

## INTERVIEW

# A conversation about *Music and Autism: Speaking for Ourselves*

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### ABSTRACT

In this conversation, music therapist Kenneth Aigen interviews ethnomusicologist Michael Bakan on the subject of Bakan's recent book, *Music and Autism: Speaking for Ourselves*. Numerous topics and issues are addressed, from autistic self-advocacy and neurodiversity to comparative considerations of music therapy-based vs. ethnomusicological approaches to engaging with autistic people through music. In the course of the dialogue, Bakan chronicles the various stages of his work in this area, from the Music-Play Project, to the Artism Ensemble, to the "Speaking for Ourselves" book project. Unifying all of this work has been a consistent emphasis on endeavouring to understand people on their own terms—as experts at being who they are—rather than on trying to change people through therapeutic interventions. This perspective is ultimately revealed as both a fundamental distinction and a powerful point of convergence between ethnomusicological and music therapy-centred approaches.

### KEYWORDS

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neurodiversity,  
Artism Ensemble,  
E-WoMP (Exploratory  
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Playground),  
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autism spectrum  
condition,  
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**Kenneth Aigen:** Michael, before we talk about your recent book, can you provide some background for our readers? You're an ethnomusicologist with a history of working with autistic folks. What were the origins of that interest? And what forms did it take?

**Michael Bakan:** Well, the origins of that interest go back to about 2003, when a young member of my family, "Mark," was diagnosed with an autism spectrum condition. Suddenly, autism, which I knew

very little about at the time, became a central part of my life. The pivotal moment occurred during a post-dinner drum jam session with my then-new Florida State University (FSU) ethnomusicology colleague Benjamin Koen. Ben and I were playing together. My eyes were shut. Then I felt a light tap on my leg and when I opened my eyes, Mark was sitting on the floor looking up at me. There was a pair of bongo drums beside him, and it appeared that he was asking my permission to play with us. I nodded and smiled, and he joined right in, and it turned into this kind of cathartic experience.

Anyhow, that was the spark: I realised that I had to find some way to capture that lightning in a bottle, to use the skills and training I brought to the table as a musician and ethnomusicologist to recreate that experience of our drumming together, specifically for the benefit of other kids on the spectrum, of other families. But where to begin? With Google, of course. So, I started Googling in keywords – autism, ethnomusicology, music therapy – and one name kept coming up, yours: Kenneth Aigen! I don't know if you remember this, Ken, but I just cold-called you one day back in 2003 at NYU [New York University] and, amazingly, you answered the phone. We had a great, long conversation, which really helped me to define the potential points of intersection between ethnomusicology and music therapy vis-à-vis autism, and that proved pivotal in launching the various projects in which I've been involved ever since: first the Music-Play Project from 2005-2009, then the Artism Ensemble from 2011-2013—which was supported for those three years by grants from the [US] National Endowment for the Arts—and most recently the “Speaking for Ourselves” project, which gave rise to the book we're talking about here. I should note for our readers that this book was first published in 2018 by Oxford University Press (OUP) with the title *Speaking for Ourselves: Conversations on Life, Music, and Autism*, but that OUP is releasing it again this fall [October 1, 2020] in a paperback version with a new title, *Music and Autism: Speaking for Ourselves* (Bakan, 2020). I'm very excited about that. So, a belated thank you for your help with everything, Ken. [laughter]

*Kenneth:* Sure.

*Michael:* Seriously, though, that phone call was a big moment for me. After that, Ben Koen and I got to work developing what would ultimately become the Music-Play Project, or MPP. We received a small, in-house grant from FSU for the pilot study in the summer of 2005 and recruited an interdisciplinary team of research collaborators comprising faculty and graduate students from across the university, including a paediatrician at the medical school, a cognitive psychologist, and the eminent autism researcher Amy Wetherby.

Working with the SCERTS (Social Communication, Emotional Regulation, and Transactional Support) Model for autism assessment developed by Wetherby, Barry Prizant, and their colleagues (Prizant et al., 2006) as the basis of our study, we used coding of video recordings of the participating children in the project to measure targeted social-emotional growth indicators. The videos followed the individual children (three or four per play group) as they navigated the free-play, improvisatory environment of a specially designed E-WoMP, or Exploratory World Music Playground. Ben and I were the designated music-play facilitators, responding through our improvisational activities in the E-WoMP to child-directed musical/social leads. The parents of the children, or in a couple of cases other caregivers, were active music players in the group as well; that

was really important. Our measures yielded both ethnographic and statistical data, and there was convergence of those streams to some extent, especially in demonstrating gains in the children's expressions of success and confidence (Bakan, 2009). So this went on for several years and it was rewarding and revealing work, but there was an increasing pull toward quantification and assessment, toward converting this musical, playful, spontaneous enterprise into something that would yield outcomes suited to publications in scientific journals, to securing grants from scientific research-funding organisations, all that kind of stuff. And the more "scienceward" the project went, the more the soul of what I had originally conceived for it seemed to be slipping away.

I became increasingly unhappy with the direction things were going, and so, in 2010, I just, well, stepped away from it all. By that time, there was a series of publications issuing from the work, and we had done some good in the world, I imagined (see Bakan et al., 2008; Bakan, 2009). Meanwhile, Ben had upped and moved to China to take a university teaching position there. It seemed like a good time for a new life chapter, and I figured that was pretty much that. But a couple of months later, quite out of the blue, I was contacted by the Florida Division of Arts and Culture in the Department of State. They were launching a new, joint programme with the National Endowment for the Arts aimed at developing innovative programmes to serve underrepresented populations in the state of Florida. They were familiar with my music and autism work and asked whether I might consider submitting a grant proposal in that area. So I thought to myself, 'Well, okay, we're talking arts here, we're talking culture. These are my comfort zones, my familiar places. This sounds good!' I wrote the grant and it was successful, and that's how the Artism Ensemble was born.

Artism certainly had its roots in the Music-Play Project concept, but it was a boldly different kind of undertaking. Over the three years of the group's life (2011-2013), there were either four or five children on the spectrum in the group at any one time; all were "graduates" of the Music-Play Project who had thrived in that environment. As before, parent involvement as active music players was essential. As for the music-play facilitators, rather than just having two, as we had in MPP (Ben and me), there were now six or seven professional musicians/ethnomusicologists from countries—and representing musical traditions—all over the world: China, Bolivia, Trinidad, the U.S., etc. All of them had in their various ways found their way to Tallahassee, most as graduate students in the ethnomusicology programme at FSU. But there were a couple of music therapy students involved, too, and even a professor from down the road at Florida Agricultural and Mechanical University (FAMU): the great jazz bassist Brian Hall. And right from the start, this was not a play-lab kind of deal but a real performing *band*, which was designed to go out and play public concerts and do other outreach events to promote autism acceptance throughout the state and beyond. The idea was not to "measure" or provide "interventions" for autistic kids – quite the opposite. Our mission was to put a different public face on autism, to compel our neurotypical-dominated audiences to see this neurodiverse, intergenerational group of adults and kids, musicians and "non-musicians," autistic people and non-autistic people, sharing social and musical space with creativity, humour, compassion, and a sense of advocacy, an advocacy born of a desire to *force* the world to see and appreciate the essential humanity and sociality of autistic people.

Artism was thriving, and then came what appeared to be the capstone event of our musicultural journey to date: a featured performance at the opening general session of the international conference of the Society for Disability Studies in 2013, which took place in Orlando,

Florida. That was the furthest our group had ever travelled—our events to that point had all been in Tallahassee or close by—and it was a major undertaking to get the whole show on the road, as you can surely imagine. But we pulled it off and it seemed like a great success – standing ovations, lots of praise, the whole nine yards. And then, crisis. The rest of the group returned to Tallahassee the day after the show but I stayed in Orlando to attend the rest of the conference. A couple of days in, I attended a roundtable organised by Elizabeth J. Grace, aka Ibby Grace, and a panel of her fellow autistic self-advocates. The final hour was dedicated to open discussion and a question-and-answer session. To this point, I had never had the opportunity to get significant feedback on Artism from a cohort of autistic adults, let alone autistic adults actively involved in neurodiversity studies and advocacy initiatives like these folks clearly were. I was eager to get their perspective. So, I raised my hand and asked a question: ‘Were any of you at the Artism Ensemble concert the other night? What were your impressions of it?’ One member of the panel literally jumped to the centre of the room and told me that he had found the concert “offensive.” He then proceeded to lay out a thoroughgoing critique: ‘Why were there only autistic children and non-autistic adults in the group?’ he complained. ‘That reinforced mythologies of autism as a “children’s disease,” and it deprived the kids of positive, adult autistic role models as well. Why the use of percussion instruments that could be disturbing to autistic people (like himself) with hyper-sensitivity to loud sounds?’ he continued. And most importantly, he asked me why the reviled phrase “autism awareness” appeared on the NEA evaluation questionnaire I had prepared and distributed to the audience? Was I a “plant” from Autism Speaks sent to infiltrate this safe-space meeting?

Wow! This was not what I was expecting, I can tell you that. Thankfully, I did manage to keep my cool, though my heart was racing and I was sweating profusely. It was pretty intense, really stressful. When he was done, I took a deep breath and did my best to give a measured response. I explained that I was very sorry, that I wanted to learn, that I was committed to doing better. And Ibby Grace, in that beautiful, calm Ibby Grace way she has about her, brought all the tension down to calm. “We can help you with all that,” she said reassuringly, and afterward she gave me her card, and I contacted her, and, to make a very long story short, that was the *next* big moment in this whole odyssey, the one that would shift me from Artism toward the “Speaking for Ourselves” project, and eventually the new book. Ibby is one of my ten co-authors on that project, I’m proud to say. All ten of them, despite their immense diversity on other levels, basically share two things in common: an autism spectrum diagnosis and a life in which music plays a major role, whether they are musicians per se (as several are) or not (as several are as well).

*Kenneth:* For folks who we want to interest in reading your book, you describe that experience, of being taken to task at the Society for Disability Studies conference, in the chapter you co-wrote with Ibby Grace, and I’d like all the therapists out there to know that you really approach the whole topic with a high degree of reflexivity and self-critique. I think therapists, part of whose training is to engage in those processes, will find your ability to speak with candour and to look at your interactions critically very engaging and refreshing.

*Michael:* Thanks. I appreciate that. I mean, I really felt that there was no choice in the matter. These were people speaking from the inside of the autistic self-advocacy world. They had a valid set of

criticisms. And what sparked the whole fiasco was that reference to “autism awareness” in the NEA questionnaire that I mentioned earlier. It had not even occurred to me that this might be inflammatory. The question read something like this: In terms of promoting autism awareness, this concert was (a) Excellent, (b) Very good, (c) Satisfactory – and so on. Pretty benign stuff, or so it seemed, but it turns out that “autism awareness” is a phrase you did not want to be bandying about with people in the autistic self-advocacy community at that time, because it’s closely associated with the Autism Speaks organisation, which they felt had been involved historically in a lot of the wrong kinds of priorities—research on prenatal detection, efforts to “cure” autism, remediation and intervention programmes—whereas autistic people in the community that I’m speaking to are saying, ‘We are who we are. We’re fine the way we are, being who we are, and what we mainly want is *acceptance*. We don’t want awareness. We want to be accepted for who we are, as we are.’ As an ethnographer, an ethnomusicologist, honouring that desire, that initiative, makes the greatest sense in the world to me, so I owe people like Ibby, and Amy Sequenzia, and all of my other *Music and Autism* co-authors—among other folks with whom I’ve worked and played music—a tremendous debt of gratitude for calling me out and helping me to see better paths forward.

*Kenneth:* Right. And in the current climate, using that phrase, autism awareness, is akin to saying that we’re increasing “racism awareness,” and with that not being nearly enough at this point. I think people want change, not just awareness, of a problem.

*Michael:* That’s right. I think the analogies between the heated response I got at that time, which quite honestly really blew me out of the water, and what we’re seeing right now around a lot of issues affecting people who have historically been disenfranchised, marginalised, and suppressed, are spot-on. These different communities are each engaged in their unique situations, but they also share a great deal in terms of the types of common struggles they have faced, and continue to face. In joining voices with my autistic co-authors in the book, I hope we are contributing something of real value to these larger conversations at this critical, precarious historical moment.

*Kenneth:* The “Speaking for Ourselves” portion of the title suggests the idea that disability rights are civil rights. Is this interpretation correct and does it align with your intentions for the book?

*Michael:* Yes, that’s right. The idea of “speaking for ourselves” is key to the sociopolitical mission of the book, in that if there’s one thing that needs to be addressed right now in the realm of autism—in autistic lives, in autistic discourses, in public policy—it’s that people from within the autistic community are motivated to speak on their own behalf, are capable of speaking on their own behalf, and need to be *heard* speaking on their own behalf. And it’s not just a matter of being heard either. They need to be really *listened* to—carefully, thoroughly, compassionately—because they bring to the conversation an awful lot of knowledge and insight and understanding, of forms and ways of knowing that, quite simply, no one else can possess, let alone convey. It’s the same conversation that’s going on around race right now, where you or I, as white people, and as white men in particular, it doesn’t matter how much we read or align or engage in productive forms of activism. There’s still a fundamental level at which we can *never* fully understand the experience of being Black in the United

States. We need to accept that, and we need to really listen to people who know what they're talking about, on that deep, experiential, existential level. The exact same rule applies with autistic people, and that is a key point of the book.

*Kenneth:* Maybe just a word on the process of the book. Even though most of your co-authors, I think all except one, seemed to be adept at spoken, oral communication, you opted to engage in dialogue through text-based messaging. I was wondering why you made that choice and how you think it influenced the nature of the interactions and the content that you received.

*Michael:* That's a great question. I'd like to say that it was all carefully planned out ahead of time, but, as is the case with most ethnography and field-research-based work, a lot of what happened was happenstance. The first two chapters are actually based on face-to-face conversations, and those conversations were with two girls—now young women—who were members of the Artism Ensemble. In those chapters, then, we were essentially recreating those dialogues. All of the rest of the chapters, however, stem from texting-based, typing-generated, online dialogues, most of which took place using the Google Hangouts platform.

Where that format began was with my co-author in Chapter 4, who goes by the pseudonym Donald Rindale. Donald was living in Boston when he first contacted me via email. At the time, he was finishing up a master's degree in musicology up that way, but he was interested in transferring to FSU for his doctoral studies. Part of the motivation was to work with me. He had seen a TED Talk I had presented (Bakan, 2012), which had inspired him to combine his musicological interests as someone on the spectrum with an interest in issues of autism and autistic representation.

I told Donald I'd be happy to speak with him about the FSU graduate musicology programme and we set up a meeting, but I also took the opportunity to ask him if he would consider being interviewed for a book I was working on, since, as a musician and musicologist on the spectrum, he seemed like a perfect "candidate." He was excited to be part of the project, but I didn't have any kind of grant to go flying up to Boston or to fly him down to Tallahassee, so we looked at what our options might be and decided that the texting-based Google Hangouts approach would be a good way to go for a couple of reasons. First, Donald was very comfortable with the idea of our using typing as our main mode of communication, and, as I was to discover, many autistic people actually feel *more* comfortable with that mode of interaction than with speaking, face-to-face-type communication, because it takes away the eye-contact pressures and the social pressures—you know, 'I can't stim because people are watching me.' So that was one plus for the texting approach.

Another—and in all honesty this one spoke to my own selfish interests in the enterprise—was that Google Hangouts generated a transcript of the whole texting-based conversation *instantly*, with no need for tedious transcribing, no worrying about 'Wait, did I hear what he said correctly?' Plus, with that complete transcript in hand right from the get-go, we could go back and do dialogic editing as much as we wanted to, so we could both be looking at the original transcript and he could say, 'Well, that's not really quite what I wanted to say,' and then we could go in and make tweaks. It was a real revelation, actually a real liberation!

So we did the first interview using this Google Hangouts typing/texting format and it went great. And after we were done, I pulled up the transcript and started to read it, and then I started to

panic. Donald wrote so lucidly, so brilliantly, that it was essentially a finished product, ready for prime time. It was like looking at those original Mozart manuscripts where there are no cross-outs, no edits; everything's just as it should be right out of the gate. So then I'm freaking out, you know, 'But wait a sec, I'm an ethnographer. I'm supposed to be taking the words of the people that I collaborate with and shaping them into narratives, contextualising them relative to my own interpretive frames,' all that stuff. But there was none of that to do because Donald had already articulated his thoughts and ideas so perfectly, so eloquently. The guy's basically a genius; he's already interpreted *himself*. And I'm thinking 'There's really no job for me to do here,' and that was disheartening.

But then I had this flash of insight. I thought, well, if I'm not going to represent Donald in this book, then I will *re-present* him instead. And that became the theoretical hub of the whole project, this move away from representation toward re-presentation. The conversations that went down *are* the ethnography, not the basis of the ethnography. The interpretation, the analysis, all of that – it's in the conversations themselves, and the book is a collection of conversations first and foremost. Yes, I'm there in a kind of narrator's role – "Blah blah blah," Donald exclaimed; "Blah blah blah blah," I replied, stroking my beard in contemplation...' – but that's kind of the long and the short of it. I try to stay out of the way as much as possible (other than through my presence as my co-authors' main partner in dialogue, which is, granted, significant), to let the *conversations* speak for themselves, so that brings us back to the title again, I guess.

*Kenneth:* Well, okay, but you also share some of your thoughts in those conversations, which sometimes take the form of self-critique: reflecting critically on the questions you were asking, or on the ways you had misinterpreted things your interlocutors were telling you, or how you had pushed the conversation in a counterproductive direction. It's more than just the dialogue.

*Michael:* Yes, that's right, that's true. I guess what I'm trying to get at here is the idea that the interpretation—to the extent that I'm making interpretations, or that I'm making inferences about things that are going on "between the lines" of what the other person is saying *in* the conversation—is essentially built *into* the conversation, as opposed to being extracted out of the conversation. There isn't this kind of, 'Well, here's the dialogue transcript, now let me tell you what's *really* going on.' And that makes me feel comfortable, at least relatively so, with the "speaking for ourselves" tag. I feel that my role in this book is less that of an author per se than, say, that of the producer of a film.

*Kenneth:* Right. You are one of the people in the book speaking for *yourself*, but you've also given the participants an opportunity to speak for themselves. You're not speaking for them. And their voices aren't mediated through your concepts and interpretations, and that's one of the real benefits of that approach.

*Michael:* Well said, and I'll let you speak for yourself on that! *[laughter]*

*Kenneth:* I'd like to get into some specific questions. Again, we have a readership of music therapists and other music and health professionals, and I've got some things to ask you about that I think

might be of particular interest. A few of the participants [in your project] talked about how they can engage in levels and types of social interaction in musical situations that would be much more challenging outside of music. Do you have any thoughts to share on what is it about musical engagement and interaction that afforded this sort of difference in functioning level or difference in interactive capacities?

*Michael:* As a kind of preface to my response to that question, one thing that comes through in the individual chapters is how incredibly diverse this group of ten people is. Yes, they all share an abiding passion, of some kind or another, for music, and they all share the fact of an autism spectrum diagnosis. But beyond that, it's all over the map as far as how they're interacting with music, with people, and basically everything else. So, there's no one answer to that question. The best way for me to respond would be with a couple of specific examples. If we look at Chapter 3—the Mara Chasar chapter—she was a seven-year-old girl when we started playing music together in the Music-Play Project, and then we continued collaborating through various later projects. In fact, we have a new, co-authored chapter coming out soon; it will be in the forthcoming Oxford Handbook on early childhood music learning and development, and Mara, who is now nineteen, is first author!

Mara has actually had had some very *negative* experiences with music outside of our projects, because of the specific kinds of expectations and demands that those other musical experiences imposed on her. A prime example was her high school choir, where she was required to wear tight and uncomfortable dresses, perform with no freedom of movement at all, and be in total conformity with her fellow singers pretty much all the time. She found that all to be incredibly oppressive, even traumatic. She claims that what made Artism so different—and so vastly preferable—was that there were no predefined expectations in terms of outcomes. The music didn't have to come out sounding any way in particular, and where it was going to end up was mainly up to the kid in the group—Mara or one of the others at any given moment—whose turn it was in that moment to be in charge, to be the director, the composer, the lead performer. Artism's creative process, its *social* process, was always a process of becoming, and being in a space where there were by definition no wrong notes, no wrong ways of being or doing (so long as no one was getting hurt or disrespected), was really liberating, not just for Mara and the other children in the band, but for the parents and the professional musicians, too.

That E-WoMP was a really special place, not perfect, but definitely special. I think it provided a model of a type of musicultural environment that many music therapists could benefit from knowing about. I encourage everyone who does this kind of work to consider the possibility of engaging musically with people on the spectrum (actually with all kinds of people) through methods that don't predetermine *any* specific repertoire or desired musical outcome. Think of it as 'We're having a conversation; it might go here, it might go there, and we're going to simply try to follow each other's flow, damned be the consequences.' It's not an easy thing to do. It can actually be pretty terrifying—and it's definitely tough on the ego if you're the type who prides themselves on high "performance standards" when on stage—but the rewards can be great if you just allow yourself to yield and give in to the process. Easier said than done, though.

*Kenneth:* The next question I have is complementary to what you've outlined. I don't want to reframe

what you're saying from the music therapist's point of view; however, what you discovered in your work is basically a tenet of what we call "music-centered music therapy" (Aigen, 2005), which is really an outlier in the field, the idea being that you actually get better non-musical outcomes when you're not playing music to change somebody. You get increased social and emotional benefits when you're not trying to force that, when you're fully engaging the person in the music. It seems like you empirically discovered the benefits of this music-centered approach. Not that this approach is not problematic in its own right. It goes against the conventional wisdom in music therapy, which is that music therapy is the use of music to achieve a non-musical goal. This definition of music therapy is not accurate for music-centered approaches. Sometimes we see benefits in non-musical areas, but they come about because the person was fully engaged in the music. That seems to be what you did coming in with your ethnomusicological approach: 'We're here to play music with people, not to change them.'

*Michael:* Precisely, and allow me to build on that idea through a couple of different examples. Here's the first one. When I'm in the E-WoMP, I'm a musician and an ethnomusicologist, which is exactly what I was many years ago as well while doing intensive ethnomusicological fieldwork with gamelan beleganjur musicians in Bali, Indonesia (Bakan, 1999). When I went to Bali, I went there with the assumption that my job, first and foremost, was to try to understand this Balinese musical system and its cultural world, and to do so, at least as well as I could, in the ways that the people who lived in that world understood and experienced it themselves. I went in with an attitude of 'I'm here to observe. If they invite me to participate, then I'll do that, too.' Later on, I would be able to step away, to look back at my notes, reflect on my experiences, analyse my video recordings, and hopefully come away with some insights into how and why these Balinese people I had come to know were musical people, how they were experts at being who they are, and how their being musical was a part of what *made* them Balinese, and vice-versa.

And that's pretty much the whole deal. There's no sense in me going in and saying, 'Okay, I see what you're doing, and it's all very good, but you might consider having a conductor lead the gamelan rather than the drummer; that would be more efficient. Oh, and you also might want to rethink the tuning of your instruments. Don't you think A440 would be a better way to go here, rather than this odd, male-female paired-tuning *ombak* thing you do?' [*Kenneth laughs*]

You're laughing at the absurdity of the prospect of an ethnomusicologist even thinking such thoughts, let alone acting on them. Yet, when I tell people about my work with autistic people, they're immediately like, 'Oh, what problems are you addressing? What interventions are you using? What are the outcomes and improvements you're seeing?' Trust me, nobody asks me those questions about my gamelan research.

But to me it should be exactly the same. It's not about changing people, let alone "improving" them. It's about understanding people. When I go into the E-WoMP, I'm playing music and I'm being an ethnomusicologist, just like in Bali. I'm in the E-WoMP to observe what the people who are the insiders of this music culture, these being the autistic members of the group, are doing, and how and why they are doing it. What makes them tick? How are they defining their own identities and interactions within the space? How do *they* manifest the reality of their being experts at being who they are? If I'm fortunate enough, they'll invite me to participate in that musical word with them.

And then, afterwards, hopefully I can step back out and come up with something meaningful and true that I can “translate” and then share with other people. That ethnomusicological method is absolutely what I’m applying. There’s no desired outcome other than to understand. To understand, we observe, we listen, we participate. Then we try to interpret or try to re-present (as opposed to represent).

My second example takes us back to the early days of the Music-Play Project, circa 2005 or 2006. There was this one kid (“Frank” in the 2008 *Ethnomusicology* article “Following Frank...”; see Bakan et al., 2008) who was quite destructive. He would knock down the instruments, hit himself or others with mallets (fortunately they were made of soft rubber), all kinds of stuff. But then he was usually able to calm himself down and get back in sync. In the moment, I never knew what accounted for those transitions, but months later, in analysing the documentary videos of his sessions, I discovered that he had developed a real method for his emotional self-regulation. When he was dysregulated, he would quite consistently do one of two things: either go wrap himself around Ben Koen’s didgeridoo while Ben was playing it, or else go sit in front of the largest gong of the gamelan (sessions at that time were held in the FSU gamelan room) and strike it repeatedly. And whenever he used these methods, you could literally see the tension, frustration, and anger melting away and being replaced by relative calmness. I deduced that this had to do with the low frequencies and strong vibrations of these instruments, that this kid was using a kind of low-frequency, somatic therapy on himself.

So, this was a big breakthrough for me. I was all excited, and I rushed home from the video analysis lab to tell my wife, Megan (a cognitive psychologist who at the time was a collaborator on the project), about my discovery. I stormed into the kitchen and started babbling on about my ‘eureka moment’ and the apparent therapeutic effects of low-frequency tones on emotional dysregulation in autism, yada yada.

And Megan just cut me off, full stop, and she was like, ‘You just don’t get it, do you, Michael? You’re always all about what’s going on in the music and the vibrations and the this and that. That’s all fine and good, but what’s *really* happening there is that you’re walking into this room with these kids and their parents, and the kids, who are always being measured as coming up short, whether it’s on the soccer field or in a piano lesson or at school, they’re getting to succeed instead. You’re closing the door and you’re creating a safe space where they can just *play*, without any expectation of what that’s going to produce, what the music is going to sound like; and as long as they’re not hurting each other or breaking things, they’re basically free to do what they want. That freedom for those kids, and also the chance their parents get to play with them in this safe, non-judgmental place—and where they get to see their children succeeding for a change, because they’re not being evaluated in terms of “measures of success”—that’s where the magic happens.’

And you know what, I’ve got to admit that Megan was right (though I still think there’s something to my low-frequency/emotional regulation theory, truth be told). The idea is that the experience *is* the method, with participation itself being the outcome, and also the measure of success.

*Kenneth:* That’s right. Success is participating.

*Michael:* And that success can involve participating in a seemingly non-participatory way as well.

*Kenneth:* Right, even if it's listening, it's participating. It's being in the sound environment. In music therapy, receptive methods that utilise music listening are not passive but can be considered an active method because the participant's mind is actively engaged. So, let me ask you about another of your collaborators on the book, Ibby Grace, your Chapter 5 co-author and conversational partner. Some of the participants in the project talked about social participation, while others talked about how, through music, they could gain insight into the inner worlds of other people, how they had developed an enhanced capacity for what psychotherapists call intersubjectivity. Ibby, in particular, talked about how she hears people as music. In some forms of music therapy, this ability to create a portrait in sound of the inner person is an important skill. Drawing from the conversations in the book, can you speak a little bit to how it seemed that for some autistic folks, music was a medium which allowed them to understand other beings as having inner worlds that somehow they could get inside of? The other aspect of that had to do with their ideas about how they understood emotions through music, about how verbal language may have been opaque in terms of how words related to feelings, whereas somehow in music this ability to feel the universality of human experience was enhanced.

*Michael:* Yes, great. There's a lot in that question! Let's start with Ibby. She talks about a couple of different things. One is this idea that she "thinks in music" in the same way that Temple Grandin "thinks in pictures" (Grandin, 2006). It's just a different kind of cognitive process than we're normally expected to rely on, given the profusely language-centred society in which we live. Our social institutions, our educational systems, our professional structures are all generated around these ideas that the lowest common denominator is language. If we can't language it, then it can't really be. It's empirically not present. Now, Ibby works in logic, so she's actually a very sophisticated thinker in those languaging ways. But as she says of herself in the chapter, "I suck at languaging feelings." By her own account, thinking musically enables Ibby to bypass the strictures of language. She can thereby connect the sonic, embodied experience of music to her own feelings, as well as to her perceptions of the feelings of others.

Where I think this becomes especially important as a therapeutic modality, and also in terms of the importance of what we were talking about earlier, is that we really need to listen to what autistic people are saying about what matters, what they need, how to proceed with all of this work. Ibby claims, and I have no reason to not believe her claim, that she hears people *as* music, that she actually experiences people as music. So when she meets two people, she gets a sense of how they will likely interact "harmonically" with one another, and from that she can deduce whether or not they are likely to get along. One of the big problems that we have in this area of work is that because books are things of words—because communication in the neurotypical world generally is premised on words, in fact—we end up greatly privileging the communications of autistic people who speak over those who do not in publications (though *all* autistic voices have been marginalised historically, but I digress). And among those who do not speak, those who at least have other means of communication (such as typed language) have a distinct advantage over those who do not. That would be the case, for example, with the well-known author, autistic self-advocate, and social activist

Amy Sequenzia, my Chapter 10 co-author.

But there are so many autistic folks who do not speak, and who have not yet found effective ways of communicating their thoughts and ideas to others in ways that are understood. Ibby's thinking-in-music process holds real potential for bridging the gap. Through that process, her process of perceiving people as music, she asserts that she is often able to understand and interpret what non-speaking autistic people are saying, and I absolutely believe that this is indeed the case. So, there's a kind of empathy across the continuum of the autism spectrum that gives Ibby this capacity to connect, to on some level represent and re-present the unspoken thoughts and ideas of non-speaking autistic people, which would otherwise be unavailable to the rest of us who don't (yet) possess her skills of perception. Now, I realise that this is controversial. It's problematic. It can all be challenged. But I am convinced beyond the shadow of a doubt that it is all profoundly real, and that Ibby brings true credibility to the claims she makes.

*Kenneth:* It's actually very similar to what happens in Nordoff-Robbins music therapy, where the idea is that you let yourself resonate to something unseen in the person, or maybe it's to body language or facial expression, and you put that into sound. You play it and it engages the person; it validates your impression that whatever sound you're creating is some sort of a reflection or representation of that inner being.

*Michael:* And that's applied, empirical research.

*Kenneth:* Right, so it's saying use your intuition, and if it seems mystical or esoteric, that's only the source. It's validated by whether it works to engage the person. So, to me, that's what warrants it in a professional, clinical domain.

*Michael:* What would be really wonderful in a clinical context like Nordoff-Robbins, I think, would be to have an autistic facilitator, someone like Ibby, with her special skills of intersubjectivity and empathy, be an integral part of the clinical team when working, say, with a non-speaking autistic client. That could be a quantum leap, building from that intuitive response of a skilled therapist, like yourself, toward some kind of empirical validation from an autistic consultant, like Ibby. These kinds of possibilities are so exciting, when we can envision—and ultimately bring to fruition as well, hopefully—synergistic modes of collaboration across intersecting communities of neurodiversity and interdisciplinarity: music therapy, autistic self-advocacy, ethnomusicology. Wow, we could do some great work!

*Kenneth:* You know that I'm doing a similar project to yours now called "Music in Everyday Autistic Life." It is a project being funded by the American Music Therapy Association (AMTA) and it demonstrates how mainstream thinking in music therapy has come around to understanding the importance of including neurodiverse perspectives in research. I'm doing this project a little differently from how you did yours, more as a traditional, bounded, social science research study with two neurodiverse people on the research team. I've had about five or six conversations so far. Something that's come up, that a few of my interlocutors have highlighted, is how, when they

experience sensory meltdown, they might turn to music. It may seem counterintuitive for them to increase sensory stimulation when they're feeling overwhelmed on a sensory level, but what they say is that the music actually functions to give them a sense of control so they can manage the meltdown, maybe even at times deliberately choosing music that's going to push the meltdown further so they can move through it and come out the other end. Some of your co-authors mentioned something similar. Addison Silar, in Chapter 11, talked about how music blocks out the multiple bombardments of sensory stimulation that would otherwise make it hard for him to function. I'm wondering if you have any thoughts about music and sensory stimulation and meltdowns. One thing we're really interested in with my project is the question of how do autistic folks already use music in daily life as a health resource. You have all these music therapists deciding how to use music, but we've never talked to autistic folks about what resources they already have that we could learn from.

*Michael:* Ha! That reminds me of my earlier account of "Frank" in the E-WoMP with the didgeridoo and the gongs. In terms of my collaborators on the book, though, my conversations with Addison, and also with Amy Sequenzia, could be especially revealing in this arena. At the time we were working on our chapter together, Addison, then a teenager, was writing a science fiction novel called "The Unfortunate Project." Music listening was absolutely integral to his creative process. He would put on a piece of recorded music, allow it to inhabit his cognitive space, and then "translate" what he was perceiving in the music into the various aspects of his literary production: the plot, the development of characters, the relationships between the characters—basically he was channelling the music into the form of his novel. Really fascinating stuff!

Yet for Addison, music listening was a double-edged sword. It was fine as an immersive medium for writing fiction, but he got so deeply into it when he was trying to do other tasks—reading, homework, computer programming—that it often became a distraction which impeded his ability to get things done. But he kept listening when doing them nonetheless, which didn't make sense to me. I asked him why he did that. I still recall his response: "And why do I do it if it is sometimes distracting? Because it's even more distracting without."

This was a revelation for me. It actually brings to mind some of the things I learned from my research on the culture surrounding Balinese gamelan, strange as that may seem. In Balinese cosmology, you have this large range of "evil spirits" of the Lower World. They're all evil, but some more so than others, so the Balinese people of the Middle World recruit some of the less malevolent Lower World spirits to *protect* them from the really nasty ones. That's why you see evil spirit images carved onto the sides of many gamelan instruments. They're there to protect the gamelan! It's risky to align with these relatively benevolent malevolents, but it's a risk worth taking to prevent the most dire consequences. It's kind of like having a guard dog. You've got a big Rottweiler who could turn on you, but you hedge your bets that he's on your side. That's what Addison was describing. Yes, music has the power to distract and get in the way, but it can also keep at bay sources of distraction and destruction that are a lot worse.

*Kenneth:* Can you ride the tiger? Can you control the force? Think of cultures where psychedelic drugs, plants might be used a certain way. There's a danger there, but there's also something really positive and instructive.

*Michael:* Right, and you could add prescription medications to that list as well! Before we move on to your next question, let me return to the last one—about how autistic people use music as a health resource—relative to Amy Sequenzia. Amy is non-speaking, as I mentioned earlier, and she also has cerebral palsy and a range of other conditions, including seizure disorder. When we started working together on our chapter, Amy knew she liked music, but she had not yet really thought through how significant a role music played in her life. According to her, it was actually *through* our conversations for the book that she became cognizant of just how important music was to her, which was a very cool process for me to be a part of. Anyhow, one area of particular importance had to do with sensory issues. Amy's relationship with her physical body is complex. She often does not experience normal pain sensations, which can of course be dangerous (e.g., touching a hot stove). She also has problems with processing bodily functions, like knowing when she needs to go to the bathroom. Music helps her to navigate these challenges. Listening puts her quite literally in tune with her body, in ways that stimulate her abilities to experience physical pain, to know when she needs to go to the bathroom, and so on. Music listening serves as a coping mechanism. On this level, at least, there is nothing abstract about it at all.

*Kenneth:* It's amazing. So many things you're mentioning have parallels in different areas of music therapy practice. For example, music therapists work in pain relief and find that they can use music in a way that radically reduces people's need for pain medication, the idea being that music occupies the neural pathways that block the pain signals. That reminds me of what you're talking about with Amy. People have taken up Oliver Sacks's work a little bit to show how music can animate, how it can help motor rehabilitation by connecting people to impaired pathways or impaired limbs, how it can be effective in stroke rehabilitation. It's amazing to me how in this small subset of people, of autistic people, we're seeing so many of the generalised functions of music therapy. The concert pianist Dotan Nitzberg, your co-author in Chapter 6, talked about how he had been told his playing had a deficit of emotion, but he countered that it in fact was characterised by an overdose of emotion. This brings up a really important question. It seems to me that people often conflate how expressive a person is outwardly with what that person may be feeling inwardly. They are judging what the person is feeling. If they don't see the outward manifestation, they think they're not experiencing it inwardly. I've always felt that is a common error made by neurotypical people in trying to understand autistic individuals. In the 1970s and 1980s, I remember textbooks saying autistic kids must be unfeeling, right? I want you to speak to that in general, based on your intimate knowledge—you've gotten to know a number of autistic people in a more intimate way—and I'd also invite you to speak more about their emotional lives. If you want to reference Dotan in particular, I'd be interested in your thoughts about that issue of the conflating of feeling versus showing.

*Michael:* Sure. There was a point at which I had written a draft of the concluding chapter for this book that I ultimately decided to throw out, the rationale being that it was philosophically antithetical to the ambition of the project. I had tried to take all of these conversations and identify a half-dozen themes to summarise and coalesce them into a cohesive whole. In theory, that may be a great thing to do, but for this particular project, I decided it wasn't the right way to go.

But I still have the notes on all of that, and if there's one theme that came up over and over

again, in more chapters than any other, it was this theme of emotional expression and empathy. In one manner or another, every one of my ten collaborators stated something to the effect of the following: 'I experience emotion at least as deeply as your average, neurotypical person. I experience empathy at least as deeply as well. If I have any kind of problem in that department at all, it's that I experience these things too much, not too little, and that can prove debilitating in this neurotypical-dominated society in which we live.'

In the case of Dotan, this challenge manifests on at least two levels. The first level relates to what you're talking about vis-à-vis the feeling-versus-showing conundrum. Dotan's stage demeanour is different from that of your "average" concert pianist. Because he bows in a different way, because he interacts with the audience in a different way, because his facial expressions show things you wouldn't expect to see and don't show things you would expect to see, some audience members at his recitals will infer that there is something not "right" here: he can't be a *true* concert pianist, a *true* musical artist, because he doesn't look the part; he doesn't satisfy their central casting desires of what a concert pianist should "be like." Now, there are musicians who have managed to overcome those sorts of prejudices. On the one hand, you had the violinist Jascha Heifetz, who stood still as a statue, seemingly devoid of emotion altogether, when he played, but was lauded for his artistry nonetheless. Or there's Keith Jarrett...

*Kenneth:* The opposite.

*Michael:* Right, the opposite!

*Kenneth:* He's dancing, grunting, and moaning...

*Michael:* Exactly, but that became his thing, and people eventually accepted him on his own grunting-and-moaning terms. Now with a musician of Dotan's calibre, the artist that he is (and I've heard him play often – he's brilliant!), the potential for that same kind of acceptance, despite the "eccentricities," could be there as well. But there's an additional variable with which he has to contend, which is that people know he's autistic. And because they know he's autistic, they also "know," even though it's patently false, that autistic people are not emotional and are not empathetic. Therefore, it is one of those "if A+B=C, then C+D must equal E" kinds of things – no truth to it, but people believe that there is, so it doesn't matter. Clearly, they surmise, he is emotionally deficient, and *that's* why he looks the way he does when he plays, *and I can hear it*. But can they really? Almost surely not, because what they are so sure of is a fiction; there's no there there. But we convince ourselves otherwise, because that's what us neurotypicals do. That's our strategy for cognition and interpretation, right? We tell ourselves that because this person looks different and because this person is autistic, those two factors together lead to the "inevitable" conclusion that the music cannot be emotional because the person is not emotional. And that becomes crippling, debilitating; how can you win with the deck stacked against you like that, especially in a cut-throat, competitive business like the concert piano world?

This is a great example of the medical versus the social model of disability, right? The medical model is saying 'here is a particular pathology, here's what's going on'; the social model is saying 'no,

it's the environment that's creating the disability,' or the *disenabling* effect, you might say. If you are a classical pianist who is autistic and is known to be so, and who manifests that autistic-ness in ways that make it easy for people to pick on you—because that's the way you look, so that must be the way you are, and in turn the way you play—then you are immediately discriminated against, and you are ultimately pushed out. This is a form of bigotry that deprives many people of their ability to live their lives as they wish to, and to express and benefit from the talents they possess, from which they ought rightly deserve to benefit.

*Kenneth:* That reminds me a little of Maureen Pytlik, in Chapter 8, who talked about how her flexibility in teaching was actually a product of her Asperger's. You described this as turning another stereotype about autistic people—that they lack flexibility—on its head. It just seems like there were a lot of things about the conventional wisdom about autism that doing this project contradicted for you.

*Michael:* Absolutely! Conventional wisdom can be a very dangerous thing. Yes, the chapter with Maureen offers many great examples of the fallacies surrounding essentialisms associated with autistic personhood. Her explanations of how she teaches clarinet, as well as music theory, effectively debunk many common misconceptions. As a teacher, she is deeply in tune with her students; with their unique approaches and learning idiosyncrasies, their emotional and motivational challenges. She is ultra-flexible, ultra-empathetic, the opposite of what the textbooks would tell us autistic people are like. She has the patience to stay with her students through their processes and challenges. So yes, turning conventional wisdom on its head for sure. It's a case of things being exactly what we don't assume to be true, and being exactly what turns out to *be* true.

*Kenneth:* So, last question, Michael. The book's been out for two years now. Are there any particular reactions, particular perspectives, that you've found gratifying, surprising, difficult...anything about the reactions to the book that you'd like to share?

*Michael:* I've been pleasantly surprised at how positive the reaction has been, especially from within the autistic community. I think that's no credit to me in particular, though; it's just that the people I had the honour of collaborating with were so darned eloquent, intelligent, and insightful. It's their book. Hopefully I did a decent enough job of not stepping on their toes in the dialogues; of amplifying their voices through the construction of a narrative that does their thoughts, ideas, and passions justice; and of bringing attention to the very important things they have to say in the context of a publication that has the potential to reach readers and audiences that they might not have reached otherwise. I'm excited that the book is now being released in paperback, and with a new design that puts the names of all of my co-authors on the front cover where they belong. I fought hard for that design change and I'm really thankful to Oxford University Press for honouring my request!

*Kenneth:* I'll just sum up for our music therapy readership that what you did was you engaged with these people, with these representatives of a culture, to be understood on their own terms, not as a people or a group of people who are broken and who need to be fixed or changed. I think that's where

the world is moving to in terms of understanding autism. Just like forty years ago, if you were gay and got a diagnosis, that was a reason to be in therapy. Likewise, it used to be—and still often is—that because you were autistic, that was a reason to be in therapy. We're moving beyond that formulation, and your book represents that very impressive development. I want to encourage all readers of the journal to get it in its latest version.

*Michael:* Thank you. It's been a great conversation. It's really gratifying for someone like me, who is not a music therapist, to get to talk to you, a music therapist of great distinction, about this work. Everything that you have said—the questions you asked, the comments you made, the observations you shared—suggest to me that you absolutely get it. As for what can come out of this book and how it can be applied by other people doing other kinds of work, I would like to conclude by saying that if the music therapy profession as a whole ends up engaging with this work with the kind of insight and depth you have, I predict some wonderful developments and innovations moving forward. I hope to be an integral part of that bright, interdisciplinary, and neurodiverse future, so be sure to keep me in the loop!

## ACKNOWLEDGMENTS

We would like to thank Abby Rehard for transcribing the interview.

**Correction notes:** The last sentence in Kenneth Aigen's biography was corrected after the initial publication of the paper. The corrected version was published on 23<sup>rd</sup> September 2020.

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## Ελληνική περίληψη | Greek abstract

### Μια συζήτηση για το *Music and Autism: Speaking for Ourselves*

Michael B. Bakan | Kenneth Aigen

## ΠΕΡΙΛΗΨΗ

Σε αυτή τη συζήτηση, ο μουσικοθεραπευτής Kenneth Aigen παίρνει συνέντευξη από τον εθνομουσικολόγο Michael Bakan πάνω στο θέμα του πρόσφατου βιβλίου του Bakan, *Music and Autism: Speaking for Ourselves*

(Μουσική και Αυτισμός: Μιλώντας για τον Εαυτό μας). Πολλά θέματα και ζητήματα εξετάζονται, από την προάσπιση του αυτισμού και την νευροποικιλομορφία έως τις συγκριτικές συνεκτιμήσεις και αντιπαραθέσεις μουσικοθεραπευτικά βασισμένων και εθνομουσικολογικών προσεγγίσεων για την εμπλοκή των αυτιστικών ατόμων μέσω της μουσικής. Κατά τη διάρκεια της συζήτησης, ο Bakan εξιστορεί τα διάφορα στάδια της δουλειάς του πάνω στο θέμα, από το Music-Play Project (το πρότζεκτ Μουσική-Παιχνίδι), στο Σύνολο Artism, μέχρι το πρότζεκτ για το βιβλίο *Music and Autism: Speaking for Ourselves*. Όλο αυτό το έργο του το διατρέχει η συνεχής επισήμανση για την προσπάθεια κατανόησης των ατόμων σύμφωνα με τους δικούς τους όρους –ως ειδικοί στο να είναι αυτό που είναι– σε αντίθεση με την απόπειρα της αλλαγής των ανθρώπων μέσω θεραπευτικών παρεμβάσεων. Αυτή η αντίληψη ουσιαστικά προσδιορίζεται διττά, τόσο ως θεμελιώδης διάκριση όσο και ως ένα ισχυρό σημείο στο οποίο συγκλίνουν εθνομουσικολογικές και μουσικοκεντρικές μουσικοθεραπευτικές προσεγγίσεις.

## ΛΕΞΕΙΣ ΚΛΕΙΔΙΑ

εθνομουσικολογία, νευροποικιλομορφία, Σύνολο Artism, E-WoMP (Exploratory World Music Playground), μελέτες για την αναπηρία, αποδοχή του αυτισμού, εκ νέου παρουσίαση (re-presentation), διαταραχή αυτιστικού φάσματος, ενσυναίσθηση (στον αυτισμό), αυτο-προάσπιση του αυτισμού (autism self-advocacy)