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## Autism Spectrum Disorders in Global, Local and Personal Perspective: a conference report

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By Elizabeth Fein

Last September, a group of scholars gathered at the State University of Rio de Janeiro for “Autism Spectrum Disorders in Global, Local and Personal Perspective: A Cross-Cultural Workshop”. The event was organized by Clarice Rios, a postdoctoral fellow at the State University of Rio de Janeiro, and Elizabeth Fein, a professor of psychology at Duquesne University, and funded by the Lemelson/Society for Psychological Anthropology Conference Fund, made possible by a generous donation from the Robert Lemelson foundation. Aiming to destabilize the centrality of approaches from the global North in discussions of global mental health, the workshop sought to integrate North American psychological anthropology with the South American field of Collective Health, a field characterized by attention to the social production and reproduction of disease and health.

The workshop brought together a diverse group of scholars from northern and southern hemispheres. Participants varied in their main disciplinary affiliations: cultural and psychological anthropology; psychoanalytic psychiatry and phenomenology; philosophy; ethnomusicology; primatology; developmental psychology and linguistics; and disability studies, to name just a few. Some participants were on the autism spectrum, some were not; some had family members with autism spectrum conditions, some did not. But all of us shared a commitment to considering autism in social and relational context, across its experiential, intersubjective, and sociopolitical dimensions.

Here, we will briefly describe the many events and lively discussions that took place at this workshop. For those who want to find out more, video recordings of many of these events are also available on the [Vimeo channel of the Society for Psychological Anthropology](#).

### **Day 1: Introductory Remarks**

On Friday evening, Benilton Bazerra and Kenneth Camargo opened the event with an introduction to Collective Health and a history of Brazilian psychiatric reform. Tom Weisner followed with an introduction to

psychological anthropology and its contribution to the study of disability. The discussion that followed explored the similarities and differences between the history of psychiatric reform and de-institutionalization in Brazil, the United States, and Italy (where several workshop participants had lived or worked), particularly focusing on the role played by developments in psychoanalytic and psychopharmacological technique in each of these countries.

Video [Part I](#) – [Part II](#) – [Part III](#)

## **Day 2: – Workshop Presentations**

Our first day of workshop presentations began with Elizabeth Fein’s presentation, titled “What Do I Study When I Study Autism?” Drawing on multiple ethnographic and meaning-centered studies of Asperger’s Syndrome and related autism spectrum conditions in the United States, Fein’s presentation invited us to reconsider autistic cognitive styles “as modes of engagement characterized by a deep involvement with external systems of organization – systems which are by their nature limited and limiting”. Picking up on the theme of autism as a way of knowing about the environment, discussant Dawn Prince described how the devastating sensory impingement that results from her profound sensitivity to the world around her can also function as a warning signal about increasingly uninhabitable human environments. Though she was speaking from her own experience as a person on the autism spectrum, she observed that the search for order and repetition is central to academia as well as autism. “We all find ways to cling to the patterns we’re used to: we hold on to methodology, field of study, professorship” when we find ourselves in situations that are unexpected or overwhelming. Certainly this was true for all of us present, on some level or other, and her comments echoed in our ears as we attended to our own patterns of orientation and disorientation throughout the rest of event. ([Video](#))

Continuing the theme of departure from, and connection to, familiar disciplinary spaces, Clarice Rios was next, with “Doing Ethnographic Research Outside Anthropology: An Ethnography of Autism in the Context of Collective Health”. Rios described Collective Health as “a project for a radical political reconfiguration of the concept of health” that “conceives health and disease phenomena as part of broader social and political processes that reflect and reproduce deeply entrenched social inequalities”. She shared a series of lessons from her work doing anthropologically informed ethnographic research in Brazil within this framework, concluding that ideally, this ethnography should attend to what is at stake for the people involved without losing track of larger political issues. Her presentation also focused on how she decided to focus on the intersections of lay and professional expertise as her research object.

Discussant Tom Weisner picked up on this theme, inviting us to consider the ways in which many so-called “experts” mirror what their audiences expect to hear. What of our responsibility to our own expertise as academics? Weisner introduced the concept of a *committed, fair witness* to conceptualize the opportunity and ethical responsibility held by researchers. ([Video](#))

Jurandir Freire Costa spoke next, describing some of the work that he and his colleagues in a weekly seminar have been doing analyzing first-person narratives of autism. Costa and his colleagues prioritize phenomenology, developmental psychology and philosophy of mind over DSM-style descriptive psychiatry to articulate an understanding of cognition as “the ability to justify the way we know things”. Looking at accounts from autistic authors such as Tito Mukhopadhyay and Sean Barron, Costa argued that their ability to justify their way of knowing things attests to their rationality. Discussant Richard Grinker connected this approach with the classic anthropological studies by Evans-Pritchard on witchcraft, and the various critiques posed toward that work and its epistemological stances, centered around these same questions: how do we understand and accommodate worlds very different from our own? The group discussion focused on these issues of intelligibility and incommensurability. ([Video](#))

Pamela Block’s presentation described the intellectual lineage and evolution of her work on social movements, autism and disability: from her work on cognitive disability in Brazil to her current project, “Occupying Disability”, and her evolving autoethnographic work with her sister, Hope, who is autistic and co-authors with her through facilitated communication. Her presentation highlighted significant themes in the cross-cultural study of disability: the ways disabilities get grouped together or kept separate in various social movements and bureaucratic infrastructures; the relationship between actual social change and the symbolic representation of social change; the impact of austerity and structural inequality on the lived experience of autism. As discussant, Rossano Lima directed our attention to the parallels and differences between the politics of disability advocacy in the United States and Brazil, where the word for disability translates most closely to “deficiency” and has thus been more difficult to re-appropriate as the center of an empowering social movement. ([Video](#))

Historian of science Enrico Valtelina’s presentation wove together his “personal journey into the autism spectrum” with a discussion of the genealogy of autism. In particular, he asked how we can conceptualize autism prior to Kanner’s foundational work in the 1940’s, suggesting the term “relational disability” to describe “nonconformity to expectations of the other in face-to-face interactions”. Valtelina discussed his own experience of “interpellation” by Asperger’s Syndrome and discourses of neurodiversity, and the ways this experience has been complicated by

examining such “cultural objects” in their historical context. Francisco Ortega’s challenging discussant remarks kicked off a lively discussion about the power and consequence of labels such as neurodiversity, autism, and Asperger’s. If we broaden the word “autism” to include all sorts of quirky malcontents, as Valtelina’s work at times seems to do, won’t it lose its analytic power? Doesn’t the term “neurodiversity” excessively foreground an essentialized biological difference? And, as Tom Weisner provocatively suggested, why are we so focused on all these shifts in terminology, anyway – why aren’t we focusing our efforts instead on the common suffering of autistic people and their families, some of which difficulties seem to be shared across cultures and throughout history? ([Video](#))

Dawn Prince closed out our first day by weaving together many of the themes that had begun to emerge throughout the event into her narrative of her own struggle as an autistic person to make herself intelligible. A primatologist who feels a close sense of kinship with both nonhuman and human primates, Prince shared a series of vignettes about her interactions with gorillas, academics, and other structured social groups. Discussant Ariel Cascio asked her about a previous piece of writing in which she had announced her intention to stop writing about autism in an academic idiom. What followed were some passionate critiques and equally passionate defenses of the representational and analytic processes of “making things up” that characterize both academics and humanity at large – sometimes to our betterment, sometimes to the detriment of other things that matter. Prince highlighted in particular the importance of staying connected to direct, embodied experience of the natural world as we struggle to evaluate conflicting truth claims. ([Video](#))

### **Day 3: Workshop Presentations**

Sunday morning, Barbara Costa Andrada gave an account of the “autism controversy” that has been raging in Brazil. Costa Andrada and her research team, led by Clarice Rios and also including Clara Feldman, have been mapping the consequences of a major political shift around autism classification and treatment in Brazil. Once considered a form of “mental suffering” best treated within a public health system heavily influenced by psychoanalysis, autism is now being reclassified as a disability (*deficiência*). A vocal group of parents advocate for autism-specific specialized services that teach specific behaviors; the post-reform public health care system in Brazil is oriented more toward recognizing and addressing broader forms of shared psychosocial distress. Many children are now receiving services within both systems, with each system unaware of what the other is doing. Discussant Pamela Block highlighted the exciting research potential of such a historic moment, encouraging the team to further investigate how children and families

respond differently to these different services. Laura Sterponi pointed out ethnographers may here have a responsibility to move from an emic to an etic stance, in order to recognize and critique the “ideological erasure” that occurs when these different systems look right past each other, unseeing and seemingly unaware of each other’s work.

Ethnomusicologist Michael Bakan’s presentation was titled “Music and Autism: Representation and Re-Presentation in Anthropological Perspective”. After giving some background on his work in an improvisational music ensemble featuring both autistic and non-autistic musicians, Bakan chose to devote the majority of his presentation time to “re-presenting” (rather than analyzing and “representing”) the words of autistic musician and former professor Gordon Peterson [a pseudonym]. Peterson eloquently describes his struggles with an inner life that is beautiful and generative, but difficult to share with others. Discussant Laura Sterponi compared Bakan’s “performance” of silence within his own presentation to the radical paradigm shift in notions of authorship that John Cage suggested with his “silent piece” 4’33”. (As it turned out, Bakan has also worked with Cage!) As we discussed the figure of the composer whose deliberate act of self-silencing foregrounds the previously disregarded and unheard, Elizabeth Fein suggested that we not forget “the authorial power we have when we select whose voices to re-present”. The “neurodiversity paradigm” plays a powerful role in Bakan’s work; some discussion continued to interrogate that term and its uses. ([Video](#))

Ariel Cascio’s talk “Autism as a Way of Being in the Narratives of Parents, Professionals and Youth with Autism” presented ethnographic data from their research in autism-specific settings in Northern Italy. In their presentation, Cascio focused on how people diagnosed with autism spectrum conditions, parents, and professionals use a particular way of understanding autism – “as a way of being” – to make sense of their experience. In the process, they also shared some cogent observations about “social” and “medical” models of disability, a distinction less frequently drawn in the Italian context than it is in the US and Britain. Discussant Enrico Valtelina observed that the “avante garde” of political struggle in Italy to radically overhaul education and treatment for people with disabilities was largely led by professionals; he drew a contrast to the United States, where people with disabilities led a political struggle that often brought them into conflict with professional “experts”. These different histories have led to different sets of tensions in the present day. In Italy, use of the term neurodiversity – and appreciation for the phenomenon it describes – seems to co-exist more comfortably with talk of treatment and even cure. As Jurandir Costa and Benilton Bezerra suggested, a different question can be raised from the Brazilian perspective, where psychoanalysis (less interrupted by the emphasis on

mother-blaming that caused it to fall out of favor in the US) is still central to autism treatment: why don't we talk about *psychodiversity*?

Laura Sterponi's presentation "invited us to reappraise echolalia with a sensibility toward the experiential affordances that language yields". Sterponi brings methods from Conversation Analysis and linguistic anthropology to her close analysis of videotaped, spontaneous interactions of children with autism and their family members in their homes, as they engage in everyday tasks like drawing pictures and fighting over finishing vegetables. Rather than depicting echolalia and other language phenomena typically associated with autism as purposeless speech or as markers of individual impairment, Sterponi sees them in their interactional contexts as agentic acts, in which a child is pursuing or resisting particular courses of action. As discussant, Rossano Lima invoked phenomenological theory to explore different kinds of embodiment and meaning making. In the discussion that followed, participants explored different ways of engaging "worlds filled with worlds", allowing for ways of relating that are preconceptual, and prereflexive, engaging language in ways not necessarily symbolic. ([Video](#))

Richard Grinker provided a suitably provocative finish to the workshop talks with his talk "Who Owns Autism?" Autism, he observed, is inextricably bound up in a complex web of financial and economic interests, across multiple levels of governance, which he referred to as the "autism-industrial complex". Discussant Michael Bakan grappled with the troubling implications of this paper, and the "paradoxical quagmires" it creates for us as scholars – what kinds of research can best elucidate, rather than perpetuate, such a complex? And what about our informants and research collaborators, many of whom make active use of autistic diagnostic labels and the experiences those labels facilitate. Are we, and they, thus "inescapably complicit?" In the discussion that followed, we generated ideas for addressing these questions, and shared our own experiences wrestling with the ethical stakes of research and practice that aims to be both critical and constructive. ([Video](#))

At the end of each day, we spent an hour or so identifying and discussing themes shared across presentations, so that these themes could guide the organization of our edited volume.

#### **Day 4: Outreach**

Monday was devoted to forging connections with the broader clinical and scholarly community of Rio de Janeiro.

Monday morning we held a public meeting attended by about 150 educators, clinicians, parents and activists. Assisted by live translation via

headset, the nine visiting scholars briefly presented our work – including some experiential music and movement exercises from Michael Bakan and Dawn Prince. We then took questions from the audience; the wide variety of topics ranged from how to deal with aggressive behavior to how people affected by autism in the US and Brazil can continue to learn from each other. We were joined for lunch by graduate students from Rio de Janeiro and surrounding cities, seeking mentorship and consultation on their ethnographic research projects. After lunch, we spent the last few hours of our time together planning the publication that will arise from the workshop, an edited volume featuring a number of co-authored collaborative pieces, which we aim to publish in both English and Portuguese. ([Video](#))

In addition to these scholarly activities, we also had the opportunity to immerse ourselves in the sights and sounds and smells and tastes of Rio – dancing together at *sambas*, drinking *caipirinhas* while listening to a live *choro band*, sitting among giant, tangling tree-roots in the Botanic Gardens, and wandering together with our knowledgeable guides through rain-swept city streets at night. On the last day, a few of us traveled to Nise da Silveira's *Museu de Imagens do Inconsciente* (Museum of Images of the Unconscious). A central figure in Brazilian psychiatric reform, da Silveira is known and loved for refusing to administer the crude biological interventions then in vogue for psychiatric illness – primitive electroshock, lobotomy – instead developing an expressive arts program that gave voice to some of the most marginalized people of her society, as well as giving a start to many successful artists. We explored the many floors of the *Hotel da Loucura*, where psychiatrist Vitor Pordeus carries on da Silveira's mission of healing through theater and art. As we ascended the painted stairwells, marveling at the images that covered every wall, we were once again reminded of the power of images to express what words cannot capture, and the power of embodied experiences and physical journeys to transform the lived world.

[Elizabeth Fein](#) is an Assistant Professor in the Department of Psychology at Duquesne University. Her work is situated at the intersection of culture, cognition and subjectivity, focusing especially on adolescents and adults in the United States with autism spectrum conditions and other neurodevelopmental differences.

[Clarice Rios](#) is a postdoctoral research fellow at the Institute for Social Medicine, at the State University of Rio de Janeiro (UERJ). In her work she uses methodological and theoretical approaches from psychological anthropology to address the challenges and questions raised by the field of Collective Health in Brazil.

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