

The Musicality of Stimming: Promoting Neurodiversity in the Ethnomusicology of Autism

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Abstract: In the symptomatology of autism spectrum disorders (ASDs), the practice of “odd, unusual, or repetitive behaviors” such as hand flapping and body rocking is referred to as stimming (Hammel and Hourigan 2013: 75). Stimming is routinely cast as problematic and targeted for reduction or elimination in therapeutic modalities for autistic individuals, including music therapy. In an alternate frame of reference grounded in the epistemological foundations of neurodiversity, however, stimming is subject to a very different kind of interpretation in which such behaviours are embraced as productive, communicative, pleasurable and even socially valuable for those who perform them—as manifestations of difference, not symptoms of deficit. This mode of interpretation forms the basis of the present article, which highlights the words and views of a 10-year-old girl on the autism spectrum who plays music and stims, and which more broadly draws upon theoretical and methodological premises of ethnomusicology to advance a neurodiverse perspective on autism.

Résumé: Dans la symptomatologie des troubles du spectre autistique (TSA), les « comportements étranges, inhabituels ou répétitifs » tels que les battements de main ou le balancement du corps sont appelés gestes répétitifs ou stimming (Hammel et Hourigan 2013 : 75). Ces gestes répétitifs sont le plus souvent considérés comme problématiques et les modalités thérapeutiques, y compris la thérapie musicale, s’efforcent de les réduire ou de les éliminer chez les individus autistes. Mais dans un cadre de référence alternatif, issu des fondements épistémologiques de la neurodiversité, les gestes répétitifs font l’objet d’une interprétation totalement différente, à savoir que ces comportements sont considérés comme productifs, communicatifs, sources de plaisir, voire même comme ayant une valeur sociale pour ceux qui s’y livrent, en tant que manifestations de la différence et non comme symptômes d’un handicap. Ce mode d’interprétation constitue la base de cet article qui souligne, sur le spectre de l’autisme, les mots et les points de vue d’une petite fille de dix ans qui joue de la musique et fait des gestes répétitifs ; cet article, plus largement, se fonde sur les prémisses théoriques et méthodologiques de l’ethnomusicologie pour proposer un nouveau point de vue sur l’autisme, incluant la neurodiversité.

January 31, 2011. Tallahassee, Florida. 10-year-old Zolabeen sits in a chair staring blankly at the wall, flapping her hands, repeatedly straightening and bending her legs. Occasionally she looks down and twists and pulls on her fingers; sometimes she stands up and paces, stiff-legged, around the room.

The behaviours she performs align well with a diagnosis that she has received, a diagnosis of a so-called ASD, or autism spectrum disorder, called Asperger's Syndrome. Her flapping, her leg movements, her pacing and finger twisting—all of these fit neatly into a symptomatic profile of autistic stereotypy, or self-stimulatory behaviour. Within this symptomatic rubric, Zolabeen may be said to be “engaging in odd, unusual, or repetitive behaviours, known as ‘stimming’” (Hammel and Hourigan 2013: 75). In an alternate frame of reference grounded in the epistemological foundations of neurodiversity and autistic self-advocacy, however, what she is up to as she stims is open to an entirely different kind of interpretation.

Neurodiversity, as defined by the Autistic¹ self-advocate Nick Walker, is “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: 233).² Conceptualizing and framing autism in such terms facilitates an adoption of what Walker calls the *neurodiversity paradigm*, wherein variation in the configuration and functioning of human brains and minds is regarded as “a natural, healthy, and valuable form of human diversity” (Walker 2012: 228). This is in contrast to the long-dominant *pathology paradigm*,³ which insists on a “right,” “normal” or “healthy” way for human brains and minds to be configured and to function, and claims that substantial divergence from this dominant “normal” standard equates with the blanket assessment that there is “Something Wrong With You” (Walker 2012: 227—caps in original).

Walker asserts that neurodiversity should replace pathology as the guiding paradigm for discourse, research, public policy and social action relating to autism and Autistic people. Here I adopt that stance within the context of an ethnomusicological consideration of stimming as a manifestation of autistic neurodiversity rather than a symptom of autistic disorder. I define ethnomusicology as the study of how people make and experience music, and of why it matters to them that they do. Moving toward understanding and appreciating stimming in ethnomusicological terms is this article's primary objective. It is ultimately through Zolabeen's own words, presented in a dialogue transcript that appears toward the end of the work, that this objective is most fully realized.

“What Is Autism?”

It is at this point that custom dictates I should introduce autism and the autism spectrum in terms of the traditional tropes of disability, disorder and impairment—and of lack, loss and tragedy—that are by now so common and familiar. That is what people who write scholarly journal articles about autism and ASD are generally expected to do, and it is what I have done in several single- and co-authored articles on the ethnomusicology of autism dating back to 2008 (Bakan et al. 2008a, 2008b; Bakan 2009; Koen et al. 2008).

I will fulfill the expectation here as well, but with a twist, for in presenting a “What is Autism?” framework from which to proceed, I will rely not on information provided by standard medical/scientific sources such as the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5) (American Psychiatric Association 2013), the Centers for Disease Control and Prevention (CDC 2014), or the National Institutes of Health’s (NIH) National Institute of Neurological Disorders and Stroke (NINDS 2014), as I have in other of my writings, but will instead employ a 2014 “What Is Autism?” introductory piece written by the Autistic author and scholar Nick Walker.⁴ Walker is a prominent figure in both the autistic self-advocacy and neurodiversity movements. The epistemological stance of the present article derives its principal points of orientation from these movements, as shall soon become clear, and it is therefore appropriate to commence this venture into the ethnomusicology of autism from such a vantage point.

Walker’s prefatory remarks to his “What is Autism?” blog post are important to include here as well, for they contextualize the thorny epistemological and ideological terrain of his contentious subject while implicitly supporting the anthropologist and autism researcher M. Ariel Cascio’s claim that the neurodiversity movement “takes an identity politics approach to autism spectrum disorders” (Cascio 2012). Walker writes:

I’ve seen so many versions of that obligatory “What Is Autism” or “About Autism” text. And they’re almost all terrible. For starters, almost all of them—even the versions written by people who claim to be in favor of “autism acceptance” or to support the *neurodiversity paradigm*—use the language of the *pathology paradigm*, which intrinsically contributes to the oppression of Autistics.

On top of that, most of these descriptions of autism—even many of the descriptions written by Autistics—propagate inaccurate information and false stereotypes. Some are so bad

that they actually quote the DSM.

What is needed is some good basic introductory “What Is Autism” text that is:

- 1.) consistent with current evidence;
- 2.) not based in the pathology paradigm;
- 3.) concise, simple, and accessible;
- 4.) formal enough for professional and academic use.

Since I couldn’t find such a piece of text elsewhere, I wrote one ... [which] I hereby give everyone permission to reprint, ... in whole or in part, whenever you need a piece of basic “What Is Autism” or “About Autism” text. (Walker 2014)

Here, then, in its entirety, is Walker’s “What Is Autism?” piece:

Autism is a genetically-based human neurological variant. The complex set of interrelated characteristics that distinguish autistic neurology from non-autistic neurology is not yet fully understood, but current evidence indicates that the central distinction is that autistic brains are characterized by particularly high levels of synaptic connectivity and responsiveness. This tends to make the autistic individual’s subjective experience more intense and chaotic than that of non-autistic individuals: on both the sensorimotor and cognitive levels, the autistic mind tends to register more information, and the impact of each bit of information tends to be both stronger and less predictable.

Autism is a developmental phenomenon, meaning that it begins *in utero* and has a pervasive influence on development, on multiple levels, throughout the lifespan. Autism produces distinctive, atypical ways of thinking, moving, interaction, and sensory and cognitive processing. One analogy that has often been made is that autistic individuals have a different neurological “operating system” than non-autistic individuals.

According to current estimates, somewhere between one percent and two percent of the world’s population is autistic. While the number of individuals diagnosed as autistic has increased continually over the past few decades, evidence suggests that this increase in diagnosis is the result of increased public and professional awareness, rather than an actual increase in the prevalence of autism.

Despite underlying neurological commonalities, autistic individuals are vastly different from one another. Some autistic individuals exhibit exceptional cognitive talents. However, in the context of a society designed around the sensory, cognitive, developmental, and social needs of non-autistic individuals, autistic individuals are almost always disabled to some degree—sometimes quite obviously, and sometimes more subtly.

The realm of social interaction is one context in which autistic individuals tend to consistently be disabled. An autistic child's sensory experience of the world is more intense and chaotic than that of a non-autistic child, and the ongoing task of navigating and integrating that experience thus occupies more of the autistic child's attention and energy. This means the autistic child has less attention and energy available to focus on the subtleties of social interaction. Difficulty meeting the social expectations of non-autistics often results in social rejection, which further compounds social difficulties and impedes social development. For this reason, autism has been frequently misconstrued as being essentially a set of "social and communication deficits," by those who are unaware that the social challenges faced by autistic individuals are just by-products of the intense and chaotic nature of autistic sensory and cognitive experience.

Autism is still widely regarded as a "disorder," but this view has been challenged in recent years by proponents of the neurodiversity model, which holds that autism and other neurocognitive variants are simply part of the natural spectrum of human biodiversity, like variations in ethnicity or sexual orientation (which have also been pathologized in the past). Ultimately, to describe autism as a disorder represents a value judgment rather than a scientific fact. (Walker 2014)

Ethnomusicology, Autism and Neurodiversity

In writing about Balinese people and their music earlier in my ethnomusicological career (Bakan 1999), I did not focus on their impairments or deficits. I assumed them to be experts at being who they were, and at being Balinese, and I assumed that their ways of being, of living, and of making music, culture, and community were reflections of this expertise. To do otherwise would have

been an affront to the most basic tenets of my discipline; it would have defied the most foundational ethnographic priorities of humanistic relativism.

The assumptions from which I operate today in relation to Zolabean and the other Autistic people with whom I play music and make ethnomusicology are essentially the same: they are experts at being who they are and thus at being Autistic. I regard their characteristic ways of being and thinking, of doing and musicking, not mainly in terms of disorder and disability but rather in terms of agency and culture and community. They are the culture-bearers of the musical communities we have collaboratively forged.

This position places me in close alignment with a small but growing cohort of music theorists and musicologists who have written on music and autism from related vantage points. The pioneering edited volume *Sounding Off: Theorizing Disability in Music* (Lerner and Straus 2006) includes three such contributions in the form of chapters by Dave Headlam (2006), S. Timothy Maloney (2006), and Stephanie Jensen-Moulton (2006), respectively. As Headlam astutely observes in his chapter, entitled “Learning to Hear Autistically”:

... although autism is typically seen as a defect, evidence from the writings and lives of autistic people suggests that, on the contrary, autism may be better understood as a culture. One of the defining attributes of this culture is the role of music.... autistics hear and conceive of music in distinctive ways that differ significantly from the ways in which music is heard and understood by people who are *neurologically typical* (NT). I suggest that trying to understand this distinctive approach to music—learning to “hear autistically”—may be an enriching experience for all of us.... (Headlam 2006:110)

Joseph Straus, in his essay “Autism as Culture” (2013), broadens the framework of Headlam’s autistic hearing idea to propose the existence of a distinctive “autistic cognitive style” that he situates within an epistemological framework of neurodiversity.⁵ Straus explicitly connects the theoretical premise of neurodiversity to an affirmative and culture-centered approach to scholarship on autism. He writes:

Using the concept of “neurodiversity” as a point of departure ... I will explore features of a distinctively autistic cognitive style and creative imagination. I will seek to understand autism as a way of being in the world, a world-view enshrined in a culture: to echo a

familiar rallying cry from the disability rights movement, autism is a difference, not a deficit. (Straus 2013:467)

The positions of Straus, Headlam and other music scholars who have approached the subject of autism from kindred perspectives⁶ speak both to the growing influence of the neurodiversity movement per se and to broader shifts in the epistemological landscape of autism discourse more generally. So too does the work of a range of scholars in other disciplines, such as disability studies and anthropology, whose approaches to the study of autism have likewise been either explicitly or implicitly directed toward neurodiverse orientations.⁷

Neurodiverse perspectives, as well as studies investigating the neurodiversity phenomenon itself, have even begun to appear in articles published in the kinds of peer-reviewed medical, scientific and social science journals that were formerly resistant to the inclusion of such work (Griffin and Pollak 2009, Cascio 2012, Jaarsma and Welin 2012, Lorenz and Heintz 2014). Especially noteworthy in this area of literature is the article “Deficit, Difference, or Both? Autism and Neurodiversity,” published in the journal *Developmental Psychology* (Kapp et al. 2013). The lead author, Steven Kapp, is an Autistic educational research psychologist with close ties to the Autistic Self Advocacy Network (ASAN), the foremost autistic self-advocacy organization. He and his co-authors conducted online survey research with 657 participants focusing on how the “neurodiversity movement challenges the medical model’s interest in causation and cure, celebrating autism as an inseparable aspect of identity.” Their findings suggest “a deficit-as-difference conception of autism wherein neurological conditions may represent equally valid pathways within human diversity” (Kapp et al. 2013).

Such a conception is foundational to the basic stance taken by Julia Bascom in her Foreword to the anthology *Loud Hands: Autistic People, Speaking*, which was published in 2012 and arguably stands as the most important compilation of writings by Autistic authors published to date.⁸ “It starts with the basic, foundational idea that *there is nothing wrong with us*,” writes Bascom. “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 2012: 10). Expanding on this premise in his contribution to *Loud Hands*, Steve Silberman eloquently problematizes and nuances Bascom’s frank assertion:

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 deserve an education, access to communication, and a place in society as we become adults. We deserve to live without fear of being abused, manipulated, or hurt.... Because we are disabled to varying degrees and in multiple ways, we need support, services, and accommodations to successfully navigate a world not made for us ... [and] we are usually the people who can best define what types of support and services we need, especially once we become adults ... 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: 364-65)

The voices and perspectives of autistic self-advocacy and neurodiversity proponents such as Walker, Bascom and Silberman are important, compelling and persuasive, but they cannot be said to speak for all Autistic people, let alone for other stakeholders in autism-related discourses, policies and priorities. Despite my realization of that fact, I privilege such voices and perspectives here. To acknowledge this is to acknowledge a limitation in the purview of this article. Underrepresented or entirely absent from the discussion, for example, are the voices of individuals on the autism spectrum who contest, and in many cases even resent, the “we are fine”-type proclamations of Bascom and others; of non-verbal Autistics on whose behalf their more verbally adept counterparts cannot unequivocally claim the right to speak; of family members, teachers, colleagues, therapists (including music therapists⁹), physicians, and researchers who live and work closely with Autistic people and are themselves deeply invested in the Autistic community; and of the many individuals who have been diagnosed with autism spectrum conditions who regard the “autistic” aspects of their beings as subordinate and peripheral to others, and who may regard the entire project of “autistic self-advocacy” in its current guise as fundamentally

flawed due to what they perceive as the essential (and essentialist) narrowness of its purview.

Autism and the autism spectrum are extremely complex, and in privileging neurodiversity over pathology and autism acceptance over autism treatment as I do here, the nuances of this complexity are inevitably compromised. This is a compromise I am willing to make, however, for I am firmly of the conviction that unless non-Autistic people start from a premise of accepting rather than pathologizing Autistic people, and of listening to and engaging with them rather than trying to “fix” or “improve” them, the right kinds of progress are not likely to be achieved.

Zolabeen Stims, Artism Plays

To return now to our main story, Zolabeen is stimming, and as she does so the people around her are making music—fun, uplifting music, improvised but with a compelling Afro-Peruvian *festejo* groove. There are about 18 players taking part in all: adult professional musicians, adult “non-musicians” with no formal musical training or background and five children ranging in age from 7 to 14. Three of the children are girls: Zolabeen, Maya and E.S. Two are boys: NICKstr and Coffeebot (these are all stage names that the children chose for themselves). All of the children have some kind of an autism spectrum diagnosis; none of the adults do. The “non-musician” adults are parents of the participating children, while the professional musicians are a mix of music students and faculty members from Florida State University (FSU) and Florida A&M University who have variously found their way to Tallahassee from points of origin far and near: China, Peru, Bolivia, Atlanta.

This is the first time that all of the members of this eclectic band have ever come together, though the planning for this moment has taken months, in a certain sense years. What we are all experiencing as an emergent musicultural community (Bakan 2012) on this late January 2011 evening in Tallahassee is the inaugural gathering of the Artism Ensemble. Buoyed by a grant funded by the National Endowment for the Arts and administered by the Florida Department of State’s Division of Cultural Affairs, and additionally aided by various forms of support from FSU, Remo Inc. and the Council on Culture and Arts for Tallahassee/Leon County (and in later years by the Tallahassee Youth Orchestras as well), Artism has finally become a reality.

I am not the director of the Artism Ensemble per se, but I am its *de facto* ringleader. The group represents the latest phase in a longstanding project on the ethnomusicology of autism with which I have been involved. Following

in the wake of an earlier program, the Music-Play Project (MPP), which ran from 2005-2009 and yielded a series of publications (Bakan et al. 2008a, 2008b; Bakan 2009; Koen et al. 2008), this new Artism Music Project has been conceptualized with the intent of taking applied ethnomusicological work with Autistic people in a new direction. Where MPP was about using music-play activities to address challenges of autism faced by children on the spectrum and their families, Artism is to be a *bona fide* performing band. We are going to go out in public and play concerts, and promote autism acceptance by giving people an opportunity to see kids who are on the spectrum not as disabled individuals or tragic figures, but rather as the caring, creative, socially engaged, resourceful and fun-loving people they are.

Artism is about music and community and ability, not therapy and isolation and disability. It is about letting people be who they are, not trying to measure their aptitudes and change them in ways that will make them more “normal” or “acceptable” in the eyes of others. It is the children in the group who are in charge. There is no specific musical repertoire to be learned, no set musical standards to be achieved, other than whatever ones *they* may choose to enlist or define. Through their improvisations and their compositional ideas, the children will lead and guide the rest of us. This is their musical space, their musical culture. They are the experts, the leaders; the rest of us are there to nurture and support, to inspire and to be inspired.

All of the children in the Artism Ensemble are alumni of the Music-Play Project. There they operated in a quasi-clinical “play-lab” environment within the context of a research study. Here they are instead true members of the band, co-creators of an emergent community of music-makers that has essentially been built in advance to form around them in the present. From an ethnographic perspective, it is an undeniably peculiar entity, this Artism community, for it is a community in which the designated “cultural insiders” are the children, despite the fact that they themselves did not organically form it. Skeptics might say that it is a fabricated or contrived community, not an “authentic” one, but the alternate view is that in its becoming it becomes real. If the children take ownership of what is happening, if they are invested in it, if it matters to them and they actively contribute to the making of its cultural world, then this community is as real as any other (cf. Turino 2008: 155-58).

As I look around the room, that kind of investment and ownership are what appear to be unfolding. The children, moving freely around an array of percussion instruments and playing whichever ones they want to however they want to, are finding spontaneous and beautiful common ground with the professional musicians, some of whom, like me, are also playing percussion

instruments, others of whom are playing other instruments: guitars, electric bass, flute, *zheng*, didgeridoo. The parents, too, are finding their place in the musical proceedings. Some are vigorously mixing it up with the rest of us as neophyte percussionists. Others are laying back but still contributing actively through their more reserved participation.

It is working, this ambitious experiment in forming a band that is founded on and celebrates neurodiversity. This intergenerational, intercultural, intermusical and inter-neurophysiological group of people is connecting, enjoying being with one another, reveling in the excitement of new opportunities and good musical sounds that this E-WoMP, or Exploratory World Music Playground, environment we have concocted provides. To a man and woman, to a boy and girl, everyone is basically in sync.

Everyone except Zolabean, that is.

And the odd thing there is that prior to the present moment, Zolabean had been my odds-on favourite of all of the five children participating to thrive here. She was a star of the Music-Play Project back in 2009, an active and innovative musical player, a leader on many occasions as well. Back then, she was consistently on task; back then, she rarely stumped, and if she stumped at all it was only for fleeting moments.

Zolabean's mother, Suzanne, has conveyed to me on a few different occasions in recent weeks—in emails, on the phone—that Zolabean is “very excited” about this new Artism project. I learn from Suzanne that Zolabean has been playing guitar at school a lot lately, developing a real musical sensibility and identity. She can't wait to play with a “real band,” with “real musicians” in Artism; she is convinced that this is going to be a big step up music-wise from the free, unstructured “music-play stuff” we did in MPP.

So then why is she sitting there staring off into space? Why is she not playing instruments like the other kids are? Why is she stumping all the time? What accounts for this apparent regression vis-à-vis her autism, or Asperger's, or whatever we may choose to call it?

Maya Spins

Skip ahead briefly to August 2013. I am in my office at the university conversing with another member of the Artism Ensemble, 12-year-old Maya. We are talking about her experiences in the group specifically, and of living with autism generally. Maya is certainly engaged in the conversation, but as we broach a variety of interesting topics and issues, she incessantly spins round and round and round again in a black office chair.

“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 Maya, 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?*” Maya asks, seemingly confused. “What *is* that?”

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

Maya laughs harder now.

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

There is a brief pause in the conversation as Maya 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. Maya stops spinning, leans forward, and points to the spot on my computer monitor where I have just transcribed her last remark.

“Just say that I said that sarcastically,” she insists. “I don’t want to offend the President.”

Stimming, Officially Speaking

“Stereotypy or self-stimulatory behavior refers to repetitive body movements or repetitive movement of objects,” writes the autism researcher Stephen M. Edelson in a brief article on the subject posted on the website of the Autism Research Institute. “This behavior is common in many individuals with developmental disabilities; however, it appears to be more common in autism” (Edelson n.d.). Edelson goes on to list a variety of common stims, including hand flapping, rocking side-to-side or front-to-back, and smelling or

licking objects. He concisely outlines several theories pertaining to causality: some studies suggest that stereotypy occurs in response to under-stimulation (hyposensitivity); others indicate that it is a response to over-stimulation (hypersensitivity).

Either way, Edelson writes, the underlying issue has to do “with some dysfunctional system in the brain or periphery,” and research has shown that “stereotypic behaviors interfere with attention and learning.” He does acknowledge that “Interestingly, these behaviors are often effective positive reinforcers if a person is allowed to engage in these behaviors after completing a task.” Beyond that, however, stereotypy is essentially cast as symptomatic, as a problem to be treated therapeutically with the intention that it be eliminated, or at least diminished: “There are numerous ways to reduce or eliminate stereotypic behaviors, such as exercise as well as providing an individual with alternative, more socially-appropriate, forms of stimulation ...” (Edelson n.d.). That such goals of treatment are desirable is assumed, and the assumption is rarely brought into question in such discursive contexts.

Good Stimming

But should the endeavor “to reduce or eliminate stereotypic behaviors” even be seen as a goal, as has generally been assumed? Perhaps not, at least in the vast majority of situations in which stimming takes place, that is, in situations that pose no risk of harm or injury to either the stimmer or anyone else. There is a growing sentiment, especially among neurodiversity proponents, Autistic self-advocates, and anthropologists specializing in the study of autism, that stimming is not problematic at all, that there is nothing socially inappropriate or undesirable about it. This is the position advanced by the anthropologist Nancy Bagatell in her ethnographic study of “a group run by and for adults with autism” to which she ascribes the pseudonym AACT (Autistic Adults Coming Together). Bagatell writes 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 [of AACT] 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)

Stimming is presented in Bagatell's work as a valuable mode of self-expression, a powerful vehicle for deep and meaningful communication, and a bridge to forming friendships and establishing communities. This position is echoed by Autistic self-advocates such as Jim Sinclair, who has written that "interactive stimming" is a key dimension of "autistic socializing" (Sinclair 2012: 25-26). Though not identified as such, interactive stimming is essentially what Oliver Sacks seems to have observed and appreciated back in the 1990s, too, when he wrote of an "autistic family" he had visited in California, "the B.'s," that enjoyed nothing better than to "jump and flap their arms" together on their well-used trampoline in the backyard (Sacks 1995: 275-76).

From such vantage points, stimming is seen as a good thing, a positive thing. But as I watch Zolabean stimming during our first Artism session back in 2011, I am as yet unaware of such positive glosses on stimming, or indeed of the autistic self-advocacy or neurodiversity movements altogether. To my eyes, There is Something Wrong with Zolabean, and this perception puts me in a conflicted place. On the one hand, I am committed to the idea—to the Artism philosophy—of letting her be who she is on her own terms, but on the other hand I am perplexed and disheartened by her evident "autistic regression." Why must she just sit there staring blankly, stimming, pacing about, ever so occasionally "joining in" when prompted by other members of the group to play on instruments, but always for just a brief moment and in lackluster fashion before lapsing back into detachment and self-isolation? Why can't she get with the groove like everybody else? These are thoughts and desires that I do not want to be having, but I am having them nonetheless.

An Apparent Contradiction

There is more to consider as well, an apparent contradiction, for while the symptomatic profile of autistic stereotypy unfolding before my eyes seems crystal clear, it is complicated and confused by Zolabean's equally explicit projection of poise, calmness, and contentment, which contrasts markedly with what I recall of her from 2009, when she was certainly "competent" musically and even socially, but often seemed anxious and on edge, and rarely smiled. Now she looks "spacy" and preoccupied, but she is *smiling* throughout almost the entire session, and her smile is gentle and comforting; it is the smile of a girl who is basically feeling happy and at ease, both within herself and within her surrounding environment. I cannot make sense of this.

The session ends. A week passes. Another Monday evening Artism session arrives, but this time Zolabean and her mother, Suzanne, do not. I have

heard nothing from them in the interim. I am disappointed, but not surprised. I assume that they have dropped out of the program and just haven't gotten around to letting me know that yet.

But the following week, they are back again. It happens to be Valentine's Day.

This session unfolds much like the first one for Zolabean. She spends most of her time stimming and staring off blankly. She only very occasionally plays on any of the E-WoMP instruments. When she does, it is always because someone—typically either one of the other adults or I—has coaxed her into it. Her playing never lasts for more than a few seconds at a stretch, and it is always lethargic. It is in those instrument-playing moments, pretty much exclusively, that Zolabean appears *not* to be happy or content, that her peaceful, contented smile disappears.

The session ends and as everyone is packing up the instruments, Suzanne approaches me and asks whether she, Zola and I can step outside for a moment to discuss something important. We certainly can, I reply.

Zolabean stands beside her mother, mainly looking down, while Suzanne speaks to me on her daughter's behalf. Suzanne explains that both in the session that just concluded and in the first one a couple of weeks ago, Zolabean felt "very stimulated, in a positive way," by the music. She was especially excited by the virtuosic guitar playing of "the two Carloses" (Odría and Silva) and the captivating sounds of the zheng as played by our resident virtuoso Deng Haiqiong (an internationally renowned performer on the instrument). Suzanne tells me that on the car ride over, Zolabean told her that she *was* really enjoying the sessions, but that she wanted to just listen and respond to the music "in her own way." For now, at least, her own way was about hand-flapping, finger twisting, and pacing; it was not about playing instruments. Moving in these ways was simply what Zolabean did with her body when she was excited. It was not a sign of stress or distress. It was *positive*, not negative.

Zolabean accepts all of this as "perfectly fine," Suzanne continues. She doesn't judge it. She feels she has the right to be herself as she wishes to be, especially in this Artism environment where that is supposedly what we're all about anyhow. Suzanne admits that her initial impulse was to "correct" Zolabean when she engaged in these kinds of behaviours, but that she has come around; she accepts Zolabean's resolve to do things her own way.

So what Zolabean wants, Suzanne says, what she needs, is for me and everybody else in the group to let her be. Don't hand her instruments and encourage her to play, as many of us have been doing. Don't look at her quizzically when she flaps or twists her fingers or paces about.

Is this okay, Suzanne asks. Zolabean looks up at me too. Is it possible?

It's definitely okay, I respond, self-conscious in the realization that this is how we should have been running things all along, that I thought we had been but in actuality we hadn't, that were it not for the courage of Zolabeau and Suzanne to confront me on the matter and keep me in check, I might never have figured out how big the divide between my theory of Artism and my practice in Artism actually were.

I call everyone over at the beginning of the next week's session and say that Zolabeau has made a request of all of us that I am now going to pass along to the group. Zolabeau has her own way of being in the band, I explain, and that generally involves moving in certain ways rather than playing instruments. If she wants to play instruments, she will, but if she doesn't, she won't, and that is totally fine. Let her do things her way; don't hand her instruments or coax her to play. For her, and for all of us, having that kind of freedom is really important.

It works. Everyone in the group, from the kids to the parents to the professional musicians, is respectful of the request and Zolabeau seems freed by the shift. Her stimming becomes more fluid and expressive; her self-consciousness seems to melt away. And by the middle of the following week's session, she is actually playing instruments too, even creating and directing an arrangement of her own—a clever rendering of the Beatles' "A Hard Day's Night" in which she leads the ensemble on steel pan (steel drum). As the weeks pass, her active musical involvement as an instrumentalist, composer, and arranger continues to grow, but so too does her active involvement *with* the music through stimming. It is clear that for Zolabeau, neither mode of participation is superior nor inferior to the other; they are just different ways of being engaged, each preferred at different times for different reasons. I embrace both, too, though the matter of the reasons behind Zolabeau's choices remains largely a mystery to me.

Reasons

The Artism Ensemble's inaugural season concluded in April 2011 with a concert at FSU. Zolabeau's "A Hard Day's Night" arrangement was a highlight of the show, as it had been of two earlier concerts we played as well. In the ensuing months, I organized a series of one-to-one sessions with the participating children and their families at their homes. These sessions, which ran from two to three hours each in length, provided opportunities for music making and interesting conversations. They often included introductions to siblings and other family members, especially pets. The kids opened up about their diverse

interests and passions, which ranged from video games, Transformer action figures, model trains, dogs, and cats, to classical piano, Indian and African musics, dreams of rock stardom, and Chinese cultural history.

We also talked about challenges that life brought—at school, in therapy sessions (speech, occupational, etc.), in organized activities like team sports, in the course of dealing with puberty—and in some cases the children spoke with me candidly on the subject of autism and their experiences living with it, or at least living with the label of it. Common themes emerged across multiple sessions: feeling lonely, being sad that “everyone at school thinks I’m weird,” feeling beaten down by frequent experiences of being ignored and misunderstood, righteous indignation toward classmates, teachers, siblings and parents who just didn’t seem to “get it” and who so often mistook intelligence and insight for weirdness or cluelessness, incredulity toward other people—children and adults alike—who seemed incapable of grasping “the most obvious things,” like that you should always be honest and tell the truth, possibly even if that means hurting other people’s feelings.

Sometimes “having autism” was no big deal, other times it was a very big deal indeed. Overall, though, the message that came through most loudly and clearly from many corners was that these kids were quite comfortable being who they were, the way they were most of the time, but were very uncomfortable with the fact that other people so often seemed uncomfortable around them, let alone willing to accept and include them in their social circles and activities. Actual exclusion and the fear of it (every bit as powerful as the real thing) frequently led them to feel anxious, sad and full of self-doubt, and additionally contributed to a general penchant for harsh self-judgment.

As for what they wanted, a common thread running through multiple conversations highlighted the children’s desire to have their “difference”—whether stemming from autism or not—recognized as “something different than undesired difference,” to borrow a phrase from the disability studies scholar Tanya Titchkosky (2007: 9). Their views and opinions made sense to them, but it was deflating—and ultimately exhausting—to again and again find themselves in situations where no one seemed to hear what they were saying, or perhaps more precisely, where nobody seemed to really be listening most of the time. The frustrations experienced by these children on this level echoed those expressed by many of the Autistic adults with whom Nancy Bagatell spoke during her research. Bagatell notes that her consultants generally seemed to be “particularly interested in my desire to hear their narratives. Many of the participants mentioned to me that no one, including professionals and researchers, had ever asked to hear their stories but were more concerned with uncovering deficits” (Bagatell 2010: 44). From Bagatell’s anthropological

vantage point, and likewise from my ethnomusicological one, this constitutes a highly problematic state of affairs.

Zolabean Speaks

Ethnography is first and foremost about listening, and it is from listening to the people whose lives, cultures, musics and the rest we endeavor to understand that we learn more than anything. The following transcript of a conversation involving Zolabean, her mother Suzanne and myself (with a cameo appearance by Zolabean's younger brother, Roger) is a case in point. The conversation took place at Zolabean's home on May 19, 2011. In its course, Zolabean, through her narrative, effectively overturns several sacred cows of autism research. Her story enables new horizons of perspective and understanding: "performing well" is here revealed as a charade masking anxiety and thwarting agency; a classic "symptom" of autism, stimming, is revealed as a powerful expression of musical and social engagement, as well as of cultural co-creation; and ostensible manifestations of autistic forms of self-absorption and social withdrawal are recast as poignant manifestations of a process of cognition and narrative construction that is as intensely social and integrative as it is imaginative and artistic.

Michael (M): So, let's talk about Artism for a minute.

Zolabean (Z): Okay.

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.

M: When you were in the Music-Play Project?

Z: ... The very first one [MPP 2009], yes. 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. And I was kind of scared because this one boy's mom had, like, really gross, like, acne on her face, and it scared me to death.

M: Wow!

Z: And, like, a bad sunburn. Her skin looked like leather, and it just really made me feel sick. . . .

Suzanne (S): I thought [the reason you didn't play in Artism at first] was because with the addition of the other musicians and instruments, that it was *so* stimulating to you that you just couldn't [Suzanne is cut off mid-sentence as Zola jumps in excitedly].

Z: Oh, I have an explanation for that.

S: Ohhh!

Z: During the Artism project [Zolabeen 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 diagnoseses [*sic*].

S: Umm-HMM. Have they always? Because I know you've had these characters in your head for a very long time.

Z: Yes, yes . . . Well, the thing is there's kind of like a lot [of characters].

S: Oh *real-ly*? [chuckles]

Z: Yeah, there's this one band of brothers and there are, let me count [pauses, counts in her head] ten of them. And I have a few other bands of brothers who they, like, play with.

S: You mean, like, bands, like music bands.

Z: No, no.

S: Oh. Just bands of brothers.

Z: Yeah.

S: Gotchya.

Z: 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: Ah, very cool.

Roger: And one of them on the sitar, and one on that weird Chinese instrument.

Z and S (in spontaneous unison): The zheng.

(Roger impersonates Haiqiong playing the zheng.)

S: That thing's cool! I was spellbound by [Haiqiong's] performance . . . just watching her play and how much she loved it and all.

Z (animated and smiling): She's, like, amazing. She, like, goes into a trance and goes [Zolabeen does a semi-comical impersonation of Haiqiong playing the zheng; she plucks the imaginary zheng's

strings animatedly, looks upward with half-closed eyes and a trance-like expression, and partially sticks out her tongue. Suzanne, Roger and I laugh.]

S: Yeah, it was really beautiful to watch *and* listen to...

Z: So did she [Haiqiong] really grow up, did she grow up in China?

M: Yeah, she did.

Z: You know, the whole time I was there I was fighting an urge to ask her a million questions about back when she was [in] China, how much she knew about Tiananmen Square.

M: Oh!

Z: I was desperate to ask her, "Have you ever seen the famous picture of Tiananmen Square where there's a guy jumping on a tank? Have you?" [Zolabeen gets very excited and starts to bounce up and down in a "stimming" manner, then freezes in a still position.] ... Well, I thought it might be rude [to ask]...

M: [So] we were talking about how at the beginning [of Artism], how you didn't really play much, and now you've explained that 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. So just sort of take me through the process of how the whole Artism project unfolded for you and what it's done for you, good, bad or otherwise.

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

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

"Okay," I say to Zolabeen. "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 Zolabeau, 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 okay for her to have characters in her head, that it's okay for them to merge and become her, that it's okay 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. Zolabeau has made the connection. Suzanne and I "get it" now.

Conclusion

Listening to Zolabeau's story can teach us so much: about agency, neurodiversity and acceptance; about how what may appear as a deficit may in fact be a strength, or how an ostensibly negative behaviour may actually be a positive mode of expression and inventiveness. Zolabeau's story reveals that her decision to not play instruments early on in Artism was just that: a decision. It was something she chose (not) to do, not an action of retreat or regression determined by her autism.

If it was prompted by her autism at all, it was a decision that was so prompted in a spirit of creativity, exploration and imagination, not one of isolationism, lack of social awareness and ability or impairment. When she later chose to connect in a more conventionally "musical" way—playing instruments with the other children and adults, interacting, leading the group at times and following the direction of her fellow players at others—this did not constitute progress or a positive outcome of a successful therapeutic intervention. Rather, it simply made manifest a fluid progression between different modes of productive engagement, the one more listening- and introspection-oriented, the other more performance-directed and explicitly active. 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 different ways of being musical and being tuned in, which is a far cry from the alternate view that they are oppositional ways of being musical versus being tuned out.

Ethnography teaches us that listening is, and ought to be, our highest priority in endeavouring to understand and relate to people whose lives, worldviews, communities and modes of cultural production—including musical ones—form the subjects of our inquiries. Music, too, teaches us the absolute primacy of listening as a pathway to myriad forms of comprehension, revelation and enlightenment. It is therefore not just a possibility, but perhaps a responsibility as well, for ethnomusicologists to both model and promote ways of engaging with people, all people, that take listening as the crucial first step to understanding, and that center our listening attention on the premise that we are always hearing from people who are experts at being who they are, people whose “differences” are not symptoms or deficits in need of solutions, but aspects of being that reflect the many forms of diversity, including neurodiversity, that define not just what humanity is, but what it ideally can become. 🌱

Notes

1. Following the model of Silberman (2012), I capitalize “Autistic” when referring to a specific individual or group of individuals (e.g., “the Autistic author Nick Walker,” “Autistic self-advocates”) but use lowercase in other, more generic instances (e.g., “autistic symptoms,” “behaviors associated with autism”).

2. The term *neurodiversity* was initially popularized by the sociologist Judy Singer in the late 1990s (Singer 1999; Fein 2012). The anthropologist and clinical psychologist Elizabeth Fein explains that it “connotes a pluralist acceptance and sometimes embrace of atypical neurological development. . . .” She notes that while in theory “the term encompasses all the many variations of human neurology[,] in practice, it is most often used by people on the autism spectrum who value their condition as an intrinsic and in some ways beneficial part of who they are” (Fein 2012: 16). Like many people who might be described in such terms, Dr. Elizabeth J. Grace, an Autistic faculty member of the college of education at National-Louis University in Illinois, is both aware of and sensitive to such impressions. “Neurodiversity is not autistic,” she proclaims in a 2014 blog post. “In another context, a few of us wrote this litany, to which we keep adding: ‘mad, developmentally disabled, learning disabled, autistic, intellectually disabled, mentally disabled, brain injured, and neuro-muscularly disabled people, including those with conditions like epilepsy and migraine. . .’—see where I’m going with this? Things that have to do with your brain are neuro” (Grace 2014). Grace and other neurodiversity proponents are insistent on the point that to equate neurodiversity with autism is to

concede to a misleading form of essentialism. Humanistic expansionism, not scientific reductionism, is the basic prerequisite of a neurodiversity-informed perspective.

3. Walker's conception of the pathology paradigm is closely analogous to what disability studies scholars have conceptualized as the medical model of disability, contrasting that medical model to the social model of disability that has been largely paradigmatic within the disability studies discourse. On medical and social models of disability, see Shakespeare 2013 and Straus 2013.

4. Autistic self-advocates such as Walker often oppose so-called person-first language constructions such as "person with autism" and prefer to identify themselves and to be identified by others as Autistic (or autistic) people. The capitalization of "Autistic" connotes a kind of Autistic cultural identity, akin to talking about "Canadian people" rather than "canadian people." There is as yet no accepted standard of designation along these lines, however, in the case of autism.

5. Straus's essay appears in the 4th edition of the *The Disability Studies Reader* (Davis 2013a). The book is an excellent primer on the disability studies field. While not focused on autism per se, the following chapters address key theoretical issues of identity politics and epistemology that underscore this article: Davis 2013b; Shakespeare 2013; Siebers 2013; and Garland-Thomson 2013.

6. Beyond works in this category already cited, see also Straus 2011, Lubet 2011 and Marrero 2012.

7. See Ochs et al. 2001, 2004, and 2005; Kremer-Sadlik 2004; Sterponi 2004; Nadesan 2005; Grinker 2007 and 2010; Murray 2008; Osteen 2008; Eyal et al. 2010; Sirota 2010; Solomon 2010a and 2010b; Sterponi and Fasulo 2010; Brezis 2012; Hendriks 2012; Silverman 2012; Davidson and Orsini 2013; and Cascio 2014.

8. Other notable publications in this category include Williams 1992; Lawson 2000; Shore 2003 (of additional interest on account of Shore's professional status as a musician and music educator); Miller 2003; Prince-Hughes 2004; Biklen 2005; Ariel and Naseef 2006; Tammet 2007; Robison 2007; Prince 2010; and Mukhopadhyay 2011 [2008]. The best-known Autistic author writing in this medium is Temple Grandin, who has written many books and achieved considerable fame both as an Autistic advocate and animal scientist (Grandin 1995; Grandin and Scariano 1986; Grandin and Johnson 2005; Grandin and Panek 2013). Grandin was also the subject of the title-bearing chapter of neurologist Oliver Sacks's best-selling book *An Anthropologist on Mars: Seven Paradoxical Tales* (Sacks 1995).

9. For diverse examples of music therapy approaches to autism, see Edgerton 1994; Aigen 2002; Kern 2004; Whipple 2004; Walworth 2007; Gold 2011; Reschke-Hernández 2011; Simpson and Keen 2011; American Music Therapy Association 2012; and Hammel and Hourigan 2013. For critical considerations of music therapy in the treatment of autism from the perspectives of ethnomusicology and disability studies, see Bakan 2014 and Straus 2014, respectively.

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