at my office rather than in the much more hospitable and familiar environment of the E-WoMP.

So now here we are, sitting in the stillness of my fake wood-paneled digs in the College of Music at Florida State University, surrounded by computer and audio equipment and shelves stuffed with books and folders. It’s got to be a bit off-putting. She probably thinks she’s in trouble, that she’s done something wrong and I’m about to reprimand her or something like that. Maybe this was a bad idea.
But things immediately change for the better the moment Mara feasts her eyes on the nice black office chair sitting adjacent to my desk. She plops herself down and gives it a good kick start.

"Whee!!" she exclaims with glee as she tucks up her knees and whirls about in the chair, over and over and over again. The downcast eyes alight and open wide. The frown becomes a radiant smile and Mara's laughter fills the room.

"I love spinny chairs!" she shrieks. "Spinny chair! Everyone loves the spinny chair!!"

She spins and spins, round and round, and she continues spinning as she quickly modulates from her playful tone to a more serious one.

"So what do you want?" she asks me.

I'm a bit thrown off by the question.

"Want?" I say, pondering, searching for just the right way to put it. "Oh, what do I want—well, I just want to talk to you, about autism and Asperger's and stuff like that," I venture, not sure how that's going to go over. Mara continues to spin. "You know," I continue, "you had such wonderful things to say about all that stuff during the question-and-answer session after our Orlando concert with Artism, and since then I've been reading this book written by autistic people—it's called Loud Hands: Autistic People, Speaking (Bascom, 2012a)—and what you were saying is really in line with what they're saying. So now I'm trying to write about music, and autism, and Artism and all that, and I think it would be great if you could write with me, because you have such amazing insights and I think having you share those would make the things I'm working on way better than anything I could write by myself."

"So you want me to help you write a book?"

"Well, yeah, a book, some articles, a few different things actually. Is that okay?"

"I think that sounds cool."

"Great. So how about you talk and I'll type out what you say, or else you can just sit here at the computer and type yourself if you prefer. That's fine, too."

"You type," she says. "I like spinny chairs!"

"Remember how our concert in Orlando was at that conference, you know, the one for the Disability Studies society?"

"Yeah."

"Well, after the rest of you guys left, I stayed around for the rest of the conference. There was this one session that was run by people who do disability studies but who also have autism themselves, and they thought that our concert was sponsored by this big organization called Autism Speaks. It wasn't, but they thought it was because I had
handed out this questionnaire to the audience and one of the questions had to do with ‘promoting autism awareness.’ Well, it turns out that ‘autism awareness’ is a phrase that these people, and a lot of other autistic people, too, really hate. They think it’s offensive, because what they want is autism acceptance, not autism awareness; because a main mission of Autism Speaks is to find a cure for autism, to get rid of it, and these people with autism say they don’t want to be cured, they just want to be who they are and to be accepted for being who they are. So then—”

“Who says autism is a bad thing?” Mara interjects in a tone of righteous indignation. “It sounds like this [Autism Speaks] organization is treating autism like cholera. 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. I mean, you can’t accept cholera; it’s a disease.

“You told me that a lot of people find this organization offensive,” Mara continues, “and honestly, you know, [from what you’ve said about it.] I do too. Awareness and acceptance are a lot different from each other. Yeah. Awareness means you know it’s there, but acceptance means you know it’s there and it’s not going to go away. Of course, you can’t accept something if you don’t know it’s there, so I guess we have to be aware of it and accept it. So if that organization’s thing is ‘Autism Awareness,’ maybe they should change it to ‘Autism Awareness and Acceptance.’ And honestly, curing autism doesn’t come in some kind of a pill or medication. And there is no cure. There really isn’t. It’s just there, wound into your personality.”

Mara has stopped spinning momentarily. Now she resumes. “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, and the people in those organizations like Autism Speaks, 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 spinnny chair and sometimes he spins around.”
"Which president? The President of the United States or the President of Autism Speaks?"

"Both of them," she fires back. "I'm sure they look around and see if their security guards are around, and if they see the coast is clear they just kind of silently spin around in their chair. They probably don't laugh like I do because the President doesn't laugh, or at least lots of people think that, but that's just another stereotype—but still. Spinny chairs. I *like* spinny chairs."

There is a brief pause in the conversation as Mara continues to spin.

"I like to talk a lot," she explains, "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. Mara 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."

"I have something else I wanted to say," Mara announces after another brief pause, resuming her spinning at the same time. "You know, I think there should be a type of therapy that involves spinny chairs. There should be a room where there are rows and rows of spinny chairs, and a bunch of people would file in and sit down, and they'd all talk to each other and say, 'I wonder what this new therapy is?' And then the therapist would walk in and tell everyone to be quiet, and then he or she would say, 'Now, spin around in your chairs really fast!' and everyone would at first be really skeptical, but then someone would try it, whirling around and around. They'd say, 'Hey, this is fun!' and everyone else would start to do it, and then the whole room would be spinning around and around, or at least to everyone in the spinny chairs. Or a therapy where everyone gets together and just types or writes stories together. When I'm bored or sad or stressed, I like to sit down, ignore everyone, and just write for hours on end.

"You know, when I hear about people saying people with autism aren't 'normal' and get surprised when we do things like use big words or do things they can't, I just think: We *are* normal. We learn things just like 'normal' people do, we talk when we feel like it to who we feel like talking to just like 'normal' people do, we play and dream and laugh and love just like 'normal' people do, even if we're too shy to admit it sometimes.

"Some of us have a few problems, but why do 'normal' people have to be the ones to 'fix' them?" Mara asks rhetorically, after which she instructs me to be sure to put scary quotes around each iteration of "normal" and around the word "fix" in the preceding section.

"Why are all the therapists 'normal' and we're not?" she adds. "In fact, the therapists should be people who used to have severe autism or Asperger's, or *whatever*, and then found out how to deal with their problems. Having a Ph.D. in psychology doesn't always
make you an expert."

“What about people like me,” I ask, “you know, who aren’t autistic but work with people who are?”

“Well, you people seem pretty nice,” Mara answers matter-of-factly, “and you seem to know what you’re talking about, so people like you would be pretty good for that role. But I still like the idea of doctors and stuff who have autism.”

We eventually return to the subject of the ensemble.

“…of course the Autism Ensemble [sic] is not a cure,” Mara tells me. “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.”

I ask her to elaborate on that last point.

“Well, what I mean is, a lot of famous people were autistic or Asperger’s or something,” she explains. “[My] Mom tells us that people like Einstein and Marie Curie and a bunch o’ other famous people had it. 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. (Once again, 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. What I meant by helping with the bad parts but not restricting the good parts is that Artism kind of helps with my anger issues without restricting my creativity, and that’s all I got to say.”

“Well, OK,” I venture, pausing and trying to figure out a way to get Mara to expand on that topic just a bit more. “I know we’ve been at this for a while, but can you just tell me a little bit more about how that works?”

“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.”

“Is that the most important one,” I ask, “the one about not being told you’re doing it wrong?”

“Yeah.”

“Why is that so important, not to be told you’re doing it wrong?”
"Because I’m told that every day. I want a break from it!” She laughs. “Spinny chairs! ... 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...."

"If Artism continues next year and you stay in the group," I ask, “what would you think about having an adult musician with autism join the band?"

“That would be good actually; it sounds pretty cool. I’d like that.” Mara pauses and redirects her attention. “I like spinny chairs, paper clips, wolves, and a bunch of other things.”

“What do you think it would add?”

“It would add to themselves and to us. It would be cool seeing an adult with autism in the group instead of just kids with autism. And the autistic adult would be happy to see so many autistic kids being happy too.”

“Are you an autistic kid or a kid with autism?”

“It doesn’t matter. It’s like asking a zebra, ‘Are you black with white stripes or white with black stripes?’”

“Would it be good to have kids who weren’t autistic in the group as well?”

“What do you mean?” Mara asks, looking perplexed, as though the question doesn’t even make sense. “Well, why not?!” she finally exclaims. “Does it matter? I mean, just because it’s called the Artism Ensemble doesn’t mean we only have to have autistic kids in there.”

“Did it ever bother you that that was the way it was?”

“No, not really. 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?”

**Concluding Thoughts**

I assume that the above questions posed by Mara back in August 2013—who cares whether or not we’re autistic, and why does it matter if we are—were meant to be rhetorical, though I cannot say that for sure (it did not occur to me at the time to ask her; ethnography is not an exact science). Either way, it seems worthwhile to briefly address them head on: who does care, and does it matter?

There are a great many people who do care about whether or not people are autistic. That interest and concern extends across myriad domains encompassing families, communities, societies, cultures, states, and nations; it cuts through countless spheres of scientific, medical, therapeutic, and critical inquiry and activity, and of social action and activism; it animates intersecting spheres of political endeavor, public policy, ideological debate, economic initiative, and educational philosophy, often in contentious ways.
And it does matter. It matters because the ways in which people think about and perceive autism, be those Autistic people or their neurotypical counterparts, greatly impact their life prospects and their quality of life, on many levels and in the most profound of ways. There is so much at stake, for so many, and the deceptively simple questions of “who cares” and “why does it matter” open a Pandora’s box of problematic complexities that can never be fully resolved to the satisfaction of all implicated and affected parties—not even close.

Yet for all that, a reasonable first step in the right direction is perhaps not so hard to take.

“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,” writes the Autistic self-advocate Julia Bascom in her foreword to the Loud Hands anthology (Bascom, 2012b, p. 10). If we were to approach such a premise, essentially a premise of neurodiversity, as the basic point of entry for whatever we do and however we think in and around the construct of “autism” and the human realities and potentialities that issue from it, how different everything would be. If we were to privilege listening to what our Autistic interlocutors had to say about what they think they need and what matters to them over acting on the assumption that our main responsibility is to change them “for the better” in accordance with the conventions of a pathology-based model of wellness and functionality, think how radically altered the landscape of therapeutic interventions might become. If we were to enter into every encounter presuming that the ostensibly disabled individuals with whom we are engaging are instead the leading experts at being who they are—and that that is a fine way to be rather than an impaired one—how different might our relationships take shape, personally, professionally, musically, and otherwise.

It is these kinds of epistemological positions, and the frames of possible action and perception that emerge from them, that I hope this article can in some small way inspire at the interlaced junctures of music therapy, ethnomusicology, disability studies, autistic self-advocacy, neurodiversity, and identity politics. In attempting to determine what the most productive and efficacious positions and frames might actually be, for all of us, I believe it will be helpful to keep in mind the following poetic words from wise-beyond-her-years Mara, this time drawn from a 2014 online chat she and I had almost exactly a year after the 2013 conversation upon which much of this article relies. Mara’s eloquence seems a fitting close to this piece, so I defer to her for the final word:

Living with Autism shouldn’t be hard
And we don’t want to make it hard
So even if you can’t
Just try to understand
That all we need from the world is acceptance, inspiration, and love.

Notes

[1] Though the approach of the present article represents a departure from my earlier published works on the ethnomusicology of autism in key respects, it offers aspects of continuity with those earlier publications (e.g., Bakan et al., 2008a, 2008b; Bakan, 2009)
[2] A note of explanation is in order regarding my use of phrases such as “Autistic individuals” rather than person-first constructions such as “individuals with autism,” as well as relative to my capitalization of “Autistic” in reference to particular individuals or groups of individuals (e.g., “the Autistic scholar Nick Walker,” “Autistic self-advocates Jim Sinclair and Elizabeth J. Grace”) but not of the words “autism” or “autistic” in more generic frames of reference (e.g., “autistic behaviors,” “symptoms of autism”). Both of these representational choices of language usage were inspired by the autistic self-advocacy literature. As Jim Sinclair, a pioneering Autistic self-advocate, writes in his essay “Why I Dislike ‘Person First’ Language,” “Saying ‘person with autism’ suggests that the autism can be separated from the person. But this is not the case....Autism is hard-wired into the way my brain works. I am autistic because I cannot be separated from how my brain works....[Moreover, saying] ‘person with autism’ suggests that even if autism is part of the person, it isn’t a very important part....[and finally, saying] ‘person with autism’ suggests that autism is something bad—so bad that it isn’t even consistent with being a person....It is only when someone has decided that the characteristic being referred to is negative that suddenly people want to separate it from the person” (Sinclair, 2012, pp. 223-24).

As for the capitalization of “Autistic” in reference to individuals or groups of individuals, this relates to the growing movement to regard Autistic people as members of a cultural rather than a pathology-defined group (see Straus 2013). The distinction between when to capitalize or not capitalize autism/autistic has not yet yielded a consistent model, even in the autistic self-advocacy literature and discourse community; my own practice in that regard is modeled after Silberman (2012). I should also mention that, like Elizabeth Fein (2012), I ultimately take a contextual approach to the identification of specific individuals or groups relative to the “autism/autistic” descriptors with which they are associated, whether by themselves and/or by others; not all people on the autism spectrum ascribe to the views of Sinclair or other Autistic self-advocates, and many do prefer person-first language constructions. Therefore, I attempt to use the specific language of identification preferred by the people about whom I am writing to the greatest extent possible.


[4] Ethnographic approaches to the study of autism have been developed extensively within the fields of cultural, linguistic, and psychological anthropology. Representative publications in the anthropology of autism include Bagatell, 2010; Brezis, 2012; Fein, 2012; Grinker, 2007 and 2010; Ochs et al., 2001 and 2004; Prince, 2010; Sirotta, 2010; Solomon, 2010; and Solomon & Bagatell, 2010.

[6] In addition to works cited elsewhere, the following are noteworthy for representing and promoting such perspectives, as well as for their respective critiques of more conventional medical/pathology-centered approaches: Biklen, 2005; Davidson & Orsini, 2013; Eyal et al., 2010; Hendriks, 2012; Murray, 2008; Nadesan, 2005; Osteen, 2008; Silverman, 2012; and Cascio, 2014.

[7] Of related interest, see Helen Loth’s article “How gamelan music has influenced me as a music therapist: A personal account” (Loth, 2006).

[8] Though funded by the National Endowment for the Arts, the grant was mainly administered by the Florida Department of State’s Division of Cultural Affairs. Additional support and resources have been provided by the Florida Council on Arts and Culture, the Remo percussion instrument company, the Council on Culture and Arts for Tallahassee/Leon County (COPA), the Tallahassee Youth Orchestras, and the College of Music, College of Medicine, Autism Institute, and Center for Autism and Related Disabilities at Florida State University.

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

[10] Video footage from Artism Ensemble concerts or rehearsals featuring compositions by some of its child members include the following: “Purple eggs and ham,” by Mara C., at [http://www.youtube.com/watch?v=C1tqzvA96-E]; “Joobai I” by E.S., at [http://www.youtube.com/watch?v=2ZVHiDQJLJo]; and “Steel percussion,” by NICKstr, at [http://www.youtube.com/watch?v=SjkrjHf_cSI]


[12] 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.

[13] Straus’s essay appears in the fourth edition of The Disability Studies Reader (Davis, 2013), which is an excellent primer on the field of disability studies.

[14] The child’s parent was present, though was not in the room 100% of the time. The level of trust and familiarity we had built was such that the parent felt comfortable being
on hand but stepping out occasionally to check phone messages, etc.

References


Grandin, Temple, & Panek, Richard. (2013). The autistic brain: Thinking across the


