

The Emergent Landscape of Autistic Communities and Autistic Studies

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Temporality and the Life Course

I am the younger sister of Hope Block, an autistic woman well into her fifth decade. I had hoped that the two of us would collaborate in a submission to this special issue, but it was not meant to be. We lost our mother just over 2 years ago, in February 2013, and our father passed in May 2014. We are still reeling as a family from these losses, and for Hope it is particularly significant as she no longer has family living near her—I am the closest, at 4 hours away. As depicted in Block (2010), Block et al. (2012b), and Kasnitz and Block (2012), our mom was central to Hope’s communication access by supporting her typing, so her ability to collaborate with me in writing projects has been disrupted. Of course, emotionally, it is harder for us to write about the role of autism and neurodiversity discourses on our family’s life course as we careen down that course with bruising impact—too many changes happening too quickly for scholarly distance. But we are both heartened by the changes we see in how autism is being represented, studied, and lived. I am gratefully excited to be able to participate in this special issue and discuss the twenty-first century emergent landscape of autistic community, autistic studies, and perhaps even “Autistic Culture.” By emergent, I mean both temporally emergent, as in emerged over time and as a result of historical processes, and also emergent in the sense of a gathering critical mass.

My scholarship focuses on autism from the perspectives of cultural anthropology and disability studies. Hope and I are in our fifth decade of negotiating autistic and family

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identities within shifting conceptualizations of autism. From our own life experiences in the United States from the 1960s to the present, we know how changing clinical and educational theories intersect with socio-cultural and economic changes over time. Life course processes that Hope and I have written about, or would like to write about, include early diagnosis, education, communication, employment, community living, romance and intimacy, deaths of parents, and the challenges of aging. Theoretical and practical shifts have been extreme over the five decades of Hope's life. She was born in an era of institutionalization, when the "refrigerator mother" theory was in vogue. Our family witnessed and experienced profound transformations in psychiatric, educational, and communication theories and practices. We lived through policy changes supporting community inclusion and threatened by fiscal austerity. We participated in the emergence of neurodiversity and autistic-self advocacy, which provide counter-narratives to traditional clinical and parental representations of autism. These theoretical shifts influenced changes in policy and practice, and have influenced identity formation and life opportunities for Hope. We have seen, with the transformation of how we conceptualize autism, an emergence of new possibilities for Hope and others but also new ambiguities, spaces of confusion and uncertainty, and a sense that what gains we have made could easily be snatched away from us.

Liminal Spaces and the Borderlands of Autism

Where does autism exist? The spaces where autism is discussed in this special issue include shifting discursive spaces, as we negotiate between DSMs, between paradigms, between historical epochs of refrigerator mothers, psychotic patients, sensory-sensitive immature nervous systems, conceptions of "rigidity" (Cascio), and sites for the cultural production of neurodiversity (Fein). We see how autistic/autism spaces are negotiated differently in different cultural and regional contexts (Rios and Costa Andrade, Brezis, et al., Sarrett). We see how various therapeutic spaces are helpful or hindering, empowering, or disempowering (Fein, Solomon). These articles reveal spaces betwixt and between diagnosis, therapy, custodial care, and the acceptance of autism as Neurodiversity. Sarrett says that in the United States, the availability of so many treatments can interfere and delay acceptance. In Sarrett and Cascio, it seems that slower but still progressing developmental trajectories can be mistaken for treatments leading to cures. Diagnosis can be a given, or not. It can be a convenience, or not. In Kerala, as depicted by Sarrett and Brezis et al., parents of autistic children are not accepting Neurodiversity (as a concept) so much as accepting the reality of the persistence of characteristics that must be negotiated in their world. At the borderlands of autism, does it really matter what side of the border you are on?

Emergence of Autistic Communities

Autistic worlds, communities, and cultural expressions are emergent—they are emerging over time and also gathering critical mass. In the December 2014 meeting, organized by Matthew Lerner and Mark Aronoff at Stony Brook University,

“Conversations in Autism and Sign Language” (Lerner and Aronoff 1914), we discussed the possibility of autism as an emergent disability community (or communities) with shared cultural practices. In my presentation at that meeting, I compared the US and other Autistic communities in the global north, the oldest of which are barely 15 years old, to (also largely US and Western-based) well-established multi-generational Deaf communities. In contrast to “Deaf Culture,” for and by Deaf people, which has seemingly had centuries to emerge, “Autistic Culture” is just coalescing. The camp described by Fein is a brilliant example of that emergence. Fantasy worlds, such as the one created in the camp Fein studied, rewrite and expand social possibilities. They allow youth to slay their dragons and develop skills that can be generalized—*but on their terms*—in a way that values and even valorizes autistic traits, autistic community, and “autistic culture.” Rios and Costa Andrade’s discussion of how autism has been defined and redefined in Brazilian policy is another example of the emergent nature of autistic community. As discussed in Rios and Costa Andrade and also in Block and Cavalcante (2014), Brazilian social movements for psychiatric liberation were initiated by professionals, not psychiatric survivors. Mad Pride and Autistic Pride are new concepts in Brazil, and for these to join together in solidarity with movements for disability access and social equality is a very recent and emergent shift in autistic community building (Block and Cavalcante 2012, 2014).

Presuming Competence or Incompetence

Solomon’s work approaches the issue of presuming competence or incompetence of autistic people, as discussed so eloquently in Biklen and Burke (2006) and Kliwewer, Biklen, and Kasa-Hendrickson (2006). We see what we expect to see, but if we look from a different angle or context what we perceive can shift dramatically. Our perceptions and how we choose to structure our interactions radically alter what we observe and how we relate to autistic people. Solomon’s analysis reveals disturbing truths about how communication and sociality are bound within relations of power. In animal-assisted therapy, Kid is the protector; she has the power to shelter her animal companion. In contrast, Rosalyn in the therapy session is definitely not empowered. She is encouraged to communicate only when it suits those structuring the dialog, and only in the ways and times that they considered it appropriate for her to do so. Otherwise, her communication was discouraged, if not silenced; it was “glossed over,” “intercepted,” and “pre-empted.” Cascio notes something similar in her discussion of rigidity. She discusses how the concept is often used by professionals as a descriptive autistic trait, even while those same professionals expressed their concerns that their own approaches to autism and autistic people may lack flexibility. If we expect to see rigidity, is that all we see? And who are really the rigid ones? In the heated and dialectical debates concerning autism treatment, what can we learn about rigidity and alternatives to it, competence and its opposite?

Conclusion

This special issue runs the whole gamut of current cultural research in autism, focusing on autistic people, parents, professionals, and policymakers. Two of the articles, by Fein and Solomon, focus directly on the experiences and perceptions of autistic people, while Cascio analyzes professional discourse, Sarrett and Brezis, et al., focus on parental approaches and attitudes, and Rios and Costa Andrade discuss culturally influenced policy shifts. None of the authors identify as autistic, and this is a sad omission, as autistic scholars play an essential role in the emergence of autistic studies. It has already started, and knowing that a number of promising autistic scholars are coming down the pipeline, I expect that, within the next 5–10 years, there will be a transformation of formal scholarly discourse (Autism Self Advocacy Network 2012, Milton DEM 2014, Prince-Hughes 2004). We will see what is already quite robustly visible in the blogosphere—a profusion of scholarly works authored by autistic scholars describing and analyzing autistic communities. I say with thrilled anticipation: Get ready for what is emerging, in some cases has already emerged, despite structural barriers to graduate study, getting published, hired, and tenure.

One of my mother's friends had an autistic brother, born in the 1940s, a secret brother who lived institutionalized for most of his life. My sister Hope did not have the chance to go to or graduate from her local high school, or even to be successfully supported in her segregated school toward literacy and independent communication. If she had access to the communication strategies and technologies available to children today, what might have been? If she had been institutionalized at birth, what might have been? I am not sure what is in our future. Will we be able to co-author again? It is not our first priority right now. We are concerned about affordable housing, transportation, safety, friendship, love, staying connected, trying not to lose more than we have already lost, while still celebrating what we have gained.

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