

UC Santa Cruz

UC Santa Cruz Electronic Theses and Dissertations

Title

On The Spectrum: Autistics, Functioning, and Care

Permalink

<https://escholarship.org/uc/item/8707b86c>

Author

Moore, Matthew J

Publication Date

2014

Copyright Information

This work is made available under the terms of a Creative Commons Attribution-NonCommercial-NoDerivatives License, available at <https://creativecommons.org/licenses/by-nc-nd/4.0/>

Peer reviewed|Thesis/dissertation

UNIVERSITY OF CALIFORNIA

SANTA CRUZ

**ON THE SPECTRUM:
AUTISTICS, FUNCTIONING, AND CARE**

A dissertation submitted in partial satisfaction
of the requirements for the degree of

DOCTOR OF PHILOSOPHY

in

HISTORY OF CONSCIOUSNESS

by

Matthew John Moore

June 2014

The Dissertation of Matthew Moore
is approved:

Distinguished Professor Emeritus
James Clifford, Chair

Distinguished Professor Emerita
Donna Haraway

Professor Emerita
Adele Clarke

Tyrus Miller
Vice Provost and Dean of Graduate Studies

Copyright © by

Matthew J. Moore

2014

Contents

List of Figures		iv
Abstract		v
Acknowledgments		vii
Introduction	On the Spectrum: Autistics, Functioning, and Care	1
Chapter One	Human Kind(s) in Motion: Articulations and Idioms of Biosocial Becoming	28
Chapter Two	Beside the Autism Wars: Navigating an Epidemic	80
Chapter Three	Meetings: Wrestling with Spectra	139
Chapter Four	Critical Studies of Autism, Or: How I Learned to Stop Worrying and Love Neuro-essentialism	205
Conclusion	Situated Functioning: Facilities and Difficulties	259
References		288

List of Figures

96	A 6,000% Increase in Autism
128	CDC: 1 in 68 Children
129	The Cost of Autism
133	Innovative Models for Funding: Working beyond the science to deliver the science
187	Cerebrum: Brains and Dollars
188	Psychiatry as a Clinical Neuroscience
228	Neurodiversity: A Symposium
263	Autism Parenting Magazine: Exposing Autism Speaks

Abstract

On the Spectrum: Autistics, Functioning, and Care

Matthew J Moore
University of California Santa Cruz

On the Spectrum explores the recent flourishing of autistic self-advocates as social actors, stakeholders, and co-creators of autism worlds. In the contentious and contradictory discourses surrounding autism, it considers ways that all participants – medical practitioners, researchers, educators, parents, and autistics – are interested actors. To understand how and why autism worlds both overlap and diverge, contemporary concerns are examined in terms of inherited legacies from earlier historical ‘turns.’

In recent decades, an autism ‘spectrum’ and ‘epidemic’ emerged together as some parent-advocates redirected efforts toward development of biomedical treatments. Autistic self-advocacy simultaneously emerged as a social movement, where previously there had been virtually no recognizably autistic voices heard publicly. Self-advocates locate themselves in relation to powerful discourses shaped by psychiatry, bio-medicine, and “cure autism now” parent advocacy organizations. Rather than minimize the distance between what have come to be known as pro-cure and pro-acceptance (or neurodiversity) positions, *On the Spectrum* sustains the tension as necessary for movement toward a re-articulation of contentious encounters.

The analytic work is grounded by engagement with autistic self-advocates and participant-observation at autism conferences. Professional, community, and policy meetings are described as important sites of negotiation where public discourses reflect

multiple personal and ontological commitments. Actors engage one another in an effort to reformulate ways of talking about and living with autism, understood variously as disease, disability, and difference. A theoretical framework is assembled to consider how autism simultaneously exists as a behavioral disorder and biomedical disease, alongside emergent formulations of autism and autistic personhood which are significantly depathologized. It shows how autism becomes recognizable as a diagnostic category, boundary object, cultural resource, and biosocial entanglement.

In the conclusion, an idiom of *situated functioning* is proposed as a way to rethink normative assessment practices, where notions of intelligence and functioning are understood to be personal qualities and contained fully within individuals. In contrast to how autistic populations are typically labeled as either high-functioning or low-functioning, a non-binary twining of *facilities* and *difficulties* productively disrupts the tendency to talk and think about assessment as locating fixed attributes and the upper limits of individual potential.

Acknowledgments

I want to thank my wonderful advisers and committee members: James Clifford, Donna Haraway, Kimberly Lau, Susan Leigh Star, and Adele Clarke. Jim and Donna have been with me since the beginning and my gratitude to both is immeasurable. Both Donna's and Adele's thinking are evident throughout the dissertation, but I want to acknowledge here the way the two worked together to ensure that Leigh Star influenced the project from start to finish. I hope Leigh is proud of this work.

Stacy Kamehiro provided support in a variety of ways during my studies, especially facilitating my growth as a teacher. And Paula Holtz helped me find my way, as well. My grad student colleagues offered steady inspiration and I want to acknowledge in particular: Raissa DeSmet Trumbull, Cindy Bello, Robert Trumbull, Adam Hefty, Kris Weller, Lindsey Collins, Sandra Koelle, and Harlan Weaver.

I wish I could describe the entire spectrum of support my family provided even at times my progress was not discernible to them. Both of my parents – Bert Moore, Ph.D. and Joy Williams Schilling, Ph.D. – have contributed meaningfully to the thinking represented here. It was only with my mother's assistance that I was able to meet institutional deadlines and express ideas as well as I have. I marvel at the lengths both my mom and dad have gone to help me accomplish my goals.

Some of my extended family I see daily while others cross oceans to visit. All have been there for me: Dru Sherrod, Arden Reed, Lynne Kirk, Glen Schilling, Kory Kirk, Anne Kirk, Wendy Schilling, John Moore, and Linda and Peter Barter. Special gratitude is reserved for Hai Ho and Ngọc Anh Nguyễn who have been working so hard and loving their grandkids so well.

Maichi Thi Ho is simply a remarkable person and I am truly fortunate to have her in my life. Graduate school was more than we bargained for when we began the journey together, and I hope the extra time I needed benefits our family. I like to imagine that all the writing might make a difference for our children, Reef and Curren, as well as the social worlds they come to inhabit.

I didn't foresee how much I would learn from autistic self-advocates about how to accept and work with my own difficulties. I know better now how to stick with the trouble and identify areas where I benefit from additional support. Thank you.

Introduction

On the Spectrum: Autistics, Functioning, and Care

Colette in Transition

As far as I know, the first person with an autism diagnosis I met was in early 2001 while substitute teaching in the San Francisco Unified School District. The autistic woman, whom I refer to as Colette, was nineteen-years-old at the time. When I met Colette she had already received her certificate of high school completion. Legally, however, she was considered an “incompetent” under the guardianship of her mother. She continued to receive educational services from the public school system as part of the Community Access and Transition (CAT) program for young adults labeled with moderate to severe disabilities – a program designed to teach life-skills so that persons with cognitive disabilities would be able to live as fully and independently as possible.

A month earlier, I had earned my master’s in education and an elementary school teaching credential from San Francisco State University. My “general ed” teaching credential only included one course on how to include students with special needs. I can’t say that I learned anything specifically about autism in my studies. My knowledge of autism did not extend much beyond what I learned from Dustin Hoffman in *Rain Man*.

I reported to the CAT classroom on a brisk January morning, located in a high school even though the students were not considered to be *in* high school anymore. It was difficult to get oriented. When I came in, there was another, preoccupied, teacher in the classroom and more paraprofessional staff, a.k.a. “paras,” than I had ever seen before

in one place. They gave curt greeting but no one made introductions or offered instructions. Everybody looked busy. I later learned unfamiliar “subs” were considered more hindrance than useful, an extra person needing direction. I initially thought I had walked into the break room by accident, because it was not immediately evident to me who were students and who were staff.

Mainly Colette stands out from that first day. Moments after I came in, Colette’s mother brought her into the room, saw me, and asked me to sit with Colette. As Colette and I sat down side-by-side, her mother warned me to be careful of my eyeglasses because Colette liked to snatch at them. I have good peripheral vision and what I consider pretty quick reflexes, but as I turned my head slightly to watch her mother walk to the front of the classroom, Colette swiped my glasses and flung them across the room. Just like that. Didn’t touch my face at all. Quite a surprise, despite her mother’s warning. I remember that being caught so thoroughly off-guard, only seconds after such an explicit warning, made me laugh out loud. The paras were quick to see if I was all right and scolded Colette profusely.

My usual non-intrusive way of interacting fit in well with the program, and I quickly became the go-to sub. The classroom had two credentialed teachers and five paras, all of whom I would substitute for, so I quickly began spending a substantial number of my sub days with this in CAT. I became a regular presence, especially because more than once someone needed to take an extended leave of absence.

We constantly talked about “going out in the community,” where students and staff dispersed for the majority of each day. That space, outside the school environment, represented our goal for social participation. Out in the community was where we

imagined full, maximally independent personhood would be achieved. We were trying to fulfill the public school's obligation in the wake of deinstitutionalization to normalize the presence of disabled people in the community.

The paras and I sometimes talked about how it was a pain to wander around near the school if we got back too early from another part of the city. Occasionally it would have been nice to come back to the school early in order to have lunch together as a group. We hardly ever went out together with more than two staff and three or four students. The stated rationale was that we wouldn't be able to blend in out in public if we went in a large group.

The politics of visibility and full-inclusion for disabled people are complicated. Many of our students didn't "look disabled." Some had unusual body types, movements, or affects, while some did not. A few regularly exhibited notably atypical behavior in public, most didn't. Among the autistic students, some had visible perseverations and/or vocalizations that could be characterized as disruptive, but not all of them. The expectation for our model of inclusion was to organize a single or few disabled people to be in the presence of many non-disabled – on the MUNI, at work, in a store or restaurant, or walking on the street.

Because we only met briefly in the classroom during the morning and afternoon, there was not enough opportunity for the students to socialize with their peers and to generate a sense of community – which probably was not an easy process for autistic students. There was a classroom culture, but the students did not have much say in how it was structured. Although we were supposed to empower the students to make decisions for themselves, they mostly made choices about where to eat and what to buy.

That isn't close to a full picture of all the kinds of activity that went on in the CAT program, but it does characterize how it felt to me sometimes.

I shared a considerable amount of time with Colette over the next two years. She never went for my glasses again over that period, although, occasionally, she did give me a whack to the arm. Not hard, almost like a pat, enough to remind me how quickly she could move. In the classroom and out in the community, Colette required constant one-on-one attention. Certain paras refused to work with her and it seemed to me that the teachers dedicated more time to instruction and interaction with other students in the class.

Colette was small and appeared non-threatening, but she regularly reached out to hit, grab, poke, and pull at others. She was particularly prone to making a grab for the area around the face, including eyes and hair. I didn't learn until much later that this behavior is not all that uncommon among autistics. I hardly ever remember seeing her hand in motion to reach or strike others. By the time my eyes could focus on Colette's movement, her hand was either making contact with the intended target or back at rest.

The staff referred to Colette's undesirable propensities – she also liked tearing things up – as an issue of impulse control. But I had the distinct impression she bided her time, waiting for an opportune moment. I believe she watched for openings. I learned to anticipate situations or triggers that might put Colette into motion or strike her fancy. I tried to be ever vigilant, but she was even more skilled at registering the moment my guard dropped, whether over a period of hours or weeks. We both constantly moved in relation to one another and in response to dynamic, fluid contexts.

For me, Colette was fun to work with despite, or perhaps because of, the way she called for utmost alertness. She did not speak, but would signal assent with a high-pitched yip and a raised finger. She understood a great deal, and perhaps everything, that was said in her presence. I never stopped wondering exactly how much. She followed directions for the most part, and the power of a verbal command could, usually, bring her up short, which was important when she made a move to strike another student or unsuspecting passerby. I always felt that we got on together rather well, but thought that she probably understood me better than I did her, or at least knew better what to expect from me. I enjoyed going with her to piano lessons and to her job in a thrift store where she did tasks such as collect and sort hangers.

Colette had a mischievous streak. For example, I had to check the toilet every time she came out of the bathroom to make sure she hadn't thrown all the toilet paper she could find into the toilet. (We always had to make sure Colette went to the bathroom regularly, because she couldn't, or at least wouldn't, communicate that she needed to go. She wore adult diapers for incontinence. But if there was an accident, she would have to wear them all the way back to school, and possibly until she got home if there were not female staff around to help her change.)

Colette's mom told me that sometimes late at night Colette would sneak out of her bedroom and into the hall of their apartment building. She would go to the door of each of her neighbors and ring the doorbell. Her idea of a prank, perhaps – what my friends and I used to call ding-dong-ditch.

One time in the classroom, when I was standing near Colette's chair, leaning across the table to help another student with something, Colette groped me. At first, I

just felt pressure on my butt, which I hardly noticed. Then, she surprised me by reaching between my legs from behind to grab my genitals. I spun around and she was standing there, out of her seat, grinning that unsettling grin. I don't remember what I said, but one of the class paraprofessionals looked up from what they were doing and asked if she had hit me.

This probably sounds odd, given my description of what transpired, but I later told a co-worker that I didn't believe Colette meant to grab me in a sexual way. He responded that she most certainly did. Obviously! But to me, Colette had been an utterly asexual person. I did eventually learn to recognize our adult students as sexual beings, but it was only later that I learned that intense sexuality was once seen as highly correlated with cognitive impairment.

We went out another day, just the two of us, and took the bus all the way down Fulton Street to the end of the line by the Safeway at 48th Avenue. It was one of our "free," unscheduled days, when I or another staff member was able to choose how we spent the day with Colette. We walked across Golden Gate Park, the narrow way not lengthwise, toward Lincoln Way. At one point we had to make a dash along the path where a sprinkler rotated back and forth. We weren't actually going to get wet, or maybe just a little, but I had a heck of a time getting Colette to do it. It was a good way back to where we could take another route, so I pulled her hand gently, but she pulled back hard. Her face told me she was scared. She was also afraid of dogs, which we passed on the streets regularly, but this was the only other time I saw fear in her eyes.

I was finally able to coax her through the wet section, and we made our way over to Java Beach, where the N Judah train ends. I bought myself a coffee and used money

she earned through the school district's "work-ability" program to buy her a pastry. Almost every other student carried their own money. But Colette enjoyed tearing things up. With coffee and pastry in hand, we crossed The Great Highway and walked over the sand dune to look at the grey ocean. Somebody on the staff had told me once that Colette liked to sit on the beach, running sand through her fingers. But she wasn't interested in sitting down this day.

Afterward, we rode back up past UCSF, where the train goes underground briefly at Cole Street, as it cuts over toward Market. We got off and began walking toward The Haight. We only went about fifty feet before Colette abruptly stopped, in her jerky way. She swiftly pulled down her pants and began peeing on the sidewalk. I'm sure that I remembered to take her to the bathroom before we left Java Beach twenty minutes prior! I heard the toilet flush, no roll of paper lodged at the bottom of the bowl.

Regardless, she was now peeing right there out in the open, publicly. I told her to stop but the pants were already at her ankles and pee was flowing. I looked up and down the street but saw nobody looking at us. Then, I laughed. She pulled her pants up and we kept walking. I was impressed by what to me seemed like audacity, although that might not be the right word. Nonchalant, maybe. For obvious reasons, I was grateful she didn't pee in her pants. I still smile whenever I think of it.

I never saw Colette seriously hurt anyone, but I knew I had to stay close and remain alert. She would semi-regularly manage to hit, poke or tug a fellow passenger on the bus. One warm, sunny day, she poked another student in the eye, right after we got off the MUNI bus outside the school. Everything had gone great up until then, I thought, and the other (also non-speaking) student seemed to recover after a few anxious tears. At

such times, Colette would grin broadly, like under no other circumstances. I got down in her face, grabbed her hands, perhaps a bit too tightly, and the grin disappeared from her face. It was our only real confrontation since the first day she threw my glasses.

Some on the teaching staff found her “impulse” to lash out profoundly disturbing. I almost never did. I wondered about her thoughts, motivations, and understandings. Still, there was something unsettling about the grin. I needed to remember that Colette *was* dangerous. Before I had come into the CAT program that first day, she had once sent the class’s most vulnerable and immobile student to the hospital, also with an eye poke. After that, the furniture in the classroom was rearranged so that desks boxed Colette in, and staff was forthwith strategically placed to block her movements.

A year or so after Colette had graduated the CAT program, I saw her in a dance class at a studio on Mission Street, where I was exploring recreational opportunities with other students. When I came over to say hello, Colette went for my glasses repeatedly, but unlike that first day, I was quick enough to avoid her grasp. I still wonder about her motivations, and I wish that I better understood her behavior. I once felt unsure of Colette’s capacities for affection and attachment, but thinking back, I no longer doubt their existence.

Acceptance, Cure, and Commitment

When I met Colette in 2001, the language of epidemic was already attached to autism and really gaining momentum. Over next decade it became hard to think or talk about autism publicly without addressing or being drawn into the question, why an autism epidemic? This was true even for those skeptical about whether the epidemic was in fact *real*, as well as those who dismissed the relevance of an epidemic model or

metaphor for understanding what was then considered a genetically based neurodevelopmental disability. If you had reason to care about autism, and even if you hadn't previously, you couldn't help but wonder why autism's prevalence kept increasing so dramatically. At the same time, autism's new pervasiveness generated curiosity and new social spaces where different questions and concerns emerged.

This dissertation is an effort to negotiate the space between epidemic and other ways of understanding autism, such as disability and non-normative neurological difference. I became confused as I heard more and more about an epidemic. I had trouble connecting the epidemic discourse with the autism I knew, both the calls to fight and to cure. Colette and other students I worked with taught me that there was often something about autistic-ness that I *liked*. I felt an affinity of some sort, which was particular, born of specific encounters and relationships. The project is also about my effort to know autistic people.

I became motivated to investigate after I learned of an emergent autistic rights movement, which positioned itself in opposition to both the desirability of a cure and the very idea that such a thing were possible. In fact, I began my doctoral studies with a different topic and was only drawn to this project after reading an article by Amy Harmon about the autistic self-advocacy movement.¹ The article explained that self-advocacy coalesced around issues such as rights, identity, and culture. Two things particularly stood out: self-advocates were saying they did not want to be cured and they insisted that they *were* autistic, as opposed to persons *with autism*. A cure was either an impossibility or a violation of their personhood. It was also clear that a significant

¹ Harmon, "How About Not 'Curing' Us, Some Autistics Are Pleading."

amount of mutual animosity had developed between self-advocates and parent advocates who viewed curing a disease as the primary goal.

This tension between the goals of cure and acceptance is central to how I make sense of autism/autistic politics in the present moment. It also shapes how I read histories and imagine possible futures. In reality cure and acceptance are hard to hold apart as polar opposite goals. There is a vast space between, where therapeutic options are less than curative, and desires for (self-)transformation are not entirely accepting. And, of course, a pro-cure parent wants much more than a cure for their child, and an autistic person seeks (and needs) much more than just acceptance. One approach to understanding the tension is to show how the actual lived practice of acceptance and cure are not really so distinct, to attempt to bring closer together the interests and concerns of advocates, who are aligned with one position or the other. Several studies that I draw from in my work make versions of this move to various degrees. For the most part I do not.

I consider *cure* and *acceptance* keywords thrust to the fore as binary by the discourse of epidemic. The terms are over-determined in what they express, and the opposition is itself a crucial part of their significance. They are also boundary markers that help inhabitants of autism worlds set priorities and guide frames of action. Different worldings become possible or impossible depending on how people position their commitments in relation to them. I focus on the cure versus acceptance opposition, also, because I think the terms often reflect, and inflect, not just incommensurate but directly conflicting ontological commitments. What is needed, I believe, is not to simply show

that actors share common ground, but to explore how these commitments help to redefine the grounds they (will) stand on.

The cure versus acceptance problematic, and how that tension both is and isn't defined by the positioning of actors as parents or autistics, has remained a focal point since I began my project. In other respects, the dissertation turned out very differently than I expected even quite late in the research process. I planned to write about how autistic individuals and communities re-articulate autism and autistic-ness in relationship to psychiatric diagnostic criteria and biomedical discourses. My research efforts reflect that: I studied the history of the *Diagnostic and Statistical Manual of Mental Disorders* and attended meetings of the American Psychiatric Association; and I attended five gatherings of Autreat, the annual conference and retreat organized by Autism Network International to facilitate development of autistic community, thinking, and culture. The question of how autism is known (and could be known differently) is certainly here, but I don't think that concern with the institutional discourses and resistance to them captures what this dissertation ended up doing.

On the Spectrum is really much more about figuring out how to carefully navigate through contentious issues and contradictory discourses surrounding autism. It is an attempt to understand what is at stake in contemporary autism politics, for autistics in particular, but also for family members and caregivers. The focus ends up centering on what it is that autism problematizes: ways of organizing and evaluating relationships; judging social and intellectual functioning; the health of individuals in relation to their environment (and vice versa); painful legacies and hoped for futures. It is a wrestling

with autism as a problematic – not a single conceptual problem but a knot of questions and concerns brought into relation.

When the *DSM-5* was published in 2013, autism officially became defined as “autism spectrum disorder,” although the term “spectrum” had been in common use since before the publication of *DSM-IV* in 1994.² The co-emergence of an autism spectrum and an epidemic of autism are tied together in important and complex ways. My analysis is focused on the period from the early 1990s through 2013 as defining an historical turn toward autism as spectrum and epidemic. In many respects, the co-production of an autism spectrum and autism epidemic defines the dissertation’s central problematic, which helps me to make sense of both how some autism parents radically redefined their advocacy efforts toward an emphasis on biomedical treatments and how autistic self-advocacy emerged as a recognizable social movement where previously there had been virtually no recognizably autistic voices heard publicly. At the same time, I try to keep in view ways that recent developments have been shaped by earlier histories of autism’s identification as a distinct diagnostic category during World War II and its postwar re-articulation. I consider the influence of that social inheritance on how we are coming to understand autism presently, and how we might want to rethink it going forward.

Autism’s History in Four Turns

People in the United States found autism fascinating even when the diagnosis was considered rare in the decades after Leo Kanner began writing about the syndrome in the early 1940s, just as we do now that it has become common. I think the enduring interest

² American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders*; American Psychiatric Association, *DSM 5*.

has as much to do with the socio-historical and ontological tensions held together by its diagnostic prism as what autism *is* and who autistic people *are*.

I consider there to be four significant turns in the history of autism, which reflect important legacies that help define the central tensions and concerns I work with in the dissertation. Autism emerged in a moment of crisis during World War II, when aspirations of modernity seemed to have spiraled out of control into total war and technologies of human extermination. There is a sense in which the abrupt identification of autism as the inability to relate to other people can be imagined to contain the full horror of that historical moment. Autism was born in the modernist borderlands, where both ‘the social’ and ‘the mental’ are split into domains of binary opposition, between intellect and affect, dearth and excess. The definition of autism as an *affective* problem simultaneously reflected a movement to open up feeble-mindedness, or mental deficiency, as a space amenable to therapeutic intervention. It shifted the problematic of (some) mental defect from below the threshold of abjection to a diagnosis with hope.³

Eugenically infused thinking played an important role in the mid-20th century spiral of signification and genocidal in/action. In the eugenic logic that began to take root during the latter part of the 19th Century intellectual deficiency was recast as feeble-mindedness and mental defect, which increasingly appeared as self-evidently undesirable and a major obstacle to human progress. If insanity seemed to warrant more study, intellectual deficiency seemed largely transparent in its congenital inheritability and association with undesirable populations. By 1942, the logic was such that an

³ See Hughes for more on modernity and civilizing projects becoming ontologically invested in aversion for and disposal of disability: Hughes, “Civilising Modernity and the Ontological Invalidation of Disabled People.”

editorial in the *American Journal of Psychiatry* supported the proposal to seek legislative backing for a policy of *disposal* of mental defectives by euthanasia, presented by Cornell University chair of neurology Robert Foster Kennedy, who concluded:

...Should the social organism grow up and forward to the desire to relieve decently from living the utterly unfit, sterilize the less unfit, and educate the still less unfit – then the Law must also grow along with the amplitude of our new ideals for a wiser and better world, and fit the growing organism easily and well; and thereafter civilization will pass on and on in beauty.⁴

The figuration of mental deficiency as “nature’s mistake,” was a lynchpin precisely because of the lack of differentiation within the category and the seeming obviousness of deficiency.

First Turn

I have always been struck that the two original papers of Leo Kanner on “autistic disturbances of affective contact” and Hans Asperger on “autistic psychopathy” were published in 1943 and 1944 during the height of the Second World War.⁵ Asperger introduced the concept of autistic psychopathy several years prior during a lecture at the Vienna University Hospital, shortly after Germany annexed Austria in 1938.⁶ He emphasized the previously unrecognized intellectual strengths and “special gifts” of many children at the University clinic in part to make an argument for their social value in the face of Nazi eugenics. Asperger asserted that the good of the “living organism of the nation” was supremely served by helping abnormal individuals to find their place as

⁴ Kennedy, “The Problem of Social Control of the Congenital Defective: Education, Sterilization, Euthanasia.”

⁵ Kanner, “Autistic Disturbances of Affective Contact”; Asperger, “Die ‘Autistischen Psychopathen’ Im Kindesalter.”

⁶ Bush, “Constructing an ‘Autistic Pathology’: Hans Asperger, Austria & the Profession of Psychiatry, 1900-1945”; Feinstein, *A History of Autism*.

workers, and concluded, “we must never give up on the education of abnormal children,” because, “all of a sudden – at puberty, for example – there may appear strengths and capacities which we would not have suspected existed in these children or we could not have foreseen would have been of any importance.” He introduced the autistic child as part of an argument that abnormal individuals may also someday yield socially useful attributes.⁷

In 1942, a year prior to publication of his autism article, Kanner also argued against eugenic policy proposals, in a paper published in the *American Journal of Psychiatry*. His paper, “Exoneration of the Feeble Minded,” appeared alongside the paper by Robert Foster Kennedy which proposed that mentally defective children be euthanized when they reached five years of age.⁸ Kanner’s plea relied heavily on the argument that the “feeble-minded” or “mentally deficient” were not a homogenous group. While he denounced euthanasia for even the “absolutely deficient,” he focused a good deal on the greater majority of so-called feeble-minded who were only “apparently inadequate.” He said psychiatry needed to do a better job of delineating specific forms of psychopathology from “the fictitious notions of homogeneity and absoluteness” of mental deficiency, which notably would include specification of mental inadequacy in the realms of emotional and conative function. He further maintained that psychiatrists should assume the role of friendly planners and helpers, better identifying the “misfits in life” so that they could be properly fitted “for the things which they can do with profit to

⁷ The Gestapo twice came to the clinic for Asperger himself, but he was saved both times by his superior who was a National Socialist. Feinstein, *A History of Autism*.

⁸ A medical review board would be authorized by law to make the determination of “hopeless” deficiency upon the request of parents. Kanner, “Exoneration of the Feeble-minded”; Kennedy, “The Problem of Social Control of the Congenital Defective: Education, Sterilization, Euthanasia.”

themselves and their communities.” In the following year, Kanner insisted that the autistic children he had identified were “unquestionably endowed with good *cognitive potentialities*” in his article on disturbances of affective contact.

Kanner and Asperger both “discovered” autistic children with previously unrecognized cognitive potential among what were considered hopeless cases of mental defect. During a moment when policies of eugenic sterilization were already in effect and psychiatrists and neurologists appeared close to lending their expert opinion to authorize euthanasia in both the United States and Nazi occupied Austria. In this light, hidden and difficult to measure intellectual potentials were cardinal features of the autism diagnosis. The identification of autism as a distinct diagnostic category can be partially understood as a strategic intervention to resist the movement toward systematic euthanasia for “the defective child.” As part of a turn *away* from a eugenic future, an alternate path had to be imagined, built, and sustained. Thus, simultaneously, the two psychiatrists embraced another logical development in psychiatric expertise, helping to open up a new diagnostic and therapeutic space of intervention that could exist between idiocy and madness, between mental deficiency and mental illness.

Although it remained a rare diagnosis for many years, Kanner’s syndrome became a symbolically important element in the temporary ascendance of Americanized psychoanalytic theory during the postwar years. According to Kanner, the autistic child appeared to lack interest in or concern for other people and, indeed, seemed more interested in non-human objects, frequently treating other people’s bodies in the same manner as objects in the environment, yet there was no identifiable moment of withdrawal from contact. Kanner wrote, “The outstanding, ‘pathognomic,’ fundamental

disorder is the children's *inability to relate themselves* in the ordinary way to people and situations from the beginning of life."⁹ Autistic children were like test cases not just for theories of causation, but also whether empathic traits and reciprocal behaviors could be cultivated or instilled. Kanner waffled (or hedged) repeatedly on whether autism's origins were primarily organic or psychogenic in origin, and he was the one who first began to speak of autistic children being raised by "refrigerator parents."

Second Turn

The tendency to locate responsibility for the autistic child's problems with the parent (mother), and the experience of feeling blamed, helped provoke what I view as the second major turn, during the mid- to late-1960s, toward co-producing parent knowledge as *expert* knowledge and autism as a neurologically based disorder. Countering blame of parents was a self-conscious motivation for psychologist and autism parent Bernard Rimland's argument for the reconsideration of autism as an inherited neurological disability and his critique of psychodynamic explanations.¹⁰ Rimland's authority as a scientific expert was crucial, but equally significant was how he joined with other parents such as Clara Claiborne Park to found the National Society of Autistic Children (NSAC). Park's hugely influential book, *The Siege*, laid out in memoir form the affective and experiential basis for developing parents' highly attuned observations of their atypical children into an effective practice of therapeutic parenting.¹¹

Park's *Siege* was published in 1967, the same year as Bruno Bettelheim's infamous *Empty Fortress*, which became emblematic of the harm inflicted on autism

⁹ Kanner, "Autistic Disturbances of Affective Contact."

¹⁰ Rimland, *Infantile Autism the Syndrome and Its Implications for a Neural Theory of Behaviour*.

¹¹ Park, *The Siege: The First Eight Years of an Autistic Child: With an Epilogue, Fifteen Years After*.

families by psychoanalytic theory and the postwar trend toward institutionalization of young children.¹² It is not incidental that Bettelheim first came to fame with his 1943 article, “Individual and Mass Behavior in Extreme Situations,” based on his experience in a Nazi concentration camp; nor that in the *Empty Fortress* he likened the retreat of autistic children behind psychic defenses to the total dehumanization and fear of annihilation experienced by prisoners in the camps.¹³ In Bettelheim’s metaphor, autistic children continued to experience themselves existentially at risk of extermination in a Cold War psychodrama, which was problematically contained within the mother-child relationship of the middle-class nuclear family.

Bettelheim proved to be an effective foil against which to build parent and community based therapeutic and care practices away from state residential institutions and minimally influenced by psychiatric authority. For his part Bettelheim never abandoned the conviction that his was a loving and optimistic vision for autistic children, which offered the greatest chance of recovery. Kanner officially “acquitted” parents at the first national gathering of NSAC in 1969 and was warmly received there by parent advocates; nevertheless, he continued to publish material that suggested a dynamic and experiential factor, including “emotional frigidity,” as contributing to the genesis of autism.

Third Turn

The third turn that I suggest is important for understanding the co-emergence of an autism spectrum and epidemic can be located in the years just before and after the

¹² Bettelheim, *The Empty Fortress: Infantile Autism and the Birth of the Self*.

¹³ Bettelheim, “Individual and Mass Behavior in Extreme Situations.”

publication of the *DSM-III* in 1980. The publication of the *DSM-III* is itself momentous in the history of American psychiatry for numerous reasons, notably for ushering a (re-)turn to descriptive nosology which laid the foundation for the ascent of bio-psychiatry and the corresponding decline in influence of psychodynamic theory. Again, an autism parent-expert played a pivotal role in shaping this turn of events. Psychiatrist Lorna Wing, who co-founded the British National Society of Autistic Children prior to Rimland, Park, and others in the US, is widely recognized for drawing attention to the work of Hans Asperger with an article published in 1981.¹⁴ Wing forged a link between Kanner's and Asperger's syndromes to form an autistic continuum, which she said extended almost to the point of merging into the normal continuum of social functioning. She also argued that autism was prevalent among both those with and without mental retardation, which became key in later formulations of the spectrum.

The linking together of Kanner's and Asperger's work was indeed a significant development, and provided a compelling narrative, but it came after Wing had already begun to formulate the basis for an autistic continuum/spectrum. In 1979, Wing co-authored a paper on the results of an epidemiological study in which they organized the diagnosis around what would become known as autism's defining triad of impairments, which could manifest in both severe and mild form.¹⁵ In effect, Wing's work capitalized on the growing emphasis on epidemiological data collection and codification of diagnostic nosology to broaden the diagnosis to include "more capable" or "higher functioning" individuals under the autism umbrella. At the same time, it strengthened the

¹⁴ Wing, "Asperger's Syndrome: A Clinical Account."

¹⁵ Wing and Gould, "Severe Impairments of Social Interaction and Associated Abnormalities in Children: Epidemiology and Classification."

rationale for “comorbid” diagnosis of autism among individuals diagnosed with mental retardation and low IQs.

The expanded conceptualization tapped into desires expressed by parents involved in both the US and British NSAC. And it occurred during a period when the educational and therapeutic services used to address autism were organized mostly outside the purview of psychiatrists and other medical professionals. Wing worked to broaden the definition of autism in the interest of parents not so much to access medical services, but rather to become integrated into what was then an expanding community based network of expertise, pedagogical practice and care. Again, autism was being redefined within the historical circumstances to generate what appeared the most hopeful vision available to individuals experiencing social, intellectual, and developmental difficulties.

Fourth Turn

The fourth turn marks the historical period that I analyze in more detail with the dissertation. In the early 1990s, “the autism spectrum” began to enter the popular lexicon, as well as professional literature, and prevalence data began to be collected which combined with other factors to co-produce an epidemic discourse. I address these developments at some length elsewhere. Here, I introduce another feature of the turn as an important basis for my project: the emergence of an *autistic* community, which self-advocates describe as taking shape around the margins of the parent and expert defined “autism community.”¹⁶

¹⁶ The emergence of the autistic movement is intertwined with the spectrum and epidemic but hardly a “result” of those developments, as some have argued.

Jim Sinclair's "Don't Mourn for Us," delivered at the International Conference on Autism in Toronto in 1993, marks a pivotal moment when autistic adults began to organize and assert themselves in spaces where previously they had played a narrow, circumscribed role. It is said to have been the first time that autistic self-advocates gave notice of their dissatisfaction with being cast as tragic figures, when Sinclair asserts:

Autism isn't something a person has, or a "shell" that a person is trapped inside. There's no normal child hidden behind the autism. Autism is a way of being. It is pervasive; it colors every experience, every sensation, perception, thought, emotion, and encounter, every aspect of existence. It is not possible to separate the autism from the person--and if it were possible, the person you'd have left would not be the same person you started with.¹⁷

In later writing, Sinclair emphasizes the influence of interpersonal connections and encounters with other autistic people, as well as how parent organized conferences set the stage. Some of the early connections among the first generation of autistic activists were coordinated through a pen-pal network maintained by a parent organization for "high-functioning" or "more able" autistics, but pointedly emphasizes that each of them had "fit descriptions of 'low functioning' autistic people" when they were younger.¹⁸

In Sinclair's recounting, it is clear that what became a broader movement to promote autistic rights, identity, and culture began to take shape in specific community gatherings. Sinclair describes the origins of xyr speech as part of a longer history of collective action, stemming from the difficulty Sinclair and a small group of autistic adults experienced negotiating conference spaces which were structured around the

¹⁷ Sinclair, "Don't Mourn for Us."

¹⁸ Sinclair, "Being Autistic Together."

interests and needs of non-autistic parent advocates and professionals.¹⁹ Autistic adults were often asked to perform a service for parents by describing their experiences with autism, useful as novelties and informational resources, listened to almost exclusively to glean strategies for reaching autistic children. As a former participant, Sinclair coined the term “self-narrating zoo exhibit” to describe the dehumanization of autistic experience in these exercises.

Sinclair portrays the conferences as uncomfortable, autistic-unfriendly spaces that did not allow autistic people to connect with each other: “There's simply too much going on--too many people, too much movement, too much noise, often fluorescent lights, and above all, the overwhelming onslaught of speakers and articles and exhibits all stressing that there's something terribly wrong with us, that we're a horribly defective type of human, and that our very existence is a source of never-ending grief for our families.” The social space of parent organized conferences here serves as an analogy for the way all “neurotypical” (NT) space is designed to suit particular (non-autistic) needs. It also suggests ways that not all “differences between the behavior of autistics and NTs” should be viewed as “‘symptoms’ of some ‘disorder’ in autistic people.” As Sinclair’s essays demonstrate, autistic writers and speakers who began to claim and receive recognition in the 1990s had to counter the presumed limitations of people diagnosed with autism, as they organized socially and communicated dissatisfaction with the status quo, which continued to portray autistic people primarily as mute children.

The self-conscious definition of the principals of autistic community was a key

¹⁹ Sinclair prefers the use of gender-neutral pronouns. The online sites Wiktionary.org and AllWords.com credit Sinclair as coining *xe/xyr/xem/xyrs/xyrself* for that purpose. <http://en.wiktionary.org/wiki/xe>, <http://www.allwords.com/details-xe-3469088.html>

feature in the genesis of an autistic rights movement. The organization Sinclair co-founded, Autistic Network International, began for the purpose of organizing meetings of Autreat, an annual gathering planned by and for autistic people. It should be noted however, that every Autreat since its inception in 1996 has welcomed family members, professionals, and researchers, as well as autistics with or without formal diagnoses. The home page of Autism Network International describes the event:

Autreat is an opportunity for autistic people and those with related developmental differences, our friends, and supporters to come together, discover and explore autistic connections, and develop advocacy skills, all in an autistic-friendly environment. Family members and professionals are welcome to attend, but the structure and content of this event will be determined by the interests and sensibilities of autistic people.²⁰

The space of Autreat is explicitly social in an autistic way, structured around the sensitivities and preferences of autistic people, while still open to non-autistic neurotypicals. Sinclair's account offers a lineage for the politics of autistic rights and "neurodiversity" that I directly address in the dissertation. But there were clearly multiple sources of autistic emergence into public discourse occurring around the same time.²¹

²⁰ Autism Network International, "About Autreat."

²¹ For example, Oliver Sacks published a profile of an autistic family in *The New Yorker* in 1993, which provides a glimpse of ideas that became integral foundations for autistic culture: "While they were well aware of many of the problems of their autism, they had a respect for their differentness, even a pride. Indeed, in some autistic people this sense of radical and ineradicable differentness is so profound as to lead them to regard themselves, half jokingly, almost as members of another species ("They beamed us down on the transporter together," as the B.'s liked to say), and to feel that autism, while it may be seen as a medical condition, and pathologized as a syndrome, must also be seen as a whole mode of being, a deeply different mode or identity, one that needs to be conscious (and proud) of itself." Sacks, *An Anthropologist on Mars*.

On the Spectrum: Chapter Overview

The dissertation focuses on a later period in what I describe above as the fourth turn, which includes the emergence of organized autistic self-advocacy, as they increasingly mobilized in overtly political ways. During the late 1990s and 2000s, web-based guerilla campaigns targeted what were increasingly prominent parent advocacy groups. And organizations such as the Autistic Self Advocacy Network began to intervene in national forums related to public policy and scientific research. Throughout, *On the Spectrum* examines self-advocate positioning in relation to powerful discourses shaped by psychiatry, bio-medicine, and “cure autism now” style parent advocacy organizations. And it turns out to require careful thinking to decide where hope currently lies on the spectrum between acceptance and cure.

Chapter One, *Human Kind(s) in Motion: Articulations and Idioms for Biosocial Becoming*, develops a theoretical framework for examining autism as a psychiatric “disorder” category and biomedical disease, as well as emergent formulations of autism and autistic personhood that are significantly, or even completely, *depathologized*. The emphasis is on historical specificity and contingency, and the manner in which all participants - medical practitioners, researchers, educators, autistics, and parents – are interested actors moving with/in social worlds which overlap but diverge in important ways and articulate autism differently. Theories of biosocial personhood together with a particular genealogy of psychiatric diagnosis provide an opportunity to examine how an emergent discourse of autistic becoming relates to, working both with and against, autism which previously was defined largely as pathology, impairment, tragedy, deficit, dysfunction, etc. This becoming autistic – with emergent communities, identities,

cultures and associated movement for rights – both draws heavily from biomedical knowledge and deviates from experts’ prescribed scripts for pathological disorder.

Chapter Two, *Beside the Autism Wars: Navigating an Epidemic*, focuses on how autism discourses became swept up in the swirling imaginaries of epidemic, crisis, risk, and cure during the 1990s and 2000s. I borrow Paula Treichler’s concept of an “epidemic of signification” to help denote the ways that mobilizing the language of epidemic activates particular ways of understanding disease, social context, and the nature of autism. This chapter focuses on how parents, or more specifically parent-advocacy groups, came to locate themselves on an autism battlefield. A central problematic of the chapter is to draw together the wealth of recent social science literature that seeks to explain the emergence of an autism epidemic and, then, to suggest why and how the question of the “reality of epidemic” can be addressed sufficiently well to make more room for other questions. The assertion – that we can move on now – is based not on an argument so much as a hope that this historical and theoretical work has successfully accomplished an important task and that we are entering a new conjuncture when “epidemic” no longer appears such a pressing concern.

Chapter Three, *Meetings: Wrestling with Spectra*, locates the analytic work of the dissertation as emerging through particular encounters. I describe two meetings: an hybridized academic conference at Fordham University, “Autism and Advocacy: A Conference of Witness and Hope,” which brought together academics, clinicians, activists, laypersons, and clerics; and a meeting of the Interagency Autism Coordinating Committee on the campus of the National Institute of Health, where advocates sought to influence the direction of research as well as the tenor of the national conversation about

autism. I examine the meetings as sites of encounter, negotiation, and confrontation. Written in participant-observation mode, the chapter is located in the middle of the dissertation with the intention of grounding what precedes and follows.

Chapter Four, *Critical Studies of Autism, Or: How I Learned to Stop Worrying and Love Neuroessentialism*, as the title suggests is a provocation which attempts to reframe academic discourse related to autistic rights/identity/culture away from enduring preoccupations with the problem of essentialism and complicated histories of political movements rooted in and routed through “identity.” I explore how the trajectory of scholarly work, both an emergent “Critical Autism Studies” and wider examinations of cerebralized subjectivity in light of the rise of neuroscience, has a mutual, co-constituting influence on “neurodiversity” and autistic rights movements. It is argued that even efforts to take the movements seriously must contend with persistent anxieties about reinforcing essentialist divisions (e.g. autistic/neurotypical and biological/social), even as critics tend to naturalize other binaries prevalent in public autism discourses under scrutiny (e.g. low/high functioning, nonverbal/verbal, pathology/difference). I suggest that a possible path for becoming less stuck with this predicament is to pay careful attention to how autism parents and autistic self-advocates are themselves active participants in academic and critical studies of autism, which may open up a new ecology of care and new opportunities for engagement with dissimilar understandings of autism *and* autistic understandings.

The Conclusion, *Situated Functioning: Facilities and Difficulties*, raises the possibility that the historical turn toward an understanding of autism as both a spectrum and an epidemic has become well-established and now more-or-less common sense. At

the same time, the underlying tension between the impulse to cure and the desire to accept remains evident in how autism is framed variously as disease, disability, and difference. Here, I offer a depathologizing idiom for rethinking the not-so-easy problematic of how to assess, generously, the uneven rates of learning and potential limitations apparent among different individuals, whether they are NT, autistic, or otherwise developmentally a/typical. I argue that *facilities* and *difficulties* are only articulate-able within specific arrangements and situations, which are malleable both socially and technically. In contrast to IQ testing or global functioning assessment, which are embedded in apparatuses and practices that locate fixed attributes and stabilize hierarchies in ability/capability, the evaluation of *facilities* and *difficulties* simply expresses that some skills and competences come more easily *and* difficultly in the present moment and circumstances, (bio-)marking loci for pedagogical practices, support strategies, and (maybe) therapeutic interventions. As an idiom, *situated functioning* and the non-binary twining of *facilities* and *difficulties* is a way of talking and thinking about the assessment of “the individual,” while at the same time moving away from the imagined task of assessing intelligence and adaptive potential, or diagnosing brain disease, defined by two +/- poles on a continuum.

Chapter One

Human Kind(s) in Motion: Articulations & Idioms for Biosocial Becoming

Introduction

Tensions and ambiguities in how people should properly think and care about autism rake across many lives. The relevant questions and the frames with/in which they are posed have shifted over time. This chapter collects conceptual tools to help identify, sort, and talk about the multiple ways that the category of autism is in the process of being redefined, re-articulated, and re-used. I don't see my task as one of critique but that of joining with others – medical practitioners, researchers, educators, autistics, and parents – in an attempt to think through ways to better theorize a phenomenon initially defined (almost) entirely as pathology, impairment, tragedy, deficit, dysfunction, etc., but which has become something(s) much more complex, varied, and interesting.

These days, autism can become overwhelming in its sheer pervasiveness, its overabundance of meanings and representations, its prevalence as a popular diagnosis and implications for individuals and families across multiple domains of social life – education, social service, public health, politics, environmental policy. There is need for a tactical approach to research and analysis that helps to distinguish divergent trajectories – to examine how myriad discursive threads are woven together and arranged, in particular articulations of autism, which serve a given purpose. Those meanings and purposes can both overlap and run counter to the strategic goals and aspirations of other actors who simultaneously use many elements of “the same” autism discourses and often

move along the same institutional channels, but differently. Autism is understood, embodied, and lived in ways that are multiple and sometimes conflicted. Tremendous effort is required to develop and hold together a useable and *coherent enough* definition of autism, one able to travel across multiple locales and serve partially aligned, and sometimes discordant, purposes.

This chapter introduces my approach to what Ian Hacking calls “how we have been learning to talk about autism,” ways of attending to how actors hold multiple identifications and move through social worlds which overlap, as well as diverge and articulate differently.¹ I engage theories of biosocial personhood and tools for analyzing autism across different communities of practice, while exploring them in relationship to a particular genealogy of psychiatric diagnosis, in order to examine how they relate to and work with (and against) an emergent discourse of autistic becoming. This becoming autistic – with emergent communities, identities, cultures and associated movement for rights – both draws heavily from biomedical knowledge and deviates from experts’ prescribed scripts for pathological disorder.

Diagnostics

Autism is multifaceted and multivalent, difficult to hold together as a phenomenon, disease category, or diagnostic entity. The language of disorder, disease, and disability all continue to be used describe autism. However, certain discursive apparatuses have especially potent histories and lasting reach. Annemarie Mol writes, “...One of the dominant ways Western cultures live their ‘illnesses’ is by taking them to

¹ Hacking, “How We Have Been Learning to Talk About Autism.”

be ‘diseases.’ Things doctors know about.”² Mol likens the distinction between illness and disease to other nature/culture splits; for example the differentiation between and sex and gender, biological parenthood and kinship systems, and race and culture. But, she asserts, “recent transformations in health care, like those that make patients into the guardians of their own therapies, are in the process of undoing the former divisions.”³ Mol elsewhere investigates how specific health management techniques, such as different dieting techniques, “do not mobilize different representations of a single reality. Instead, each of them engages with (enacts, invokes the action of) its own reality.”⁴ In other words, not only is the body multiple, but so too are the realities that health technologies and techniques engage and enact; so, in the case of dieting, “The food that is relevant to one dieting technique is simply not the same thing as the food relevant to another,” just as “the specificities of the body that is being submitted to rational control differ.”⁵ In light of this sort of multiple enactments, it becomes important to attend to both the various ways that durable binaries, such as those Mol points to, are being undone and alternately being re-enacted in modified forms. Disease, as well as pathophysiology and ab/normality, are ever present, if sometimes unspoken, framings for autism in biomedical discourses. They are central to the ongoing negotiations and contestations surrounding pathology-centered models of autism that I explore in my project, as with much of what I address and loosely characterize as critical autism scholarship.

In biomedical terms, autism is most consistently defined as a neurodevelopmental disorder. The *DSM-5* consolidates it within a single category, Autism Spectrum

² Mol, *The Body Multiple: Ontology in Medical Practice*, 21.

³ Ibid.

⁴ Mol, “Mind Your Plate! The Ontonorms of Dutch Dieting.”

⁵ Ibid., 380.

Disorder (ASD), what in the fourth edition had previously been four separate disorders – Autistic Disorder, Asperger’s Disorder, Childhood Disintegrative Disorder, and Pervasive Developmental Disorder Not Otherwise Specified – reflecting “scientific consensus” that they are “actually a single condition with different levels of symptom severity.”⁶ The triad of behavioral impairments, a research literature touchstone for three decades, similarly condensed the previously distinct domains of social communication and social interaction; “ASD is now characterized by 1) deficits in social communication and social interaction and 2) restricted repetitive behaviors, interests, and activities (RRBs).”⁷ In addition, a new disorder was created, Social Communication Disorder, to be diagnosed “when no RRBs are present.”⁸ These changes are par for the course – significant changes have accompanied each subsequent edition of American Psychiatric Association’s diagnostic manual since autism was first included as a disorder in 1980 with the third edition.⁹

Silverman characterizes the diagnosis of autism as ambiguous and in flux throughout its history. “Diagnostic categories are mutable things,” she writes.¹¹ Rendered visible in the present through particular contemporary social and medical technologies, autism has become “the subject of legislative acts and surveillance systems, congressional appropriations and parent activism.”¹² Indeed, diagnostic criteria are principal sites where medical professionals, autistic individuals, and their families negotiate clinical practices. According to Silverman, “Disorders are useful ways for

⁶ American Psychiatric Association, “Highlights of Changes from DSM-IV-TR to DSM-5.”

⁷ Ibid.

⁸ Ibid.

⁹ American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders*.

¹¹ Silverman, *Understanding Autism*, 29.

¹² Silverman, “A Disorder of Affect: Love, Tragedy, Biomedicine, and Citizenship in American Autism Research, 1943-2003,” 212.

doctors to think about medical categories, but just what symptoms – or type of person – a disorder refers to may change a great deal over time, whether through bureaucratic fiat or through the activism of groups who adopt or reject a medical definition.”¹³ Nevertheless, the definition of ‘disorder’ itself remains unstable, warranting its own work group during the development of *DSM-5* to evaluate research and re-conceptualize construct parameters.

Within psychiatry, it is often said that clinicians and researchers are adept at distinguishing disorder from typical behavior and development, but at the same time commonly acknowledged that the boundaries drawn around diagnostic categories provide a poor map for disorders in nature.¹⁴ The move to adopt an autism spectrum framework in *DSM-5* has been described as a move to stop trying to carve or cleave “meatloaf at the joints.”¹⁵ The analogy of meatloaf to nature’s body has been used to argue for the spectrum nature of mental disorder in general and, alternately, as a pragmatic, presumably temporary, necessity given the state of knowledge about autism’s clinical presentation and pathophysiology. Each successive edition of the *DSM* addresses the underlying basis for disorders as a question of clinical utility; as restated in the fifth edition: “Until incontrovertible etiological or pathophysiological mechanisms are identified to fully validate specific disorders or disorder spectra, the most important standard for the *DSM-5* diagnostic criteria will be their clinical utility for the assessment of clinical course and the treatment response of individuals grouped by a given set of

¹³ Silverman, *Understanding Autism*, 29.

¹⁴ Zachar and Kendler, “Psychiatric Disorders”; “Evolution of the DSM Conceptual Framework: Development, Dimensions, Disability, Spectra, and Gender/Culture.”

¹⁵ Happé, “Criteria, Categories, and Continua: Autism and Related Disorders in DSM-5”; American Psychiatric Association, *Draft Criteria for Autism Spectrum Disorder*; Lai et al., “Subgrouping the Autism ‘Spectrum’.”

diagnostic criteria.”¹⁶ Thus, the category of disorder, as well as the specific disorders themselves along with their associated diagnostic criteria, are all moving targets; as outlined above, so too are type of person, disorder spectra, treatment response, diagnosed population, and etiological or pathophysiological mechanisms.¹⁷ As with the publication of *DSM-IV* in 1994, explanations of pathogenesis and identification of bio-behavioral markers re-emerged as particularly thorny issues for psychiatric knowledge and practice.

Silverman describes diagnostic technologies as central to the production of autism as a disorder, as both “practical and bureaucratic means of organizing disease and treatment.”¹⁸ Clinical and research practices make use of specific diagnostic tools, continually and differentially reproducing autistic subjects through which autism as disorder becomes known. Silverman refers to these processes as “constituting autism,” and elaborates: “Diagnosis acts as a node: it renders legible the activities of diverse individuals and communities around the population that the category constitutes.”¹⁹ The relationships between diagnosis and research practices and affected populations are deeply interdependent. And, far from disinterested, “research programs and careers depend on the existence of autism as a specific and discrete diagnostic entity and on the techniques used to identify it as such.”²⁰ In autism worlds, all participants are interested actors. Autism is a “matter of concern,” inspiring deep commitments for multiply situated actors, who relate to autism, themselves, and one another in unpredictable

¹⁶ American Psychiatric Association, *DSM 5*, 20.

¹⁷ Eyal et.al write, “Clearly, terming something a ‘disorder’ is merely a way of flagging it as a problem.” Eyal et al., *The Autism Matrix: The Social Origins of the Autism Epidemic*, 31.

¹⁸ Silverman, “A Disorder of Affect: Love, Tragedy, Biomedicine, and Citizenship in American Autism Research, 1943-2003,” 212.

¹⁹ *Ibid.*

²⁰ *Ibid.*, 211.

ways.²¹ The entanglements of autism reveal both a virulent disease, as well as something more benign and, in some instances and/or situations, a welcomed presence

Institutional Histories as Analytic Tools

In order to consider the use, criteria, and mobilization of autism as a diagnostic entity across and with/in space and time, I find it useful to keep in play a genealogical understanding of the history of psychiatry and its systems of classification. Historians of American psychiatry view the preparation and publication of *DSM-III* as a major turning point in psychiatric medicine. It marked a shift in emphasis away from psychoanalytic traditions – a turning away from both *the psyche* and *the analysis*, as well as the short-lived primacy given to “dynamic” models and case studies as theoretical loci and sites for understanding human nature and society – coinciding with a turn towards (and in some respects a return to) the body and its pathophysiologies as defining and organizing problems. The *DSM-III*'s codification of mental disorders reflects an emphasis on diagnostic entities themselves as opposed to the analysis of mental processes, per se. Here, I briefly reconsider why the *DSM-III* is considered such a crucial event in American psychiatry in order to keep that genealogy in mind and slightly reframe it in order to mobilize certain kinds of big-picture questions.

Keeping in mind that Kanner's and Asperger's articles were published in 1943 and 1944, historian Gerald Grob describes World War II to have been a watershed moment in American psychiatry.²² The mass mobilization of the U.S. military led it to intervene in psychiatric classification in new ways, focusing less on screening for fitness

²¹ Latour, “Why Has Critique Run Out of Steam: From Matters of Fact to Matters of Concern.”

²² Grob, “Origins of DSM-I”; Grob, “The Transformation of American Psychiatry.”

to enlist and more on how to return soldiers to the battlefield as quickly as possible when they became incapacitated. Equally significant, in Grob's view, military psychiatrists returned from war with a sense of empowerment in their success at helping return soldiers to battle-readiness. He argues that experiences during the war combined with contemporary intellectual trends in psychodynamic theory to foster "a spirit of therapeutic optimism" among a new generation of psychiatrists, who were motivated to mobilize psychiatric practice as a form of social activism and community improvement.

William Menninger, one of the activist "young turks" in the APA told a colleague in early 1947, "I do feel that American psychiatry needs renovation in the sense of consideration of social problems and social needs."²³ Menninger and colleagues formed a group called the Group for the Advancement of Psychiatry, which drafted a report that advocated for psychiatry to be used in the service of social action, which they defined as "a conscious and deliberate wish to change society," urging psychiatrists to get "out of the hospitals and clinics and into the community."²⁴ The more expansive sense of psychiatry's importance in social affairs was also predicated on a decidedly dynamic attitude about the nature of mental illness. This historical backdrop shaped the production of what is now referred to as *DSM-I*, entitled *Mental Disorders: The Diagnostic and Statistical Manual*, which was both taken up as a reluctant enterprise prior to its publication in 1952 and which ended up thoroughly steeped in the language of psychodynamic theory. Grob suggests that the new, expansive approach to treatment and social life "appealed to a broad public eager for assistance in dealing with the problems

²³ Quoted in Grob, "Origins of DSM-I," 428.

²⁴ Ibid.

of ordinary life.”²⁵ He argues that there was indeed a public appetite for a psychiatric expertise which, it has been argued by others, increasingly insinuated itself into family life, which is important to keep in mind as a specific form of expertise and an obviously very unevenly shared ‘appetite’ that developed at a particular historical conjuncture.

The dynamic approach and attitude was championed by Adolph Meyers, who greatly influenced Leo Kanner. Kanner is often referred to as the founder of child psychiatry and founded the first academic child psychiatry department at John’s Hopkins.²⁶ In the 1957 edition of *Child Psychiatry*, Kanner described prewar approaches to diagnosis as unenlightened, because “who the patient was seemed less important than what the patient had. For this reason, the psychiatry of that day has been referred to as static, descriptive, nosographic (disease-describing) psychiatry.”²⁷ Lakoff explains that descriptive and nosographic are code words for the diagnostic system originally espoused by turn of the century German psychiatrist Emil Kraepelin, the model adopted for the *Statistical Manual for the Use of Institutions of the Insane* up until its publication ceased in 1942. The differences between the approach associated with Kraepelin and psychodynamic theory were as much about emphasis on the diagnostic entity versus dynamic mental processes as they were about biological versus social causation, the proverbial nature/culture split.²⁸

²⁵ Ibid.

²⁶ Schopler, Chess, and Eisenberg, “Our Memorial to Leo Kanner”; Sanua, “Leo Kanner (1894-1981)”; Neumärker, “Leo Kanner.”

²⁷ Lakoff, “Adaptive Will: The Evolution of Attention Deficit Disorder,” 154.

²⁸ See Grob (1991) for a fine overview of the historical trajectory of diagnostic classifications of mental illness and mental defect in the United States leading up to the period immediately after World War II – from the *Statistical Manual for the Use of Institutions of the Insane* published by the Association of Medical Superintendents of American Institutions for the Insane; to the incorporation of rudimentary categories of insanity/idiocy in the U.S. Census beginning in 1840; to the influence of the National Committee for Mental Hygiene and the legacy of psychologist Henry H. Goddard and “the

In other words, at issue were questions about which objects and processes needed emphasis, as well as how to describe their nature and how they functioned.

Psychodynamic psychiatry did not necessarily reject the biological foundations of mental illness outright:

Their interest in the nature of personality (normal as well as abnormal), the role of childhood and influence of parenthood, and the ability of the organism to adjust to the environment in ways that were both effective and satisfying, however, led them to use a quite different terminology. Their new language emphasized the need to assist unhappy and neurotic individuals, presumably through different psychotherapies.²⁹

Under the influence of this model and away from the setting of mental hospitals, Grob writes that they thought in terms of “a *continuum* from mental health to mental illness” and “increasingly shifted their activities away from the psychoses toward the other end of the spectrum in the hope that early treatment of functional but troubled individuals would ultimately diminish the incidence of the more serious mental illnesses.”³⁰ Their interest was trained on a different set of problems and conditions outside residential institutions.

The ascendancy of psychodynamic and psychoanalytic theory in American psychiatry after World War II, whether modeled after Meyer’s or a neo-Freudian approach, was to be short lived. According to Lakoff, in the years after World War II, psychiatry became a discipline concerned with normality, but, as Mayes and Horowitz

menace of the feeble minded;” to the American Psychiatric Association’s early reluctance to involve itself in the creation of diagnostic nosologies. Grob argues that psychiatrists in the 19th century were not particularly interested in constructing formal classificatory systems for mental illnesses, writing: “Like other physicians, they conceived of disease in individual rather than general terms. Health was a consequence of a symbiotic relationship or balance among nature, society, and individual.”²⁸ Grob explains that disease, then, was an imbalance or disruption of natural laws that governed human behavior which was associated with factors ranging from constitution to moral character to stresses due to poor living conditions. Diagnostic categories and descriptive nosologies tended to be fluid and general, rather than detailed and elaborated. Grob, “Origins of DSM-I,” 421–431.

²⁹ Ibid., 428.

³⁰ Over the same period the National Institute of Mental Health was established as a central hub of scientific research. Emphasis added. Ibid., 427.

explain, the broadened focus “made the profession vulnerable to criticism that psychiatry was too subjective, medically unscientific, and overly ambitious in terms of its ability to explain and cure mental illness.”³¹ Psychiatry came under attack on a number of fronts which helped motivate the resurgence of a descriptive, nosological diagnostic system during the 1970s. The *DSM-III*, in turn, was explicitly designed to remedy what was considered by its designers to be a deficit in earlier editions, since explicit criteria were not provided, “the clinician is left largely on his or her own in defining content and boundaries of the diagnostic categories.”³² According to Lakoff, the new “diagnostic machine” was meant to “liberate psychiatry from the idiosyncrasies of subjective judgment.”³³ In dynamic psychiatry, therapeutic knowledge was produced through example and analogy; “The expert’s charismatic authority relied on his or her exegetical prowess and technical skill in psychotherapy,” but now, with diagnostic machine in hand, the psychiatrist was to be “measurer rather than interpreter.”³⁴

A critique commonly leveled against the drafters of the *DSM-III* is that they seized the opportunity to revise the lightly used manual in an effort to expand psychiatry’s disciplinary power or because they wished to overturn the influence of psychodynamic theory. However, I think something important is lost if we do not attend to the myriad ways that psychiatry was under assault in the late 1960s and 1970s from a variety of sources, so that, to some extent, the turn toward (or re-turn of) “descriptive, nosographic” taxonomies emerged, in part, due to a sense that psychiatry was in crisis.

³¹ Mayes and Horwitz, “DSM-III and the Revolution in the Classification of Mental Illness,” 250.

³² American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders*, DSM-III:8.

³³ Lakoff, “Adaptive Will: The Evolution of Attention Deficit Disorder,” 2000, 159.

³⁴ *Ibid.*, 158.

Mayes and Horowitz provide a persuasive case for the numerous ways in which the changing character of psychiatric authority symbolized by *DSM-III*, and subsequently enacted through institutional reliance on its disorder codes, had the effect of ceding psychiatry's disciplinary authority, as well as that of individual practitioners. It could be argued that psychiatry began to let go of disciplining and disciplinary power, while at the same time helping to lay the foundations for powerful new biomedicalized discourses, authorities, and knowledges/powers.

On many level, the *DSM-III* was wildly successful in establishing the new ecology of psychiatric authority. More copies of the *DSM-III* were ordered in the first six months than all previous *DSM* editions combined and ultimately there were 30-plus reprintings.³⁵ Allan Young writes that within a few years, American medical training incorporated examinations based on *DSM-III* criteria, and academic journals and manuscripts were expected to be written in its language: "...It was simply assumed that psychiatric research proposals would conform to its conventions. Researchers and clinicians who resisted these conventions could assume that they would be excluded from these arenas and their resources."³⁶ Government agencies of all sorts adopted *DSM-III* diagnoses to organize funding and establish eligibility for services. The disorder categories seemed tailor made for use by increasingly influential health maintenance organizations (HMOs). And Lakoff has explored the role of post-*DSM-III* revisions in abetting new procedures for "the genesis of psychiatric fact" and the making of new

³⁵ Mayes and Horowitz, "DSM-III and the Revolution in the Classification of Mental Illness," 264.

³⁶ Young, *The Harmony of Illusions*, 102.

patient populations into suitable targets for new drugs, as well as other forms of “pharmaceutical reason” in both local and global economies.³⁷

On another level, post-*DSM-III* psychiatric authority became much more concentrated, or circumscribed, in the twin roles of gatekeeper for the disorder categories themselves and as prescribers of pharmaceuticals. Furthermore, professional authority became increasingly dependent on the demonstrable validity of the diagnostic categories, their reliable identification, and measures of their effects. The significant struggles and controversies both inside and outside the American Psychiatric Association cannot even be touched on here, nor can the extent to which psychiatrists themselves recognized the professional stakes at the time of *DSM-III*'s revision and publication; but a quote from Theodore Millon, a distinguished psychologist involved in the *DSM-III* revision process, indicates that they were well recognized by (some) participants; “...to attribute marital conflict or delinquency... to a biological defect, to biochemical, nutritional, neurological, or other organic conditions... is to sell our psychological birthright for short term gain.”³⁸ At the time, *DSM-III* framers claimed to have adopted an “atheoretical” framework, with no inherent bias or presupposition about the nature and etiological foundations of disorders as either psychogenic or biogenic in origin and basis. I think that even within psychiatry, and certainly from outside, the proposition that they maintained such an atheoretical position appears dubious with several decades hindsight - atheoretical really

³⁷ Lakoff, *Pharmaceutical reason*; Lakoff, “The Right Patients for the Drug: Pharmaceutical Circuits and the Codification of Illness”; Das and Das, “Pharmaceutical in Urban Ecologies: The Register of the Local”; Lakoff, “The Right Patients for the Drug: Pharmaceutical Circuits and the Codification of Illness.”

³⁸ Mayes and Horwitz, “DSM-III and the Revolution in the Classification of Mental Illness,” 260.

meant not-psychoanalytic theory.³⁹ On the other hand, the *DSM-III* was just a first step toward the biomedicalization of psychiatry and the enactment of what could be argued is still a nascent bio-psychiatry.⁴⁰

Managing the Foucault Effect

The *DSMs* subsequent to the third edition mobilize a discourse with the power to interpellate which I consider unparalleled among contemporary realist texts.⁴¹ I find it uncanny how it makes us speak a certain way and the way it forces readers/users to make and fill-in sense as we navigate its multi-faceted (and in *DSMs III* and *IV* “multi-axial”) continuities, gaps, exclusions, co-morbidities, and transmogrifications. It forces us to find a way to make it work – true for clinicians, researchers, diagnosed populations and family members, institutional infrastructures, and critics. The *DSM* discourse and structure works through you even when you try your best to understand how the criteria and definitions relate to each other within a single edition, or to compare how a single diagnosis has changed and is handled differently across editions, while trying to hold at bay the categories’ endless permutations and popularizations outside the text.

³⁹ In 2003, Darrel Regier, Vice-Chair of the DSM-5 Task Force, wrote that inaccurate diagnostic theory (i.e. psychoanalytic theory) can have a strong negative impact on society and hinder the progress of scientific research: “It is hard to dismiss the impact on parents and families that psychoanalytic disease theories have had in assigning blame to ‘schizophrenogenic’ mothers, when the only causal mechanism considered for all mental disorders, on a continuum from mild anxiety conditions to schizophrenia, was a ‘reaction’ to early childhood development and child-rearing experiences.” Closer to the publication of *DSM-III*, Bayer and Spitzer’s 1985 article, which appeared in an effort to settle the still simmering dispute, is a remarkable read in terms of selective omissions and omissions. Bayer and Spitzer, “Neurosis, Psychodynamics, and DSM-III: A History of the Controversy”; Regier, “Mental Disorder Diagnostic Theory and Practical Reality,” 22.

⁴⁰ Clarke, Shim, et al., “Biomedicalization”; Clarke, Mamo, et al., *Biomedicalization*.

⁴¹ I use the terms interpellate and over-determined in some of the senses described by Althusser but, especially, as diffracted through Hall and Haraway. Althusser, “Ideology and Ideological State Apparatuses (Notes Towards an Investigation)”; Hall, “Signification, Representation, Ideology: Althusser and the Post-structuralist Debates”; Haraway, “Situated Knowledges”; Haraway, “The Promises of Monsters: a Regenerative Politics for Inappropriate/d Others.”

The *DSM* is its own interweb and/or labyrinth, and it's very easy to get caught, lost, overwhelmed, and over-determined. Critical reading practices are not sufficient prophylaxis, in my experience, so I have found it helpful to approach in a spirit of play, to examine the *DSM*'s truth effects as serious matters of concern while also dancing around with their truthiness.⁴² But some other sort of counteractive effect is needed, such as a dose of Foucault in the form of his genealogy of knowledge/power. I think of the genealogical form as particularly well suited to making visible the historical conditions that enable interpellation and the ongoing effects of over-determination. But the Foucault effect interpellates, too, so we must take care. Enmeshed in the Foucault effect, it can be difficult to look away from governmentality and to what else is going on with and around the constitution of not so "docile bodies."⁴³

In his 1974-1975 lectures at the Collège de France, Michel Foucault described a nineteenth-century turn away from a "type of mental medicine [that] is medicine as imitation," and elaborated that the prior configuration was a "type of psychiatry that could really become a medicine only though [sic.] a number of what I would call imitative processes."⁴⁴ Foucault then went on to describe the model that psychiatry had sought to imitate, "It had to establish symptoms as in organic medicine; it had to name, classify, and organize different illnesses in relation to each other; it had to produce the same kind of etiologies as found in organic medicine, by looking in the body or in

⁴² For me it alternates – both laughter and unlaughter. Dodds and Kirby, "It's Not a Laughing Matter."

⁴³ Martin, *Flexible Bodies: Tracking Immunity in American Culture from the Days of Polio to the Age of AIDS*; Taussig, Rapp, and Heath, "Flexible Eugenics"; Tremain, *Foucault and the Government of Disability*.

⁴⁴ Foucault et al., *Abnormal*, 306.

predispositions for elements that could explain the formation of the illness.”⁴⁵ In Foucault’s view, in order to become legitimate scientific knowledge and medical knowledge, psychiatry paradoxically had to stop trying to model itself after organic medicine.

To make this transformation and to “constitute itself as a general authority for the analysis of conduct,” psychiatry needed the universalizing figure of the child and to define its “behavioral and structural infantilism,” which in turn established the need for a science of normal and abnormal behavior.⁴⁶ Foucault argued that psychiatry transformed itself and became generalizable in large measure by adopting and making central the joint configuration of the child and childhood, so it was “the problematization of childhood which makes possible the generalization of psychiatry.”⁴⁷ By “taking childhood as the target of its action,” it was possible to make the conditions of normality and abnormality paramount as problems of development. These were essential moves in the reconstitution of psychiatric power/knowledge because, “then to psychiatrize any conduct it is no longer necessary to insert it within an illness, to situate it within a coherent and recognized symptomatology...”⁴⁸ According to Foucault:

...when childhood becomes the focal point around which the psychiatry of individuals and behavior is organized, you can see how psychiatry can be made to function through correlation rather than imitation; the neurology of development and of arrested development, just as general biology with the analysis of evolution at the level of individuals or species, provides both the gap in which and the warranty with which psychiatry can function as scientific knowledge and as medical knowledge.⁴⁹

⁴⁵ Ibid.

⁴⁶ Ibid., 307.

⁴⁷ Ibid., 306.

⁴⁸ Ibid., 304.

⁴⁹ Ibid., 307.

He then asserts, “Quite simply, it dispenses with illness. Psychiatry ceases then to be a technique and knowledge of illness, or becomes such only secondarily and as a last resort,” continuing, “what it considers now is behavior with its deviations and abnormalities; it takes its bearings from a normative development.”⁵⁰ The key point here is simply that what he suggests was the core necessity.

Looking at the constitution of psychiatric knowledge in terms of the *longue durée*, as Foucault did, and which we can consider here as merely *a* possibility:

“Depathologization of the object was the condition for the generalization of psychiatric power that was nonetheless still medical power.”⁵² What psychiatry needed in order to generalize its power into a controlling discipline of behavior – for reach, for medical and scientific legitimacy, and for overarching authority – was to identify “an object that is not so much, and perhaps even not at all, an illness or pathological process, but a certain unbalanced condition, that is to say, a condition whose elements do not function pathologically and that is not the basis for disease, but a condition that is nonetheless not normal...that should not normally appear within the constellation in which it figures.”⁵³

The system of reference and domain of objects that “it tries to divide up and control” is

⁵⁰ Foucault said, “...by taking childhood as the target of its action, both of its knowledge and its power, that psychiatry succeeds in being generalized. That is to say, childhood seems to me to be one of the historical conditions of the generalization of psychiatric knowledge and power.” He continued, “Childhood as a historical stage of development and a general form of behavior becomes the principal instrument of psychiatrization. Moreover, I would say that it is through childhood that psychiatry succeeded in getting hold of the adult and the totality of the adult. Childhood has been the principle of the generalization of psychiatry; childhood has been, in psychiatry as elsewhere, the trap for adults.” *Ibid.*, 308.

⁵² For my purposes, I do not need to attend to the precise details of the cases Foucault utilizes to pin down the exact historical period (1850-1870). Although, I do find it suggestive correlation that categories of mental illness and idiocy were first used in data collection for the 1840 US census, but essentially collapsed into one undifferentiated category until 1880, when there was an entire separate volume ordered and published to sort out different classes of dependency, entitled *Report on the Defective, Dependent, and Delinquent Classes... As Returned at the Tenth Census, (June 1, 1880)*. Grob, “The Transformation of American Psychiatry.” Foucault et al., *Abnormal*, 309.

⁵³ Foucault et al., *Abnormal*, 307.

“not ill in itself, that is healthy in itself, but which it is abnormal to see appearing here and now, so early or so late and with so little control...”⁵⁴ Thus, the knowledge/power is constituted as a sort of developmentalism, in which the child and childhood contain and prefigure the course of normal human development, and define the normative bases on which behavioral deviation will and must be medicalized.

This knowledge/power is not constituted along the behavior/body divide – both are taken up as relevant constituents of syndromes and conditions. He offered, “Both physical illnesses can be linked with a condition: dysmorphia, a functional disorder, a drive, an act of delinquency or drunkenness can all be linked to a condition.” And any bodily element or deviant behavior can be “connected with a sort of unified background – a background that differs from the state of health but nonetheless is not an illness.”⁵⁵ Foucault saw depathologization as the “central problem of psychiatry...this medical power exercised over the nonpathological.”⁵⁶ The problem of psychiatry, this process of psychiatrizing non-pathological domains of living, is one of medicalization. Foucault understands the problem as psychiatry’s historical reconstitution of itself in such a form that it “made itself a kind of general controlling body of conduct, the titular judge, if you like, of behavior...” It is psychiatric knowledge of the normal and abnormal, which exerts biopower in the form of governmentality, that especially concerns him. For me, the provocative questions emerge from the proposition that depathologization could become the basis for medical power, and then linking that to both a reformulated

⁵⁴ Ibid.

⁵⁵ Ibid., 312.

⁵⁶ Ibid., 309.

genealogy of psychiatric knowledge and a reconceptualized vision of developmental trajectories.

As noted above, these lectures were delivered during 1974 and 1975, a two year span between the American Psychiatric Association's declassification of homosexuality as a mental disorder to when the American Psychological Association Council of Representatives followed suit. Furthermore, the genealogy was presented to a public audience right in the moment of a neo-Kraepelinian revival in American psychiatry and just a few years prior to the publication of the *DSM-III* in 1980.⁵⁷ This is precisely the moment which Andrew Lakoff describes as a dissolution of "the dynamic attitude" as a defining force in American psychiatry and the rise of a new "diagnostic machine."⁵⁸ So, then, Foucault's analysis of psychiatry's turn toward normality and abnormality as an organizing framework, which he considered to have extended right up to his present day, as well as the argument that they were part of a move in which psychiatry dispenses with illness, pathology, and, at least in certain respects, organic medicine as its bases for authority, occurred right in the midst of or just prior to psychiatry's return to a nosological medicine rooted in a taxonomy of bio-behavioral pathology and a move toward becoming increasingly tied to the discipline's ability to define embodiments of illness as loci for therapeutic intervention.

I consider Foucault's genealogical analysis as offering three gifts for my study – which are also predicaments. First, it designates the child and childhood as powerful

⁵⁷ For further relevant background on psychiatry's renewed emphasis on embodied disease entities and nosological classification, see: Feighner et al., "Diagnostic Criteria for Use in Psychiatric Research"; Bayer, *Homosexuality and American Psychiatry-The Politics of Diagnosis*; Kendell and Jablensky, "Distinguishing Between the Validity and Utility of Psychiatric Diagnoses"; Zachar, *Psychological Concepts and Biological Psychiatry*; Kutchins and Kirk, *Making Us Crazy*; Conrad, *The Medicalization of Society*.

⁵⁸ Lakoff, "Adaptive Will: The Evolution of Attention Deficit Disorder," 2000, 154, 159.

nodes for the condensation of psychiatric knowledge/power, which is critical to recognize, but other theoretical work could have offered that insight. More important is the way the child/childhood configuration is fundamentally intertwined with/in this great paradox. The paradox is the second gift, the simple idea that depathologization *could be* a path to becoming legitimately scientific and aid in the production of medical knowledge. We need not assume this genealogy of psychiatry to be exactly true as Foucault presents it, but take seriously the implication that we need to interrogate the very idea that psychiatry needs to move toward embodied illnesses and its taxonomies in order to function as scientific knowledge and as medical knowledge. The third gift is the luminous (non-) coincidence that Foucault presented this great paradox more or less at the precise moment when the disciplinary authority of this form of psychiatric knowledge/power is in the process of disarticulating, yet he does not quite see it from where he speaks. What other insights of a genealogical sort might come into view by noting Foucault's own historical position?⁵⁹

Foucault makes an important move to link surveillance of developmental trajectories with the emergence of ab/normality as a critical nexus, upon which to employ technologies of social organization and to exercise techniques of population management. It is not the case that the *DSM-III* marked the wholesale embrace of disorders as biologically defined disease states, although as Mayes and Horowitz write, "With the

⁵⁹ Although not critical to the point I am making here, it is also worth keeping in mind the extent to which psychiatry ever dispensed with the pathological was decidedly more partial than it often seems in Foucault's account. Also, it would be important to consider the different psychiatric traditions, especially since to this day psychoanalytic theory garners much greater status in French society and intellectual traditions. For insightful commentary on how autism continues to be framed in what could be considered psychodynamic or psychoanalytical terms by contemporary French psychiatrists, as well as countered as biomedical and neurodevelopmental disorder by French autism parents, see: Chamak et al., "The Autism Diagnostic Experiences of French Parents"; Chamak and Bonniau, "Changes in the Diagnosis of Autism: How Parents and Professionals Act and React in France."

DSM-III, biomedical investigators replaced clinicians as the most influential voices in the field.”⁶⁰ Psychiatry’s definition of disorder and subsequent revisions suggest that framers sought to retain degrees of latitude with a balance between emphasis on clinical discretion in determining ab/normal behavior, on one hand, and the implication of pathological structures, on the other. In other words, post-*DSM-III* psychiatry continued to embrace the abnormal even as the nosological description of the pathological became crucial.⁶¹ So, we need to attend to the complex ways that both disease and other configurations of pathology (e.g. disorder and dysfunction) continue to interact with a multitude of ideas and figurations associated with abnormality, normalcy, and normalization in a dynamic, differentiating fashion.

It might be tempting to say, from our current conjuncture looking back, that psychiatry attempted to have it both ways, in a sense acting in bad faith, as part of a power grab to swallow up and contain within its domain both the pathological and the abnormal, both psyche and brain. But as I have suggested, a more careful look at the unfolding histories suggests a discipline struggling to adapt to changing sociopolitical landscapes, a discipline in conflict both within and from without, as well as increasingly under the sway of what Clarke and colleagues describe as the processes of biomedicalization.⁶² Once you recognize that psychiatric authority has become increasingly dependent on the ability to remain the gatekeeper of mental disorders, and the associated role as provider of access to medication, it clarifies how the APA itself has

⁶⁰ Mayes and Horwitz, “DSM-III and the Revolution in the Classification of Mental Illness,” 265.

⁶¹ Mayes and Horowitz write, “The *DSM-III* emphasized categories of illness rather than blurry boundaries between normal and abnormal behavior, dichotomies rather than dimensions, and overt symptoms rather than underlying etiological mechanisms.” *Ibid.*, 250.

⁶² Clarke, Mamo, et al., *Biomedicalization*.

become interpellated and over-determined by the *DSM*, as well as absorbed as just another (albeit important) node within larger institutional trends reshaping biomedicine.

Haraway describes how the productive powers of biomedical knowledges are not simply attained and fixed in place; they are mobilized and condensed through descriptive metaphors and enacted practices. She writes:

The power of biomedicine and biotechnology is constantly reproduced, or it would cease. This power is not a thing fixed and permanent, embedded in plastic and ready to section for microscopic observation by the historian or critic. The cultural and material authority of biomedicine's productions of bodies and selves is more vulnerable, more dynamic, more elusive, and more powerful than that.⁶³

In this light, what if the field of psychiatry is currently in the midst of losing its historic grip on the taxonomic authority to define phenomena which are no longer simply “mental disorders,” (which, of course, they never really, were in the first place)? How do we come to better recognize the ongoing hybridized biomedical assemblages that define normal and abnormal ways of life differently for different populations and across different sites? What of counter-moves and resistance movements which embrace abnormalization and/or enact alter-normalizations? Can we imagine how a non-pathological and less-normative, but still legitimately medical and scientific, developmental medicine might function? Or, alternately, what kind of networks of expertise could constitute legitimately therapeutic technique adjacent to and partly connected with biomedical knowledge?

So, by taking Foucault's genealogical formulation to be not so much accurate as provocative – and adopting the more modest proposition that the configurations and instrumentalizations of childhood, development, and ab/normality were and remain key

⁶³ Haraway, “The Biopolitics of Postmodern Bodies: Determinations of Self in Immune System Discourse,” 204.

developments in the accumulation and expansion of psychiatry's disciplinary and disciplining power/knowledge – more intriguing questions (and densely knotted entanglements) begin to coalesce for my project. How might we better take into account the ways that the publication of *DSM-III* both marks a move toward powerful new assemblages of biopsychiatry and biomedicine, as well as a ceding of important forms of psychiatric authority? In particular, how might the diminished role of the individual analyst as social interpreter have effected psychiatrists' ability to provide what Eyal and colleagues characterize as “medical diagnosis of social destiny,” especially in light of their argument about how autism figures prominently in the new matrix of institutional arrangements and renegotiated networks of expertise in the wake of post-1970s deinstitutionalization trends?⁶⁴ Along the same lines, what role might those reconfigurations of power and authority have played in opening up institutional gaps and social conditions of possibility which, in turn, facilitated the emergence of powerful new roles and discourses which have been developed, subsumed, and co-constituted by autism parent-experts and by autistic self-advocates?⁶⁵

Do we need to reconsider the figure of the autistic child and its hyper-visibility as public and expert preoccupation – as well as the saturating discourses articulating children and childhood as at risk from an “autism epidemic”? And how autism problematics operate, register, and work through concerns that are, simultaneously, about the constitution of power, knowledge, and expertise, the enduring legacies and

⁶⁴ Eyal et al., *The Autism Matrix: The Social Origins of the Autism Epidemic*; Eyal, “For a Sociology of Expertise.”

⁶⁵ And new knowledge/power creation by patient groups and health movements more generally? And new openings for biological citizenship and biosocial identifications more broadly?

inheritances from post-Enlightenment Great Divides, and the difficult roads traveled by individuals and families affected and often troubled by life on the autism spectrum?

Again, this chapter is meant to identify helpful theoretical tools and describe relevant historical and methodological problematics, rather than follow up on emerging routes and put the tools to heavy use. Furthermore, this study as a whole is not attempting to find answers per se, but instead trying to better understand what's going on, to identify who the relevant actors and configurations are, and to (re-) consider generative approaches, techniques, histories, and idioms that might prove useful in sticking with the trouble. I take Foucault's genealogical account to work as a condensate, particularly useful in combination with the problematization of *DSM* histories and its hailing, interpellative effects. The most intriguing questions generated for this project center on what kinds of reworlding might be made possible with a depathologized and counter-normative autism knowledge, which in turn, provokes us to also explore what sorts of concerns and problems arise from such a proposition.

Biosocial Identifications, Looping Effects, and Human Kinds

In a development previously believed impossible, many autistics are today advocating for themselves and are deeply immersed in sorting through and reinterpreting the medical and scientific literatures that describe them. The emphasis on the concept of self-advocacy follows a distinction drawn by individuals labeled as mentally ill and mentally retarded in the mid-20th Century, between advocacy done by caregivers and that done by organized self-advocacy groups.⁶⁶ Although they adopt, or appropriate, the category of *autistic*, self-advocates reject autism as a disease category even as they use

⁶⁶ Carey, *On the Margins of Citizenship*.

medical knowledge to re-articulate what being autistic means. Autistic actors are actively forging new pathways for living autistic lives as they navigate categories of disability and natural variation, re-coded as *neurodiversity* and neurological difference.

The term *autist* has faded from use in U.S.-centric biomedical and psychiatric discourse but, for some, there is still something in the term *autistic* that suggests the entire person has been captured and overwhelmed by autism. For this reason, many organized parent advocacy community promote what is termed person-first language, e.g. “a person with autism.” Their rationale centers on removing stigma and not wanting the label to define the person. Self-advocates argue the additive “person with” formulation reflects the mainstream parent community’s hope and goal, that a cure for autism (understood as a disease or disorder) will be found. Further, it will remove Autistic Disorder’s unwanted, invasive presence from their family life; or that the person will recover from their ailment, thus freeing their child to become who they were truly meant to be without the impediments and difficulties caused by pervasive neurological impairment. The autistic rights and neurodiversity movements, on the other hand, prefer the term “autistic” as a way to identify with a core constituent of selfhood, inseparable from the person and not wholly negative.

The recognition of oneself as part of a particular class of individuals can lead to political mobilization, and people diagnosed with autism are intervening more and more in the discursive terrain of autism. For them, autism is an essential aspect of being, and this experience and sense of self is pivotal to the unfolding politics of autism. In addition to the oft cited, “Don’t Mourn for Us,” Jim Sinclair published a series of essays online in the late 1990s and 2000s which helped lay out and circulate a number of important

positions and formulations about what it was coming to mean to be autistic, as well as to define and share an autistic rights based politics.⁶⁷ Sinclair, along with Cal Montgomery and Amanda Baggs were among a growing number of autistic thinkers/writers whose work was influential during that critical period. Their writing heavily influenced my own thinking about the significance of being autistic; and they collectively helped define a core set of issues and institutional struggles, as well as foregrounding both inter-personal and intra-personal difficulties that help make up disability-based autistic rights politics.

Ian Hacking is among the growing number of writers in the academy interested in how autistic actors are challenging standard definitions of autism as a ‘disorder’, what he calls the current “standard euphemism for mental illness.” Noting how conceptions of autism continue to evolve, Hacking writes, “Many advocates for autism insist that it is neither a disorder nor an illness but a disability.”⁶⁸ Hacking describes how the classification of autism and autistic individuals dynamically reshapes the other through what he refers to as “looping effects.” Specifically, Hacking notes how classifications loop back to transform labeled individuals, so that “when known by people or by those around them, and put to work in institutions, change the ways in which individuals experience themselves – and may even lead people to evolve their feelings and behavior in part because they are so classified.”⁶⁹ Hacking describes the knowledge practices and discourses surrounding autism as co-producing a new kind of person which is, in an important sense, *made up*.

⁶⁷ Sinclair, “Don’t Mourn for Us”; Sinclair, “Medical Research Funding”; Sinclair, “Person First Language”; Sinclair, “Bridging the Gaps: An Inside-Out View of Autism”; Sinclair, “Is Cure a Goal?”; Sinclair, “Autism Network International: The Development of a Community and Its Culture.”

⁶⁸ As I explore elsewhere, emphasis on disability in contrast to other disease/deficit frameworks is a central site of negotiation in autism politics. Hacking, “Kinds of People: Moving Targets,” 301.

⁶⁹ Hacking, *The Social Construction of What?*, 104.

Hacking explores the medicalized terrain where biomedical categories and the people living with them help produce autism and autistic modes of being. He is particularly interested in autism because the diagnostic category has not yet been ‘black boxed,’ and the dynamics of its production remain visible as do the multi-directional influences and negotiations among the classified individuals and groups, institutions and experts, and the categories of knowledge themselves. Hacking points out how we tend to think of kinds of people as stable and natural types:

We think of these kinds of people as given, as definite classes defined by definite properties. As we get to know more about these properties, we will be able to control, to help, to change, or to emulate them better. But it is not quite like that. They are moving targets because our (social science) investigations interact with the targets themselves, and change them. And since they are changed, they are not quite the same kind of people as before. The target has moved. That is the looping effect. Sometimes our sciences create kinds of people that in a certain sense did not exist before. That is making up people.⁷⁰

Hacking’s approach focuses attention on the flows and disjunctures of historical experience and how the instruments of knowledge production both shape and, in turn, get reshaped by dynamic, relentlessly social, and contingent practices.

Together, classifications and human kinds evolve over time. In a dynamic, ongoing relationship, actors engage medical classifications, both performing and actively redefining diagnostic labels and their meanings. Clinical and research practices encourage productive relations with the self, and emergent selves subsequently loop back to re-articulate categories and ways of life – human kinds and specific persons in motion and forming in relation to one another, constantly becoming with the social worlds they inhabit. Bowker and Star’s concept of *torque* reminds us to attend to multiple trajectories

⁷⁰ Hacking, “Kinds of People: Moving Targets,” 293.

moving in different directions and at different velocities, putting categories, institutions, and people in tension.⁷¹ The body, experience, and classification all change over time to create misfits as well as types, and it is helpful to think in terms of intra-action, diffraction and torque as well as assess the ‘targets’ themselves.⁷²

More recently, Hacking reassessed his use of the term *human kinds* and described it as “a horrible label” because the term assumes unwanted connotations from its association with the concept of “natural kinds.” Although he initially developed human kinds intentionally based on that association, Hacking has determined, “It took me all too long to realise that my notion of human kind was totally confused. I was helped in jettisoning the term by the collapse of the idea of natural kinds itself.” He expresses dismay at how the term has been adopted in work that attempted to validate racial classifications, “for exactly what I did not intend.”⁷³ But I think it is worth holding onto the idea of human kinds and not deferring to potential misuse.

It is unfortunate that Hacking’s term was misappropriated and perhaps deserving of response by him. And perhaps Hacking’s earlier work drew on the idea of natural kinds in ways that he now finds regrettable or problematic. Nevertheless, human kinds continues to do important tropological work *because* of how we read it *with* the still recent reappraisal of what is meant by the concept of natural kind. Hacking describes his notion as “totally confused,” but I would suggest that we take advantage of that still ongoing history of confusion, even draw rhetorical attention to it, rather than jettison what Hacking still acknowledges is a powerful trope. At various points, I fore ground the

⁷¹ Bowker and Star, *Sorting Things Out: Classification and Its Consequences*.

⁷² See Haraway, *Modest_Witness@Second_Millennium*; Barad, *Meeting the Universe Halfway*; Hayward, “Sensational Jellyfish”; Weaver, “Monster Trans”; DeSmet Trumbull, *A Liquid World*.

⁷³ Hacking, “Kinds of People: Moving Targets,” 291–92.

idea of human kinds as useful precisely *because* of how it resonates with the messy history of defining kinds of humans, naturalizing racial and other types as fundamentally different in kind, often in ways that deny access to full human-ness.

Used with care, *human kinds* problematizes systems of classification that stabilize the expectations for sets of fixed, divisible kinds of people. I think Hacking's other terms *making up people*, *moving targets*, and *looping effects* do a fine job of denaturalizing typologies, as well. Still, I am of the opinion that using human kinds is particularly effective for illuminating the medico-scientific production processes involved in the creation of taxonomies for kinds of humans – and the (dis)orders that might define them. I point to how these terms denaturalize typologies and examine how taxonomies are produced not to expose them as somehow fraudulent or immaterial, but rather, to help identify opportunities for understanding how human kinds come into being, through processes and encounters of *becoming*, and to imagine how they might be enacted and inhabited differently.

Treating (as) Symptoms, Or Not

Medical and scientific expertise exert tremendous authority in delineating the range of (ab)normality, health, and disease – concepts intrinsic to the biopolitics of inclusion and citizenship. But biosociality and biological citizenships are constantly reformulated – and not all of the power and agency is directed from the top down.⁷⁴ Rose and Novas explain biological citizenship as a form of knowing and engaging that is both individualizing and collectivizing. Individuals come to relate to themselves based on

⁷⁴ Paul Rabinow, "Artificiality and Enlightenment: From Sociobiology to Biosociality," in *Essays on the Anthropology of Reason* (Princeton University Press, 1996).

learned knowledge about their “somatic individuality” and, in turn, begin to engage in new social relationships based on that self-understanding and self-identification, as well as what they expect their body-brains be in-capable of and how they expect them to react.⁷⁵

Tamar Judith Posner suggests a need to explore the idea of neurological citizenship as a subcategory of biological citizenship.⁷⁶ She examines a hierarchy of disorders where some are viewed as “more real” than others and thus less stigmatizing. For the “dyscalculic in the making” legitimacy hinges on popular and scientific understandings of biologically based mathematical difficulty as somehow recognizably distinct from an individual’s general level of intelligence. Posner describes how the *DSM* defines the disorder of dyscalculia as the neurobiological condition, where there are no known biological markers to assist in identifying or localizing the condition, features considered essential for a genuinely “medical” diagnosis. As a result, the basis for the classification, across valences both scientific and cultural, remains “vague” and contested. Posner describes neurological citizenship as analytically useful in exploring how individuals diagnosed with neurologically defined disorders often face particular challenges to their condition’s legitimacy. She explains:

...Neurologically-based groups are organized around somewhat messier disorders. These may be mental disorders, often without clear symptoms, diagnostic criteria, treatment procedures, etiology, boundaries (as many are comorbid with other disorders), or legal definitions. There are also particular stigmas associated with neurological diseases in our culture. They are related to

⁷⁵ Rose and Novas, “Biological Citizenship.”

⁷⁶ Posner, *Dyscalculic in the Making*.

the privileging of intelligence and to the functioning of the 'central' unit of the body - the brain.⁷⁷

Biological markers, and perhaps biologically defined etiology, serve as “a passport” for entry to full legitimacy as observably real medical condition in this hierarchy of medical knowledge. As with autism, even as dyscalculic identifications are constituted with a diagnostic label, many of the people so diagnosed actively reject significant elements of a medical discourse that defines them in terms of pathology. Yet they may remain invested in their status as bearers of legitimate neurobiological difference and/or disability.

In many non-medical contexts, the language of *symptoms* seems out of place or even antithetical to how autism is being experienced or approached. Diagnostic categories such as autism that are grouped under the rubric of developmental disabilities can work in ways that diverge from strict conceptions of pathology. This often occurs in locations outside those usually considered primary sites of biosocial activism. For example, in schools teachers and other educational service professionals who commonly work with youth diagnosed with autism, such as speech and occupational therapists, almost never use the most pathologizing discursive conventions of medical symptomatology. Medical language affects educational institutions in myriad ways, but diagnostic labels are also recoded and, sometimes, radically transformed.

In recent years, schools have become primary sites for articulating a different sort of hybrid pedagogical-therapeutic discourses of inclusion, skills development, and adaptive strategies. In this world, autistic students are not *sick* or *disordered* but, rather, *developmentally delayed*. But, at the same time, medical diagnoses are the key to gaining

⁷⁷ Within a similar framework Ortega and Vidal explore cerebral subjects and neurocultures, including those rooted in autism (see chapter four.) Ibid., 67; Ortega, “The Cerebral Subject and the Challenge of Neurodiversity”; Ortega and Vidal, *Neurocultures*.

accesses to educational and other forms of therapeutic services and resources.

Psychiatric knowledge has a profound impact on American public education, even as the professional priorities (and affective commitments) of teachers and other experts lead them to adopt alternate idioms to talk about children with psychiatric labels and to create a less disordered space.

The role of parents as intermediaries and advocates is key here. Eyal and colleagues argue that in the wake of state hospital deinstitutionalization, a whole new network of expertise developed with and around parents and not-quite-medical therapists – such as occupational therapists, speech therapists, ABA specialists, behavioral psychologists – where new forms of “socially innovative therapies” help create a new balance of power, as well as a more distributed and shared, or “generous,” version of expertise.⁷⁸ They write:

As normalization redefined the goal of treatment from cure to habilitation and its object from retardation to developmental disability, the therapies flooded into the space opened up between medicine and special education and began contracting with parents to decenter the subject of treatment from the sovereign psychiatrist to a network of expertise, increasingly including parents.⁷⁹

Eyal and colleagues maintain that while these therapies are normative, “training individuals to pass for normal,” in order to “‘camouflage’ the disorder,” they also at the same time “reconfigure what counts as normal and how someone can pass as such.”⁸⁰ They describe how autism therapies become “technologies of the autistic self,” which can be used to “reconfigure the goal of treatment,” but also, I would add, can be mobilized in

⁷⁸ Eyal et al., *The Autism Matrix: The Social Origins of the Autism Epidemic*, 39.

⁷⁹ *Ibid.*, 258.

⁸⁰ *Ibid.*, 263–264.

domains well beyond the therapeutic milieu.⁸¹ In this way, educational and therapeutic environments emerge as critical spaces for the re-articulation of autistic biosocial identities; they are spaces that are not entirely medicalized and which address autistic actors as not exactly disordered. This pedagogical and therapeutic mode of engagement is perhaps not wholly depathologized, but it clearly gestures in that direction.⁸²

Defining autism in terms of symptoms is not pre-given or immutable. To describe autistic individuals in terms of “symptoms” casts their diagnostic label in the harsh light of a disease category, activating an entire socio-medical discourse that many autistic people actively reject along with other disability rights activists.⁸³ Although autistic *symptoms* continue to define autism in the majority of biomedical situations, I have been surprised by the speed with which authors publishing in scientific journals have begun to adopt the term “neurotypical,” for non-autistic persons; interestingly, journals have been slower to adopt the popular term *neurodiversity*. The asymmetric adoption possibly reflects that *neurotypical* offers a relatively neutral sounding term when compared to the obvious alternative, *normal*, while *neurodiversity* clearly conveys the connotation of a biopolitical re-valuation of autistic difference. In this context, *neurotypical* leaves the research object and research population as minimally troubled,

⁸¹ Ibid., 264.

⁸² It needs to be said that autistic self-advocates have raised serious concerns about how the balance of power operates in these more “innovative” and “generous” arrangements, too, which will be explored more later.

⁸³ The following sources have been particularly helpful for thinking about autism as a developmental disability and site of abnormality: Davis, *Enforcing normalcy*; Goodey, “What Is Developmental Disability? The Origin and Nature of Our Conceptual Models”; Goodley, “‘Learning Difficulties’, the Social Model of Disability and Impairment: Challenging Epistemologies”; Goodley et al., “Self-Advocacy, ‘Learning Difficulties,’ and the Social Model of Disability”; Goodley and Hove, *Another Disability Studies Reader?*; Goodley and Roets, “The (be)comings and Goings of ‘Developmental Disabilities’: The Cultural Politics of ‘Impairment’”; Roets and Goodley, “Disability, Citizenship and Uncivilized Society”; Goodley, Hughes, and Davis, *Disability and Social Theory*; Strauss, “Autism as Culture.”

still common sense targets for certain kinds biomedical intervention. *Neurodiversity*, on the other hand, seems to suggest the possibility that the research object and population must be reconsidered in terms of natural variation, which might be legitimate and perhaps even valuable, rather than with default presumption of pathology.⁸⁴

It is important to keep in mind that in the hands of (most) autistic self-advocates, terms such as neurodiversity, neurological difference, and natural variation do not automatically suggest the desirability of all aspects of autistic behavior, sensory-processing, neurological configuration, and “brain wiring.” Similarly, the desire to discipline, manage, improve, or otherwise intervene in the autistic self is hardly absent. As Taussig, Rapp, and Heath argue, such concerns are prevalent even among activists who work to overturn normative standards in biomedicine, attempting to counter recent biomedical relocation of “long-standing biases against atypical bodies.”⁸⁵ They write, “Yet, like the rest of us, they may desire individual improvement or perfectibility in other ways that are deeply consonant with shared aspects of our cultural milieu.”⁸⁶ Access to healthcare is important to self-advocates, but autism per se may or may not be the frame they consider relevant to addressing their concerns in a particular situation.

I find it curious how often the autistic rights movement and the emerging politics of neurodiversity are depicted as taking the position that autism is not a disability or that activists claim that all autistic people need is acceptance. Autistic self-advocacy is a position staked out in opposition to histories and practices which treat autism as disease, deficit, and tragedy, which traditionally addresses autistics in terms of having a

⁸⁴ In Chapter Four, I argue that “neurotypical” can function as a destabilizing term in certain contexts.

⁸⁵ Taussig, Rapp, and Heath, “Flexible Eugenics,” 60.

⁸⁶ *Ibid.*, 71.

pathological condition and a stigmatized identity. Scott Robertson writes, “Whereas the deficit model portrays autistic people as ill, broken, and in need of fixing, the neurodiversity perspective portrays it as a form of human diversity with associated strengths and difficulties.”⁸⁷ It is an evolving discourse, with articulations both more and less nuanced, but you don’t have to look very hard to see that disability and the difficulties associated with being autistic drive much of that side of the conversation.

Although historically autism has been defined as pathological social disengagement, for some people the biomedical label offers new tools for pushing back against isolating social stigma. Concepts such as Rabinow’s biosociality and what Rapp and colleagues refer to as genetic citizenship suggest a biopolitical field where a range of tools are newly available to groups marked as “genetically disabled.”⁸⁸ Caregivers too have deep investments in genetic and other biosocial discourses, and parents emerge as pivotal advocates, representatives, and spokespersons for their children. In the work of Carey, Silverman and Eyal, the histories of parent advocacy organizations are essential to understanding how parental expertise, now often valorized, was achieved incrementally through political struggle and strategic alliance building.⁸⁹

Families navigate a social landscape where presumably inherited traits and behaviors are evaluated for signs of autistic symptoms in order to receive a diagnosis, which is required to access the services they need. While necessary, the diagnosis provides merely a tool in ongoing struggles. In “Enabling Disability: Rewriting Kinship,

⁸⁷ Robertson, “Neurodiversity, Quality of Life, and Autistic Adults.”

⁸⁸ Rabinow, “Artificiality and Enlightenment: From Sociobiology to Biosociality”; Rapp, Heath, and Taussig, “Standing on the Biological Horizon.”

⁸⁹ Carey, *On the Margins of Citizenship*; Silverman, *Understanding Autism*; Eyal, “For a Sociology of Expertise.”

Reimagining Citizenship,” Rayna Rapp and Faye Ginsburg explore the “vast gap that remains between the rhetoric of public inclusion that mandates everything from universal design to inclusive classrooms and the battles that still have to be fought on a daily basis to ensure their availability—battles which not everyone can or will fight.”⁹⁰ They describe both “a grim social landscape” and the potential for change that comes with new discursive tools and new ways of understanding different abilities and differences.

In a neoliberal political climate defined by “austerity,” where resources for people with disabilities are in decline and under further threat, Rapp and Ginsburg offer a reminder that struggles over the rhetoric of ability and difference are about personal value, whether discussed in terms of disability, disorder, or disease. They write, “... We recognize this narrative as grounded in a potentially productive tension between a capacious view of liberal democracy, in which law and social services are expanding to accommodate the needs of people with disabilities, and the reality of the daily tasks of caretaking, which remain in the household, dependent on family – and overwhelmingly female – labor.”⁹¹ The tides of inclusion/exclusion have perhaps changed from what Rapp and Ginsburg hoped and assumed would be increasing legal protections and better social services for people with disabilities. Both a lack of material support and increased burdens of labor are being thrust back into the “private” space of family, to be born disproportionately by women. Rapp and Ginsburg suggest the need to consider both the rhetorics of power and inclusion, as well as the intimate, sometimes dirty, work that gets care done.

⁹⁰ Rapp and Ginsburg, “Enabling Disability: Rewriting Kinship, Reimagining Citizenship,” 541.

⁹¹ Ibid.

Similarly, Majia Holmer Nadesan worries whether, in the wake of ongoing financial-economic crisis, there is the possibility that economic and social stressors will combine with new prenatal testing technologies to further shift “eugenic decision making to prospective parents who then are made financially responsible for their children’s conditions.”⁹² Nadesan argues that the prioritization of inborn genetic frameworks “could undermine support for costly educational and therapeutic supports, thereby having the potential to reduce autistic persons to a form of bare life denied social equality and political representation.”⁹³ Diagnostic labels and the institutional frameworks that assign responsibility for the care of bodies and selves, and the language used to talk about and renegotiate them, play a critical role in how resources will be allocated.⁹⁴

Co-productions, Boundary Objects, and Agencies

I have found it useful to look at autism, and describe its articulations, as emerging through processes of *co-production*. Sheila Jassonoff describes the *idiom of co-production* as a mode of interpretation that strives to account for complex phenomena shaped through the interplay of social, cognitive, epistemic, and material forces. She writes, “Co-production can...be seen as a critique of the realist ideology that persistently separates the domains of nature, facts, objectivity, reason and policy from those of culture, values, subjectivity, emotion and politics.”⁹⁵ The idiom of co-production is one

⁹² Nadesan, “Autism and Genetics: Profit, Risk, and Bare Life,” 137.

⁹³ Ibid.

⁹⁴ Andrew Lakoff asks suggestively, “If the post-World War II welfare state was a critical condition of possibility for the expansion of autism, is the category now in danger of shrinking back – of once again being conceptualized as a specific disease entity susceptible to medical cure? Perhaps we are nearing a time in which the open space of autism will begin to be carved up again.” Lakoff, “Autism and Its Milieu.”

⁹⁵ Jasanoff, “The Idiom of Co-Production,” 3.

tool, among many, to soften or smudge overly concretized divisions between forms of knowledge – the boundaries that delimit knowledge as either solid/natural or cultural/undependable.

Autism is an entity/object and phenomenon co-produced through a multitude of entangled relations articulated in clinical settings, on school playgrounds, and through online social networking sites. For example, key role players in the ongoing co-production of autism as an object and site of knowledge include the twelve members of the Neurodevelopmental Disorders Work Group who revised the diagnostic criteria for the 2013 publication of the *DSM-5*. Researchers at the National Institute for Health contribute to autism knowledge differently from occupational therapists, social service case managers, or members of the Autistic Self Advocacy Network. Yet all are members of dense webs of relationships that constitute, support, and, at times, undermine autistic lives. Every actor is situated multiply – this awareness can both help us to better recognize, for example, the deft negotiations required of prominent psychologists who are also parents of autistic children and to acknowledge the unique perspective of parents who are themselves diagnosed with autism. (It remains surprising to many that there are autistic people who form intimate bonds, marry, and/or have children!)

As Star and Bowker note, the relationships involve both persons and objects; “Everyone is part of multiple communities of practice. Things may be naturalized in more than one social world – sometimes differently, sometimes in the same fashion. Both people’s memberships and the naturalization of objects are multiple, and these processes are, furthermore, intimately intertwined.”⁹⁶ An idiom of co-production allows

⁹⁶ Bowker and Star, *Sorting Things Out: Classification and Its Consequences*, 286.

room for a range of stories about the way sources of powerful institutional authority, such as the APA and health insurance companies, impose structure on autism worlds but also respond to intricate ecologies of care shaped within and among autism families and autistic communities. Diverse fields of inquiry and varied institutional infrastructures set conditions for how autism is known and autistic lives lived, and shape struggles over many kinds of resources, amid concerns that are at once personal, cultural, and scientific.

For related reasons, the concept of *boundary object* is an essential tool for tracking the circulation of autism. Autism serves as a potent boundary object, described by Star and Griesemer as a physical and/or conceptual tool both flexible enough to be used across different sites and projects, yet robust enough to retain a common identity and serve as a vehicle to import meaningful information. Autism retains core, recognizable features in translation across socially and geographically distant spaces, yet maintains core meanings sufficiently malleable for specific local uses. Boundary objects structure relations within particular social worlds and assume central importance in exchange across the junctures between them. Whether a specimen, document, or, in this case, category, boundary objects become sites where social formations and allegiances both form and fracture. Boundary objects are shared resources which disparate groups use to delineate common goals and develop cooperative strategies, helping to define social worlds. At the same time, differently situated actors maneuver within contested arenas with objects such as autism to locate and defend sites of political struggle.⁹⁹

Parents, autistic self-advocates, doctors, and public health officials vie for the power to define how autism fits within and re-defines existing relationships and

⁹⁹ Clarke and Star, “The Social Worlds Framework: A Theory/methods Package.”

institutional structures, although the groups possess unequal access to the routes and obligatory points of passage which are so critical to the process of knowledge production.¹⁰⁰ Already controversial in the U.S. since the 1950s – during the height of “the refrigerator mother” theory – autism resurfaced in the 1990s as a pivotal, although recast, boundary object with profound implications across social arenas that are at once vast, intimate, and specific. I am particularly interested in the sort of boundary object autism becomes in ongoing discussions about its subtyping, phenotyping, and spectrification. How does it continue to cohere and under what conditions do earlier, no longer pertinent materialities become obscured or, alternately, reemerge? How does autism become, continue, and cease to be useful for particular kinds of boundary work?¹⁰¹

I have been struck by the ways in which autism produces and acts with something akin to agency, both as a *DSM* defined category of disorder and as something more. It acts upon the world, productively in tension with efforts to shape it – in part, because people engage autism as a social actor, or *actant*, as well as a knowable object. I am drawing from the concept of *actant* in actor network theory (ANT) in the spirit Bruno Latour suggests, as a tool to enhance nimble thinking.¹⁰² In *Reassembling the Social*,

¹⁰⁰ Law and Hetherington, “Materialities, Spatialities, Globalities.”

¹⁰¹ I am also attentive to the ways in which autism as a boundary object is useful to some analytic work “and not to others, is subject to partial usage and analysis, and is limited by scale and scope.” In addition to issues of appropriateness of scale and scope, I wonder about Star’s point that boundary object is a conceptual tool that is fundamentally about accomplishing co-operative work, and her raising the question of how boundary objects are born and die. The constant institutional reproduction of residual categories is one place Star thought deserved more attention: “As these categories become inhabited by outsiders or others, those within may begin to start other boundary objects... a cycle is born. One of the things that I have become aware of in trying to capture this complex and longitudinal phenomenon is the need for methods for capturing each aspect, including the nature of the back-and-forth between ill structured and well structured, the architecture of the infrastructures involved; and especially the movement within and from those inhabiting residual categories, and how they form new boundary objects.” Star, “This Is Not a Boundary Object,” 614.

¹⁰² Law and Hassard, *Actor Network Theory and After*; Latour, *Reassembling the Social: An Introduction to Actor-Network-Theory*.

Latour describes the many ways nonhuman agencies “make actors *do* things.” Agency, in this sense, can be used as a narrative device. Latour argues that literary theory helps ANT observers be “less rigid, less stiff in their definition of what sort of agencies populate the world.” Latour concludes that ANT writers benefit from this “freedom of movement,” suggesting, “It is for the same reason we refuse to be cut off from philosophy. It is not that sociology is fiction or because literary theorists would know more than sociologists, but because the diversity of the worlds of fiction invented on paper allow enquirers to gain as much pliability and range as those they have to study in the real world.”¹⁰³ It is an analytic strategy that allows for the ways autism does more than just exist outside of human bodies as a discursive object or, alternately, simply reside inside bodies as a neurological condition; autism literally becomes a player in how the ongoing drama unfolds.

Although I mostly describe the negotiation of autism and the emergence of autistic social-material relationality in terms of the reconfigurations of autism worlds and their worldings, rather than as linkages and nodes in a network, Michel Callon suggests a useful version of a networked and agential world that “is not a network connecting entities which are already there, but a network which configures ontologies. The agents, their dimensions, and what they are and do, all depend on the morphology of the relations in which they are involved.”¹⁰⁴ I take that relational emphasis on connecting, along with the re-configuration of ontologies, to align well with a social worlds/arenas framework emphasis on historicity, emergence, and coalescence. I likewise populate autism worlds utilizing a varied language of subjectification and personification – with characteristics

¹⁰³ Latour, *Reassembling the Social: An Introduction to Actor-Network-Theory*, 55.

¹⁰⁴ Law and Hassard, *Actor Network Theory and After*, 185–186.

and characterizations alternately described as actors, persons, identifications – but mostly mobilize idioms of persons, selfhood, and people because the legitimacy of autistic personhood is central to claims of autistic self-advocates and because autism continues to be described as impairment in core attributes associated with personhood, the human, and the self. These, too, are problematically bounded and contingent formulations, both rooted in and routed through commitment to certain ontological politics, forms of action, and sociomaterial realities. Both personhood and social worlds, articulate discursively in a rich sense, described by Star and Clarke, “As social worlds intersect or grow to become arenas, their joint course of commitment and (inter)action are articulated through discourses. Discourses here, then, mean those assemblages of language, motive, and meaning, moving toward mutually understood *modus vivendi* – ways of (inter)acting.”¹⁰⁵ The tentative boundaries drawn between individuals and social worlds, and commitment to their legitimation, are the center of the action.

I am drawing on revised figurations of personhood as co-constitutional in nature, such as Lucy Suchman describes; “The person figured here is not an autonomous, rational actor but an unfolding, shifting biography of culturally and materially specific experiences, relations, and possibilities inflected by each next encounter – including the most normative and familiar – in uniquely particular ways.”¹⁰⁶ The presence of agency is presumed, or perhaps deferred, to focus on the ongoing, always unfinished processes and entanglements of objectivized subjectivities and the subjectification of objects. Drawing on Karen Barad’s agential realism, Suchman argues that the cuts that make up differences and likenesses are the core labors and practices embedded in boundary work, and insists,

¹⁰⁵ Clarke and Star, “The Social Worlds Framework: A Theory/methods Package,” 116.

¹⁰⁶ Suchman, *Human-Machine Reconfigurations*, 281.

“boundaries are necessary for the creation of meaning, and for that very reason, are never innocent.”¹⁰⁷ Along these lines, she says, attention to particularity requires recognition of asymmetries across boundaries, as all presences, both human and nonhuman, are continually stabilized through particular, more and less durable, arrangements, necessitating more or less constant reiteration and/or reconfiguration.¹⁰⁸ Thus, autistic and neurotypical persons, as well as autism(s), emerge relationally, in part by design and in part by happenstance, always entangled with contingency, historicity, and situatedness.¹⁰⁹

Autism circulates through scientific and popular discourses, where it consolidates interests even as human agents set to work on it. Autistic identities are forged with diagnostic criteria and folklore, understood broadly here as shared cultural stories, prompting new forms of behavior and modes of social organization. Support groups like Autastics in San Francisco provide new social outlets based on autism’s life altering presence, and activist groups, such as Autistic Self Advocacy Network, organize to oppose specific ways the autism diagnosis gets instrumentalized in research and therapeutic practices at clinics such as NYU’s Child Study Center and in the Phenotype Project at the UC Davis’ MIND center.¹¹⁰ Autism helps gather up resources and mobilize

¹⁰⁷ I consider Barad’s influence, as well as Haraway’s, to be intra-woven all the way through the dissertation. Ibid., 285.

¹⁰⁸ Ibid.

¹⁰⁹ Clarke and Star describe this sort of illuminating, worlding, boundary work as situational analysis, “The conditional elements of the situation need to be specified in the analysis of the situation itself as they *are constitutive of* it, not merely surrounding it or framing it or contributing to it. The *are* it... Such analyses are both complicated and enhanced by the fact that there are generally *multiple* discursive constructions of both the human and nonhuman actors circulating in any given situation.” Emphases in original. Clarke and Star, “The Social Worlds Framework: A Theory/methods Package,” 128–129; Clarke, *Situational Analysis: Grounded Theory After the Postmodern Turn*.

¹¹⁰ Murray, “On Autistic Presence”; Murray, “Autism Functions/The Function of Autism”; Kras, “The ‘Ransom Notes’ Affair.”

interest alongside and in conjunction with federal agencies, channeled through the Interagency Autism Coordinating Committee at NIH established by Senate Bill 843, the Combating Autism Act of 2006. Non-profit organizations devoted to the eradication of autism, portrayed as a nefarious child-snatching villain, orchestrate multi-pronged, well-funded agendas. Examples include the pervasive presence of the group Autism Speaks, which among other things coordinates a wide variety of parent activist groups at both the state and national level through the website, Autism Votes, and the parent-coordinated founding of the Autism Genetic Tissue Exchange, which collects and distributes brain samples to researchers around the country.¹¹¹ And autism sets the stage where incipient cultural formations coalesce, online at the websites WrongPlanet and Aspies for Freedom, and in-person at annual gatherings such as Autreat and AutCom in the US and Autscape in the UK.

Objective-Self Fashioning

Many of the theoretical tools presented here, from Hacking's notion of "moving targets" to various ways of formulating biosocial identities, articulate a language for talking about the ways that people are both constituted within powerful systems of knowledge and they, in turn *and* simultaneously, engage in their own projects of selfhood, often reshaping the terrain of knowledge in the process. The final section of this tool-building chapter, explores Joseph Dumit's concept of objective-self fashioning as particularly helpful for understanding the ways that diagnosed individuals and loosely bound movements, such as autistic rights and neurodiversity, are acting in a landscape

¹¹¹ Tabor and Lappé, "The Autism Genetic Resource Exchange: Changing Pace, Priorities, and Roles in Discovery Science"; Lappé, "Anticipating Autism: Navigating Science, Uncertainty, and Care in the Post-Genomic Era."

where developments in biomedicalization, technoscientific practice, and institutionalized expertise are increasingly distributed and heterogeneous. As biopower is never totalizing or entirely coherent, autism knowledges and facts are subject to renegotiation, and both offer fundamental tools for how autistic individuals understand themselves and their attempts to make themselves understandable for others.

Researchers, drug makers, and government institutions continue to rely on the American Psychiatric Association (APA) to define the diagnostic criteria that they use to identify research subjects. In this sense, clinical practices and the use of diagnostic apparatuses, legitimated by professional associations such as the (APA) establish obligatory passage points, where expert authority evaluates bodies and behaviors to assign mental (dis)order and (dys)function. The wielding of that authority and those assignments constitute important matters of fact about autism.¹¹²

Steven C. Ward describes the powerful role that professional associations play in establishing and perpetuating “hard knowledge.” Ward argues that professional bodies select and fashion “the raw data of observation and immediate experience into a nicely packaged and delineated form” through their practices, cultures, and technologies. They set the standards and rules, but also “chop up” into digestible pieces and delimit what is knowable. Ward goes on to say, “Knowledge must be embedded within a self-reproducing professional culture and in a specific form of institutionalized practice in

¹¹² The pharmaceutical industry is beginning to play a larger role in shaping the course of autism. In 2006, the FDA approved the first drug, risperidone, to treat symptoms associated with the disorder. Although, in practice, doctors have long been prescribing a variety of medications off-label for years. Risperidone was approved to treat “irritability associated with autism,” including “aggression, deliberate self-injury, and temper tantrums” in children over five and adolescents.” Mcnamara, *FDA Approves First Agent for Treating Autism Symptoms: Risperidone Approval Called , “Breakthrough.”*

order to socialize the next generation of knowledge makers, or it faces extinction.”¹¹³ Knowledge and skill need to be transferred to the next generation and that “can only be accomplished as knowledge becomes arranged into autonomous, self-reproducing organizations replete with insider vocabularies, students, unique skills, publication outlets, formal connections to other professional knowledge-producing organizations and, in some cases, specialized equipment and techniques.”¹¹⁴ The APA continues to exert this principal disciplinary power in biomedicine, but the authority is becoming more negotiated with and distributed among other institutions.

Professional authority and institutional structures play an outsized role in the production of knowledge and power, but other dynamics are crucial to consider, as well. In "Beyond Normalization and Impairment: Theorizing Subjectivity in Learning Difficulties – Theory and Practice," Yates and colleagues provide a useful framework for visualizing Foucault’s dynamics of power:

This work comprised three interrelated domains of critical inquiry relating to the ways in which human beings become subjects, all of which are important: the constitution of people in systems of knowledge, their attendant creation as subjects of power and projects of governmentality and (the often-neglected third domain) the ways that people understand and form relationships with themselves and their own conduct... Foucault’s third domain of inquiry is crucial. It is here, at the heart of everything, that there is a subject both constituted as an object of thought within systems of knowledge (power) and at the same time actively engaged in their own projects of selfhood and struggling with the ways that their subjectivities are constituted and power takes hold of them.¹¹⁵

To the final claim – that, crucially, subjects actively struggle “with the ways that their subjectivities are constituted and power takes hold of them” – I would add the following:

¹¹³ Ward, *Modernizing the Mind*, 25–26.

¹¹⁴ *Ibid.*, 26.

¹¹⁵ Yates, Dyson, and Hiles, “Beyond Normalization and Impairment: Theorizing Subjectivity in Learning Difficulties - Theory and Practice,” 256.

the diagnosis itself becomes a powerful tool that can be taken up and used in self-making projects, helping individuals to take hold of themselves, in effect. Rather than the autism diagnosis just imposing a set of objective facts, the reality of bio-identities and social bodies is more like an interwoven, multidirectional co-constituting worlding where discourses, bodies, subjects, and objects move and morph together, in tension, and in relation.¹¹⁶

Diagnostic technologies increasingly travel outside the control of institutional authority. Individuals and communities access medical knowledge and use their diagnosis to self-objectify for strategic purposes; they take hold of their very being with the objective knowledge claims of science, and make (counter-) claims on sites of governmentality.¹¹⁷ In certain contexts, “the patients” wield their own diagnoses and gain degrees of empowerment with which they hope to create newly welcoming spaces. The act of diagnosis is a regulatory form of biopower, but once a psychiatric diagnosis exists in the world, as a condensed, taxonomized, referenced node of knowledge, and a collection of individuals are being re-defined by it, and beginning to recognize themselves with it, the diagnosis itself can be subverted and appropriated.

Psychiatrists, biomedical researchers, and public health officials are among the most powerful actors in the contentious fields of autism knowledge production, but since the late 1960s, parent-advocates have also been remarkably efficacious in influencing the direction of research and institutional practice. They too have become experts. The state of knowledge regarding autism continues to be pushed in new directions from outside the

¹¹⁶ As James Clifford says, “We can be grateful for the inability of hegemonic common sense to subsume alternatives, to round up, to account for, everyone. What new identities, alliances, social struggles, and modes of conviviality are emerging?” Clifford, “Feeling Historical,” 425.

¹¹⁷ Epstein, “Patient Groups and Health Movements.”

medical establishment, despite intense pressure to attain a better, more stable understanding of autistic atypicality. Stabilization efforts have been contested and overturned repeatedly, and parent activists have become more forceful in their demands for other kinds of research, focusing on potential environmental causes and alternative interventions in addition to continued research on autism genetics.¹¹⁸

As a “disease constituency,” autism parent activists tend to operate as a sort of proxy for children diagnosed with autism. They help to construct “illness identities” for their children and a broader identity for themselves as autism families. Parents and allies’ status as proxies is not unproblematic, nor are the categories on which their roles as spokespersons are based. Autism “patients” are often presumed to be “too young or too physically or mentally incapacitated to advance his or her own interests.”¹¹⁹ Steven Epstein uses the term “patient groups and health movements” as an elastic classification to invoke a broad array of social formations, including advocates and other non-patients, and instances where “patienthood itself may be a murky status.”¹²⁰ The increased visibility and proliferation of disease-based social formations facilitates cross-pollination and the emergence of a common discourse. Autism parent advocacy efforts may fit the model of a disease constituency in the manner outlined above, but what about the autistic self-advocates who outright reject the formulation of autism as any sort of illness in the

¹¹⁸ Singh, *Autism Spectrum Disorders*.

¹¹⁹ Steven Epstein, "Patient Groups and Health Movements," in *The Handbook of Science and Technology Studies*, ed. et al. Edward J. Hackett (Cambridge, Mass: MIT Press, 2008). 504.

¹²⁰ Epstein provides a list of useful questions to ask of health movements, including, “How do the actions of patients or their lay representatives change the way that medicine is practiced, health care services are distributed, biomedical research is conducted, and medical technologies are developed? What is the character of experiential knowledge of illness possessed or cultivated by patient groups or health movements? What sorts of challenges do these lay actors pose to the authority of credentialed experts, and what kinds of alliances with professionals do they construct? What sorts of ‘politics of the body’ do such groups put into practice, and how are bodies transformed as a result?”
Ibid. 499-500.

first place? I find that other conceptualizations of how self-making projects work, which remain contingent upon and actively engaged with medical knowledge systems, prove more useful in this instance.

Dumit's concept of *objective-self fashioning* clarifies the ways that a psychiatric diagnosis can help make the material of personhood more readily available for (self-) control, both in a positive and negative sense. In other words, technologies such as a medical diagnosis, especially traditionally hard to visualize psychiatric diagnosis, lead to productive acts of self-objectification, which can be especially powerful given how mental illness tends to call into question the person's capacity for objectivity, precisely that which has been placed in doubt. Dumit offers the following to clarify the implications of objective-self fashioning:

We keep a hyphen in *objective-self* because we need to highlight the fact that it refers to how we are to ourselves and to society an object of science and medicine, not how we "objectively" are to science and medicine. Our concern thus centers around the *object* of science and medicine, not their *methods* – not what justifies mental illness, but how it is specified by a set of practices, documents, institutions that enable it to be "objective."¹²¹

Dumit makes an argument against viewing the situation as one where the self is made observable, put under the microscope, so to speak, without simultaneously scrutinizing the practices and techniques of objectivity-making. He also explores how we can and do use the tools of objectivity to reshape the selves we hope to become. He makes clear that the fashioning of an objective-self can be a positive development for an individual struggling with societal expectations.

¹²¹ Dumit, *Picturing Personhood: Brain Scans and Biomedical Identity*, 187.

Dumit explores how pictures of personhood produced with brain scan imagery help establish an objective reality. Bioscience is integrated into knowledge of the self at multiple levels, and imaging technologies work with categories of personhood in complex ways. This newly objectified self-knowledge can easily operate with entrenched binary oppositions, such as, “normal versus not normal – demarcations that are shorthand for the ways in which attributions of agencies, functions, and types are distributed, disputed, and constrained.” But with his own work, Dumit seeks “to locate contests over the true nature of human nature, sites where metaphors are incomplete or excessive and where they are changing. I am interested in the mechanisms of these shifts, their uneven spread, the coexistence of opposing discourses, local existences, and conflicts that involve [brain] scans.”¹²² Autism research is such a site where the production of knowledge is up for grabs. Imaging technologies lend substance to nosologically defined categories, such as autism, helping to both contain and stabilize meanings. The autistic brain is being imaged in labs, where new knowledge is being produced about its structure and functioning (although imaging technology is more slowly entering everyday clinical practice). Dumit’s emphasis is on how these sorts of facts emerge through practices and contests over meaning and interpretation, pivotal “contests over the true nature of human nature.” These newly minted, objective facts matter to us and make important differences in the world.¹²³

The production process for the *DSM* is a site where contests over particular, historically specific, beliefs about human nature occur. The binding of criteria into an

¹²² Ibid., 11–12.

¹²³ Objective-self fashioning helps us think through how we might be simultaneously objectified and subjectified, as the coshapings of selves, kinds, and worlds are done with and in “a subject- and object-shaping dance of encounters.” Haraway, *When Species Meet*, 4.

official diagnostic manual transforms contested knowledge into a collection of facts that structure practice. Once a diagnosis is officially incorporated into the *DSM*, many of what had previously appeared as contestations become more settled and certain questions about the nature of the disorder are more difficult to pose subsequently. However, Dumit helps us to recognize diverse agencies working with techniques of objective-self fashioning to make new spaces for personhood, as well as the ways that individuals get locked into institutional categories.

The facts of biomedicine remain flexible and contestable to a certain degree; and neuro-scientific objectivity and objects are potentially re-fashionable. As actors engage in projects of objective-self fashioning based on data collected in studies, innovative technologies and methods can, in turn, “provide the means for social action, justifications for support of certain kinds of research, and arguments for a biological understanding of mental illness.” Biology here should not be thought of as inalterable nor automatically presumed an instrument of naturalization for the existing social order. The categories used to characterize biological knowledge – such as illness, disorder, disability, etc. – are also at stake. Thus, new facts and emergent ontological politics can enable groups “to further promote a category of the objective person that does not, in their view, prejudice them and condemn them to blame and guilt. This involves understanding the many very different ways facts (science, technology, nature) and experience (subjectivity, personality, culture) are constantly shaping and tripping over each other.”¹²⁴ Autistic actors form surprising collaborations and wield a variety of tools to creatively refigure

¹²⁴ Dumit, *Picturing Personhood*, 168.

responsibility and enhance accessibility, as well as response-ability, with the goal of gaining control over important parts of their worlds.¹²⁵

For me, objective-self fashioning cuts to the chase and helps me avoid getting swamped by an over-abundance of biosocial “-izations,” as well as to remember that self-objectification can sometimes provide a point of leverage for marginalized peoples. It focuses attention both on the transformations that occur as our selves are made objects of science and medicine, and how we can be at the same time “rendered capable” to re-enter our objective-selves in the loops of world making and to co-shape our becoming as human kind(s).¹²⁷

As Charis Thompson points out, it has become less tenable in the age of biomedical modes of reproduction to “maintain that natural kinds are essential” and “that social kinds are socially constructed.”¹²⁸ What concerns us here is the manner in which “all kinds are specified and differentiated by strategic naturalization and socialization.”¹²⁹ Whether understood as autistic individuals or as individuals affected by a disorder called autism – framed either as a kind of person or a person with a form of disorder – people diagnosed with autism are understood through biomedical discourses and, to some extent, have come to understand themselves differently through those diagnostic prisms as well. An important question for me then becomes, how then are autistic self-advocates going about rearticulating and co-producing their body-mind-personhood by drawing on these ‘same’ historically situated tools, practices, and categories which enable objectivity?

¹²⁵ For more on worlding with *response-ability*, see Schrader, “Responding to *Pfiesteria piscicida* (the Fish Killer): Phantomatic Ontologies, Indeterminacy, and Responsibility in Toxic Microbiology”; Barad, “On Touching—The Inhuman That Therefore I Am”; Hayward, “Sensational Jellyfish.”

¹²⁷ Despret, “The Becomings of Subjectivity in Animal Worlds.”

¹²⁸ Thompson, *Making Parents*, 13.

¹²⁹ *Ibid.*

Chapter Two

Beside the Autism Wars: Navigating an Epidemic

Introduction

In the mid-2000s, the controversies surrounding autism began to be described by both observers and participants as The Autism Wars. Hostility and adversarial maneuvering seemed appropriate or necessary to many of the actors involved – autism parent warriors dedicated to preventing their children from exposure to dangerous environmental toxins and government sponsored vaccine injections; scientists and public health officials under assault for their alleged participation in a cover-up to protect vaccine producers, and other nonspecific child polluters, from liability; and autistic self-advocates who heard the clarion call for autism cure or, more imminently, prenatal screening as a threat to the existence of their kind. The entrenched positions of the various constituency groups likely appeared extreme to non-participants, but they represented high stakes encounters for people in intimate relationship with autism, who sometimes know and experience autism phenomena and autistic becoming quite differently from one another.

This chapter focuses on how autism discourses became swept up in the swirling imaginaries of epidemic, crisis, risk, and cure. Once autism was widely accepted as a biologically rather than psychogenically based disorder, concerned parents and others increasingly drew from discourses associated with infectious disease, even though autism is not considered communicable. Mobilizing the language of epidemic activates

particular ways of understanding disease, seeing social context, and hearing autism idioms. Paula Treichler's concept of an "epidemic of signification" helps denote the ways that discursive, meaning-making encounters can spiral to create their own sort of contagion effects. She argues that illnesses, as well as our responses to them, assume their specific forms through language, both constituting and constituted by medical practices, procedures, and discourses.¹ Treichler maintains that, despite all our efforts, it is impossible to see through discourse to the reality that we habitually presuppose lies beneath, both deeper than and separate from, language.

Here I draw from and elaborate on the social science literature that has sought to explain or "unpack" the emergence of an autism epidemic. Most directly I develop an analysis that builds on Grinker's description of "the perfect storm of autism," Kaufman's analysis of parents' intensified responsibility for risk assessment and maximization of child potential, as well as both Silverman's and Eyal's emphasis on the increasing entanglement of parent advocacy and scientific expertise, in particular the conjoined figure of parent-expert.² It is worth noting at the outset that there is irony in the fact that, after spending decades fighting so hard to have autism recognized as a chronic developmental disability, autism parent advocacy groups, bolstered and propelled by a surge in new parent organizations, began to push new theories of environmental pathogenesis to the fore of national and global priorities for autism research and public

¹ Treichler, "AIDS, Homophobia and Biomedical Discourse: An Epidemic of Signification."

² Grinker, *Unstrange Minds: Remapping the World of Autism*; Kaufman, "Regarding the Rise in Autism: Vaccine Safety Doubt, Conditions of Inquiry, and the Shape of Freedom"; Eyal et al., *The Autism Matrix: The Social Origins of the Autism Epidemic*; Silverman, *Understanding Autism*.

policy.³ My particular concern is to find a way to simultaneously think critically about and take seriously parent insistence – and advocacy group promotion of the idea – that increasing rates of autism diagnosis constitute an epidemic and crisis.

Medical practitioners and researchers are hardly dispassionate actors in these contests over social meanings and the biosocial onto-epistemologies that shape and re-align ways of living in the world. Their presence and personal investment are obvious if somewhat muted in this chapter, except for the ways expertise is engaged and embodied by parent advocacy. In contrast, for the most part I bracket the concerns of politically engaged autistic people, and “allies” such as parents who strive to be affirming and supportive of their children *as* autistic, while remembering that they hope to re-articulate an autistic spectrum outside strictly disease/cure frameworks, a position formulated in terms of autistic rights, neurodiversity, and acceptance, as well as with the traditional disability/pedagogy idioms of accommodation and inclusion.

³ This statement – about the irony in the history of autism advocacy and disability – intentionally mirrors Feinstein, who says something similar of autistic self-advocates. According to Feinstein, self-advocates present “autism and Asperger’s syndrome as positive differences, rather than disabilities.” Feinstein writes, “...it is ironic that, after decades of ultimately successful battles in many parts of the world to persuade governments to accept autism as a disability, many vocal advocates with the condition are now claiming that it should not be referred to as such.” I draw attention to this parallel to highlight, once again, a pair of fundamental tensions that cannot be resolved fully, but instead need to be revisited and resituated repeatedly. First, although there are different “models” for framing and sorting problematic differences into categories of disease and disability, there is no ultimate, decontextualized dividing line between “positive differences” and “disabilities” or, for that matter, between disabilities and diseases. Second, I believe Feinstein does a disservice to the sustained and concerted efforts of self-advocates who have sought first and foremost to recast autism *as* disability, framed in “the social model,” as opposed to the biomedical disease framework or “the medical model” of disability. There are few self-advocates who have sought to deny that autism is a disability, and this is a rather curious and consistent misreading of how self-advocates generally talk about the way (some) autistic differences can be seen as positives, given the right context. I am not trying to single out Feinstein. I am pointing out that the compounding of this mistake is pervasive and easily falsifiable. Most autistic self-advocates do consider autism a disability and, equally important, positive differences and disabilities are hardly mutually exclusive. More proactively, I want affirm that parent advocates have never been monolithically advancing an “epidemic” discourse or a “disease and cure” model for autism. What I am interested in is how these frames became dominant in public discourse, to the extent that they came to define the standard platform for virtually *all* major autism parent advocacy organizations. Feinstein, *A History of Autism*, 271.

Self-advocates reenter the analysis in subsequent chapters, but I briefly locate them here to draw forth the contrast with a pro-cure stance. Autistic self-advocates and allied “neurodiversity folk” position themselves in opposition to the more dominant biomedical paradigm, which views autism as tragic malady and something to be gotten rid of. Neurodiversity folk critique the most prominent parent groups for exploiting an autism as tragedy framework. They oppose groups considered fundamentally locked in “the medical model” and individuals sometimes referred to as “curebies.” *Curebie* is used most often in reference to parent advocacy groups, and spokespersons whom I refer to as pro-cure parents, because the concept of cure (and prevention) functions as their clear and overarching goal with little room left for other forms of response to autism. It is worth noting, though, that the term curebie is also regularly applied to health workers and others considered overzealous in their desire to prevent or cure.

This chapter is about parents who locate themselves on an autism battlefield, where children are notably missing, silent, unreachable, or assumed to be submerged beneath difficult behaviors.⁴ At the same time it is a search for the kind of focused, generous engagement with oppositional viewpoints out of which I hope will emerge different, less fractious ecological patterns of knowledge-making, concern, and care. The autism wars metaphor is actually used to describe two somewhat different zones of combat. In one usage, the Autism Wars label is used to describe the pervasive infighting

⁴ The experience and understanding of autism from the perspective of diagnosed children is under-explored to date, but the work of Ochs, Solomon, Park, and self-advocate author/filmmaker (as a minor) DJ Savarese are noteworthy: Ochs et al., “Inclusion as Social Practice: Views of Children with Autism”; Ochs and Solomon, “Autistic Sociality”; Solomon, “What a Dog Can Do: Children with Autism and Therapy Dogs in Social Interaction”; Solomon and Lawlor, ““And I Look down and He Is Gone””; Savarese, “Communicate with Me”; Park, “Beyond Calculus”; Park, “Pleasure, Throwing Breaches, and Embodied Metaphors: Tracing Transformations-in-Participation for a Child With Autism to a Sensory Integration-Based Therapy Session.”

among stakeholder factions, experts, and institutions, but the language of warfare is also widely deployed in the fight against autism itself and, in particular, “the autism epidemic.”

In widely shared public understandings, common sense would suggest that the battle against an epidemic of autism is straightforward, but it is important to recognize that not all actors consider autism an enemy. Here, I am addressing autism stories defined principally as tragic illness, mostly from the perspectives of autism parents. I do so in the hope of helping to make other realities possible for both parents and autistic individuals, worldings where skills development, supportive environments, and learning to live well *with* autism warrant investment and promotion, alongside “symptom reduction” measures and improved understanding of autism’s causality. In light of an autism imaginary besought by danger and violence, I want to ask two questions in particular: What kinds of wars are being fought over autism; i.e. exactly who is fighting whom and with what tactics? Secondly, what are the stakes; i.e. what is being attacked or defended and whose lives (and ways of life) are at risk?

An Epidemic of Signification

We need a “an epidemiology of signification” – a comprehensive mapping and analysis of these multiple meanings...

Paula Treichler⁵

How then should we make sense of parallel wars? On one front are battles between and among actors, stakeholder groups, experts, and policy makers; on another, with deeply entrenched logic that is hard to disentangle, autism is the enemy to be

⁵ Treichler, *How to Have Theory in an Epidemic: Cultural Chronicles of AIDS*, 39.

defeated, cured and prevented, especially because it is understood as rapidly increasing in prevalence. Returning to Treichler, she situates her theory work in the AIDS war zone, in part, to argue that it is only through devastating signification practices that we can understand the phenomenon of AIDS. She argues that the military metaphor is particularly apt due to the nature of the AIDS epidemic – necessitating a “long, devastating, savage, costly, expensive, and continuing war.”⁶ She goes on to say that the analogy of war offers “a precedent as useful as plague, polio, and more conventional comparisons.” In her view, the rhetoric of warfare helps readers to consider “the social and cultural impact, the economic toll, the multiplicity of understandings, and the unpredictable cultural upheavals and realignments that the AIDS crisis continues to generate.” Military metaphors have long provided convenient idiom when it comes to threats to the body and its immune response, triggering a search for enemies and imminent threats.⁷ War is a key sense-making trope, a useful way to mobilize politically, helping to materialize more effective response from/with/in medicine, research, and public policy. Deployment of militarized discourse lends rhetorical power to mobilize and lay claim to public resources. Linking epidemics to warfare provides a sense of scale and significance, and offers the allure of heroic battle narratives.

The enduring link between epidemic language and military metaphors helps contextualize the intensity and combativeness among war-torn autism publics. Simultaneously, autism itself has been understood as a major health threat that must be combated – it generates extraordinary fervor as it names a form of terror that demands

⁶ Ibid., 2.

⁷ Martin, *Flexible Bodies: Tracking Immunity in American Culture from the Days of Polio to the Age of AIDS*.

response. Autism is made an enemy at once mysterious and ubiquitous, one which threatens normative family life. In a review of autism literature, Jennell Johnson also draws on Treichler's concept of an epidemic of signification to describe autism discourse: "The word 'epidemic' conjures a public body that must be protected at the expense of the bodies it pushes to the margins—harbingers of a tragic future that must be avoided."⁸ Once autism is understood as reflecting an insidious threat and epidemic emergency, both simultaneously, it calls upon moral citizens to help root it out and enlist with the forces combating it. The stakes ratchet up quickly in terms of how signification practices impact both 'afflicted' bodies and emergent communities. Co-produced epidemics of disease and epidemics of signification are risky for the people's minds and bodies caught in the blitz, even though there has been vigorous controversy over the extent to which, or even whether, autism is "spreading" and in what sense the disorder has become more common.⁹

In contrast to Treichler's work on AIDS, it is important to examine metaphors of war here precisely because autism is *not* lethal or communicable.¹⁰ Grinker explores the power of the epidemic concept, how it implies danger and incites fear, like a plague "that can sweep through the streets, something contagious in the air that you breathe or in the food you eat, threatening the ones you love. With autism, the label of 'epidemic' sounds

⁸ Johnson, "Negotiating Autism in an Epidemic of Discourse."

⁹ This is a point that I return to, but see for example, King and Bearman, "Diagnostic Change and the Increased Prevalence of Autism"; Perez, "The Rhetoric of Science and Statistics in Claims of an Autism Epidemic"; Eyal, "For a Sociology of Expertise."

¹⁰ And yet horror-filled parent memoirs, such as Decker and Sekirin, *I Wish I Were Engulfed in Flames: My Insane Life Raising Two Boys with Autism*; Alan, *I Wish My Kids Had Cancer: A Family Surviving the Autism Epidemic*.

both frightening and tragic.”¹¹ The contagion threat from autism is not rooted in a traditional notion of interpersonal communicability, but the danger remains that the autism gets into children all the same. As Stuart Murray explains:

The idea of contagion is indeed a frightening one. Of course it is impossible to ‘catch’ autism from another person, but what if it can be ‘caught’ in some other way, from another entity, one that surrounds us or can enter our bodies in some fashion? ‘Epidemic’ seems to suggest such an event might indeed be possible; indeed it appears to be proof that it is already taking place.¹²

An epidemic demands war to combat it, like so many emotionally charged risks to public safety threatening the U.S. body politic.¹³

Despite the formulation of autism as disease and epidemic, which seemingly necessitate preventive countermeasures and curative purging, all domains of health are historically situated and contingent. Nadesan describes how the multiplicity of autism – explained and examined in terms of health, disease, disability, and difference – is always/already embedded in worlds of signification. Symptoms of disease, despite appearances of “brute facticity,” are constantly being “interpreted within symbolic systems of meanings, social practices, and historically and culturally variable expert authorities.”¹⁴ Prevailing understandings “shape and constrain medical researchers’ observations, interpretations, and interventions, whereas bodily symptoms and processes can at times offer material refutation of prevailing ideas about causation and cure.”¹⁵ Illness can be lived and embodied in any variety of ways.

¹¹ Grinker, *Unstrange Minds: Remapping the World of Autism*, 5.

¹² Murray, *Autism*, 78.

¹³ For a thorough analysis of the transformation of autism into a militarized discourse, see McGuire, “The War on Autism: On Normative Violence and the Cultural Production of Autism Advocacy.”

¹⁴ Nadesan, “Constructing Autism: A Brief Genealogy,” 80–81.

¹⁵ *Ibid.*, 80–81.

Autism, similar to numerous other psychiatric disorders, has historically been defined behaviorally in terms of deviance from social norms. It is in the process of being translated and re-codified in/to terms of bio-physiological markers and functional differences. Silverman uses the history of public accolades for Bruno Bettelheim's Orthogenic School and his conviction that his methods worked to provide a useful reminder. She writes that we can "read Bettelheim's story as a cautionary tale about analytic frameworks and passionate commitments in biomedicine today... Despite claims for universality and objectivity, biomedical knowledge can be both situated and pluralistic in practice, drawing on multiple and contradictory ways of thinking about disease and difference."¹⁶ As autism's epidemic became common knowledge in the late 1990s and 2000s, the appropriateness, usefulness, and desirability of a biomedical disease model already appeared self-evident. How did such certainty and urgency manifest? Treichler's call for an "epidemiology of signification" offers the possibility that the metaphors of epidemiological science might also provide tools useful for resisting knee-jerk or frictionless pathologization of disability and difference.

Mobilization and Publicizing a Real Epidemic

We need a war on autism, not a war on childhood vaccines.

Dr. Peter Hotez
CDC Media Briefing¹⁷

During the late 1980s, popular images of autism featured Dustin Hoffman's portrayal in *Rain Man*, which won him an Academy Award in 1988, and explorations of

¹⁶ Silverman, *Understanding Autism*, 91.

¹⁷ Hotez is Chair of the Department of Microbiology and Tropical Medicine at George Washington University and has a daughter diagnosed with autism. He was enlisted to help quell the parent uprising over childhood vaccines. "Telebriefing Transcript: Media Briefing on Vaccines and Child Health."

neurological curiosity exemplified by Oliver Sacks.¹⁸ Autistic individuals were highlighted for their singularity rather than linked to a broader world of autism. Donald Treffert's *Extraordinary People: Understanding "Idiot Savants,"* first published in 1989, followed the *Rain Man* savant theme. This is the milieu in which Temple Grandin was able to "emerge," although Grandin is typically represented as gifted and multidimensional, rather than stereotypically savant.¹⁹ However, during the early to mid-1990s, increasingly, the dominant image of autism returned to its prior status as tragic childhood disorder.²⁰ Over a short period, autism became one of the most publicized pediatric health conditions.

By the early 2000s, national news media regularly reported on scientific research and epidemiological findings. Local news broadcasts featured human-interest stories of families struggling to cope with the challenges of raising profoundly autistic children. Oprah Winfrey, Larry King, and Anderson Cooper all featured multiple programs on individuals and families affected by autism. The book market became flooded with titles related to autism, from advice books to children's books, autobiographies to novels. The internet was awash in treatment information, organization websites, blogs, and chatrooms dedicated to autism. A broad array of new therapeutic treatment regimens were marketed to families, while researchers scrambled for access to increases in government and foundation funding.²¹ New clinics and research centers were established around the country, with broad offerings of professional conferences and public symposia. The

¹⁸ Sacks, *The Man Who Mistook His Wife for a Hat*.

¹⁹ Treffert, *Extraordinary People*. Grandin and Scariano, *Emergence, Labeled Autistic*.

²⁰ In a study of material published by parent support groups, charitable organizations, the popular media, and the news industry, researchers found an "overwhelming proclivity for depicting autism as a disability of childhood." Stevenson, Harp, and Gernsbacher, "Infantilizing Autism."

²¹ Singh et al., "Trends in US Autism Research Funding."

financial costs associated with autism, especially costly educational and therapeutic services, became a major public issue.²²

Parent advocacy groups had enormous success pushing autism into a prominent role in public discourse and their adoption of the language of “epidemic” played a major role in increasing attention. As Jeffrey Baker notes, “It was among these parental advocacy groups, not the medical or educational professions, that the notion of an autism ‘epidemic’ first took root.”²³ Activists found an important ally in Representative Dan Burton (D-Indiana) when he initiated a series of congressional hearings on autism and vaccine safety after his grandson was diagnosed with autism following his 12-month vaccinations. The first hearing held in 2000 posed the question, “Why the increased rates?,” but by 2002 the session’s tone was notably more definitive about the existence of an autism epidemic and Burton staged the proceedings as a forum to aggressively question officials about government response.²⁴ As the Chair of the hearings held before the Committee on Government Reform, entitled “The Autism Epidemic: Is the NIH and CDC Response Adequate?” Burton stated at the outset, “Funding in basic and clinical research into autism needs to be expanded dramatically. We have an epidemic on our hands, and we in Congress need to make sure that the NIH and CDC treat this condition like an epidemic...”²⁵ Burton and other well-placed elected officials were ready to adopt the language of national emergency. The reality of an epidemic of autism, which Burton

²² “Autism Has High Costs To US Society.”
“New Research Finds Annual Cost of Autism Has More Than Tripled.”
Berr, “How Autism Can Cost Families Millions.”

²³ Baker, “Mercury, Vaccines, and Autism: One Controversy, Three Histories,” 249.

²⁴ *Autism: Present Challenges, Future Needs—Why the Increased Rates?*.

²⁵ *The Autism Epidemic: Is the NIH and CDC Response Adequate?*.

compared to the epidemics of AIDS and diabetes, was seemingly firmly established.²⁶

Amid controversy over research priorities and findings, particularly those weighing potential causes, many autism parents viewed the centers of scientific authority as adversaries. They saw major public institutions as failing to take a stand against what they understood as a readily identifiable, definite threat, namely, exposure to environmental toxicity of various, sometimes vague and sometimes specific, origin. Tensions increasingly focused on the relationship between genetic risk and environmental vulnerability, which became a contested site where individual and institutional responsibility are renegotiated.²⁷ Often it seemed that the battle lines were drawn between a health movement led by parent advocates on one side, and on the other, figures representing biomedical expertise and institutional authority on the other. The presentation of emerging scientific knowledge and the significance of various kinds of evidence frequently triggered attacks on the purveyors and arbiters of that knowledge.

A vocal subset of parents steadfastly maintained that their child's autistic behaviors appeared suddenly, without warning, with an onset which coincided with vaccinations. Medical experts argued the timing was coincidental, that typically autistic traits are only recognized once a child reaches a certain developmental stage – roughly around one-and-a-half to three years of age, around the time most children in the US and

²⁶ Burton began, “Today we are here to talk about the autism epidemic. I use the word ‘epidemic’ for a good reason. Typically, we think about epidemics in terms of infectious diseases. However, a condition is considered epidemic when it occurs suddenly in numbers that are clearly higher than normal... Is our investment in research on autism on a comparable level with other epidemics? This is very interesting. Are the CDC and NIH funding studies that will help prevent or cure autism?... The CDC is spending over \$932 million on the AIDS epidemic this fiscal year. Compare that to \$11 million for autism. AIDS deserves attention—don’t get me wrong—and so does diabetes... The autism epidemic, just like the diabetes and AIDS epidemics, is no less deserving.” *Ibid.*

²⁷ Silverman, *Understanding Autism*; Lappé, “Anticipating Autism: Navigating Science, Uncertainty, and Care in the Post-Genomic Era.”

elsewhere receive a suite of vaccinations.²⁸ *The New York Times* reported in mid-2005 on the significant numbers of militant parents at odds with health care professionals, stating that the autism-vaccine issue had become “one of the most fractious and divisive in pediatric medicine.” The deputy director of the National Immunization Program was quoted, “This is like nothing I’ve ever seen before... It’s an era where it appears that science isn’t enough.”²⁹ Around this time, conspiracy theories were advanced by David Kirby in *Evidence of Harm: Mercury in Vaccines and the Autism Epidemic, A Medical Controversy* and Robert F. Kennedy’s *Rolling Stone* essay, “Deadly Immunity.”³⁰

The hypothesized vaccine-autism link was formulated three different ways: one, “mercury poisoning” by the ethylmercury-containing preservative thimerosal; two, a negative reaction specific to the “live-virus,” concentrated, three-in-one inoculation for measles, mumps, and rubella known as MMR; and three, the overall intensity of the vaccination schedule itself “overwhelms” or “weakens” the relatively immature immune system of children.³¹ For example, Generation Rescue and SafeMinds pointed out that infants were vaccinated against only seven diseases in 1983 compared to a total of 14 vaccinations, for a total of 26 shots, in the 2000s.³² Vaccine researchers countered that total dosages were actually considerably lower than what children received in vaccines during the 1980s, years prior to the onset of “the autism epidemic.”

²⁸ Kirkland, “The Legitimacy of Vaccine Critics: What Is Left After the Autism Hypothesis?”; Brady et al., “Recommended Childhood and Adolescent Immunization Schedule—United States, 2013.”

²⁹ Harris and O’Connor, “On Autism’s Cause, It’s Parents Vs. Research.”

³⁰ Kirby, *Evidence of Harm: Mercury in Vaccines and the Autism Epidemic: A Medical Controversy*; Kennedy, “Deadly Immunity.”

³¹In 1998, three of the vaccines routinely given to infants (diphtheria-tetanus-acellular pertussis, Haemophilus influenzae type b conjugate, and hepatitis B) potentially contained thimerosal. Baker, “Mercury, Vaccines, and Autism: One Controversy, Three Histories”; Archana Chatterjee M. D., “The Controversy That Will Not Go Away.”

³² Gross, “A Broken Trust: Lessons from the Vaccine–Autism Wars,” 4.

Expert panels convened by the CDC and NIH found no evidence of correlation between vaccines and autism.³³ But it took years before researchers and health officials began to have success in reducing public fears about vaccine safety. In 2007, *Nature Neuroscience* and *The Chronicle of Higher Education* both published editorials expressing concern over the growing rancor.³⁴ Each cited a spate of threats leveled against researchers whose work raised doubts about the idea of an autism epidemic or the theory that vaccines might cause autism. The implication in these editorials and much of the news coverage was that parents were behaving irrationally out of fear and without careful evaluation of evidence. In the years since, anxiety and doubts about vaccine safety have been diminished but not extinguished.

Autism Speaks and Nation Listens

It's worse than anybody had anticipated and it's not getting any better. So we have a real epidemic on our hands.

- Suzanne Wright,
Co-Founder, Autism Speaks³⁵

After the proliferation of non-profit autism parent advocacy organizations during the 1990s, Autism Speaks emerged rapidly, focusing on consolidation, aggressive growth, and mass publicity campaigns, made possible by the organization co-founders' media connections. In February 2005, NBC Universal Chairman and CEO Bob Wright and his wife, Suzanne, formed Autism Speaks amid much fanfare, stating as fact, "We

³³ Stratton et al., "Immunization Safety Review"; Immunization Safety Review Committee, "Immunization Safety Review: Vaccines and Autism."

³⁴ Neuroscience, "Silencing Debate Over Autism," 531; Monastersky, "Is There an Autism Epidemic?"

³⁵ "The Wright Era: Q&A with Bob Wright Television Legend Hangs Up His NBC Hat, Moves on to New Challenges."

have a real epidemic on our hands.”³⁶ Autism Speaks launched with full corporate synchronicity, orchestrated by the Wrights on the heels of the diagnosis of their grandson, Christian, the previous autumn. In what was dubbed “Autism Awareness Week,” between February 21-27, the NBC broadcasting family aired segments on NBC, MSNBC, CNBC, and Telemundo as part of the series, “Autism: The Hidden Epidemic?”³⁷ According to Autism Speaks, the media blitz reached an estimated 40 million viewers and the organization claimed to have raised a corresponding \$40 million dollars in fundraising its first year. With the massive awareness campaign, in what critics have called the marketing of autism, Autism Speaks quickly grew into the nation’s largest autism advocacy organization. The outline of a blue jigsaw puzzle piece, representing the missing cause of autism and the need to find a cure, helped brand the organization. In quick succession, Autism Speaks became a “megacharity” as it merged with the Autism Coalition for Research and Education in August 2005, and in January 2006, the National Alliance for Autism Research came under the Autism Speaks umbrella, followed by Cure Autism Now in November.³⁸

In 2006, Autism Speaks and fourteen other parent organizations succeeded in lobbying Congress to pass the Combating Autism Act.³⁹ Shockjock Don Imus railed against Texas Congressman Joe Barton (R-Texas) for two weeks when he blocked the bill in his role as committee chair, following the Senate unanimous passage of the bill.

³⁶ Ibid.

³⁷ “NBC Networks to Focus on Autism.”

³⁸ In June 2009, Autism Speaks reported “a massive income of \$69 million, which accounted for over 85% of the revenue raised by all 12 of the top revenue-generating autism charities combined.” Stevenson, Harp, and Gernsbacher, “Infantilizing Autism”; Gross and Strom, “Autism Debate Strains a Family and Its Charity.”

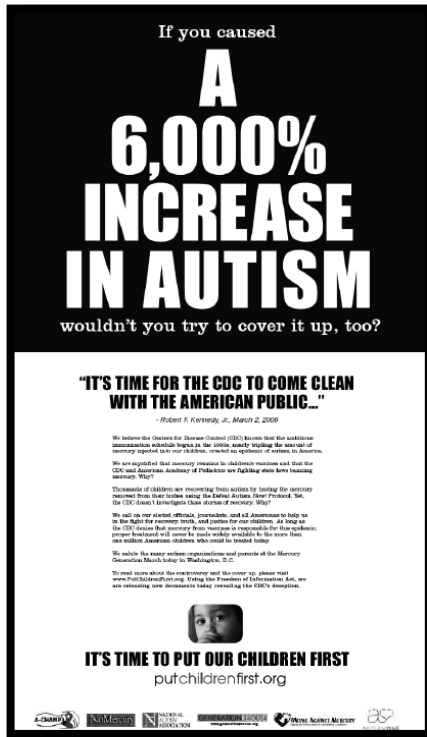
³⁹ *Combating Autism Act of 2006*.

Barton objected to the unusual stipulation in the bill that directed substantial funds specifically towards investigating a possible environmental role in the etiology of autism, refusing to mandate how the NIH should conduct research. Imus called Congressman Barton “a lying fat little skunk from Texas,” “a coward and a crybaby,” and “a congressional dirtbag.” In Texas, hundreds of parents gathered to demonstrate against blockage of the bill.⁴⁰ Barton eventually relented and Congress passed the Combating Autism Act, earmarking nearly one billion dollars for autism research over five years.⁴¹

⁴⁰ Iroegbu, “A ‘Sweet Victory’ in the Fight Against Autism.”

⁴¹ *Combating Autism Act of 2006*.

In addition, a Defense Appropriations Bill specifically allocated money for autism research as part of the Congressional Special Interest Medical Programs, funded through the Department of Defense.⁴² As Daniela Caruso writes, “The involvement of the Department of Defense curiously highlights the military emergency mode that



pervades the dominant strand of the autism social movement. The force of the autism movement is, in relative terms, remarkable.”⁴³ In the midst of lobbying for passage of the Combating Autism Act, parent organizations, such as National Autism Association and Generation Rescue, continued their strategy of taking out full page advertisements such as one which appeared in *USA Today* (pictured), demanding that the Center for Disease Control and the American Academy of Pediatrics stop covering-up evidence that the

increase in autism rates was related to childhood vaccines.⁴⁴ Soon after, the United Nations sponsored the first official Autism Awareness Day in 2008, one of only three days the United Nations dedicates to health awareness, joining AIDS and diabetes, after the Wrights of Autism Speaks solicited the nation of Qatar to sponsor the initiative.⁴⁵

⁴² Singh et al., “Trends in US Autism Research Funding.”

⁴³ Caruso, “Autism in the U.S.,” 6.

⁴⁴ “Advertisement.” For more on the media tactics, see Kerr, “The Autism Spectrum Disorders/Vaccine Link Debate: A Health Social Movement”; Kata, “Special Issue: The Role of Internet Use in Vaccination Decisions.”

⁴⁵ Zukang, “Global Awareness of Autism: Challenges, Responsibilities and Actions.”

The 2008 presidential campaign occurred during what in retrospect appears to have been a peak of autism related controversy, at least the vaccine causation theory component. Candidate Hillary Clinton took up the cause of parents working to raise awareness for children affected by autism. In a press release distributed to news media and appearing on her website, Clinton said, “It’s up to us to reclaim the future for our children, and ensure that every child can live up to his or her God-given potential.”⁴⁶ Clinton capitalized on growing parental concern, their political mobilization, and the moral force behind their efforts to “reclaim” their children. Clinton’s statement cited an Autism Speaks sponsored study, stating “this national health crisis is costing the United States at least \$35 billion each year.” More than simply on the political radar, the autism epidemic had become a talking point for candidates. While expressing concern and pledging assistance to families, Barack Obama’s campaign statement suggested a more measured approach to the increased prevalence rates, noting, “As diagnostic criteria broaden and awareness increases, more cases of autism have been recognized across the country.”⁴⁷ Clinton, Obama, and McCain each touted their support for the 2006 Combating Autism Act.

David Kirby wrote approvingly on *Huffington Post*, “I cannot recall a single disorder ever becoming so prominent in a national election as autism has been in 2008: Not cancer, not AIDS, not heart disease.”⁴⁸ In their campaigns, both Clinton and McCain emphasized the need to investigate the possible role of environmental agents in causing autism, but John McCain was the first candidate to take a stand on what the *New York*

⁴⁶ Clinton, “Hillary Clinton’s Plan to Help Children And Families Affected By Autism.”

⁴⁷ Obama, “Health Care.”

⁴⁸ Kirby, “Last Night’s Autism Debate -- Who Will Win the Special Needs Vote?”.

Times referred to as “one of the most politicized scientific issues in a generation.” What did McCain say that was so inflammatory? While campaigning in Texas, McCain said, “It’s indisputable that autism is on the rise among children. The question is what’s causing it. And we go back and forth and there’s strong evidence that indicates that it’s got to do with a preservative in vaccines.”⁴⁹ The words “there’s strong evidence” were enough for a senior ABC correspondent to declare that John McCain had formally entered The Autism Wars.⁵⁰

Knowledge Divides

We don't want the CDC to do anything. We don't trust them.

Wendy Fournier
President, National Autism Association⁵¹

Epidemiological analysis and clinical lab work have been, by their very nature, unable to refute all possibility of a relationship between autism and immunization. As Bragesjo and Hallberg explain, “Neither method can once and for all exclude such links.” What these methods can indicate is that a causal relationship is “highly unlikely,” that “no epidemiological study has as yet confirmed it, and that no laboratory analysis has been able to definitively verify that the presence of measles viruses in autistic children’s

⁴⁹ Carey, “McCain Steps Into Debate Over Cause of Autism.”

⁵⁰ Barack Obama later said at a rally in Pennsylvania, “We’ve seen just a skyrocketing autism rate. Some people are suspicious that it’s connected to the vaccines. This person included. The science right now is inconclusive, but we have to research it.” Obama’s statement was initially reported in the *Washington Post* as him indicating that he was suspicious of a vaccine connection. A campaign spokesperson then responded to the piece, saying that Obama had been pointing at the audience member who asked the question when he referred to “some people” and “this person.” The *Post* reporter reviewed video and agreed that it cast “a somewhat different light on Obama’s remarks,” but pointed out that Obama also referred to the science as “inconclusive.” The mere fact that fact checking and campaign corrections ensued is suggestive of high stakes political maneuvering. Tapper, “John McCain Enters the Autism Wars”; Dobbs, “Fact Checker - Dr. Obama and Dr. McCain.”

⁵¹ Stobbe, “CDC Finances Study Into Causes of Autism.”

intestinal organs have caused their autism.”⁵² They conclude, “But these arguments are far too esoteric to convince the doubter. Contested knowledge is itself a significant ingredient in modernity’s trust/risk-dilemma and has to be dealt with carefully so as not to further undermine the public’s trust in medical research and science.”⁵³ Actors invested in vaccine/autism causation theories focus on qualifying statements or cast doubt on the composition of the committee, speculating about the likelihood of behind the scenes influence by the pharmaceutical industry fearful of liability and government officials worried about securing public participation in childhood immunization programs.⁵⁴

Suspicion easily can be created and exacerbated by failure to bridge ontological divides, as Silverman illustrates with an incident where the group SafeMinds, a vocal proponent of the thimerosal-autism hypothesis, acquired transcripts of a 2000 closed door meeting in which the authors of a study using data from the Vaccine Safety Datalink, a database created by the CDC in partnership with private HMOs, debated prior to meetings of the Institute of Medicine (IOM) Immunization Safety Review Committee and the CDC’s Advisory Committee on Immunization Practices. The transcripts show that following what Silverman describes as “tense discussion,” the authors decided to alter the study’s sample population resulting in “the weakening of thimerosal effects in the revised models.” Parents viewed the negotiation and changes in the sample set as evidence “that CDC officials had made protection of the nation’s vaccination program a

⁵² Bragesjö and Hallberg, “Dilemmas of a Vitalizing Vaccine Market,” 120.

⁵³ Ibid.

⁵⁴ For example of how doubt manifests in accusations, see Rimland, “The MMR/Autism Controversy: Should We Believe the IOM?”; Kirby, “The Autism-Vaccine Debate: Anything But Over”; Kennedy Jr and Kirby, “Autism, Vaccines and the CDC: The Wrong Side of History.”

priority even at the cost of exposing children to a potent developmental neurotoxin.” While observers such as Paul Offit, vaccinology professor and author of *Autism’s False Prophets*, view the transcript as representing “an instance of routine scientific practice,” of “a study design that seeks to eliminate confounding factors,” such as “underlying health conditions.” But, Silverman argues, “From the perspective of parent advocates, such decisions make no sense. Children with underlying vulnerabilities – genetic conditions, preexisting health problems, family histories of illness – are more likely to be harmed by vaccine-related exposures.” Silverman’s account shows how the world looks very different to researchers who seek a sample of previously healthy children to measure whether they developed autism after routine vaccination compared to parents that see their own “immune compromised children” harmed by repeated injections with “a potent developmental neurotoxin.”⁵⁵

The internet is riddled with conspiracy theories about multiple cover-ups orchestrated by government officials and vaccine producers, bolstered by the promise of an ever expanding array of alternative therapies promising a cure or recovery – something not on offer from mainstream medicine. Karen Kaufman explores what happens when parents, who believe that the institutions supposedly put in place to protect them have failed, turn to the internet for information.⁵⁶ Rather than online research leading to more certainty about the causes of autism, “collecting more information actually increases doubt.”⁵⁷ Kaufman explains that a broadening of the means of knowledge production have become “technologies for the maintenance of doubt,”

⁵⁵ Silverman, *Understanding Autism*, 213–215; Offit, *Autism’s False Prophets*.

⁵⁶ Kaufman, “Regarding the Rise in Autism: Vaccine Safety Doubt, Conditions of Inquiry, and the Shape of Freedom.”

⁵⁷ Gross, “A Broken Trust: Lessons from the Vaccine–Autism Wars,” 6.

creating a situation in which their proliferation enables and sustains doubts persistence: “Autism has become a pivotal figure in conversations about the truth claims of biomedical science and about what constitutes evidence and credible knowledge;” adding, “it carries many meanings in a cultural milieu in which conflicts of interest in clinical medicine abound, trust in the public health apparatus and government has eroded and big pharma is held suspect.”⁵⁸ Kaufman is joined by a number of analysts of health movements who identify autism controversies as reflecting a growing incredulity toward expert authority and the wider phenomenon of failed trust in public institutions.⁵⁹

Kaufman argues that receiving immunization is a demonstration of good citizenship in a democratic society, where “one vaccinates one’s children for their own health and for the public good.”⁶⁰ It is a moral act because one’s personal decision potentially impacts others, increasingly so, as “herd immunity” fails when too many children do not receive their immunizations.

⁵⁸ Kaufman, “Regarding the Rise in Autism: Vaccine Safety Doubt, Conditions of Inquiry, and the Shape of Freedom,” 15.

⁵⁹ Kaufman does not explore a distinction between doubt regarding the balance and interpretation of evidence, in the sense of prevention of a move toward certainty in light of conflicting claims, and doubt about the motivation and objectivity of scientific and institutional authority as sources of credible knowledge. It is a crucial distinction, I think, because one could equally argue that the internet offers technologies for the fabrication of certainty, because, online, actors gain access to seemingly endless avenues for finding evidence (and allies) to support their favored positions, thus enabling and preserving their own imported ontological convictions. The technologies of doubt cited by Kaufman enable doubt about *certain* sources of expertise and authority, while also opening up new spaces for counter claims and the establishment of competing regimes of credibility. One must ask both who is doubting and who is being doubted, in addition to identifying what knowledge is or isn’t in doubt, in a given situation and at a particular conjuncture. What we are witnessing is sustained doubt regarding *authoritative* knowledge. Confidence and certainty are less widely shared and evenly distributed than in prior eras of mass information distribution (i.e. print, radio, network television). See also Rodier, “Science Under Attack”; Kirkland, “Credibility Battles in the Autism Litigation.”

⁶⁰ Kaufman, “Regarding the Rise in Autism: Vaccine Safety Doubt, Conditions of Inquiry, and the Shape of Freedom,” 19.

Panic and Control

A moral panic may be defined as an episode, often triggered by alarming media stories and reinforced by reactive laws and public policy, of exaggerated or misdirected public concern, anxiety, fear, or anger over a perceived threat to social order.⁶¹

It is tempting to view the autism-vaccine scare as a form of “moral panic,” particularly for those worried about public health and the important role played by herd immunity. However, Joel Best argues that the concept of moral panic offers limited utility as an analytic category, because, although it captures people’s imaginations, the term suffers from overuse and there exists persistent disagreement about what the term actually means. He believes the words themselves are poorly chosen: “Not only is there disagreement about whether the accent belongs on moral or on panic, people cannot agree on whether all moral panics involve moral concerns or whether they involve any sort of panic.”⁶² McRobbie and Thornton offer the following rationale for the need to rethink the concept, “The delicate balance of relations which the moral panic sociologists saw existing between media, agents of social control, folk devils and moral guardians, has given way to a much more complicated set of connections. Each of the categories described by moral panics theorists has undergone a process of fissure in the intervening years.”⁶³ As access to the technological means to broadcast opposing viewpoints has grown, the distinction between the role of moral guardian and folk devil itself begins to break down.

⁶¹ Krinsky, *The Ashgate Research Companion to Moral Panics*, 1.

⁶² Best, “The Problems with Moral Panic: The Concept’s Limitations,” 76.

⁶³ McRobbie, and Thornton, “Rethinking ‘Moral Panic’ for Multi-mediated Social Worlds,” 567.

Furthermore, although the label of moral panic has been used to describe a broad range of phenomena both in academic studies and in popular use, the term initially emphasized moral authorities whose “out of all proportion” reaction focused on deviant individuals or groups. In the case of autism, although children may be who moral crusaders claim to protect, as is typical in many studies of ‘traditional’ moral panics, the situation here is complicated by the fact that in the autism arena these same vulnerable children are themselves defined as ‘deviant’ by virtue of their autism diagnoses, with suspicion but uncertainty about widely distributed harmful influences. The very nature and sources of agency, ab/normality, affliction, inheritance, and risk are the terms in question. Stanley Cohen’s notion of “folk devil” is likewise unmoored since traditional sources of moral authority, such as public health officials, are redefined as agents of harm by activist pro-cure parent organizations.⁶⁴

An argument could be made that the moral panic label can be useful to counter some of the reactive discourses of accusation and blame entangled with vaccines and autism. The term moral panic is, after all, deployed for strategic as well as descriptive purposes, in an effort to contain public reaction considered disproportionate by the analyst – to denote the excessive intensity surrounding a particular social concern as (hopefully) episodic or fleeting, representative of fears that are (presumed to be) exaggerated or misdirected. For example, in a discussion of principles for the evaluation of scientific evidence and controversy, Harry Collins dismisses the MMR vaccine “controversy” as in reality an example of moral panic. He suggests that its origins lay in “the opinion of one maverick doctor working without evidence against the rest of the

⁶⁴ Cited in Krinsky, *The Ashgate Research Companion to Moral Panics*.

medical and epidemiological profession.”⁶⁵ Elsewhere, he writes, “One need know nothing of the biology of the gut, the nature of vaccines, the etiology of autism, or the methods of epidemiology to recognize that this case was not a ‘real’ scientific controversy. An analysis of the origins of the controversy is good enough.”⁶⁶ Collins in effect makes a containment move by designating recent, reactivated concerns about vaccine safety as simply another in a long history of vaccine-related panic episodes. He does so, in part, to advance a claim for the validity, maintenance, and appropriateness of expertise, in which he argues against the complete leveling of scientific authority in the face of populist driven health movements.⁶⁷

Collins argues that, although fortunately the MMR vaccination rate never dropped so low as to threaten collective herd immunity on a wide scale, anti-vaccine attitudes did present a health threat to the children most vulnerable to measles due to compromised immune systems. Collins writes critically of the sympathetic hearing some sociological analysts have given to parents’ worries about vaccine safety:

...it may, at first sight seem to support powerless parents against state institutions but it actually flies in the face of social scientific expertise in terms of our understanding of science, medical science, and the generation of moral panics. It encourages free-riders the result of whose actions has been suffering caused by the subsequent measles epidemics and in respect of which the truly powerless are those whose health is too poor to risk a separate vaccination against measles.⁶⁸

⁶⁵ The MMR scare had more complex origins than Collins acknowledges here. His characterization is one of too-easy dismissal. For more, see Baker, “Mercury, Vaccines, and Autism: One Controversy, Three Histories.” Collins, “The Third Wave of Science Studies: Developments and Politics.”

⁶⁶ Collins, “Actors’ and Analysts’ Categories in the Social Analysis of Science,” 109.

⁶⁷ For other authors who have explored the perils associated with the democratization of science and decried the public’s embrace of autism/vaccine causation as an example of “antivaccine hysteria,” see: Mnookin, *The Panic Virus: a True Story of Medicine, Science, and Fear*; Offit, *Autism’s False Prophets*.

⁶⁸ Collins, “The Third Wave of Science Studies: Developments and Politics.”

Collins acknowledges that there is always a sub-population of individuals at greater risk for adverse reactions in every vaccination campaign. Nevertheless, he argues against the reallocation of research funding toward the identification of those children more at risk.⁶⁹ In Collins view, in situations such as this it is crucial to maintain the role of experts in evaluating what does and does not constitute a valid scientific controversy. To do otherwise leads to the misallocation of resources, threatens public health, and causes real harm to the most genuinely vulnerable children.

Collins argues, “It disenfranchises the truly powerless – those too sick to be vaccinated – and moves the power still further into the hands of those who have the resources to make the self-interested choice and pay to have it executed through the private administration of their preferred vaccination regime.”⁷⁰ He criticizes the relative privilege of well-off parents compared to the more “genuinely vulnerable” population of “truly” sick children within a nation-bound context, but one could also make the case that fears about an autism epidemic first originated in countries such as the United States, United Kingdom, and Australia, specifically, because the populations of these nations are less prone to major (and arguably more dire) health threats more pervasive in poorer countries, where malaria, malnutrition, sanitation, etc. threaten children’s wellbeing.

So, in light of the dangers associated with widespread public rejection of child immunization, perhaps an argument can be made that justifies the moral panic label for

⁶⁹ Collins writes, “It is, of course, medical science’s dream to be able to predict the effect of a treatment on every individual by reference to their unique genetic and physical make-up but this ‘Star-Trek’ model of medical science is so far from the actuality that the double-blind, randomised, control trial, that rests entirely on small statistical effects with no understanding of the causes of variation in responses to treatment among populations, is counted still as *the gold standard* for evidence-based medicine.” Ibid.

⁷⁰ Ibid.

vaccination fears, but there are costs associated with doing so. The frame of moral panic generates problematic implications once extended to the broader phenomena surrounding parental fears about an autism epidemic. Moral panic has conceptual limitations such as the ones cited above, but more importantly, the concept's strong emphasis on moralism and its designation of disproportionality has at least two unfortunate effects: 1) It seemingly dismisses any possibility that the physiological symptoms of some children carrying the autism diagnosis might be, in some way, "caused" by environmental factors, vaccine related or otherwise, and 2) it labels parents, often mothers in particular, as panicky due to a fear "out of all proportion" to the situation, what Hall and coauthors described as reaction "above and beyond that which a sober, realistic appraisal could sustain."⁷¹ The first point extends outside the domain of analysis here.⁷² But the second is directly relevant because it essentially dismisses the concerns of a large number of autism parents as irrational, caught in a collective wave of something not too far removed from hysteria.

This is pernicious if for no other reason than the history of an earlier autism "moral panic" which originated in expert opinion, namely, the widely disseminated theory of autism causation that "refrigerator parents" and a failure to nurture made children autistic, either in part or on the whole. That earlier, expert induced, or at least expertly sustained, "moral panic" inflicted great deal harm in autism worlds. And the term 'panic' is over-burdened by the histories of ascribing and producing ir/rationality in

⁷¹ Hall et al., *Policing the Crisis: Mugging, the State, and Law and Order*. Cited in Krinsky, *The Ashgate Research Companion to Moral Panics*.

⁷² But I would not want to foreclose all possibility that there might be a need to examine whether environmental "exposures" contribute in some way to "symptoms" associated with autism and other chronic conditions.

the domain of medicalized conditions, particularly when affective and care labor remains heavily gendered. Wholehearted endorsement of the moral panic label denigrates autism parent labor and knowledge, and strays dangerously close to outright dismissal of their concerns and efforts to be heard. In the end, it does not help us to see much of what else is really going on with claims of an autism epidemic. The appellation is not a good enough way of facing up to the new facts of child rearing, where the specter of environmental risk for US middle class families is focused on potential toxic agents, whereas an earlier postwar model emphasized harms inflicted by inadequate parental nurture.

Exposures: From Injections to Epigenetics

I feel guilty that I didn't do more research on vaccines. You can't get away from the guilt, because you always need to do more reading, research. It goes on and on; it doesn't end.

Mother of two year-old "without developmental problems" ⁷³

In his 2008 overview of the autism landscape, Stuart Murray suggests with a sense of hopefulness, "...it seems to be clear that the tide has turned against the anti-vaccine movement."⁷⁴ But it is also clear that doubt and skepticism about vaccine safety remain heightened among many parents, including the author.⁷⁵ Another counterbalance

⁷³ Quoted in Kaufman, "Regarding the Rise in Autism: Vaccine Safety Doubt, Conditions of Inquiry, and the Shape of Freedom."

⁷⁴ Murray, *Autism*, 87.

⁷⁵ I find that when I am at the park with my two children and tell other parents that my research is related to autism, they continue to want to talk about vaccine risk – sometimes they ask questions but often they mainly voice how they try to make sense of and position their own uncertain navigation of vaccine/developmental risk for and with their children. And I must admit that I had to pause for more than a moment to consider again what I think I know, in 2013, when our local hospital wanted to follow the California health policy and immunize my newborn son against Hepatitis B before his release, immediately after a week spent in the neonatal intensive care unit due to respiratory distress and never-to-be-determined *in utero* infection. I thought, inwardly, he's so immature and fragile,

to Murray’s claim of decline in anti-vaccine sentiment is that it has become *a fact* that environmental “triggers” play a pivotal role in autism’s etiology, which has rapidly taken root among researchers and health officials. That fact was made central during the same period in which vaccinations risk came to the fore, even as by and large health officials dismissed the notion that vaccines present “the smoking gun.”⁷⁶ Anxiety about vaccinations exists among a host of other worries related to autism causation and, especially, the role played by harmful “environmental exposures.” Numerous environmental causation theories have been adopted by various parent advocacy groups, typically backed by support from some form of credentialed expertise. Whereas genetic research dominated in the years leading up to the early 2000s, public concern and legislation such as the Combating Autism Act insured that new funding would flow steadily toward research programs focused on environmental variables. Pro-cure parent activists played an important role in driving this trend.⁷⁷

Some parents explore alternative “biomedical” treatments and invest substantial time, energy, and resources in an effort to ‘detoxify’ their children, in the hope of producing “autism recovery” in the absence of more mainstream biomedical therapies. The healing faith cultivated in the autism recovery movement has been analyzed by some

might his immune response be compromised in that moment? These risk discourses have effects on every parent, no matter how well or poorly informed.

⁷⁶ NIMH Director Thomas Insel began reporting audiences and media, alternately, that researchers “haven’t found anything that looks like a smoking gun” and “there’s no smoking gun” that causes autism, nor for other disorders like schizophrenia or bipolar disorder. The absence of a smoking gun has become a favored metaphor for discussing the difficulty in identifying singular genetic or environmental causes. Goldberg, “Under Suspicion: Researchers Now Believe That Autism Can Be Caused by Genes in Combination with Environmental Triggers. The Question Is, What Are Those Triggers?”; Balintfy, *Transcript: NIH Podcast*; Dominus, “The Crash and Burn of an Autism Guru.”

⁷⁷ Singh et al., “Trends in US Autism Research Funding.”

analysts in terms of similarities to spiritual revival movements.⁷⁸ Silverman, in contrast, emphasizes how rationality informs parents' affective commitments. Such an analysis also suggests ways that doubt, or its absence, is directed rather than free-floating. Furthermore, the autism parent movement contains numerous offshoots, some of which are skeptical of the motivations of the larger, more mainstream organizations pressing to redirect institutional resources toward finding a cure. A distinction can be drawn between parent groups that pursue institutional channels in an effort to influence the course of mainstream science, whereas alternative 'recovery' groups are more likely to use militant protest tactics and berate health officials for denying the reality of vaccine harm.

Autism Speaks increasingly distanced itself from the more anti-establishment autism parent groups. In 2007, Autism Speaks founders Suzanne and Bob Wright had a public feud with their daughter, Katie, when she publicly accused the leadership of Autism Speaks of not pursuing the vaccine causation theory aggressively enough, stating on the Oprah Winfrey Show that she sided with "the Mercurys," at a time when continuing to do so was threatening the organization's mainstream credibility.⁷⁹ However, statements made by Bob Wright make it clear that he had not categorically rejected the vaccine-autism link.⁸⁰ There remains considerable overlap between world views among many of the pro-cure parent groups in terms of linking autism causation to

⁷⁸ Fisher, "No Search, No Subject? Autism and the American Conversion Narrative"; Murray, *Autism*.

⁷⁹ *The New York Times* indicates that the founding of Autism Speaks was, in part, "an effort to end the internecine warfare in the world of autism — where some are convinced that the disorder is genetic and best treated with intensive therapy, and others blame preservatives in vaccinations and swear by supplements and diet to cleanse the body of heavy metals." Gross and Strom, "Autism Debate Strains a Family and Its Charity."

⁸⁰ Jardine, "Should We Want to Cure Autism?"

some sort of external threat. In some ways, the differences can seem largely tactical and a matter of emphasis. For example, Kerr argues that Generation Rescue established a splinter organization, PutChildrenFirst.org, which would employ more militant tactics, while the parent organization adopted a more measured tone in an effort to court mainstream respectability.⁸¹

Both parent groups that organize around unconventional biomedical treatments and the wider pro-cure movement insist that more attention needs to be directed toward the role of environmental causation. Silverman writes:

Parents have become forceful advocates of the idea that increases in autism rates represent an epidemic. Doing so has gained them political recognition and social capital. It has also functioned as a shorthand way to demand that scientists and the public acknowledge that their children's autism is not a matter of chance and heredity, but is a preventable and treatable environmental illness demanding accommodation, remediation, and political attention.⁸²

Remarkably, cure oriented parents were largely successful in laying claim to what had been a floating signifier in the world of autism: *biomedical treatment*. Where mainstream medical practitioners had “only” been able to recommend “behavioral therapies,” and later medications for “non-core symptoms,” parents recruited experts and participated in the development of nonstandard biomedical interventions. Parent organizations steadily accumulated both technoscientific expertise and financial resources, in part by mass marketing themselves as a moral force fighting for their autistic children who were cast

⁸¹ Kerr writes, “By separating out their arguments for safer vaccines from their blame of the CDC and the U.S. government, they were able to appeal to the full autism community. Generation Rescue can bring in thousands of dollars by promoting the “safe,” non-extremist cause of greener vaccines while still funding and promoting the conspiracy theory that the government actively buried any link between thimerosal and autism.” Kerr, “The Autism Spectrum Disorders/Vaccine Link Debate: A Health Social Movement,” 118.

⁸² Silverman, *Understanding Autism*, 53.

as pity worthy. Parents too were made pitiable, at times, but their figuration as champions and warriors stand out as especially compelling.⁸³

Silverman provides a rich ethnographic study of the history of the parent community formed around the Defeat Autism Now! (DAN!) meetings, which emerged from the Autism Research Institute (ARI) in San Diego founded by Bernard Rimland, and the organization's development of the "DAN! Protocol," the most prominent of what are still controversial or alternative biomedical therapeutic interventions. Silverman cites Rimland's influence in establishing an intervention based ethos in the organization that puts parent-experts in partnership with medical experts. She explains how that ethos continues to evolve as understandings of autism change over time, both within the organization and the autism research community at large:

Despite the stability of ARI's commitment to promoting systematic medical evaluations and collaboration with parents in designing treatment programs, Defeat Autism Now!... By the end of the first decade of the twenty-first century, many presenters emphasized the interactive effects of multiple environmental and genetic factors. Ten years earlier a majority might have argued that vaccines alone accounted for the bulk of new autism cases.⁸⁴

Silverman's engagement with the Autism Research Institute and Defeat Autism Now! conferences helps us to understand where cure parents are coming from in a way that "moral panic" analysis cannot even begin to address. Silverman explains, "The first step toward embracing a biomedical framework is learning to view children with autism as suffering from physiological dysfunctions that can affect their entire bodies, as opposed to purely neurological problems manifested mainly in behaviors."⁸⁵ And she makes clear

⁸³ Sousa, "From Refrigerator Mothers to Warrior-Heroes"; McGuire, "Representing Autism: A Sociological Examination of Autism Advocacy."

⁸⁴ Silverman, *Understanding Autism*, 176.

⁸⁵ *Ibid.*, 191.

that the suspected vaccine/autism connection was but one causation theory driving parents' fears about environmental exposures.

In many respects, DAN! parents can be viewed as pushing forward the cutting edge of autism research in their emphasis on the interactive effects of multiple environmental and genetic factors. Silverman explains that as late as 1991, autism had not yet “become a ‘genetic disease.’”⁸⁶ But by the end of the decade, following on the heels of the high concordance rates found among monozygotic twins during research conducted in the 1980s, the assumption of genetic causation was widely accepted by researchers, who characterized autism as “one of the most heritable complex disorders, with compelling evidence for genetic factors and little or no support for environmental influence.”⁸⁷ Silverman’s argues that an “ever-receding genetic horizon” prevented mainstream scientific researchers from giving adequate hearing to parent concerns about the potential role of environmental influence in causation. Parents’ concerns proceeded to drive mainstream autism research programs toward what increasingly became shared and growing interest in gene-environment interactions and the dynamic fields of epigenetics.⁸⁸

Epigenetics is a fitting model here for a recast and reinvigorated theorizing of dynamic relationalities that Silverman explores as “causes” of autism. Silverman’s analysis suggests ways that pro-cure parents are not out “at the fringe” in the sense of

⁸⁶ Ibid., 147.

⁸⁷ Veenstra-VanderWeele, Christian, and Cook, Jr., “Autism as a Paradigmatic Complex Genetic Disorder.” Quoted in Silverman, *Understanding Autism*, 147–48.

⁸⁸ For more on researcher interest in the potential contribution of environmental components to autism, see: Woods and LaSalle, “Epigenetic Epidemiology of Autism and Other Neurodevelopmental Disorders”; Chaste and Leboyer, “Autism Risk Factors”; Landrigan, “What Causes Autism?”; Herbert, “Contributions of the Environment and Environmentally Vulnerable Physiology to Autism Spectrum Disorders”; Hu, “From Genes to Environment.”

rejecting scientific experimentation and rational knowledge building processes but, instead, reflective (and generative) of a movement among more and more scientists toward a search for new models that better capture the cross-pollination of genetic and environmental influences. There is a genuine tension, as well, in how to properly balance and carefully evaluate clinical description, personal testimony, emergent “folk neurology,” and traditional research practice.⁸⁹ The tension exists not just between parent activists and institutional researchers, but reflects broad, vigorous renegotiation of how to better model and deal with complex problems and multiple interactions, as “translational medicine” becomes the new normal.⁹⁰ Silverman moves to understand autism parents’ commitment to healing their children betwixt and between the uncertain interplay of genetic codings, environmental activations, and epigenetic interactions – in what is being framed, both within autism parent and expert forums, as fundamentally cure-driven and cause-centered research, which in an important sense is a “new” search, to identify the complex combination and interplay of “autism susceptibility” genes and potential “environmental triggers.”⁹¹

Silverman seeks to evaluate causal explanations for physiological symptoms with the description of biosocial becomings as she writes about the co-emergence of communities, knowledges, and bodies. Her histories of autism parent-expert-knowledge-child encounters find focus in and balance through diagnostic, therapeutic, and research

⁸⁹ Vrecko, “Folk Neurology and the Remaking of Identity”; Singh, “Brain Talk.”

⁹⁰ Rapp, “Chasing Science: Children’s Brains, Scientific Inquiries, and Family Labors”; Braff L and Braff DL, “The Neuropsychiatric Translational Revolution”; Insel, “Next-Generation Treatments for Mental Disorders.”

⁹¹ For more on the emergence of gene/environment interaction models, see: Shostak, “Marking Persons and Populations at Risk: Molecular Epidemiology and Environmental Health”; Singh, “Human Development, Nature and Nurture”; Landecker and Panofsky, “From Social Structure to Gene Regulation, and Back.”

practices. Silverman writes, "...learning to see autism in biomedical terms involves both reinterpreting daily life and transfiguring one's own beliefs about autism as an entity, [and] requires that I take a position about what autism really is."⁹² She develops her account anchored to parents' intimate knowledge of and commitment to their children.

I am trying to find a different balance, while still taking seriously pro-cure parents' "biomedical terms" for understanding autism. My attempt to get a handle on incommensurate accounts of autism leads me to locate biomedical cause and cure models, including emergence of multi-factorial and interactive epigenetics, as entangled within a broader historical-discursive net and caught in a sweeping epidemiological vision. In an emergent model of individual human development as a dys/functioning eco-self-organism, both the whole body system and the entire ecosystem are increasingly vulnerable to disorder and in need of monitoring for dysregulation.

Toxic Effects and Spiraling Significance of a 'Real Increase'

My son Mark was born in 1956. It was obvious from birth that this perfectly normal-looking infant had something drastically wrong with him. I had earned my PhD in experimental psychology 3 years earlier and had never encountered the word autism. Our pediatrician, with 35 years of experience, had never heard of autism either. Autism was extremely rare then - it is extremely common now.

Some supposed experts will tell you that the increase reflects only greater awareness. That is nonsense. Any pediatrician, teacher or school official with 20 or more years experience will confirm what the studies tell us: there is a real increase in autism and the numbers are huge and growing. The epidemic is serious and world-wide.

- Bernard Rimland, PhD
House Committee on Government Reform

⁹² Silverman goes on to say, "The doctors and researchers involved with Defeat Autism Now! Want to recruit colleagues and supporters with the objective of changing medical practice in tangible ways. A sympathetic description of them that takes seriously their claim that really listening to parents, taking case histories, and thinking about the individual before the syndrome can all work to change the clinical entity of autism means that I am necessarily participating in their system of values and judgments." Silverman, *Understanding Autism*, 195.

Testimony, April 6, 2000⁹³

Bernard Rimland is a towering figure in the history of autism and hero to many autism parents. A paradigmatic parent-expert activist, he helped co-found the first major US autism parent advocacy organization in 1965, the National Society for Autistic Children (later the Autism Society of America and then simply the Autism Society), and stands out for his early role as leading autism parent-expert with professional credentials. Indeed, for a time Rimland was considered the world's preeminent autism expert. He is widely credited with marshaling the evidence needed to overturn the psychogenic, "refrigerator mother" theory of autism and replace it with a biological, neurology-based explanation. The work earned Rimland the Appleton Century Psychology Series Award and praise for challenging a field where experts lacked relevant interdisciplinary knowledge and failed to draw on new research findings.⁹⁴ He later played a critical role in promoting research into a broad range of physiological symptoms associated with autism and in linking them to environmental toxins, arguing that both were integral features in autism's etiology.

Rimland credited his own son's significant improvement and developmental success to intensive behavioral therapy. Rimland was an early proponent of Applied Behavior Analysis, which was controversially developed by O. Ivar Lovaas at UCLA. But as early as 1972, Rimland wrote, "The ultimate answer to the problem of severe behavior disturbances in children – and adults – will come from the biochemistry laboratory, in the form of a drug or a special diet, like the one for phenylketonuria

⁹³ Quoted in Rimland, "The Autism Increase: Research Needed on the Vaccine Connection," 3.

⁹⁴ Edelson and Rimland, *Treating Autism*; Silverman, *Understanding Autism*.

(PKU).”⁹⁵ Rimland was eclectic in his search for effective treatments and was a staunch supporter of behavioral approaches even as he helped establish the biological basis for autism. Rimland later came to argue, with growing passion toward the end of his life, that the epidemic of autism was real and growing. He maintained that his son differed from younger children, who accounted for the growth in the autistic population, in that he did not appear to have suffered ill effects as a result of vaccinations.

Rimland moved early to raise questions about the increase in the rates of the autism diagnosis and moved quickly to sound the alarm, first expressed in a 1995 editorial entitled, “Is There An Autism Epidemic?,” which appeared in the Autism Research Institute’s publication, *Autism Research Review International (ARRI)*.⁹⁶ Despite the word “epidemic” in the title of the piece, he initially posed the question somewhat tentatively, “Is the increase real – does it reflect an actual increase in the prevalence of autism, or is it due to some artifact having to do with a greatly increased awareness?” He said nobody knew the answer, “at least not for sure.” He acknowledged the likely effects of growing awareness, but based on his institute’s database and parent accounts, concluded, “I believe the increase is real, and not merely an increase in awareness.” All doubt was gone five years later when his piece, “The Autism Epidemic, Vaccines, and Mercury,” appeared in the *Journal of Nutritional and Environmental Medicine*. There he wrote that though evidence of an epidemic was compelling in 1995, the case had become “overwhelming in 2000.”⁹⁷

⁹⁵ Cited in Silverman, *Understanding Autism*, 172.

⁹⁶ Rimland, “Is There an Autism Epidemic.”

⁹⁷ Rimland, “The Autism Epidemic, Vaccinations, and Mercury.”

In his 1999 *ARRI* editorial, “The Autism Explosion,” Rimland cited a professor of child psychiatry and pediatrics at the University of Chicago, Bennett Leventhal, who reportedly said in response to Rimland’s claim that the increase in autism was real and that vaccinations were a prime suspect for causing it, “Rubbish!”⁹⁸ Leventhal pointed to the mounting evidence that autism is “a genetic disorder.” Rimland responded, “How ironic! ‘Rubbish’ is what Leventhal’s predecessor at the University of Chicago, Bruno Bettelheim, said in response to my insistence in the mid-1960s that *genetics* played an important role in causing autism! No doubt genetics *do* play an important role in *some* cases of autism.” Now, however, Rimland argued, “There is no plausible alternative to vaccines as the most likely cause.” In a line used repeatedly by parents in what was becoming a face off with “the medical establishment,” Rimland continued, “I have never heard of a genetic epidemic of disease.” He then lashed out CDC officials that were dismissive of the danger posed by vaccinations. He proclaimed, “Let the CDC study autism? No, thank you!” and concluded: “Parent advocacy groups are not misled by the media blitz asserting that vaccines are so safe they do not need to be studied. They insist upon honest, effective research conducted by independent researchers and not by the likes of the CDC. Our children deserve better.” Rimland both reflected growing antagonism directed toward institutions of public health and, undoubtedly, helped to engender it.

In the earlier 1995 editorial, Rimland offered three hypotheses as to possible causes of the autism increase: 1) increased use of antibiotics, which lead to “the proliferation of yeasts, such as *candida albicans*, which exude neurotoxins as waste

⁹⁸ Rimland, “The Autism Explosion.”

products;” 2) vaccinations, given the “increasing evidence that many autistic children became autistic soon after receiving mandatory vaccinations, especially with DPT, although other vaccines are also under suspicion;” and 3) pollution, especially airborne substances, for which he was at the time especially hopeful about the ameliorative potential of vitamin B6, since he had for some time “wondered if there might be some toxic substance in the environment, perhaps in the diet or perhaps attacking the body from some other source, which greatly increased the need of some people for the vitamin B6.”⁹⁹ His concerns about environmental toxins apparently only grew, along with doubts about the justifications and benefits associated with childhood vaccines.

In the 2000 piece, Rimland claimed that the autism epidemic had become global, spreading from country to country upon implementation of the World Health Organization’s vaccine guidelines. The following year in his testimony before the House Committee on Government Reform, Rimland stated his bitter disappointment with the medical establishment and government agencies for their sixty year history of consistently supporting “outmoded, unproven and even disproven theories,” and for actively opposing the most promising approaches to the treatment of autism. In addition, he became convinced that the autism increase was related to other epidemics. He said in the hearing:

Autism is not the only severe chronic illness which has reached epidemic proportions as the number of (profitable) vaccines has rapidly increased. Children now receive 33 vaccines before they enter school - a huge increase. The vaccines contain not only live viruses but also very significant amounts of highly toxic substances such as mercury, aluminum and formaldehyde. Could this be the reason for the upsurge in autism, ADHD, asthma, arthritis, Crohn's disease, lupus and other chronic disorders?

⁹⁹ Rimland, “Is There an Autism Epidemic.”

Indicative of his beliefs about the historic significance of the autism epidemic and his degree of disgust with the medical establishment response, Rimland argued further, “The most interesting questions are not being asked: Why does the majority of the population survive such epidemics as autism, the bubonic plague, Legionnaires' disease, polio and AIDS, while relatively few succumb? The answer is that the survivors have a healthy, effective immune system.” Here, the autism epidemic is made a matter of survival and the previously lower prevalence equated with earlier generations’ more effective immune system response. Rimland appears committed to the position that childhood vaccinations are wholly unjustifiable given the risks, and he advocates an alternative approach toward “enhancing the immune system” in order for it to “function properly.”

By this point in Rimland’s role as elder autism parent-expert, the level of risk he associates with autism appears to be caught in something of a “signification spiral.”¹⁰⁰ In 2001, Rimland wrote again about the harm caused by autism and vaccines in the context of “the most horrific epidemics”:

Alternative medicine provides a much more rational approach to preventing disease – including the diseases that are a direct result of vaccines – bolstering the immune system. Even during the most horrific epidemics – the bubonic plague, smallpox, polio, and AIDS – most humans escape death, despite exposure to the pathogen. Why? Obviously, because their immune systems were competent to defend the body. That is the immune system’s job. Can we enhance the immune system’s capacity to defend us? Of course! Rely on nutrients, not drugs.¹⁰¹

¹⁰⁰ Hall et al., *The Changing Shape of “Panics.”*

¹⁰¹ Rimland added allergies and diabetes to the list of autism, asthma, ADHD, arthritis, Crohn’s disease, and lupus as likely caused by mercury laden vaccines: “During the past decade, mainstream medicine has suffered a hemorrhage of patients who have been flocking to practitioners of alternative medicine. Too often have prescription drugs been found more dangerous than the illness. When the link between the use of unsafe, mercury-laden vaccine and autism, ADHD, asthma, allergies and diabetes becomes undeniable, mainstream medicine will be sporting a huge, self-inflicted and well-deserved black eye. Then will come the billion-dollar awards, by enraged juries, to the children and their families. I can’t wait.” Rimland, “The MMR/Autism Controversy: Should We Believe the IOM?”

I am not calling into question the desirability of a more holistic approach to immune system functioning or the need to respond to the harmful impacts resulting from polluted ecosystems. However, I do have concerns about the wisdom of suggesting that nutrients provide sufficient bolster for the human immune system in the face of the bubonic plague, polio, and AIDS - as well as the implication that an autism epidemic is equivalent to outbreaks of these diseases.

Rimland was an influential figure, but reading his editorials and articles, one has the sense that in many ways he was being driven to this vision of eco-immune-vaccine crisis by his interaction with parent-expert networks brought together through the Autism Research Institute and DAN! Meetings, especially as they began to assimilate new epidemiological prevalence data which began to emerge in the mid-1990s. He constantly refers to what parents were reporting to him.¹⁰² This affirms my understanding of Rimland as not so much a primary source of “the autism epidemic,” but rather, a key figure helping to articulate an emergent public concern. In the epidemiological mapping I offer here, the sources and causal forces of autism’s epidemic of signification are better conceptualized as a convergence of actor concerns and problems both inter-acting and intra-acting with new institutional structures and emergent socio-environmental conditions.

I am suggesting the need to ask other questions, too. What changed during Rimland’s five year trajectory from suspicion that the increase in autism was “real” to what seems, from outside the parent advocacy network, an extreme stance toward the

¹⁰² Eyal and coauthors present Rimland as paradigmatic parent-expert for his systematic efforts to establish an alternative network of expertise, with himself as its overseer and parents as leading coordinators and knowledge sources, thus circumventing mainstream science and “the medical establishment.” Eyal et al., *The Autism Matrix: The Social Origins of the Autism Epidemic*.

relative threats posed by autism, vaccination, and deadly communicable disease?¹⁰³

What is the nature of the “real increase” in autism? How did this “real epidemic” emerge? And what sort of conjunctural crisis incites such extreme, adversarial positioning?¹⁰⁴

The National IDEA and Getting Real (Epidemiologically Speaking)

The sharp rise in the number of diagnoses seen in the last 10 years is almost certainly due to a number of overlapping issues... For all the passion surrounding the subject, there is no epidemic, there is simply change.

Stuart Murray, 2011¹⁰⁵

The CDC now estimates that in 2011–2012, about 1 in 50 school-aged children, or 2 percent of children ages 6–17 years have some form of the disorder. Since the average school bus holds 50–55 children, that means, statistically speaking, on average there is one child with parent-reported ASD on every school bus in America.

NIMH, 2014¹⁰⁶

A number of social scientists have joined public health officials and epidemiologists in arguing that there is no autism epidemic. For example, Roy Richard Grinker dedicates several chapters of *Unstrange Minds: Remapping the World of Autism*, to an examination of the spike in autism rates that began to ramp up quickly in the mid-1990s, in what he describes as “the perfect storm of the autism epidemic.”¹⁰⁷ Grinker

¹⁰³ The dystopic threat of “autism increase” here imagined in apocalyptic, millennial terms is mirrored by New Age utopian vision of autistic “crystal” or “indigo” children, whose arrival heralds world healing transformation and the next stage in human evolution vis-à-vis autistic children’s purportedly supernatural abilities. See Waltz, “From Changelings to Crystal Children.”

¹⁰⁴ Hall, “Gramsci and Us”; Hall, “Signification, Representation, Ideology: Althusser and the Post-structuralist Debates.”

¹⁰⁵ Murray, *Autism*, 88.

¹⁰⁶ “Prevalence of Parent-reported Autism.”

¹⁰⁷ Grinker, *Unstrange Minds: Remapping the World of Autism*, 156–162.

argues, in essence, that the epidemic is not *real*, only *apparent*. He positions the inconstant “reported prevalence” against the presumably stable “real prevalence.” I take a different approach. Rather than evaluate whether prevalence data reflects a genuine epidemic, I am more interested in *what kind* of epidemic it might be, examining its characteristics and contours, and trying to understand how autism became recognized as a common problem. And rather than asking whether the reported cases reflect a real increase, I maintain we learn more about autism’s growing presence by asking what we mean by *real prevalence*, *real increase*, and, right at the heart of the matter, *real autism*.

Grinker examines a variety of factors contributing to the apparent “epidemic,” focusing in particular on the broadening of diagnostic criteria, mobilization of parent advocacy, and changes in epidemiological methodology. The passage of the Individuals with Disabilities Education Act (IDEA) in 1990, shows how Grinker’s ‘perfect storm’ defies efforts to catalogue each and every constitutive element or data set that contributed to the moment when autism became epidemic.¹⁰⁸ IDEA illustrates the way construction of boundary infrastructure and new systems of childhood surveillance, combined with emerging cultural trends and social action, contributed to an altered national landscape and growing autism prevalence.¹⁰⁹

IDEA set the legal framework for special education in public schools, including: access to “free, appropriate, public education” in the “least restrictive environment,” based on an “individualized education program.” IDEA also mandates that state school systems collect and annually report to the federal government a “child count” of the

¹⁰⁸ *Individuals with Disabilities Education Act (Education of the Handicapped Act Amendments)*.

¹⁰⁹ Bowker and Star, *Sorting Things Out: Classification and Its Consequences*; Star, “The Ethnography of Infrastructure.”

number of disabled children served, specifying a specific category of disability with codes provided by the U.S. Department of Education. It created a powerful new database from which to evaluate a range of population trends. And, quite simply, autism would not have become as visible or prevalent in American schools without IDEA. In the decade following implementation the number of children assigned an autism classification across the country increased at a rate of approximately 25% per year.¹¹⁰

Researchers have criticized parent advocacy groups for using the autism child count data inappropriately to generate an exaggerated sense of urgency about autism. For example, the Autism Society of America used the U.S. Department of Education's child count data to publicize a 1,354% increase in the number of students with autism enrolled in American schools, over an eight-year period from 1991/92 to 2000/01.¹¹¹ As Grinker points out, autism was not even an official reporting code prior to the 1991/92 school year and mandatory federal reporting for IDEA did not begin until the 1993/94 school year. He is critical of how autism parent organizations used the newly available prevalence data, even as he explains how the implementation of IDEA's standardized taxonomy creates a radically altered picture of childhood disability.¹¹² He suggests new diagnoses are like empty vessels waiting to be filled, codes as categorical lacunae.

Much like autism, the category of "traumatic brain injury," also introduced in the 1991-1992 school year, showed more than a 5,000% increase over the same period.

¹¹⁰ Newschaffer and Curran, *Autism: An Emerging Public Health Problem*. Quoted in Kaufman, "Regarding the Rise in Autism: Vaccine Safety Doubt, Conditions of Inquiry, and the Shape of Freedom."

¹¹¹ Gernsbacher, Dawson, and Goldsmith, "Three Reasons Not to Believe in an Autism Epidemic"; Shattuck, "Diagnostic Substitution and Changing Autism Prevalence."

¹¹² The principal of Grinker's daughter's elementary school told him in 1994 that she was unfamiliar with autism, since it was a new code. She said they were only assigning it to children who were mentally retarded, because, "Parents don't like the term mental retardation anymore." Grinker, *Unstrange Minds: Remapping the World of Autism*, 16, 150.

Grinker writes, “This does not mean there was actually a 5,000 percent increase in traumatic brain injuries across the nation in the span of a few years; the new category simply opened up a way for cases of traumatic brain injury to be reported. Likewise, the new code for autism made a way for cases of autism to be reported. It also opened up a way for children with autism to begin to get appropriate help.”¹¹³ Newly standardized categories such as autism and traumatic brain injury reshape the statistical topography. Ironically, Grinker points out, IDEA child count data was lower than the prevalence found in epidemiological studies conducted by the CDC following public outcry over an emerging epidemic. In other words, special education data simultaneously underrepresented the true prevalence of autism, found subsequently by epidemiologists, at the same time it was used by autism parent groups to “artificially” inflate the rate of increase! For Grinker this indicates the actual number of autistic children in schools had in fact been undercounted. IDEA helped create the space for autism’s new social presence, which has been alarming for some but, for parents such as Grinker, it also presented new opportunities to address individual and collective need.

Grinker argues that receiving “official status” was bound to make autism a more popular diagnosis. Educational policy created new bureaucratic infrastructure, with a new imperative to collect standardized data at the national level, which was then used to further enhance awareness of the autism diagnosis. Gernsbacher and coauthors similarly, point out that the category of “developmental delay,” introduced in 1997/98, rose by 663% in its first three years of use.¹¹⁴ Although overall prevalence of disabilities across all school categories declined in aggregate between 1994 and 2003, the categories of

¹¹³ Ibid., 18.

¹¹⁴ Gernsbacher, Dawson, and Goldsmith, “Three Reasons Not to Believe in an Autism Epidemic,” 55.

autism, traumatic brain injury, developmental delay, and “other health impairments” all exhibited significant growth. Correspondingly, several of the official thirteen disability categories showed steep declines over the same period, notably mental retardation, in a phenomenon known as diagnostic substitution when a new category is used in place of another.¹¹⁵

This context is important and tells a more complicated story than what one might assume upon hearing about an epidemic of autism. With relevant back story, the reported 1,354% increase tells us more about how autism data is produced and disseminated, rather than meaningful information about the rate of change in prevalence. Somewhat paradoxically, at the same time there *really was* an increase in the number of diagnoses, being co-produced along with reports that inflated the sense of increase. Significantly, the deadline for compliance with IDEA in 1994 coincides with the publication of the fourth edition of the *DSM*, at a key moment when events converged to generate a big increase in the diagnosis of autism.¹¹⁶

DSM-IV is frequently cited as the codification of the autism spectrum. (Actually, the term “spectrum” was not formally incorporated until the fifth edition, but the concept of an autism spectrum was gaining momentum quickly during the *DSM-IV* revision process.) Much attention has been paid to ways the *DSM-IV* criteria may have “broadened” the definition of autism. Broadening has been variously framed in terms of the number and configuration of symptoms, symptom severity, level of impairment in social functioning, degree of intellectual deficit, as well as just plain and simple lack of descriptive precision. It is clear that collective understandings of what constitutes autism

¹¹⁵ Shattuck, “Diagnostic Substitution and Changing Autism Prevalence,” 1031.

¹¹⁶ American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders*.

was expanding rapidly, but it turns out to be rather difficult to pinpoint precisely how criteria were broadened.¹¹⁷ Asperger's Disorder was introduced as a type of Pervasive Developmental Disorder in the fourth edition, consistent with *DSM-III* nomenclature and its categorical taxonomy of distinct disorders. This helped establish a new prototype for an autistic person and facilitated a transition to understanding autism as a spectrum.¹¹⁸

Although Asperger's syndrome captured the popular imagination, it was actually the residual category of Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS) that showed the most explosive growth. Epidemiological studies indicate that the diagnosis of PDD-NOS was being applied more than Autistic Disorder and Asperger's Disorder combined.¹¹⁹ A seemingly small but actually quite telling editorial oversight occurred with the publication of the *DSM-IV* in 1994, one which lowered the threshold for PDD-NOS down to only one out of the three areas of impairment, instead of the intended two out of three, for the remainder of the decade.¹²⁰ Rather than thinking of the typo as *causing* PDD-NOS to be over-diagnosed, I consider it as much a reflection of the fundamental problem in specifying the exact point of transition where a person's

¹¹⁷ The drafters of DSM-IV maintain that they attempted to "narrow the definition of caseness." Ibid., DSM-IV:774.

¹¹⁸ See Murray, Nadesan, Hacking, and Eyal et al. for explorations of how the prototype of Asperger's figures in popular imaginaries in ways that overlap and inform clinical (and epidemiological) practice. Nadesan, *Constructing Autism: Unravelling the "Truth" and Understanding the Social*; Murray, *Representing Autism*; Eyal et al., *The Autism Matrix: The Social Origins of the Autism Epidemic*; Hacking, "Kinds of People: Moving Targets"; Hacking, "Autism Fiction."

¹¹⁹ Fombonne, "Epidemiology of Autistic Disorder and Other Pervasive Developmental Disorders."

¹²⁰ In a key sentence, the criteria for PDD-NOS were supposed to list the pattern of symptoms as, "impairment in social interaction *and* in verbal or nonverbal communication skills." But an "or" was inserted instead of an "and." Grinker, *Unstrange Minds: Remapping the World of Autism*, 140–141; American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders, Text Revision*, DSM-IV-TR:830.

behavior becomes atypical, dysfunctional, or pathological, and how that threshold fluctuates with changing cultural norms as well as symptom checklists.¹²¹

Despite epidemiologists' and social scientists' arguments for the role of confounding variables in the ascertainment of "social" causes of the increased autism rates, it is impossible to absolutely rule out the possibility of "some real increase in autism risk."¹²² Diffusion of emergent categories, changing diagnostic criteria, and the practice of data collection *all* contribute to how we recognize and count autism.¹²³ It hardly makes sense at this point to argue that the autism epidemic and increasing rates are somehow anything less than real. Furthermore, accusations that parent groups intentionally inflated the rate of autism increase for strategic purposes almost seems beside the point, or at least must be put into the context of complex, multi-directional networks and effects.

In 2006, a study found a prevalence of 1 in 86 for a London neighborhood based on follow-up screening of children initially identified in the special needs register of child-health services.¹²⁴ At the time, the findings were met with both alarm and skepticism in the United States. But soon epidemic skeptics had less firm ground to stand on as the new CDC sponsored surveillance system, authorized by the Children's Health

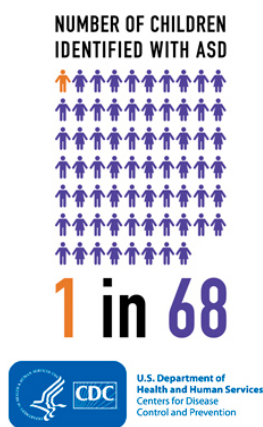
¹²¹ The ubiquitous "NOS" categories were among the most commonly assigned for many *DSM-IV* diagnoses, and it was a major issue that the *DSM-5* was intended to address. Similarly, the problem of "threshold" and "clinical significance" is one of the primary drivers in the DSM-5 Task Force's partially successful effort to incorporate "cross-cutting dimensions" into the diagnostic system.

¹²² Newschaffer, "Investigating Diagnostic Substitution and Autism Prevalence Trends."

¹²³ For more on epidemic controversy see, Newschaffer et al., "The Epidemiology of Autism Spectrum Disorders"; Rutter, "Epidemiological Methods to Tackle Causal Questions"; King and Bearman, "Diagnostic Change and the Increased Prevalence of Autism"; Bresnahan, Li, and Susser, "Hidden in Plain Sight"; Liu, King, and Bearman, "Social Influence and the Autism Epidemic"; Perez, "The Rhetoric of Science and Statistics in Claims of an Autism Epidemic"; Whalen and McKay, "Fifteen Years After Autism Panic, a Plague of Measles Erupts."

¹²⁴ Baird et al., "Prevalence of Disorders of the Autism Spectrum in a Population Cohort of Children in South Thames."

Act of 2000, began to release prevalence data in the latter part of the decade, headlined by evermore alarming denominators. In 2007, the Autism and Developmental Disabilities Monitoring (ADDM) Network reported rates of 1 in 150 and two years later, 1 in 110.¹²⁵ By 2012, the ADDM reported 1 in 88.¹²⁶ Another Department of Health and Human Services study, based on parent reports and published in 2013, found a rate of 1 per 50 school age children.¹²⁷



What are autism facts telling us when the risk of a US child being diagnosed with autism shoots to 1 in 68 (or 1 in 50, depending on the sampling technique) over the course of two decades? How, then, are we to understand the nature of autism epidemiology and monitoring? Does the 1 in 38 prevalence found in a 2011 South Korean study

sponsored by Autism Speaks presage the next stage of a global epidemic, with forthcoming corroboration from the ADDM, as well as Autism Speaks funded studies being conducted in India, South Africa, Mexico, and Taiwan?¹²⁸

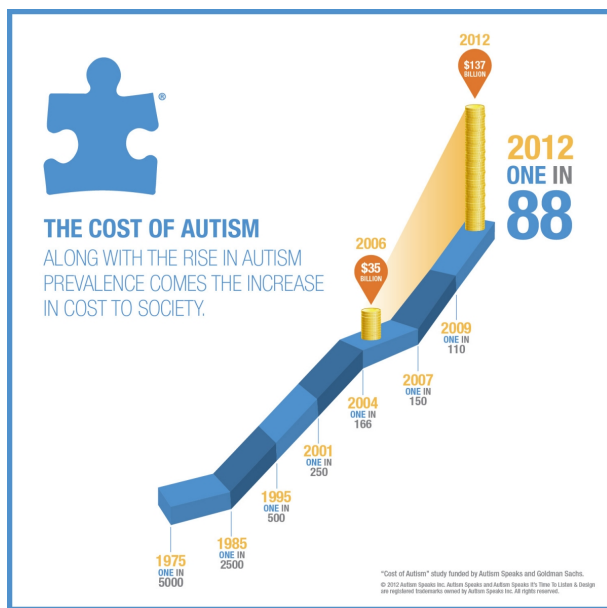
¹²⁵ *Prevalence of Autism Spectrum Disorders --- Autism and Developmental Disabilities Monitoring Network, 14 Sites, United States, 2002; Prevalence of Autism Spectrum Disorders --- Autism and Developmental Disabilities Monitoring Network, United States, 2006.*

¹²⁶ *Prevalence of Autism Spectrum Disorders — Autism and Developmental Disabilities Monitoring Network, 14 Sites, United States, 2008.*

¹²⁷ It is described in the Department of Health and Human Services report as an independent nationally representative telephone surveys of households with children. Blumberg et al., “Changes in Prevalence of Parent-reported Autism Spectrum Disorder in School-aged US Children: 2007 to 2011–2012.” See the CDC’s Data and Statistics page for Autism Spectrum Disorders for an overview of epidemiological trends, “CDC - Data and Statistics, Autism Spectrum Disorders - NCBDDD.”, and for a comparison of global data, see Elsabbagh et al., “Global Prevalence of Autism and Other Pervasive Developmental Disorders.”

¹²⁸ The subheading of Autism Speaks’ press release indicates the research “Has Potential to Increase Autism Spectrum Disorder Prevalence Estimates Worldwide.” And the text reads: “The study does not

A CDC press release in 2014, which includes the 1 in 68 infographic pictured above, promotes the campaign “Learn the Signs. Act Early.” – in order to “help families look for and celebrate milestones” and to “promote universal screening.” It was issued just five days before the United Nations/Autism Speaks sponsored Autism Awareness Day.¹²⁹ The common sense of autism awareness is now thoroughly entrenched in alarming prevalence and focused on advice to carefully monitor children. The marketing and surveillance logic is similarly disseminated by government agencies, international bodies, and pro-cure family advocates.



“Cost of Autism” study, funded by Autism Speaks and Goldman Sachs. The infographic suggests that the cost of not increasing spending to combat autism is too high, ratcheting up from \$35 billion in 2006 to \$137 billion in 2012. According to Autism Speaks’ co-founder, Bob Wright, “Autism is a global public health crisis. The costs are staggering and will continue to rise as prevalence continues to increase... The investment we make now is essential to reducing the long-term costs of autism.”¹³⁰

suggest that Koreans have more autism than any other population in the world. What it does suggest is that autism is more common than previously thought and that, if researchers look carefully, especially in previously understudied, non-clinical populations, they may find more children with ASD.” Autism Speaks is supporting the research with “the translation and adaptation of the gold-standard diagnostic instruments into languages spoken by more than 1.7 billion people worldwide.” Kim et al., “Prevalence of Autism Spectrum Disorders in a Total Population Sample”; “New Study Reveals Autism Prevalence in South Korea Estimated to Be 2.6% or 1 in 38 Children | Press Release.”

¹²⁹ CDC Media Relations, “CDC Estimates 1 in 68 Children Has Been Identified with Autism Spectrum Disorder.”

¹³⁰ “New Research Finds Annual Cost of Autism Has More Than Tripled.”

Conclusion: Taking Stock Beside Pandora's Box

I have always thought that the predominant issue raised by autism is the sheer fact of its presence; it is here and will always be so... There are now more autistic people than ever to meet, to spend time with, to help, to learn from, and to listen to. All these activities are part of everyday life, the normal activities of our world. Possibly understanding autism and getting beyond the facts through which it is too often reduced is, finally, simply about realizing that this is the case.

Stuart Murray, *Autism*¹³¹

Autism research and health policy have been significantly altered in recent years due to the influence of parents' active and sometimes militant involvement. Issues in contention include autism's causes, prevalence, and how to re-define an appropriate mode of response. With different models of intervention and care historically associated with different parent advocacy groups, the biomedical cure and prevention model is in ascendancy now, particularly as articulated by Autism Speaks.

Taking stock, three overlapping areas of contested ground emerged in my mapping of autism's epidemic of signification. First, how might the Autism Speaks model impact other stakeholders with a different model for developing therapies, funding services, and arranging support systems? And how may the organization's approach itself be influenced by other stakeholder groups, such as public health agencies and pharmaceutical companies? Second, given that both parents' truth claims and responsibilities often operate within a moral register, how do we keep a moral dimension in our critical frame, when parent concern about vaccines has been dismissed as a form of moral panic? And, finally, in what sense is the rise in autism prevalence a real increase?

Chloe Silverman suggests that the story of Pandora's Box, as an allegory of unintended consequences, accurately reflects the sentiments of many autism parents, who

¹³¹ Murray, *Autism*, 105–107.

“are certain that the world has become a dangerous place as a result of human activities and that their children are paying the price.”¹³² She describes parents that *know* their children began life developing typically but then regressed as a result of immunizations, “in some cases helped along by severe allergies, too many courses of antibiotics, or environmental toxins like lead and arsenic.”¹³³ According to Silverman, despite receiving a great deal of attention, “these parents do not receive a particularly sympathetic hearing in scientific, or media circles.”¹³⁴ Silverman’s account concludes with an actual legal hearing from “the vaccine court” Omnibus Autism Proceeding, convened during 2007 and 2008, where Department of Health and Human Services lawyers dismissed the expert testimony supporting parents’ claims as “junk science.” One lawyer said, echoing Collins’ critique of the MMR vaccine scare as a moral panic, “There is no scientific debate... There’s no scientific controversy.”¹³⁵ Silverman provides a compelling argument for why dismissing vaccine critic concerns outright is not only a problematic exertion of institutional power but also a very partial version of current scientific knowledge.¹³⁶

However, nearly a decade after the founding of Autism Speaks and the Combating Autism Act, it is also clear that (certain) autism parent advocacy organizations do indeed exert a powerful influence on research priorities and public policy decisions, which incorporate the role of environmental influences in autism’s etiology. Since some parent advocates *are* being taken seriously, then a different set of

¹³² Silverman, *Understanding Autism*, 199.

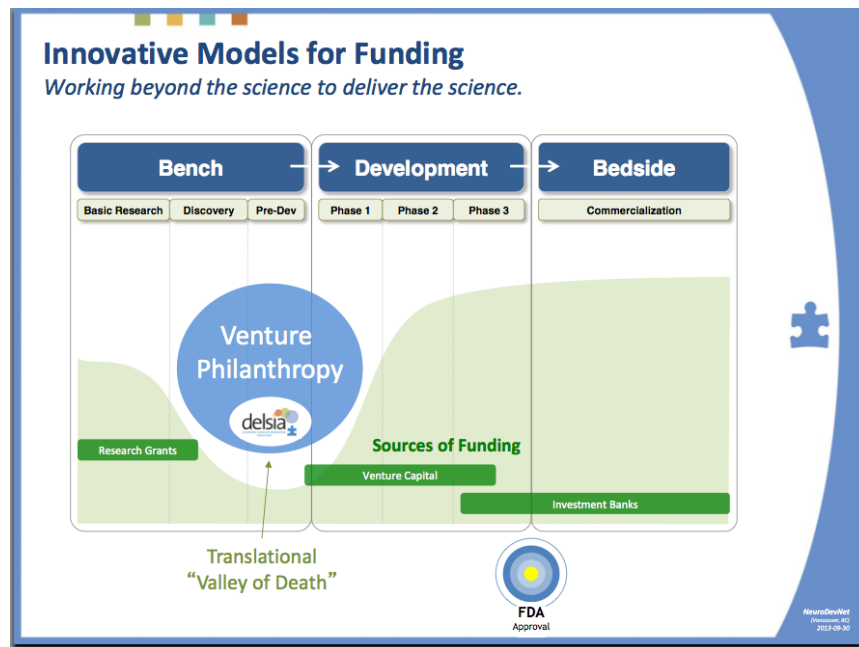
¹³³ *Ibid.*

¹³⁴ *Ibid.*

¹³⁵ *Ibid.*, 223.

¹³⁶ *Ibid.* See also Jr, “3 Rulings Find No Link to Vaccines and Autism”; Kata, “A Postmodern Pandora’s Box.”

questions come to the fore. While outside the scope of my project, it is perhaps worth asking the extent to which the dominant mega-charity model spearheaded by Autism Speaks, with its ties to global corporations and government leaders, reflects the interests that Silverman (and Rimland) found while interacting with DAN! parents. For example, some parent advocates have become disillusioned after Autism Speaks decreased emphasis on vaccines as a possible causal agent. And others are asking new questions about the organization’s agenda after the appointment of multiple former Pfizer executives to key positions (see image below). How might successful pro-cure parent advocacy efforts been aligned with, imbricated in, or co-opted by corporate pharmaceutical interests?¹³⁷



¹³⁷ “Autism Speaks Names Robert Ring to New Position of Vice President of Translational Research | Press Release | Autism Speaks”; “Dan Smith to Lead Discovery Neuroscience”; “Robert H. Ring, Ph.D. Named Chief Science Officer of Autism Speaks”; “Autism Speaks Names Paul Wang, M.D., Senior Vice President and Head of Medical Research | Press Release | Autism Speaks.”

Volunteers might wonder why former director of Pfizer's Autism Research Unit, Robert Ring, continues to provide presentations dedicated entirely to drug development as Autism Speaks Chief Science officer. Another presentation slide in this series has the words, "Not Good Enough," above a chart of various pharmaceutical company pipelines for autism treatments, with only Johnson & Johnson's Risperidone and Bristol Myers Squibb's Aripiprazole all the way to market. While some parent donors (of time, money and family member biological material) to Autism Speaks managed projects no doubt consider this an appropriate use of resources, others might reasonably ask, "not good enough" for what? Whose bottom-line is Autism Speaks advocating for?¹³⁸

Lorna Wing has referred to her influential article on Asperger's syndrome as opening Pandora's Box.¹³⁹ Wing reintroduced Asperger's work with a desire to expand the definition of autism to include a continuum of functioning in order to get needed services to more individuals. What is interesting from my perspective writing about the material-semiotic reality of an autism epidemic, is that while she readily acknowledges the introduction of Asperger's syndrome played a significant role in broadening the autism spectrum's diagnostic boundaries and, thus, increasing prevalence, she is simply not particularly bothered by that fact.¹⁴⁰

Wing expected more individuals to be identified when she began advocating (as a parent-expert) for Asperger's syndrome as part of an autistic continuum, because she *intended* for the diagnosis to become more inclusive. Her primary concern was to provide assistance and services for individuals whom she believed were in need. Wing's position makes perfect sense once you understand that she remained committed to the

¹³⁸ The presentation is currently available for viewing at <http://vimeo.com/82150064>. Ring, "Autism Spectrum Disorders: Challenges and Opportunities in Medicines Development."

¹³⁹ Wing, "Reflections on Opening Pandora."

¹⁴⁰ In 2005, Wing believed that, on the whole, describing and naming Asperger syndrome had "mainly positive effects." More recently Wing has said, "I wish I hadn't done it," but still not because the broadening criteria led to increasing prevalence. Her concern remained that its introduction appeared to lend support for a categorical rather than a dimensional approach to diagnosis. *Ibid.*; Feinstein, *A History of Autism*, 204.

service provision model adopted by the UK's National Society of Autistic Children (NSAC), which she founded three years prior to Rimland and Ruth Sullivan establishing the more advocacy oriented US Society.¹⁴¹ And Wing never became enamored with a recovery/curative model as Bernard Rimland did, increasingly so after leaving NSAC. Therefore, Wing remained firmly outside the ethical regime of intervention defined by an economy of the cure.¹⁴²

Wing serves as a useful reminder that the logic of epidemic functions within a particular ethical regime and specific moral economy. An 'epidemic' only makes sense if autism is made analogous to a certain idea of what constitutes disease and, even though Wing considers autism a form of disorder and medical pathology, her model for appropriate response is based on care and social service provision rather than recovery or cure. This is closer to the habilitation and "socially innovative therapies" model that Eyal argues replaced the institutional matrix of custodial care in US in the wake of deinstitutionalization during the 1970s and 80s.¹⁴³ Eyal argues that this therapeutic network of expertise is more collaborative, generous, and efficacious than the one it replaced. He also suggests that it is more robust, but perhaps the rise of an autism epidemic shows that, in another sense, the alignment of interests in the network is also rather fragile.

¹⁴¹ Eyal et al., *The Autism Matrix: The Social Origins of the Autism Epidemic*, 168–169.

¹⁴² Eyal et al., *The Autism Matrix: The Social Origins of the Autism Epidemic*.

¹⁴³ Rimland played an important role in crafting what Eyal and coauthors describe as the US post custodial institution matrix. See pages 244-260 for discussion of how Rimland's later turn toward experimental biomedical treatment helped blur the boundary between alternative and established medicine, as well as invigorated "something that looks like an illness model of autism." *Ibid.*, 244–260.

In that light, it is worth considering what might get lost if the imperative to develop biomedical treatments has now become dominant, seemingly shared in common among parent advocacy groups, health officials, and pharmaceutical companies. What if success in the biomedicalization of autism interventions leads to the erosion of already begrudging HMO and health agency support for the hard-won (and costly) therapeutic space carved out “between custody and cure”? Is this a threat to the leadership role that (some) parents have assumed in shaping and directing a more socially integrative and distributed network of expertise, located in a kaleidoscope of home and community based behavioral, educational, and occupational therapies?¹⁴⁴

Grinker’s perfect storm of autism is a strategic intervention used to argue that there is only *the perception* of epidemic, to lessen fear driven rhetoric and discourage reactive public policy. In his view, what has occurred is the better assessment of autism’s *true prevalence*. Getting closer to the real prevalence, for him, offers an optimistic vision of science finally getting the condition right. It is a positive development for autistic people and their families. More are receiving needed educational services and behavioral therapies. And in some formulations of the spectrum, greatly influenced by self-advocates, there emerges “a theory of sociality that can encompass a wider range of human social differences.”¹⁴⁵ Grinker is optimistic that his daughter will have a better life as a result. The language of epidemic is fundamentally incompatible with this spectrum logic.

Thus, the increase in autism rates can be viewed positively, as when Grinker sees it as evidence of science gaining a better understanding, or negatively, as with Rimland

¹⁴⁴ Eyal, “For a Sociology of Expertise.”

¹⁴⁵ Grinker, “Commentary,” 174.

seeing the rise as evidence of a global catastrophe. Or, as with Autism Speaks, the epidemic can be made a national emergency, for either living in “fear of the future” or mobilizing for full-scale, military-style action.¹⁴⁶ Or maybe the story is not yet written about how exactly autism fits – within “neoliberal topologies of knowledge about health and disease are crafted;” the “uncanny overlaps between the development of life-science epistemologies and the epistemologies of neoliberal economics;” and the logic of “drugs for life,” where “finding more and more risks to treat are explicit strategies.”¹⁴⁷ Could the autism epidemic at some point have become enmeshed in efforts to define and create a new, exploitable market segment and/or biosecurity project?

Kaufman argues that this occurs amid a crisis in trust and a breakdown in systems of risk assessment. Parents are made to feel vulnerable and uncertain, but also morally obligated to extend their own expertise amid a plethora of experts, both in order to protect a child from exposure to an ever-more toxic environment and to maximize a child’s potential in an era of brain science and the emergence of ‘new’ neurodevelopmental disorders. Kaufman writes, “Having options is part of ‘the good’ of autonomy, responsibility, and well-being in health matters today, even though those options inevitably contribute to greater uncertainty, and even though former reliance on professional expertise is being challenged and sometimes undermined.”¹⁴⁸ Self-

¹⁴⁶ “If three million children in America one day went missing – what would we as a country do?... We would call out the Army, Navy, Air Force and Marines. We’d call up every member of the National Guard. We’d use every piece of equipment ever made.” Wright, “Autism Speaks to Washington - A Call for Action.”

¹⁴⁷ Petryna, Lakoff, and Kleinman, *Global pharmaceuticals*, 25; Rajan, *Lively Capital*, 18; Dumit, *Drugs for Life: How Pharmaceutical Companies Define Our Health*, 24.

¹⁴⁸ Kaufman, “Regarding the Rise in Autism: Vaccine Safety Doubt, Conditions of Inquiry, and the Shape of Freedom,” 26–27.

responsibility and well-informed choices are all the more critical as they become more intricately tied to systems of monitoring and screening.¹⁴⁹

We need to accept that the increase in prevalence is *real* simply because the increased incidence of being diagnosed is real. Risk is widely but unevenly distributed, and it is important to remember that for some families there are greater risks (and costs) associated with *not* receiving a diagnosis. Now, more actors agree that the causes of autism are multi-factorial, but the meaning of the increase is still up for grabs – and will continue, one hopes, to be parsed by parties both committed and critical. After all, there *is* supposed to be hope at the bottom of Pandora’s box.

Trechler’s epidemic of signification helps me make sense of the twin developments of autism becoming a spectrum and, within short order, an epidemic. I have shown how autism’s *true* prevalence is always in the process of becoming, according to specific social and technical practices; autistic individuals will never be definitively countable, for reasons at once methodological, practical, and ontological. With diagnostic criteria in a state of flux, both what *is/are* being identified – namely autism – and who it is that are being counted – officially diagnosed or not – are moving targets.¹⁵⁰ The creation of epidemiological vision-systems and the production of prevalence facts are generative – acts of re/signification that help co-produce and enumerate dis/ordered populations in terms of statistical indices of risk.

I view the concept of *the true* or *the real* prevalence as an event, defining a specific moment of instantiation of somethings and someones enmeshed in processes of

¹⁴⁹ Ginsburg and Rapp, “Disability Worlds.”

¹⁵⁰ Hacking, *The Social Construction of What?*; Hacking, “Kinds of People: Moving Targets.”

emergence, and, furthermore, only visible and measurable within certain limits. Autism's presence in people's lives is always being re-composed with more variables than can ever be totally accounted for or fully counted.

Chapter Three

Meetings: Wrestling with Spectra

In late 2004, as I read Amy Harmon's "How About Not 'Curing' Us," I immediately recognized that the autistic people I knew did not need curing.¹ While I was aware I had only a vague understanding of what autism *is*, at the same time I knew that I couldn't imagine what a cure could even *mean* for the young adults I was working with in San Francisco. I had not known them as children, but they had reached a more or less healthy adulthood. I couldn't then, and can't now, see them as ill. They needed a lot of support and some, like Colette, required near constant attention, but they weren't sick. They received extended educational services in the school district's transition program because of their developmental disabilities, which had been determined to be moderate to severe. The autism I knew simply wasn't the same one explored in the prior chapter, the autism making "sick kids." I had yet to encounter that other more biomedically-weighted "diagnostic vision." What's more, I did not think of them as suffering. I knew more than a little about how difficult and demanding autistic behavior could be but, among the autistic people I worked with regularly, I could not think of one whom I considered to be suffering in some sort of existential way, and certainly not from their autism.

Re-reading Harmon's piece nearly a decade later, I see how it aligned with the way I already understood autism as a developmental disability. Harmon begins with a description of an experimental school called Autistic Strength, Purpose and Independence

¹ Harmon, "How About Not 'Curing' Us, Some Autistics Are Pleading."

in Education, or ASPIE for short. Students don't have a disease, they tell Harmon, so they can't be cured – autistic is just the way they are. They don't suffer from a devastating disorder either, although some had suffered because they were depressed due to being ostracized and picked on prior to finding “refuge” in the school's affirming pedagogical model. The curriculum teaches that “it's O.K. to ‘act autistic’ and also how to get by in a world where it is not.” Instructors train the students in self-advocacy and design lessons around students' often very intense and idiosyncratic interests.

The article addresses the language of disease and cure, but the ‘curative’ model it describes is primarily one of normalizing behavior, not employing biomedical intervention. Rather than listing symptoms, Harmon echoes the language of traits and difficulties, a need to locate strengths and coping strategies, which she says are being adopted and created by a growing number of autistics “staging what they say amounts to an ad hoc human rights movement.” The language of cure, disease, and suffering seems out of place among the claims of autistic people who seek dignity, accommodation, and acceptance, as well as to advocate for skills development, support care, and assistance with navigating a social world which can be unyielding, intolerant, and overwhelming. Harmon invokes the history and metaphor of imagining autism as a shell from which a normal child might one day emerge. “But,” she informs readers, “some advocates contend that autism is an integral part of their identities, much more like a skin than a shell, and not one they care to shed.” Some worry, she says, that the “ultimate cure will be a genetic test to prevent autistic children from being born.” Here and elsewhere, I find in Harmon's portrayal many of the key themes and tensions that are my central concerns.

There is a running narrative, available in both popular and academic forms, that focuses on what are described as high-functioning forms of autism, often associated with the Asperger's Disorder diagnosis. This version of the "geek syndrome" and "little professor syndrome" often veers toward an image of autism that suggests nothing more than social awkwardness and minimal disability, and more than likely offering a dash of genius. In contrast, Harmon does not avoid aspects of autism that can be truly difficult and (in her words) crippling, while at the same time she remains open to how autistics, "with their obsessive attention to detail and eccentric perspective, can provide valuable insight and innovation." She aptly describes a distinctly autistic "ability to develop uncanny expertise in an area of interest," rather than reiterating the more common endorsement of autistic intelligence, which sends others down a one-way, dead-end street. Harmon also makes clear that there is a persistent need among pro-cure parents and others to draw a clear line between high-functioning and low-functioning autistics, and that among the activists are people who complicate that distinction, including some who cannot use speech to communicate and who have been institutionalized.

Harmon quotes the author of a widely read parent newsletter, Lenny Schafer, who says that the autistic rights movement "might make some sense" if they would substitute the term Asperger's for "autistic." He told Harmon, "But I intend to cure, fix, repair, change over etc. my son and others like him of his profound and typical disabling autism into something better. Let us regain our common sense." Harmon cites Kit Weintraub's widely circulated essay, "A Mother's Perspective," where she writes of her two diagnosed children, "My children have autism, they are not 'autistics'...It is no more normal to be autistic than it is to have spina bifida." Harmon juxtaposes Schafer and

Weintraub with self-advocate Jim Sinclair, who did not speak until age twelve. Sinclair objects to cure and prevention of autism as obvious public goods, and far from analogous with ridding society of cancer: "What they're saying is their goal is to create a world that has no people like us in it." She quotes the site managers of autistics.org who have trouble with speech, continence, and self-injury – sharing the line which I found remarkable then and still now, “We flap, finger-flick, rock, twist, rub, clap, bounce, squeal, hum, scream, hiss and tic." Harmon’s article is how I learned about Autreat as a self-advocate effort to create autistic-friendly space, where attendees compare themselves to gay rights activists and emerging autistic culture to that of deaf people.

“How About Not ‘Curing’ Us, Some Autistics Are Pleading” began to set the scene for what I came to think of as the problematic of making a world sufficiently hospitable to accommodate – both support and work *well enough* with – struggle, social difficulty, and poor functioning. I began to reflect on how the autistic people I knew who were hardly high-functioning but, nevertheless, suggested developmental trajectories and processing difficulties poorly characterized as disease. From the outset, neither efforts to cure pathology nor normalize behavior seemed adequate responses to me. I began to sense that the terms spectrum and functioning were being used to help bridge broad conceptual gaps and to allow skipping over the articulation of complex relational dynamics.

Chapter Overview

I begin this chapter with Harmon’s 2004 article to locate myself as beginning to think about this investigation at a particular point in time; or at least to mark the moment when I began to take notice of the epidemic talk and wondering what it was all about,

what it meant for autistics who felt pretty OK with their autism, and what a cure could conceivably mean for my students. My interest gestated for more than a year before I began observational research, which gradually coalesced around meetings as sites of encounter, negotiation, and confrontation.

The chapter is divided chronologically into two parts, both organized around “meetings,” which develops material that informs the analysis of other chapters, and is located in the middle of the dissertation with the intention of grounding what precedes and follows. In the first half of the chapter, I describe two specific meetings in some detail: an hybridized academic conference at Fordham University in October 2006, which brought together academics, clinicians, activists, laypersons, and clerics; and a May 2009 meeting of the congressionally mandated Interagency Autism Coordinating Committee (IACC) on the campus of the National Institute of Health (NIH) near Washington DC. The 2009 IACC meeting in some ways forms the core of the chapter as it brought together key actors whose trajectories I follow in the second half. In between the meetings at Fordham and NIH, I describe the announcement of two large-scale autism phenotyping projects in 2006 as a key moment when major research institutions began to devote considerable resources to dividing up the spectrum into biometrically legible “autisms.”

Part II is written less explicitly in participant observation mode but is informed by research on the *DSM-5* revision process which included attendance at relevant sessions of the 2009 and 2013 annual meetings of American Psychiatric Association, both held in San Francisco. The period between 2009 and 2013 is crucial to understanding what is a still unfolding turn toward a post-*DSM-5* landscape. I describe

autism worlds as having arrived at a crossroads where the paths available are more clearly marked as either toward acceptance of important parts of autism's disability-like presence or down a path more defined by biopsychiatry remade into an emerging clinical neuroscience. The historic project of remaking mental disorders into brain diseases with measurable thresholds and biological targets for therapeutic intervention shows signs of accelerating and broadening in scope. At the same time, it is increasingly evident that many stakeholders are invested in how the autism spectrum serves myriad other social purposes that in important respects remains outside biomedical frameworks.

Self-advocates and increasingly parent-advocates are articulating an alternate social project that in many ways runs counter to the National Institute of Mental Health (NIMH) agenda embodied in an initiative called the Research Domain Criteria (RDoC) project. The name harkens back to the Research Diagnostic Criteria developed in the late 1970s, which Robert Spitzer used to help launch the *DSM-III* agenda to both standardize and make reliable psychiatric diagnoses.² RDoC, in contrast, is being imagined as a project that takes up *DSM-III*'s unfinished biomedical business, to mobilize researchers toward development of a more measurement based and etiopathologically informed "clinical neuroscience." It is an attempt to redefine the conceptual and institutional framework organizing brain-based biomedical research on neurodevelopment, (not-so-mental) social functioning, and psychopathology. During the *DSM-5* revisions, self-advocates harnessed a disability framework to articulate a compelling alternative to the vision of autism as a brain disease, which is increasingly appealing to parent-advocates

² Spitzer, Endicott, and Robins, "Research Diagnostic Criteria"; American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders*.

and others and stands in stark contrast to a public discourse that in recent years focused heavily on an autism epidemic and the search for a cure.

PART I: 2006-2009

Autism and Advocacy: A Conference of Witness and Hope Fordham University, October 27, 2006

More than a hundred people with overlapping, though not necessarily concordant, agendas gathered at Fordham University in the autumn of 2006. The event, “Autism and Advocacy: A Conference of Witness and Hope,” sought to bring together what the promotional material termed “the varieties of advocacy practiced with and by persons with autism.” Sponsored by a Jesuit institution, the audience included numerous clergy and nuns, as well as social service professionals and parents of autistic children.

The principal conference organizer at Fordham, Jim Fisher, Professor of American Catholic Studies, offered brief opening remarks. “This is a conference motivated by love,” he said. Fisher’s son, Charlie, was diagnosed with autism at the age of two. He told the audience their story of hope and progress by recounting the long, arduous, and ultimately successful process of teaching his son Charlie to ride a bike – a very recent accomplishment that his family was still celebrating. It was a metaphor that other speakers referred back to throughout the day. Fisher off-handedly mentioned his ADHD (Attention Deficit Hyperactivity Disorder), which I later learned was an official diagnosis attained in adulthood.

When I first sat down, I took notice of a woman sitting in the front row who turned out to be Jim Fisher’s wife, Kristina Chew. She stood out to me because of her intense focus on the proceedings, visible through her erect posture and frequent,

enthusiastic nodding. I also noticed that she turned around to face the audience during the applause that preceded and followed each presentation. She waved her hands in the air silently as the audience clapped, and appeared to be modeling what I took to be American Sign Language (ASL) applause. Jim acknowledged Kristina's significant contributions in organizing the conference.

I had had a brief email exchange with Chew prior to the conference and she was pleased that I was traveling from California to attend the conference. Later in the day, she gave the closing remarks, and offered us an image of Charlie in motion, once again. This time he moved gracefully among the waves breaking along the Jersey shore. She emphasized how adroit and comfortable Charlie is in the ocean. She marveled at how he glides through the waves with such skill, in a way she never could. She found that seeing Charlie in an environment where he thrives helped her to see his abilities, as well as disabilities, in a new light. After the conference, I found Chew's popular blog, *Autism Vox*, and its predecessor, *Autismland*, where her daily entries reported on life with Charlie, current autism news, and ruminations on the cultural politics of autism.

Timothy Shriver, CEO and Chairman of Special Olympics, Inc. provided the keynote address. Charismatic, smooth, and thoughtful, Shriver engaged the audience with the larger mission of the Special Olympics. He spoke of his mother, Eunice Shriver, and his desire to carry on her efforts to create opportunities for and increase acceptance of people with cognitive disabilities. Eunice Shriver had credited her accomplishments, such as organizing the first national Special Olympics in 1968, to her relationship with

her older sister, Rosemary Kennedy.³ Shriver utilized his family's prominence to good effect while addressing the conference audience. From the outset, he established that he considers himself to be carrying on his mother's work. Then, after a small joke in which he distanced himself from the politics of his brother-in-law, Arnold Schwarzenegger, Shriver focused his address on the kinds of relationships fostered by Special Olympics participants and volunteers. Shriver offered the term "diffability" as a way of reframing public conversations around disabilities to emphasize that all people have differing abilities. He located autism among the so-called "invisible disabilities." He noted that less obvious and less visible conditions, such as autism, sometimes draw controversy in the context of the Special Olympics. Shriver used this point about disabilities with an ambiguous status to emphasize that a lot of his hope derives from the expansion of an inclusive Unified Sports program, where people both with and without disabilities train and compete together.

Shriver surprised me when he reported that the Special Olympics had supported the participation of some of their athletes in "The Ringer," a film, starring Johnny Knoxville, best known as creator and star of MTV's "Jackass." Shriver remarked that this was what he considered a different approach to making intellectual disability more visible and, hopefully, less stigmatized. Shriver signed on as executive producer of the film in the belief that through humor it challenges common stereotypes and portrays, not merely asserts, "the humanity of Special Olympics athletes and all people with

³ Rosemary, who died in 2005, was characterized by her family as having been mentally retarded at birth, but her condition worsened considerably subsequent to a lobotomy performed in 1941. Eunice Shriver told NPR in 2007, "I had enormous affection for Rosie. If I [had] never met Rosemary, never known anything about handicapped children, how would I have ever found out? Because nobody accepted them anyplace." <http://www.npr.org/templates/story/story.php?storyId=9136962>, (accessed 10.17.07)

intellectual disabilities.” Shriver and the Special Olympics committee helped coordinate the inclusion of actual Special Olympics participants and issued a public letter of support for the film.⁴

In what became a consistent pattern for the day’s question and answer periods, Shriver faced two self-identifying autistic audience members who asked challenging questions about labeling terminology, in particular the use of “person-first language” (i.e. person with autism). They pressed Shriver on the extent governance of Special Olympics, Inc. includes representatives with disabilities. There were four autistic self-advocates who spoke up consistently throughout the day, three of whom identified as “Aspergers.” I also noted several less vocal autistics attending with caregivers. The four autistics asserted a unified stance during the discussion sessions throughout the day, and repeatedly pushed speakers to adopt the term “autistic” in place of “person with autism.”

In the final panel, the sole autistic speaker in the program, Kassiane Sibley (nicknamed Rett Devil⁵), stood up to the podium, and said that she would begin with “some self-advocacy.” She swung her arms over her head in a broad swooping motion, stopping just short of slamming her hands together. “Okay. This. HURTS!” After Shriver’s keynote address and the first Q&A session, Kristina Chew had asked the audience to “flap not clap,” because autistic people in attendance had auditory sensitivities. There is some variability in how the flapping gesture is performed, but generally flapping involves moving hands up and down in the air, often with a limp wrist. The silent movement approximates the repetitive flapping characteristic of many people

⁴http://www.specialolympics.org/Special+Olympics+Public+Website/English/Press_Room/Global_News_Archive/2005+Global+News+Archive/Statement+on+The+Ringer.htm, (accessed 10.15.07).

⁵ A moniker derived from her Rett’s syndrome diagnosis.

on the autism spectrum. To flap is a gesture of community and solidarity among autistic people, as well as an act of respect for audience members who cannot tolerate loud noise. Despite Kristina Chew turning to model “flapping” at each noisy eruption, more and more audience members had gradually returned to noisy hand clapping as the day progressed.

Kassiane then warned the audience to prepare to be offended and proceeded to lecture about “real autism advocacy,” not a misguided desire to “cure autism.” She loudly proclaimed, “I’m not broken. Don’t try to fix me!” Many in the audience shook their heads in dismay as Kassiane attacked Autism Speaks, the nation’s largest, and well-funded, autism advocacy organization, because “its goal is the eradication of autistics.” Kassiane’s anger quickly transitioned to grief, and she began to cry on stage when she explained to the audience why she was wearing a pink ribbon. The ribbon was in honor of autistic Katherine McCarron, who was murdered in May 2006, suffocated by her mother in a plastic bag at age three. Kassiane pleaded for a celebration of all autistic lives instead of a focus on how they are a burden.

As she finished her speech, a woman in the audience identified herself as the mother of an autistic child, thanked Kassiane for her talk, and said that she believes in the work of Autism Speaks. She argued that Autism Speaks plays an important role in confronting “the growing autism epidemic.” The mother went on to say that Kassiane’s situation is very different from that of her son, because there is no way he will ever be able to function on his own. Kassiane interrupted saying that the real problem is how society views and treats autistic people. Phil Schwartz, who had earlier identified himself as an Asperger’s adult as well as parent of an autistic child, interjected that disability may

accompany autism, but autism itself is not a handicap. Phil then agreed with another parent that services are important for autistic people, but argued that services should focus on developing skills not on making individuals “less autistic.” He said that we have to learn to separate disability from autism itself, while still addressing associated handicaps. Phil asserted that autism simply couldn’t be separated from the individual, which is a central rationale for adopting the term autistic rather than person with autism. Kassiane interjected, “We need to celebrate the lives of children. We need to look at the person and not at the services around the person.”

The discussion became heated, and a burly dad lashed out in anger, saying he was tired of hearing about how to help autistic children gain skills “because not all of them get better.” He said he had been up the last three nights with his sick son, which he linked to a gastro-intestinal condition associated with his autism. He wanted to know what to do when his son is sick all the time and looks to his father for help, but he can’t do anything. The man’s anger sputtered as he choked on tears. Even though she was the most memorable presence, Kassiane was not the only member on the panel, and another member interjected so the discussion could carry on. Remarkably, in the final round of applause, hundreds of hands were “flapping” in the air, although a few were still clapping audibly.

It was clear from this conference, the first autism-related meeting I attended outside of my teaching, that the politics of autism are multidimensional and contentious. Stuart Murray, a professor at the University of Leeds and author of *Representing Autism: Culture, Narrative, Fascination*, who I spoke to afterwards told me that clashes such as

we just witnessed happen at every autism conference he attends.⁶ Impassioned commitment to the concepts of illness, cure, and neurodiversity drive participants to collide over how to approach the condition(s) known as autism.

Toward the end of our conversation, Murray told me that people diagnosed with autism are just as diverse as people not on the spectrum. He shared an expression commonly heard at conferences and informal congregations, uttered by both parents and self-advocates: “Once you have met a person with autism, you’ve just met one person with autism.”

Phenotyping Autisms: Biomedicalizing the Spectrum

Earlier in 2006, the MIND⁷ Institute launched the Autism Phenome Project which was billed as the largest ever longitudinal study of autism. MIND’s project sought to enroll 1,800 children, ages two to four, who would undergo thorough medical evaluation in addition to “systematic analyses of their immune systems, brain structures and functions, genetics, environmental exposures and blood proteins.”⁸ In the press release, research director David Amaral spoke about the underlying variability among children with autism – that it was time to start thinking about multiple autisms rather than a singular autism. He said, “Children with autism clearly are not all the same...The tremendous variation leads us to believe that autism is a group of disorders rather than a single disorder — several autisms versus one autism. We are determined to provide the

⁶ Murray has published extensively on postcolonial encounter and settlement, but since his son was diagnosed with autism in 2002, Murray’s work increasingly focused on developmental disability and autism. S. Murray, *Representing Autism: Culture, Narrative and Fascination* (Liverpool University Press, 2008).

⁷ Medical Investigation of Neurodevelopmental Disorders

⁸ “UC Davis M.I.N.D. Institute Launches Largest Biomedical Assessment of Children with Autism.”

specific biomedical and behavioral criteria that accurately define distinct subtypes.”⁹ A recognition of such significant heterogeneity, that it was time to conceptualize autisms as multiple distinct entities, in contradistinction to a continuous autism spectrum, began to emerge right around this historical conjuncture.

The MIND Institute itself was founded in 1998 on the initiative of parents, which the UC Davis Medical Center press center has described as the product of the relentless drive and passion of “four dads.”¹⁰ One of the dads, former Secretary of the California Senate, Rick Rollens, blamed vaccinations for causing his son’s autism. At the time working for Sacramento’s largest lobbying firm, Rollens joined with other well-connected fathers to lead the fundraising drive to found the institute, and successfully solicited the California state legislature, which became the institute’s largest donor, for a contribution of \$34 million. The Institute’s mission was to fill what they considered a gap in research, since the National Institute of Health was in their view overly focused on genetic research. In testimony before the California State Assembly in 2002, Rollens said:

Not until independent science, free from the influence of the powerful vaccine machine, that is currently underway at places like the MIND Institute that examines the biological mechanisms of how vaccines are causing autism in genetically susceptible children is completed will we discover the truth about autism and vaccines. Thousands of us have suffered the ultimate betrayal of trust by blindly allowing our precious children to be injected with dozens of vaccines....¹¹

⁹ Ibid.

¹⁰ “Four Dads’ Passion Leads to New University-Based Institute for Treating Autism and Other Disorders.”

¹¹ Rollens, *Russell’s Story, One Child Every Three Hours, the Ultimate Betrayal*.

The MIND Institute's CHARGE study (Childhood Autism Risks from Genetics and the Environment), launched in 2003, has produced a steady stream of peer reviewed articles identifying possible environmental-gene relationships.¹²

Later in 2006, the National Institute of Mental Health announced its own autism phenotype study at its research center in Bethesda, Maryland, with the stated goal to more precisely catalogue biological and behavioral differences among autistic children. The NIMH press release also spoke of "autisms." It read, "Increasingly, scientists consider the likelihood of 'autisms,' that is, multiple disorders that comprise the autism spectrum." Thomas Lehner, Director of the Office of Human Genetics & Genomic Resources at NIMH, said that the initiative would seek to "comprehensively characterize a large sample of autistic children and their relatives," and to identify "biomarkers and other endophenotypes, with the goal of capturing the autism phenome."¹³ Distinct and biologically identifiable phenotypes, available for diagnostic and etiological purposes, were now considered essential for understanding autism and the development of biomedical interventions.

The idea of a "broader autism phenotype," which had emerged several years prior, was more consonant with the idea of an autism spectrum.¹⁴ Now, the path to a deeper understanding of autism was increasingly considered to lie in parsing the spectrum into distinct autisms, conceived as separate phenotypes with underlying

¹² For example, during 2011 and 2012, MIND researchers produced articles on risks ranging from maternal influenza and metabolic conditions, pesticides, parental "occupational exposures," proximity to freeways, as well as immune system function more generally. "CHARGE Publications and Presentations."

¹³ Lehner, "NIMH: Center for Genomic and Phenomic Studies in Autism."

¹⁴ Geraldine Dawson, the lead author, would later become the science director of Autism Speaks and sit on the Interagency Autism Coordinating Committee. Dawson et al., "Defining the Broader Phenotype of Autism."

pathophysiological mechanisms. In the language of the NIMH Genetics and Genomic Resources director, “capturing” the essential behaviors and biologies of autism would, it was believed, make the disorder(s) stay put – and make, what were being discussed more and more as distinct diseases, tractable and treatable. Why did it become critical to divide the broader autism phenotype into subtypes at this particular moment? Was it related to the vaccine scare and worries about exposure to environmental toxins?

Singh and coauthors found that through 2004, the study of the environmental causes of autism was not a major area of autism research at the national level in the US, UK, or Canada. Research was instead focused heavily on topics related to genetics, brain, and behavior.¹⁵ In contrast, the news media began to increasingly cover environmental factors as early as 1998, around the time the Wakefield study posited a connection between the MMR vaccine and autism.¹⁶ Singh et. al. note that major new parent advocacy groups such as Cure Autism Now (CAN) and the National Alliance for Autism Research (NAAR) were founded in the mid-1990s, followed by major research and monitoring initiatives from NIH and CDC, as well as a congressionally mandated conference on the state of autism science. News coverage then ratcheted up even more sharply between 2000 and 2002, as various other vaccine theories garnered increasing attention, with a series of highly publicized Congressional hearings over the same period.

Instead of arguing a simple cause and effect relationship, Singh and co-authors offer the metaphor of “flocking,” where individual researchers and professional organizations “naturally migrate to new ideas, new investigational tools, new discoveries

¹⁵ Singh, Hallmayer, and Illes, “Interacting and Paradoxical Forces in Neuroscience and Society.”

¹⁶ Wakefield et al., “RETRACTED.”

involving drugs or genes, and targeted funding opportunities.”¹⁷ They posit a range of contributing factors, including “emotional triggers, and the societal value attached to knowledge to be gained and the potential impact of that knowledge.” They continue, “The overall social, political and cultural climate — the *Zeitgeist* — in which a discovery is made can influence the science itself, how it is disseminated and certainly how it becomes embodied in the public mind.”¹⁸ While not a factor in the period covered by their data collection, Singh and co-authors point out that in 2006, both CAN and NAAR announced that they would merge with Autism Speaks:

These groups collectively made contributions of US\$80 million towards autism research as of 2006. They also initiated their own genetics research programmes and established numerous outreach and awareness activities aimed at families, physicians, governmental officials and the general public. Coincident with these events, five peer review journals devoted to autism were established to provide investigators with a dedicated home for reporting their discoveries.¹⁹

Additionally, they add, Congress approved a \$1 billion five-year bill called the Combating Autism Act, which stipulated research focused on environmental factors and funding for new NIH Centers of Excellence in autism and the Department of Health and Human Services’ Interagency Autism Coordinating Committee (IACC).

The above summary gives a sense of autism’s trajectory toward biomedicalization. During the mid- to late-1990s, parents founded new, aggressively pro-cure advocacy groups such as Cure Autism Now and the National Alliance for Autism Research, as well as established new biomedical research institute’s such as MIND to focus on non-genetic causation. Over the same period, the CDC and NIH launched major monitoring efforts and research initiatives. Between 2000 and 2002,

¹⁷ Singh, Hallmayer, and Illes, “Interacting and Paradoxical Forces in Neuroscience and Society,” 153.

¹⁸ Ibid.

¹⁹ Singh, Hallmayer, and Illes, “Interacting and Paradoxical Forces in Neuroscience and Society,” 156.

media attention intensified markedly as fears about an epidemic and possible role of vaccines went mainstream, highlighted by Congressional hearings. The large phenotyping projects launched by MIND and NIMH in 2006 can be seen as the start of another stage in the biomedicalization of autism, where the identification of distinct “autisms” became a priority in the effort to identify therapeutic targets.

This was also the year the FDA approved its first medication, atypical antipsychotic Risperdal, for treatment of autism related symptoms such as irritability and mood swings. Over the same period, autism was making the transformation from being seen as an inherited developmental disorder to a more complex epigenetic disease. The next section focuses on a 2009 meeting of the Interagency Autism Coordinating Committee where autistic self-advocates were attempting to gain representation on par with parent-advocates in an influential national forum dedicated to public policy and (mostly) biomedical research.

Interagency Autism Coordinating Committee Meeting

Monday, May 4, 2009

U.S. Department of Health and Human Services

National Institute of Health Campus

Bethesda, Maryland

We need a cure. We’re using leukemia as our model.

Susan E. Swedo, M.D.

NIH Intramural Research Program

May 4, 2009

The Interagency Autism Coordinating Committee (IACC) is a federal advisory committee mandated by the 2006 Combating Autism Act to coordinate Autism Spectrum

Disorder related activities across the U.S. Department of Health and Human Services (HHS). Originally convened in 2003 by the HHS as “a panel of expert scientists” to evaluate the field of autism research and to develop “a matrix of action” to guide the course of research going forward, the Combating Autism Act reconstituted the IACC to include non-federal public members appointed by the Secretary of Health and Human Services. At the IACC, government officials, scientists, and public representatives strategize and negotiate research priorities, health policy, and funding allocations. The following exploration of public participation focuses on the May 2009 meeting but traces some of the dialogue back to the first IACC meeting convened under the auspices of the Combating Autism Act held in late 2007. In 2009, there were six public members and twelve federal members including the chair, Thomas Insel, Director of the National Institute of Mental Health.²⁰

The 2009 IACC Strategic Plan introduced “Spirit of Collaboration” as one of its core values, stating, “We will treat others with respect, listen to diverse views with open minds, discuss submitted public comments, and foster discussions where participants can comfortably offer opposing opinions.”²¹ The open comment period at IACC meetings provides a forum where members of the public raise a wide range of questions and concerns about the direction of autism research and public policy, as well as level

²⁰ The IACC charter provides the following description of duties: “The Committee shall coordinate all efforts within the Department of Health and Human Services concerning autism spectrum disorder to combat autism through research, screening, intervention and education. The Committee's primary mission is to facilitate the efficient and effective exchange of information on autism activities among the member agencies, and to coordinate autism-related programs and initiatives. The Committee will serve as a forum and assist in increasing public understanding of the member agencies' activities, programs, policies, and research, and in bringing important matters of interest forward for discussion.” “IACC Charter.”

IACC Report to the Congressional Appropriations Committee on the State of Autism Research.

²¹ “IACC Public Comment.”

criticism about government agency handling of autism related controversies. The IACC posted a request that “members of the public who provide public comments or participate in meetings of the IACC also seek to treat others with respect and consideration in their communications and actions, even when discussing issues of genuine concern or disagreement.”²² The need for respectful engagement had emerged as crucial as different stakeholder groups made use of the forum, including high levels of participation by autistic self-advocates and parents of diagnosed children.

In what follows, I describe the coordinated intervention by several members of the Autistic Self Advocacy Network on the proceedings, which included prominent autism parent-advocates and representatives of major national advocacy organizations, including Peter Bell of Autism Speaks, Allison Singer formerly of Autism Speaks and now the Autism Science Foundation, and Lyn Redwood of the Coalition for SafeMinds. The participation of the following three individuals was of particular interest to me: Thomas Insel, Director of the National Institute of Mental Health, Sue Swedo, Chief of Pediatrics & Developmental Neuroscience at NIMH, and Ari Ne’eman, President of the Autistic Self Advocacy Network. In 2009, they were all prominent players in the politics of autism but still in the process of (re-)defining their pivotal roles in what I am presenting as events of genuine historical significance. The section begins with an excerpt from co-organizer of the 2006 Witness and Hope conference Kristina Chew’s comments at the first post-Combating Autism Act meeting of the IACC in 2007, when she sought to offer an alternative to cure and prevention as parents’ primary goals.

²² Ibid.

Kristina Chew, PhD
Public Comment, IACC Meeting
November 30, 2007²³

My name is Kristina Chew, and I am an assistant of classics at St. Peter's College in Jersey City, New Jersey. I am the mother of Charlie Fisher, who is 10 and a half years old and who has autism. I write a weblog about autism, Autism Vox, V-O-X, Latin for "voice," that attracts some 4,000 visitors a day from around the world, from autistic adults and parents of autistic children to doctors, teachers, journalists, and many more members of the public.

According to some autism organizations, parent advocates, and the media, it is most important to find the causes of autism and to find treatments for autism, but finding out whether or not there is something in vaccines or in the environment that is causing autism is only one among many concerns in the autism community. Families with autistic children and autistic persons have other issues than what we hear about on Oprah and Larry King and from Jenny McCarthy.

Families also want to know about education, about schools, about day care and after-school care for autistic children. They want to know about how to integrate autistic children not only into classrooms but into all aspects of everyday life in a community. They want to teach their children to be as independent as possible so that their children can learn to get jobs, to take care of themselves, and lead fulfilling lives... We need research to find out how to prepare autistic children to get and to keep jobs and to live as independently as possible, and how to best integrate autistic persons into our communities...[and to] show how autistic adults even with severe disabilities can live as full-fledged members of a community...

In closing, rather than focusing so much on preventing and curing autism, I ask the Committee also to turn attention to how to make the world a better place for autistic persons through education, jobs, and understanding, by listening to the full range of voices and perspectives of life with autism. Thank you very much.

As I sat in the conference room at the NIH campus in Bethesda at the 2009 IACC meeting, I watched parent-advocate Peter Bell watching Ari Ne'eman, the young autistic self-advocate. Bell was the handsome-enough-for-television Executive V.P. of Programs and Services for Autism Speaks. While the former President and CEO for Cure Autism Now (CAN), Bell said he "embraced the hope that an end to autism is possible" and

²³ All IACC public comment sections come directly from the meeting transcripts available at the IACC website. A few minor changes were made for the sake of clarity and to correct typographical errors. <http://iacc.hhs.gov/events/index.shtml>.

endorsed a “vision of finding a cure for autism – during our children’s lifetime.” He believed that autism had “reached epidemic proportion” and described it as “stealing a generation of our children.”²⁴ While Bell would not generally be considered a controversial figure in most public forums, in his leadership role at the world’s largest autism advocacy organization and as a committed father trying to help his son who is diagnosed with autism, he endorsed views that many autistic self-advocates such as Ari Ne’eman rail against.

Bell was a quiet observer during the day’s meeting of the IACC, but a few months prior, in February, he spoke during the public comment period. He criticized “last minute” decisions made at the January 14th IACC meeting and changes to the Strategic Plan that Autism Speaks considered to have undermined the IACC’s commitment to encourage research on the potential role of vaccines in causing autism. “Autism Speaks played an integral role in the Combating Autism Act and getting it drafted, legislated and passed over two years ago,” he chastised. “Thus, we also see ourselves as the stewards in the process of making sure that the intent of Congress is fulfilled and reflected in the strategic plan.” Bell went on to say that due to “breaches in process and trust” the organization felt compelled to withdraw their support for the plan. He exhorted the committee to “reclaim the promise” of the earlier version and to “seize this opportunity to renew confidence, trust, and a true spirit of collaboration” with what he described broadly as “the autism advocacy community.” Such renewal, Bell insisted,

²⁴ Bell and Bernard, *Fulfilling Our Vision: Cure Autism Now, 2005 Annual Report*; Bell, “Autism - From Denial to Hope.”

depended on the committee's re-institution of the targeted vaccine research objectives in their prior form.²⁵

Thomas Insel, chair of the IACC and head of NIMH, said he disagreed with Bell's portrayal of the recent changes made to the Strategic Plan, stating that the committee had merely moved vaccine research to another section of the document. Insel pointed out that substantial funds would still be designated for research on environmental risk factors, which could include vaccines, infections, and "all kinds of toxicants." Insel had anticipated backlash in his opening comments for the meeting.²⁶ He acknowledged that there was real and significant disagreement about the potential role of vaccines in causing autism, but said there was a problem of a fundamental lack of trust. Insel asked whether the IACC could become a space to develop the trust missing in public debate: "I would really like to see us take a deep breath here and look at this question and ask ourselves, can we do this in a rational, careful, scientifically-based way? Can we identify areas where we could actually improve understanding, improve public trust so that we become part of the solution, and not part of the problem." However, as Peter Bell and others made clear during the public comment period, many felt the IACC had been exacerbating misgivings rather than fostering greater trust.

²⁵ Transcript, Feb 4, 2009, available at <http://iacc.hhs.gov/events/index.shtml>. See Autism Speaks, "Press Release | Autism Speaks Withdraws Support for Strategic Plan for Autism Research, Declines Unexpected Change in Final Approval Process."

²⁶ Insel said: "There's really been a tremendous amount of internet chatter about the Committee, some concerns about our process, some concerns about the results, some name-calling and some simple questioning about, is this – are we doing the right thing and how is this Committee working."

Nancy McPartlin Gardella
Public Comment, IACC Meeting
November 30, 2007

...I happen to be a hospital administrator. I'm also the founder of a biomedical research group of parents that is a hospital-based group. We have been very instrumental in trying to move the medicine ahead.

I happen to have a child that has recovered from autism. There are thousands of us out there. Excuse me for saying this, but we are treated like we are having backstreet abortions because the doctors are not respected that we use...

There are many, many fine physicians out there that are helping to recover our children. I really would like to say that, as a stakeholder, I would be more than happy to assist you in finding stakeholders that are like myself that have recovered children that we can learn from...

Each child is unique. There isn't going to be one profile. We have to think of this like cancer. There already are six different brain prototypes that we know exist. It is not going to be one specific gene. It is going to be several different genes. We have to think of it like cancer.

I personally feel that I would be more than willing to help you as a member of the public to move this medicine along. We have many answers out there. There are pockets throughout the community, throughout the United States, and throughout the world that the children are getting better. Please listen to us and listen to the providers. They have something to add. It is an opportunity that we can really move the medicine forward.

Thank you for listening to me. I wish you godspeed in getting this mission accomplished.

But on this warm Monday in May, Peter Bell stood quietly observing Ari Ne'eman as he circulated around the conference room. Ne'eman, the twenty-one-year-old co-founder and president of the Autistic Self Advocacy Network, was still finishing his undergraduate degree in Political Science at the University of Maryland in Baltimore. In an article for *New York Magazine*, Andrew Solomon had recently described Ne'eman as "not without social graces, but you can feel the effort in them."²⁷ Ne'eman made the

²⁷ Solomon, "The Autism Rights Movement."

rounds, chatting, or if not exactly chatting, actively engaging the other attendees.²⁸ As he finished his conversation with an IACC committee member, Peter Bell and someone I took to be his assistant approached Ne’eman. It appeared introductions were being made and that this was their first face-to-face meeting.

I wondered about the way Peter’s smile seemed more practiced than Ari’s, in a good public relations kind of way. But, then, Ari likely had been formally instructed in the practice of situation appropriate smiling during social-skills training classes that he attended while growing up.²⁹ Not that either Ari’s or Peter’s smiles appeared forced, necessarily, but more a sense that their facial maneuvers were being summoned specifically for the occasion – where the precise relationships among interpersonal intent, affect, and expression are far from straight forward. In any case, the two exhibited different degrees of fluency. To be clear, I am not suggesting that either smile was necessarily disingenuous or inauthentic. Instead, I want to draw attention to how each – neurotypical and autistic alike – had acquired the strategic ability to don situation-specific smiles. Bell more successfully performed the gesture in a normative manner, but each acquired the skill through specific acculturation processes. The stereotype that autistic people do not express (or experience) emotion is inaccurate, but, speaking in generalities, they often do display affect in an atypical manner or at moments normative culture deems inappropriate. Many autistic people find it difficult to conjure “authentic” smiles on

²⁸ My impression of Ne’eman’s purposeful circulating at the meeting was echoed in a feature on Ne’eman and his advocacy efforts, which appeared in *Newsweek* two weeks after the meeting and described him thus: “Ne’eman is a master networker, a guy you’d think was born in a campaign office and bred in the halls of the Capitol. He’s fluent in policy-speak and interacts seamlessly with high-level officials (he’s just had lunch with the acting vice chair of the Equal Employment Opportunity Commission) and inquisitive reporters alike. He’s formal but sociable and has a well-timed sense of humor.” Kalb, “Erasing Autism.”

²⁹ As described in a profile appearing in his university’s publication *UMBC Magazine*. Edelson, “Abnormal Ambitions.”

demand, for events such as picture-taking or formal introductions. So, there may well be differences in the relative difficulty Bell and Ne’eman experienced in learning to recognize, adopt, and imitate a smile in the culturally appropriate moment and with genuine-enough-feeling facial manipulation.³⁰

Ne’eman in no way appeared put off by meeting Bell, who he likely considered an adversary standing in the way of autistic rights. I actually had the impression that Ne’eman welcomed the opportunity to speak directly to those with whom he disagrees passionately. He appeared to be in his element. Like Bell, Ne’eman also had used this forum to address the committee previously.

Ne’eman had caused a stir in the 2007 IACC meeting with his prepared statement. He had begun by saying that he spoke in his capacity as President of the Autistic Self Advocacy Network (ASAN), which had been founded just a year prior. He described ASAN as “a volunteer, nonprofit organization run by and for adults and youth on the autism spectrum.” He said that increased public interest and resources directed toward autism were “counterproductive without an equally strong commitment to acceptance.” He cited one of Cure Autism Now’s co-founders, who had declared upon passage of the Combating Autism Act that it amounted to “a federal declaration of war on the epidemic of autism.” Ne’eman said, “A war on autism approach is not in the interest of people on the spectrum. It offends and alienates the autistic community...” He explained that people on the spectrum are not interested in finding a cure for autism or efforts to make them appear normal. He encouraged the committee to instead consider autism a natural part of the human experience, but also acknowledged, “the very real and

³⁰ For more on autism, imitation and learning, see, Gowen, “Imitation in Autism”; Becchio and Castiello, “Visuomotor Resonance in Autism Spectrum Disorders.”

pressing hardships placed on families and people on the autism spectrum.” Ne’eman asserted, however, that to address these hardships the IACC should refocus research on ways to improve quality of life for America's many autistic citizens.

It was Ne’eman’s final comments in 2007 that had crossed the line for what Chairman Insel considered acceptable. Ne’eman criticized the appointment of Alison Singer to the IACC, who at the time was senior vice-president of communications and strategy at Autism Speaks, due to comments she made in the organization’s fundraising video, *Autism Every Day*. Autistic rights activists were particularly upset by a scene where Singer describes having felt so hopeless about her autistic daughter’s future at one time that she considered ending both of their lives by driving off the Brooklyn Bridge. Ne’eman noted that the murder of Katie McCarron occurred just four days after the video’s release and suggested that there had been a notable increase in such murders of autistic people in recent years.³¹ He went on to say, “Many self-advocates and parents believe Autism Speaks to be morally complicit in these murders through these and other examples of continued dehumanized advertising, encouraging a lesser value for autistic life.” Ne’eman closed with a plea for the IACC to break with the pattern of treating individuals with disabilities and their opinions as less valuable and less deserving of respect.

When Ne’eman finished, Insel intervened, noting that as a matter of policy the Committee does not usually speak after public comments, but in this case he needed to say something; “I really think that your comment about one of our members was

³¹ For more on parent and self-advocate responses to McCarron and other murders of autistic people by family members, see Solomon, *Far From the Tree*; McGuire, “The War on Autism: On Normative Violence and the Cultural Production of Autism Advocacy.”

disrespectful, and in many ways completely misread the intent and what I think many people experienced as the meaning of Alison's public comment.” Insel continued to say he hoped for “a little more sensitivity to both the people on the Committee and to others involved in this process... to be understanding of each other's feelings and to recognize that we have to be able to respect differences.” But at the next meeting in 2008 Ne’eman was joined by fellow ASAN member, Katie Miller, to again express concern regarding Alison Singer’s appointment.

Ne’eman said parent advocacy group fundraising tactics had created a “culture of despair and a lack of hope.” Miller said for her the most troubling aspect was that Singer made the comments in her daughter’s presence. Insel again broke protocol to admonish Miller, saying, “I don't think it really is in the spirit of what we are trying to create here to single anyone out or to make this a less safe place for people who have come here with really very good intentions.” Tensions were running high everywhere in advocacy circles during this period. Singer subsequently resigned from Autism Speaks in early 2009 amid a number of high level departures over the organization’s continued emphasis on a vaccine causation theory. She told *The Guardian*,

If you keep looking under the same rock, you're going to keep finding the same thing...Over and over, the science has shown there is no causal link between vaccines and autism. It's time to look for answers in new and different places...There isn't an unlimited pot of money, and every dollar spent looking where we know the answer isn't is one less dollar we have to spend where we might find new answers...The fact is that vaccines save lives; they don't cause autism.³²

Three months after her resignation, Singer co-founded an alternative organization named the Autism Science Foundation (ASF). The scientific community immediately embraced

³² Luscombe, “Charity Chief Quits over Autism Row.”

ASF as a ray of hope among the rapid proliferation of parent advocacy organizations spreading anti-vaccination messages, receiving endorsements from American Academy of Pediatrics, NIH, and the CDC.³³ Singer's departure was a major blow to Autism Speaks in part because of her close ties to the organizations' founders, but also because she was prepared to deploy her own industry-honed media savvy.

Before the IACC meeting vote that prompted Peter Bell and Autism Speaks to denounce the IACC, Singer had written an e-mail to co-founders Bob and Suzanne Wright, stating, "I've concluded that as a matter of personal conscience, I cannot vote in favor of dedicating more funds to vaccine research that has already been undertaken and which I and many others find conclusive," and as a result, "I feel compelled to offer my resignation."³⁴ Bob Wright knew Singer at NBC where she was Vice President of Programming in NBC's Cable and Business Development division.³⁵ She produced the CNBC portion of the multi-part series, *Autism: The Hidden Epidemic? Paying the Price*, which helped launch Autism Speaks onto the national stage. Singer told *Nature News* that she and Suzanne Wright became fast friends while using an office on the 51st floor of NBC Universal's headquarters as the headquarters for Autism Speaks. Singer said, "Suzanne doesn't take no for an answer and neither do I. So we got a lot done." In the early days of the organization Singer helped get Autism Speaks appearances on Oprah and Larry King Live, as well as coverage in *The Wall Street Journal*.

In her resignation e-mail, Singer said she and Autism Speaks had "elevated 'autism' to the global vocabulary." While Autism Speaks would not give up the vaccination issue

³³ Wadman, "Autism's Fight for Facts."

³⁴ Ibid.

³⁵ "Alison Singer | Understanding Autism."

easily, Singer’s departure marked a new chapter, and the organization soon moved away from tactics of agitation and toward a greater focus on establishing itself within a regime of scientific legitimacy. Thomas Insel said of Singer, she “is a force of nature... I have enormous respect for her abilities.”³⁶

Miribel McIntyre
Public Comment, IACC Meeting
February 4, 2009

I am a mother of a four-year-old with autism, and I'm just going to talk about how every rule has an exception. We all know that...

In theory, the human body should be able to detoxify itself from the neurotoxins contained in vaccinations, but what happens if the body cannot detoxify itself? What would be the effects, changes and consequences of having substances such as mercury and aluminum trapped in your body? What happens to those special populations that do not follow the expected process of detoxification from neurotoxin? So many questions that deserve to be answered.

This is not about placing blame. This is about understanding the mystery of autism and finding answers... as parents we notice changes in our children's development and health when exposed to neurotoxin-contained vaccinations. So, please, let's explain what we see. Let's study vaccine safety and the effects of neurotoxin on children, and remember that the goal of public health is to improve lives through the prevention and treatment of disease.

The morning session featured Susan Swedo’s presentation on the NIH Intramural Research Program. I had met Swedo briefly two years prior at a Southwestern Medical School conference on autism in Dallas, and I was particularly interested in speaking to her again because she had recently been announced as chair of the Neurodevelopmental Disorders Workgroup for *DSM-5*. It had recently begun to circulate that the Workgroup planned to consolidate autism spectrum disorders under a single diagnostic category, ASD.

³⁶ Wadman, “Autism’s Fight for Facts.”

I approached Swedo as she finished setting up her laptop, but Ari Ne’eman was there first. He introduced himself and said that he was interested in speaking with her about the upcoming changes to the autism diagnosis and, in particular, about who would be included under the altered diagnostic criteria. Swedo interrupted Ne’eman and interjected to say, rather pointedly I thought, “...*and* who should be *excluded* from the diagnosis.” I had the distinct impression that Swedo wished to convey to Ne’eman that he – or people like him – most definitely should not be included under the ASD diagnostic umbrella. Ne’eman seemed to detect a tone of hostility as well, pausing momentarily, assessing, but cordially replied that this was precisely why he very much wished to speak with her further. After Ne’eman left, Swedo told me that she considered “protecting” Workgroup members to be her most important charge as Chair. She was trying to “telegraph” likely changes ahead of time so as to prepare stakeholders. But, at the same time, she had to make sure task force members were able to deliberate freely and privately, without fear of being targeted by competing factions.

Swedo’s presentation at the IACC provided an overview of autism related research projects conducted under the auspices of the NIH Intramural Program, housed under the Developmental Neuroscience Branch. Insel had recruited Swedo to lead the effort two years prior, despite what she described as her initial skepticism. Insel interjected, “You were a little bit skeptical. I don’t think I had to twist your arm for more than about a month...” Insel likely sought Swedo to head the Intramural Program in part because of her research on the PANDAS subgroup (Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal infections). Swedo’s group had hypothesized in the early 1990s that the repetitive behaviors, anxiety, emotional liability, and neurological

abnormalities, often diagnosed as Obsessive Compulsive Disorder and other disorders, reflected sudden symptom onset due to inappropriate immune response or “neuroimmunological dysfunction secondary to anti-neuronal antibodies.”³⁷ The research had earned her credibility among autism parent activist communities focused on the possible role of immunological dysfunction. Her reputation among engaged parent-advocates may have been a factor in her selection as Chair of the *DSM-5* Neurodevelopmental Workgroup, as well.

During Swedo’s review of the Intramural Program’s research, it was obvious that the underlying frame of inquiry presumed a science and a public aligned with goals expressed in the Program’s mission statement: “Discovering the Causes and Cures of Autism and Conducting Meaningful ‘Until Then’ Research.” The “until then” pointed unambiguously to finding causes and developing cures. Swedo stressed, “We are very focused on autism rather than the entire spectrum of autism spectrum disorders.” Her presentation drove the point home repeatedly that she prioritized the development of biomedical interventions for what she understood to be a particular type of autism. She was quite explicit that biomedicine needed to carve out this more severe form from the rest of the spectrum. And, after her presentation, I had little doubt Swedo meant it when she said they were using leukemia as the model.

Susan E. Swedo
NIH Intramural Research Program presentation, IACC Meeting
May 4, 2009

As Tom mentioned, we are a relatively new program. But we're actually quite excited and as we put the slides together for this presentation this morning, I think

³⁷ Swedo, Leonard, and Kiessling, “Speculations on Antineuronal Antibody-Mediated Neuropsychiatric Disorders of Childhood.”

we got even more excited about how much we're doing and have already accomplished.

I want to point out our mission statement to you, because even though it looks somewhat casual and frankly was, the words are very carefully chosen. We are very focused on autism rather than the entire spectrum of autism spectrum disorders.

We are looking at the more severely affected individuals. We believe in a cure. We're using leukemia as our model. When I was in my pediatric training, it was the era in which the fatality rate of acute lymphoblastic leukemia was about 95 percent. By the time I finished my training and had been in practice about five years that had turned completely around, to the point where the survival rate was 90 to 95 percent, and in fact that those individuals not only survived but were cured of their cancer. We believe that the same thing is possible for at least some cases of autism...

As we keep our eye on the long-term prize, it's also very important to us to be able to help those children and families that are affected today. So that's the second part, the conducting of meaningful until-then research. Many of our treatment trials are actually designed towards alleviating suffering at the present time, even if we don't understand the mechanism behind the treatments. We hope that they will be helpful, and I'll share more about that in a moment.

As I said, we are aimed at looking at the causes and cures...

Swedo described cross-institutional research projects which incorporated numerous funding sources, interdisciplinary collaborations, technological innovations, and emergent theoretical models, all put to work on the problem of making autism more tractable. The program was explicitly designed to serve as an apparatus capable of locating autism as a pathophysiological entity, and it appeared that a new paradigm was emerging to explain what Swedo referred to as autism's etiopathogenesis. The model began with finding a cure as organizing principle, and making autism biometrically legible was the immediate task. Swedo presented the NIMH phenotype investigation's effort to identify subtypes as the program's "mainstay," and then moved to research on environmental triggers, genomics, and neurological pathways. I was impressed by the

dispersed research infrastructure that seemed organized around identifying biomarkers and physiological pathways.

The autism phenotype was understood to result from genetic vulnerability and physiologically immature bodies interacting with harmful environmental exposures. Swedo said that she wanted to point that they were investigating “the entire environment that affects the child.” I noted Swedo did not feel the need to add a qualifying statement that would distance their model of “the entire environment” from the legacy of psychogenic theories of autism. The history of blaming parent-child dynamics was completely, or sufficiently, expunged from this generation’s frame of reference, at least within the halls of NIMH.

Instead, parents’ physical bodies and their reproductive decisions were identified as crucial constituents of the environmental mix. Swedo listed exposures to maternal antibodies *in utero* and during the neonatal period as potential environmental “risks,” as well as “things like advanced paternal age.” The body’s reproductive and nurturing potentials were thus included along with monitoring other risks associated with “all of the compounds, all of the changes that have occurred in the past two to three decades.” The entire environment affects the child, and all needed monitoring, but researchers were in search of specific and specifiable triggers and exposures. Swedo commiserated, “It’s somewhat overwhelming, and so you have to keep your focus on small bits at a time.” And instead of “autism genes,” researchers were searching for “susceptibility genes” and “protective genes.” Provocatively, the brain was no longer cast in the role of autism’s domicile or underlying organic superstructure. Swedo said, nevertheless, “We do believe

that everything *ends up happening through and to the brain.*”³⁸ That sounded to me more like a nexus, meeting place, or crossroads.

I also noted the way child development came into the etiological and pathogenic frame. The imagined role for parents was a familiar enjoiner to usher children past developmental thresholds, but now they needed to protect offspring from toxic exposures during a critical developmental stage. It was evident that for Swedo children were the imagined “patients” and parents were a principal audience for the presentation. She explicitly referenced collaboration with Autism Speaks and conversing with IACC committee member Lyn Redwood while attending Defeat Autism Now! and Autism One conferences, which prominently featured controversial biomedical interventions and toxin-centered causation theories.

Swedo said something I found very odd during the Q&A period. Regarding the Intramural Program’s use of research subjects, an IACC member asked, “...I’m curious to know if you’re working with young adults or adults at all?” As part of her response Swedo said, “We haven’t actually moved into adults as our target population. We tend to use them more as grown-up children, but we have no problems with that. In fact... we’ll probably be using adult individuals in order that we can get siblings to donate skin biopsies as well.” I wondered what she intended to suggest when she reported, apparently as a point of pride, that they have no problem using autistic adults “more as grown-up children”? What she said immediately after suggests that autistic adults (and their siblings) had been assigned a purely instrumental role – such as providers of “skin biopsies.” The problem I see is not necessarily using adults for instrumental purposes,

³⁸ My emphasis.

but instead the fact that here, in the NIH's flagship autism research program, it was the *only* role afforded them.

Adults were left entirely unmentioned in Swedo's presentation until prompting, and then they were casually relegated to use as "grown-up children." To me this sounded a lot like adults were mere providers of biological material, necessary for inclusion only in so far as they could help develop cures for more promising un-grown children.³⁹

Theresa Wrangham
Public Comment, IACC Meeting
May 4, 2009

Good afternoon. My name's Theresa Wrangham. I'm the president of SafeMinds. More importantly, I'm the mother of an 18 year-old daughter with autism who's benefitted from behavioral, biomedical and CAM⁴⁰ as well.

As the IACC commences the updating of their strategic plan, SafeMinds would ask that the Committee revisit objectives already in the plan for modification and expansion, as well as the addition of new objectives to more adequately address the autism epidemic facing our nation.

The need for treatment is of primary concern...

The public understands that treatment research is desperately needed to improve the lives of affected individuals as soon as possible, to assure the best long-term outcomes. Treatment is an area that requires significant expansion to appropriately address the needs of the ASD individual.

SafeMinds also acknowledges the role of research as the cornerstone in the creation of new and effective treatments for autism. NIH has historically placed a priority on inherited genetic risk factors when funding autism research.

However, these investments have not yielded the results that would provide the urgent breakthroughs needed to respond to this health crisis. It should also be noted that genetic research is well-funded privately, while environmental research is underfunded.

SafeMinds believes that now more than ever wise research investments are

³⁹ Eyal et al. suggest that autistic adults similarly get cut from the vision of human potential and opportunity, as well as candidates for therapeutic effort, by virtue of an all-or-nothing early childhood intervention mantra promoted as fundamental to the success of behavioral therapies. Eyal et al., *The Autism Matrix: The Social Origins of the Autism Epidemic*.

⁴⁰ "Complementary and Alternative Medicine."

necessary and recommends, as did the recent UC-Davis study, shifting funding from genetic to environmental studies, as they are most likely to lead to effective treatments and prevention...

We would also request... [a] signal to the autism community and the general public that vaccine safety concerns will be addressed, free from conflicts of interest and in accordance with the Combating Autism Act. I thank you.

The public comment period was the final item on the agenda. Autism parent and President of SafeMinds, Theresa Wrangham, spoke first (see excerpt above), followed by three autistic self-advocates, all members of the Autistic Self Advocacy Network, Ari Ne'eman, Paula Durbin-Westby, and Katie Miller. Ne'eman immediately followed Wrangham, and began by expressing appreciation for the IACC's responsiveness to requests by the autistic community to invite presentations on Augmentative and Alternative Communication be incorporated into the IACC agenda, which were included at the start of the day's afternoon session, before moving on to what appeared to be a coordinated set of talking points shared among ASAN members.

Ne'eman's description of ASAN had changed subtly since he first addressed the IACC in 2007: the non-profit was now international and its agenda was stated somewhat more precisely as, "advocating for ourselves in public policy, service provision, research and media representation." As before, Ne'eman made the inclusion of autistic voices central. He said that although the IACC is a body charged with making decisions and allocating research funding "in our names and ostensibly for our benefit... the IACC continues to lack a representative from the organized autistic self-advocate community, despite having many representatives from the various factions of the organized autism parent and professional community." Ne'eman asserted that the acceptance of autistic legitimacy was essential to their citizenship, rights, and well-being. He extended the

banner of *our names, our voices, and our people* to define three issues of particular concern to the autistic community, which they wanted to see incorporated into the IACC framework.

First Ne’eman cited the need to redirect funding toward quality of life and service related issues. No longer issued as an all-or-nothing demand for the abandonment of cure and cause focused research, as in 2007, he requested that the IACC heed the message of the “cross-disability and autistic communities” to adopt dollar parity between “basic” research and quality of life/services research. A second, related concern was the disparity in health care access among autistic youth and adults in comparison to other groups. He said that research would be crucial to ensure “that autistic people across the life span have the ability to access medical services on an equal basis with the non-autistic and otherwise neurotypical population.” He cited the problem of access issues relating to sensory, social communication, and co-existing medical conditions that “prevent full access for our people,” and urged that research be funded and designed to ensure that it was “conducted with and not merely on autistic people.” The third concern related to the growing likelihood of genetic and prenatal testing for autism.⁴¹ He stated, “History has shown us that if this technology is developed, it will be utilized,” and cited the 92% rate of selective abortion for fetuses testing at high risk for Down’s Syndrome. He continued, “By making the focus of autism research preventing our very existences, our lives are devalued and the prospect of a world without the neurological diversity that has

⁴¹ Ne’eman did not cite this fact, but in 2008 Boston Children’s Hospital had (rather quietly) begun to offer genetic “autism testing” for chromosomal site 16p11.2 Deletion/Duplication (or Copy Number Variation) – which was considered a locus for autism susceptibility. This followed publication of research findings that showed that approximately 1% of individuals diagnosed with ASD contained chromosomal variation.
“Autism Testing - Division of Genetics: Autism 16p11.2 Deletion / Duplication.”

benefitted our society is a very real one.” Ne’eman thanked the committee for listening, but in the same breath reminded them, “The national conversation about autism has for too long excluded autistic people.” He asked that they, “hear our voices,” and concluded with the popular disability rights slogan, “as always, nothing about us without us.”

Autistic Self Advocacy Network member Paula Durbin-Westby had been making regular public comments at IACC meetings.⁴² Her comments on this day hit on many of the same points as Ne’eman, including the need for representation on the committee from autistic self-advocacy organizations. She referenced two of her own medical conditions to draw a hard distinction, “A chronic or fatal disease model or metaphor is not appropriate for autism. Autism is not fatal like cancer, and as an autistic person who has kidney disease, I can tell you they are not comparable.” Durbin-Westby then offered an intriguing example of the benefits and insights that autistics could offer if they were enlisted as research collaborators. She referenced recent studies indicating that autistic children spend more time looking at the mouth rather than the eyes of speakers, compared to more typically developing children. She noted that this was not news to people on the spectrum, stating, “We are often aware of the reasons and motivations for our own actions.” More strikingly, Durbin-Westby warned that researchers had jumped to inappropriate conclusions based on the results.

Researchers presumed that since autistic children were missing important social cues by not attending to other people’s eyes, they should be trained to redirect their attention away from the mouth and toward speakers’ eyes. Durbin-Westby cautioned:

⁴² Durbin-Westby gave an invited presentation to the IACC in 2008, entitled “Ethical Considerations in Autism Research,” and later in 2009 participated on a panel in the IACC’s Scientific Workshop, in preparation for revision of the Strategic Plan.

Researchers should take into consideration the numerous self-reports of people on the autism spectrum about the necessity of looking at people's mouths in order to compensate for auditory processing difficulties... so that studies involving autistic children as subjects do not cause additional difficulties when children are trained to look away from mouths and possibly lose a significant visual method of accessing receptive communications.

She worried about the potential for harm to autistic children unless consideration was given to the critical role audiovisual synchronies play for individuals with auditory processing difficulties. She argued that merely interviewing autistic people would not necessarily yield the necessary insights or draw forth the appropriate implications.

Active research collaboration with autistic individuals was needed to help more relevant questions and conclusions to emerge.

The committee and other attendees appeared particularly engaged by the comments of the next speaker, Katie Miller. Miller said, "Autism is not a disease or an epidemic. It is not contagious, infectious or life-threatening. It hurts our feelings when you describe us as a burden..." Miller's words challenged the disease and cure model dominant at the IACC, NIH, and among influential parent organizations, but they were also an appeal to remember that autistic people have something to offer, and that they most certainly have feelings which could be, and were being, hurt. Miller closed with an appeal to what might seem goals shared in common, "Let us support and educate all people and aid them in living the best possible life... and let us make the world a place in which everyone can grow, learn, work, play, love, but most of all live." I was moved by Miller's hope that members would be motivated to consider a different approach to understanding autism and toward addressing the concerns of autistic people.

She suggested that there are other ways to gather up and work with the problems and possibilities caught in autism's orbit. I imagined her to be offering an invitation to

reflect on a differently articulated and enacted set of ontological commitments, where disability, neurodevelopmental difference, and disease might be done more inclusively, and generously, through the active cultivation of an ecology of care. Nevertheless, such aspirations do not settle the tension between pro-cure and pro-neurodiversity and acceptance positions.

The comments of both parent-advocates and self-advocates suggest ways that affect helps to constitute autism research agendas and resides at the heart of scientific practice, helping make up and define subjects, objects, and objectives.⁴³ Autism parents and autistic self-advocates alike care very much about the goals to which new scientific knowledge is committed. On one hand, ASAN members reminded the committee that cure and disease frameworks often leave out much that is important about living with autism and ignore what it feels like to be autistic. They redirected attention toward the importance of education, support services, inclusion, self-representation, access to means to communicate, and broadened notions of healthcare. On the other hand, cure discourses cannot be swept aside on the basis that they can be channeled into a eugenic vision – this does not leave enough room for how pro-cure parents describe their children as sick and in need of medical care.⁴⁴

⁴³ Fitzgerald, Singh, and Lappé, as well as Silverman, explore the role of affect in autism knowledge exchange and production among researchers and parents : Fitzgerald, “The Affective Labour of Autism Neuroscience”; Singh, *Autism Spectrum Disorders*; Lappé, “Anticipating Autism: Navigating Science, Uncertainty, and Care in the Post-Genomic Era”; Silverman, *Understanding Autism*.

⁴⁴ Lock, “Genomics, Laissez-Faire Eugenics, and Disability”; Taussig, Rapp, and Heath, “Flexible Eugenics.”

PART II: 2009 - 2013

Problematizing “Difference”

In retrospect, the year 2009 was the beginning of a remarkable period when differently interested and invested actors – self-advocates, parent-advocates, researchers, and public health officials – became significantly repositioned, and began to redefine their commitments, in a rapidly changing autism landscape. In the remainder of the chapter, I describe how I came to see autism worlds realigning through the labors of Thomas Insel, Sue Swedo, Peter Bell, and Ari Ne’eman. Between 2009 and 2013 there were many developments: Ne’eman was appointed to the IACC and represented the Autistic Self Advocacy Network in major public debates; Bell left Autism Speaks and completed his transition away from his role as spokesperson for pro-cure parent advocacy; Swedo’s Neurodevelopmental Disorders Work Group completed work on the new criteria for the Autism Spectrum Disorder diagnosis amidst intense criticism of the *DSM-5* revision process; and Insel began to aggressively push an NIMH initiative to transform autism, and mental disorders generally, into “brain diseases,” driving psychiatry down the path toward becoming what he calls “clinical neuroscience.”

The re-articulation work of Insel, Bell, Swedo, and Ne’eman illustrates the importance of thinking about *meetings* as continuous ongoing encounters among different commitments and interests, rather than presupposing that particular commitments and interests automatically inhere in the actors’ roles and identities, or imagining they remain static over time. Both the personal value of acceptance and the desire to cure are densely interwoven with other interests, including economic, which are only distinguishable through specific, negotiated historical positioning. In particular, these actors’ trajectories

show that individual “positions” are not simply generalizable or assignable based on one’s role or identity as a parent-advocate, self-advocate, researcher, or public health official.⁴⁵

By 2009, the importance of environmental factors in the etiology of autism was no longer in doubt, but interest in vaccinations as *the* missing causative explanation was beginning to decline. Thomas Insel told David Kirby, author of *Evidence of Harm* and champion of vaccine theories of autism, that he did not think anybody was arguing against an environmental component.⁴⁶ He said, “The question is – there may be many, and how do we get at these, and how do we identify them?” He suggested that the real goal was prevention, but first they needed to stop approaching autism “as if it is a single thing, as if it is a syndrome that will have one cause, one treatment, and one explanation.” Insel said he thought of “it” as more akin to a fever, and that he thinks autism is “a collection of many, many different disorders.” He continued:

It’s quite believable to me that there are many children who develop autism in the context of having severe gut pathology, of having autoimmune problems, of having lots of other problems. And some of these kids really do recover. And that is quite different from the autism that was originally described in the 1940s and 50s - where it looks like you have it and you are going to have it for the rest of your life.⁴⁷

He continued, “What I think hangs up this field is the inability to identify all these different autisms – and it’s very much where we were with infectious disease 100 years ago, before we knew how to break this down into multiple different disorders, different

⁴⁵ My thinking about how personal positioning and ontological commitments get articulated and enacted through encounters is influenced particularly by Haraway, Bellacasa, and Rajan. Part of the point, I think, is that all of the interests evident here are “lively,” affective, and must be constantly re-enacted. Haraway, *When Species Meet*; Rajan, *Lively Capital*, 441; de la Bellacasa, “‘Nothing Comes Without Its World’.”

⁴⁶ Kirby, “Rising Autism Numbers -- Leading Federal Official Says ‘No Question’ That Environmental Exposures Are A Factor.”

⁴⁷ *Ibid.*

causes, different treatments. That's why fever seems like the right analogy." In other words, if autism is analogous to a fever it is an indicator of what Insel refers to as "lots of other problems."

Insel claimed that researchers were advancing along a promising path of rethinking autism in terms of epigenetics, because "some of it is probably hardwired, but a lot of it has to do with exposures." He readily acknowledged that more attention needed to be paid to the effects of experience and environment, and suggested that dividing the spectrum into phenotypes is but a first step, "I mean, frankly, we're just not where we want to be yet, and we've got to be able to break apart this spectrum disorder into its component parts and identify who's going to respond to which interventions." The emergence of epigenetics as a research paradigm reflects the influence of parent advocates, amongst innumerable factors converging to make up the Zeitgeist, who voiced concern about environmental exposures, particularly of an accumulating, toxic variety. Researchers at NIMH and elsewhere were to some extent prompted to develop more sophisticated models and approaches to help address this concern.

But I wonder how might the path forward look different if one of the relevant problems for consideration included, in a fundamental way, the fact that when Insel says at NIMH prevention is the ultimate goal, autistic self-advocates hear him as saying the goal of research is to prevent people like them from being born? Can *this* problematic problem be resolved simply by splitting autism up into more and more autisms? In this light, perhaps it is also possible to find other ways to talk and think about epigenetics and harms associated with environmental exposures which do not get stuck in preventing or curing autism per se.

Insel said that researchers need to find “the subgroups that might have specific therapies that would make a difference.” Therapies that “make a difference” suggests the possibility for an alternate register. Crucially, whatever *difference* is to be made needs to be more attentive to the kinds of differences self-advocates say matter, and in fact many parents agree matter very much, too. To take autistic persons’ concerns into account means the intervention cannot be about making people not autistic, at least not primarily. And the goal cannot be to prevent autism writ large, although preventing exposures to toxins and other environmental agents or events would seem fair game. A critical point for talking and thinking this way is that self-advocates are often very interested in interventions that support them, even sometimes ones that alter behavior, when techniques, practices, technologies, and social re-arrangements are geared towards addressing social and communication difficulties, as well as what they agree are painful “symptoms.” And perhaps it is not necessary to refer to quite so many specific differences as symptoms.

With this reframing, in terms of making “a difference,” I am not suggesting an easy or simple code switch. For instance, I doubt that a phenotyping project works, because I think phenotypes probably only make sense when configured in relation to abnormality or pathology. Insel uses the term subgroups, which might work, but it’s not entirely clear whether he means subgroups of autistic persons or subgroups of the ten or twenty different disorders that he imagines. I think the framing of “who is going to respond” is more promising. Here, the desired therapeutic response is more open ended – one could imagine addressing the needs of autistic children with severe gut pathology, autoimmune problems, and “lots of other problems,” as well as more pedagogical and occupational

therapeutic modalities, as well as social service implementation and development of Augmentative and Alternative Communication technologies. Even if the latter don't sound *medical* enough, the mandate of Insel's agency is after all nominally to serve as a broader, more inclusive institution of mental health. But I am not making an argument against neurobiological understandings or specification of physiological structures or functions, necessarily. When I use the phrase "open ended," the openness refers to a range of approaches to understanding social-developmental problems, goals, and responses, as well as thinking about how they are to be addressed. So when Insel said, "we've got to be able to break apart this spectrum disorder into its component parts," I am asking what other sorts of parts-wholes reconfigurations are imaginable?

Diseased Brain Economics

I am not arguing that Insel is actually committed to anything remotely similar to this alternate vision of a less wholly pathological view of autism. On the contrary, there is ample evidence that the NIMH agenda under his direction increasingly focuses on redefining mental illness and neurodevelopmental disorders as brain diseases, which is very much in keeping with the agency's longstanding biomedical research emphasis.⁴⁸ Insel assumed the reigns at NIMH with a clear vision that psychiatry needed to reinvent itself as a clinical neuroscience in order to "yield the biomarkers needed to revolutionize

⁴⁸ Indeed, autism as brain disease is visible in the broader NIH vision when Director Francis Collins said in 2009, "...this is a disorder that tends to recur in families and that means it's very likely there's genetics involved, but it may be autism at the DNA level is not one disease – it may be a hundred or a thousand different diseases all of which have in common this effect on the brain..." Hughes, "Video: NIH Director Has Big Plans for Autism Research — SFARI.org - Simons Foundation Autism Research Initiative"; Kutchins and Kirk, *Making Us Crazy*; Orr, "Biopsychiatry and the Informatics of Diagnosis: Governing Mentalities."

psychiatric diagnosis and treatment.”⁴⁹ And following publication of a new Strategic Plan for NIMH, Insel launched the Research Domain Criteria (RDoC) project in 2009 to move the classification of mental disorders along the road to discovery of “complex, heterogeneous disease phenotypes,” based on neurobiological measures and measurable dimensions of behavior (i.e. diagnostic tests based on identifiable biomarkers and psychometric instruments).⁵⁰

The development of RDoC proceeded in relative obscurity until a few weeks before the *DSM-5* Task Force brought the protracted and fractious revision process to conclusion with publication of the diagnostic manual’s fifth edition during the annual meeting of the American Psychiatric Association in 2013. Looking back, it was not obvious to me at the 2009 meeting of the APA that the revision process for *DSM-5* was about to spiral into crisis, but there were signs that all was not proceeding smoothly. Significantly, the Task Force reported that they no longer considered it feasible to introduce biomarkers and etiological factors into *DSM-5* criteria as hoped in the early stages of planning. It was also obvious that there was not yet an explicit plan for how to integrate “cross-cutting dimensional measures” into the category based, nosological taxonomy.

Robert Spitzer, considered the principal architect of the *DSM-III* “revolution,” had begun to raise questions publicly about a lack of transparency in the *DSM-5* process, but it was only after the annual meeting that Allen Frances, head of *DSM-IV* revisions, began his steady stream of blog entries and editorials which played such an instrumental role in

⁴⁹ Dingfelder, “A Shift in Priorities at NIMH”; Insel and Quirion, “Psychiatry as a Clinical Neuroscience Discipline.”

⁵⁰ Insel and Cuthbert, “Endophenotypes: Bridging Genomic Complexity and Disorder Heterogeneity,” 989.

putting the near-implosion of *DSM-5* on full public display.⁵¹ At the end of the contentious process, on the eve of publication, Insel was prepared to dislodge the manual as the “gold standard” for mental health research and reorient NIMH funding away from DSM defined categories and toward the emergent RDoC framework.⁵² In doing so, he put the NIMH in position to lead the diagnosis and definition of “mental disorders” away from the practice of clinical judgment and towards biomarkers and measurable thresholds for brain diseases.

In 2009, Insel was also beginning to talk about the urgent need to stimulate the next generation of more effective medications to treat mental disorders which had become “the predominant chronic diseases of young people.”⁵³ He soon joined a growing chorus of voices spreading word of a full-blown crisis in the development of new drug treatments, because the pipeline for new psychiatric drugs was essentially empty. The American Psychiatric Association held an emergency Pipeline Summit in 2012 at the request of NIMH with representatives from industry, regulatory agencies, and academic research institutions.⁵⁴ What is remarkable to me is how consistently the renewed calls for a paradigm shift feature the need to coordinate efforts across government, industry, academic institutions, foundations, and advocacy groups, as well as to redefine mental disorders in terms of drug targets, biomarkers, and disease thresholds.

⁵¹ For overview of *DSM-5* controversies, see Greenberg, *The Book of Woe*.

⁵² Insel is very explicit about the purpose: “To be concrete about this, we’re trying to get biomarkers.” DeWeerd, “Funding Agency Shifts Focus Away From Diagnostic Groups”; Insel, “Transforming Diagnosis.”

⁵³ Insel, “Disruptive Insights in Psychiatry.”

⁵⁴ The Royal Society convened a similar event in the UK in 2013. Yan, “APF Convenes Unique Pipeline Summit”; Insel et al., “Innovative Solutions to Novel Drug Development in Mental Health.”



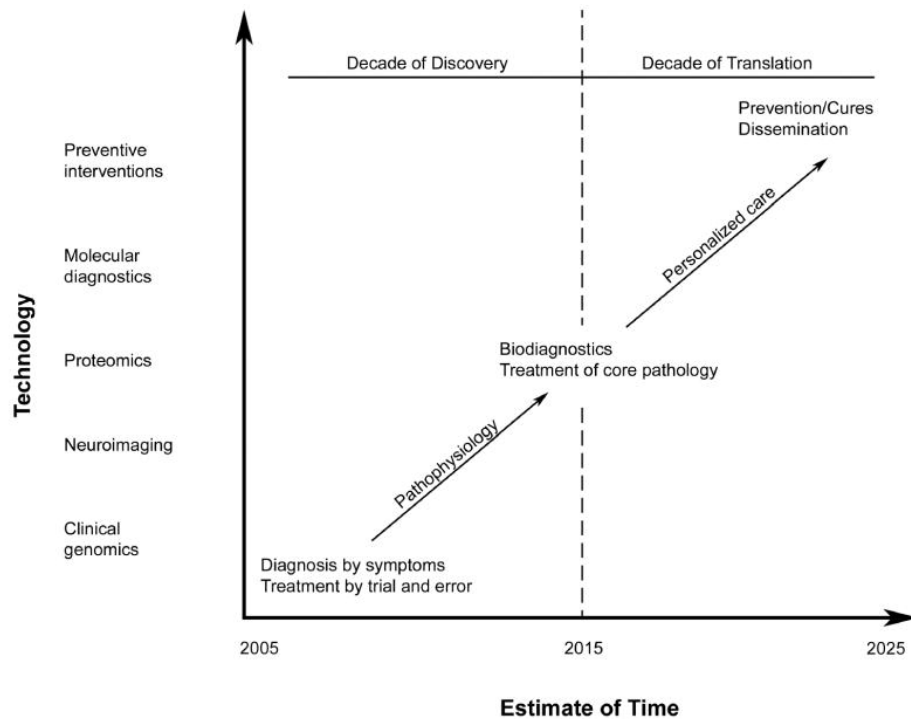
If this brain-dollar image were accompanied by an anti-psychiatry message it would have very different connotations. Instead, it appeared at the top of former NIMH Director Steven Hyman’s 2013 article, “Psychiatric Drug Development: Diagnosing a Crisis,” in *Cerebrum*, published by The Dana Foundation. The image is not a warning about pharmaceutical companies monetizing brain diseases. It should be read as an invitation to make more – money and diseases.⁵⁵

It is almost uncanny the way the same urgent language now circulates among “psychiatry stakeholders”: accelerated approval, translational medicine, pre-competitive partnerships, enhanced patent protections, private-public collaborations, and new therapeutic targets.

In 2013, Insel laid out a proposal for advancing drug development, which explicitly defines the role of government: “The public perception of mental health and pharmaceutical research is crucial to the support of this vision. The role of government should be to work together with interest groups, including patient advocacy groups, to facilitate rapid development in translation into practice of novel, safe and effective treatments.”⁵⁶ Without question a common vision is being cultivated, but I am left wondering how well the preoccupation with identifying biomarkers and marketing drug treatments reflects shared interests.

⁵⁵ Hyman, “Psychiatric Drug Development: Diagnosing a Crisis.”

⁵⁶ Insel et al., “Innovative Solutions to Novel Drug Development in Mental Health,” 2441.



This graph from Insel and Quirion’s 2005 article, entitled “A Vision for Mental Health Research,” gives a sense of the temporal and technoscientific logic and imaginary at work in *Psychiatry as a Clinical Neuroscience Discipline*.⁵⁷

Agents of Change

Peter Bell has come to represent for me a remarkable conduit in the articulation of the vision described above, but it wasn’t until two events occurred in quick succession during late 2013 that I began to realize just how fully Bell embodies the dense entanglement and multiplicity of positionalities, motivations, and commitments which have helped co-produce autism and surrounding social worlds in recent years. First, in November Johnson & Johnson agreed to plead guilty to a criminal misdemeanor charge and to pay \$2.2 billion to settle allegations that the company illegally promoted

⁵⁷ Insel and Quirion, “Psychiatry as a Clinical Neuroscience Discipline.”

antipsychotic drugs for unapproved uses, including for children and the elderly.⁵⁸ One of the medications involved is Risperdal, marketed by Johnson & Johnson subsidiary Janssen Pharmaceuticals, which in 2006 was the first drug approved by the FDA for treatment of symptoms related to autism. The second event was Peter Bell's rather quiet departure from Autism Speaks in December. I began to think again about allegations I had seen made online, both by self-advocates and parents at *Age of Autism*, that Bell had followed a suspicious path from a job marketing Risperdal for Johnson & Johnson to the role of CEO for Cure Autism Now, before its merger with Autism Speaks.⁵⁹

I found what I was looking for in papers released in prior litigation against Johnson & Johnson. An internal company document, entitled "Child & Adolescent Segment Priorities," dated July 28, 2002, reads: "Contact Peter Bell regarding relationships with external organizations and identify partnering opportunities."⁶⁰ Cure Autism Now (CAN) is listed as a possible "partner" along with several other advocacy organizations. While still working for Janssen, Bell helped Cure Autism Now organize the 2002 Autism Clinical Trials Task Force Conference, after which he became a board member of CAN. Bell then left Janssen to assume the role of CEO at Cure Autism Now in 2004. When the FDA approved Risperdal for use with autism in 2006, as a spokesperson for Cure Autism Now Bell told *The Los Angeles Times* and multiple other news agencies that the approval was "an extremely positive sign," because it signaled "that the pharmaceutical industry is

⁵⁸ As of this writing there are hundreds of Risperdal related lawsuits pending in the United States. Sell, "J&J to Pay \$2.2B for Improper Promotion of Risperdal."

⁵⁹ Bell "championed" the two organizations' merger in 2006, at which time he became executive vice president at Autism Speaks, until his departure in 2013. "National Autism Leader Peter Bell Named President & CEO Of Eden Autism Services."

⁶⁰ Bell's name appears under the heading of "Develop Advocacy Relationships," which follows "Assessment of Pediatric Market Opportunities." Alma Avila, *As Next Friend Of Amber N. Avila vs Johnson & Johnson Et Al.* (Superior Court, Commonwealth of Massachusetts 2008).

looking at autism as a future market.”⁶¹ He added, "Risperdal is not going to cure every child, and it's not going to be appropriate for all, but when used appropriately it could make a significant difference in a child's life." To me the final line sounds very much like direct-to-consumer advertising.

The Johnson & Johnson court documents are illuminating in terms of showcasing the concerted effort on the part of pharmaceutical companies to cultivate strategic relationships that span the various psychiatry stakeholders discussed in relation to Thomas Insel’s vision from NIMH. What is important in terms of Peter Bell, however, is not that he was operating as a secret agent for his employer, because, in fact, he was not acting surreptitiously, at least not at first, prior to when Johnson & Johnson came under civil and criminal investigation for its marketing practices. What matters more for what I am trying to understand with my project are the ways Bell was *not* acting on behalf of a drug company, but rather, on behalf of himself as a parent and how he believed that he could help his son. Promoting Risperdal fit quite well with how he understood his role as part of a particular parent community and an advocate for children diagnosed with autism. Bell had already been a part of Cure Autism Now advocacy culture since 1997, shortly after his son was diagnosed with PDD-NOS. The parents who founded the organization set as an explicit goal the identification of pharmaceutical agents to treat autism, part of a moral duty to harness the power of biomedicine for their children.

Clearly Bell’s activities were not only acceptable but laudable within the culture of Cure Autism Now (CAN), as can be seen in a profile appearing in the organization’s

⁶¹ In contrast to entirely positive coverage seen in other news sources, the *Los Angeles Times* paired Bell with a spokesperson for another parent-advocacy organization who expressed serious reservations about Risperdal; "...this particular drug appears to have some very serious side effects. It's a nightmare." Mitchell, "Not All Sold on Pill for Autism."

newsletter, *Advances*, not long before he was appointed CEO.⁶² As national board member and co-founder of the Philadelphia chapter, Bell forthrightly shares how he came to the realization that he could use his professional role at Johnson & Johnson to “make a difference.” In an account that recalls Fisher’s and Murray’s work on the role of conversion narratives in autism discourse, Bell describes attending a parent retreat with Cure Autism Now co-founder Jonathan Shestak.⁶³ He said it was an amazing experience to share common cause with other parents, “who were committed to the same goal. It was infectious. All of the sudden, we said to ourselves ‘We can make a difference, too!’”

Soon after, Bell approached senior management at Johnson & Johnson to propose a plan to help the company provide medications to treat autism. He reported that to his surprise they readily agreed, “I virtually had permission to talk to anyone within Johnson & Johnson about autism. Suddenly, I was an autism advocate.” According to the newsletter, within months,

Bell arranged an advisory board meeting that brought together 13 experts from the field of autism to present their findings before an audience of 35 Johnson & Johnson scientists and business managers. Bell used his networking skills and CAN relationships to identify a world-class panel of autism researchers and clinicians.⁶⁴

He told Cure Autism Now members, “It is my sincere hope that we will soon have the first approved drug in the treatment of autism,” adding that he believes his Philadelphia

⁶² Cure Autism Now, “Board Spotlight: Peter Bell.”

⁶³ Similar to how autism has become lodged in exorcism imaginaries, occasionally with fatal results, the ethos and rhetoric of Cure Autism Now style “parent warriors” has much in common with evangelical movements, including shared testimonials. See also Solomon, *Far From the Tree*. Fisher, “No Search, No Subject? Autism and the American Conversion Narrative”; Murray, *Autism*.

⁶⁴ The newsletter indicates that the meeting included a presentation on clinical trials funded by NIMH, which “examined the safety and efficacy of an existing Johnson & Johnson drug, RISPERDAL (risperidone), for the treatment of behavioral disturbances in children with autism.” Cure Autism Now, “Board Spotlight: Peter Bell.”

chapter had done Shestak proud.⁶⁵ In other words, Bell could be interpreted as working to bring Risperdal to his patient community, as opposed to identifying a new market segment for J&J.⁶⁶ At the same time, Bell's interests as a pro-cure parent advocate were very much in sync with Johnson & Johnson's marketing strategy and corporate culture.⁶⁷

Autism Worlds at a Crossroads

Already, only a year after publication, it is clear that the *DSM-5* will likely be remembered mostly for what it did *not* accomplish – for a failure to make the transition to legitimacy within the contemporary biomedical paradigm. However, it is also clear that well before publication the troubled revision process was already being seized as an opportunity to relocate functions key to orchestrating psychiatry's biomedicalization to more strategic nodes, or hubs, such as NIMH. Far from being the demise of biological psychiatry, the historic project of remaking mental disorders into brain diseases with measurable thresholds and biological targets for therapeutic intervention actually shows

⁶⁵ Bell said the board's goal was to double the organization's funding base over the next two years, "so we can fund even more science," and concluded that, "to do this, we need an even stronger network of chapters, volunteers and fundraisers. That's how we are going to reach our goal of finding a cure for autism. What a wonderful day that will be." Ibid.

⁶⁶ Although to me it looks more like an effort on the part of parents to turn autistic children into patients. There is no easy answer, but it's worth considering who stands to benefit from treatment, and benefit how, when parents, guardians, or institutional authorities unilaterally decide to medicate – especially with a sedating and dangerous medication like Risperdal, which regularly includes 'side effects' like extreme weight gain and heightened risk of diabetes, the seeping of a milk-like substance from nipples in both girls and boys, and a sometimes permanent neurological disorder causing involuntary movements.

⁶⁷ At the end of 2013, Bell left Autism Speaks to become President and CEO at Eden Autism Services. Bell said of his transition: "For the past decade, I've devoted my energies toward research, awareness and advocacy. While I still hold out hope that a solution to the autism puzzle will happen in our lifetime, I also recognize individuals with autism have opportunities to lead very fulfilling lives. Our goal is to help ensure we recognize, value and accept their differences, capitalize on their strengths and relationships, and provide the supports that allow them to live a life with respect, dignity and purpose. These are the principles I bring to Eden." The goals and values Bell cites stand in marked contrast to the language he used previously at Cure Autism Now and early in his tenure at Autism Speaks. Based on other statements Bell has made, I believe there is reason to take seriously the possibility that his perspective on autism may have shifted meaningfully over time. "National Autism Leader Peter Bell Named President & CEO Of Eden Autism Services."

signs of being accelerated and broadened in scope as “clinical neuroscience.”⁶⁸ Autism is being incorporated into this diagnostic, epidemiological, and neuro-molecular vision, but it is noteworthy what else became more visible in the unfolding controversies surrounding *DSM-5*. Autism worlds have been converging at an important crossroads and it is increasingly evident that many stakeholders are committed to, or at least invested in, the way the autism spectrum serves other social purposes not well captured within a biomedical prism defined in terms of disease, cure, and prevention.

In January 2012 *The New York Times* reported on a study co-authored by Fred Volkmar, who had quit Sue Swedo’s *DSM-5* workgroup over the decision to merge autism subtypes into a spectrum diagnosis, claiming that as many as 75% of individuals diagnosed with Asperger’s Disorder and 85% of those diagnosed with PDD-NOS using *DSM-IV* criteria would not qualify for diagnosis using the proposed *DSM-5* criteria.⁶⁹ Volkmar said that the criteria were being narrowed in such a way to end the autism epidemic, that in effect the Task Force “would nip it in the bud.” The public outcry was immediate, but what quickly became clear was that most parents, as well as self-advocates, were not so much concerned that the epidemic would be eliminated semantically by way of altered criteria but, instead, extremely worried about the prospect of losing access to special education provisions and other social services.

Swedo tried to reassure the public that they were not trying to exclude anyone who benefited from a spectrum diagnosis and that the work group’s data suggested a much smaller number would be at risk of no longer qualifying. Her efforts at damage

⁶⁸ Specification of functional domains and alterable neural circuitry, in addition to molecular targets, are key to the emerging paradigm.

⁶⁹ Carey, “New Definition of Autism May Exclude Many, Study Suggests.”

control were almost immediately contradicted by the Chair of the *DSM-5* revisions, David Kupfer. In an article appearing the following day, he told a different reporter at *The Times*, “We have to make sure not everybody who is a little odd gets a diagnosis of autism or Asperger disorder,” adding, “It involves a use of treatment resources. It becomes a cost issue.”⁷⁰ Anxieties about how revisions in *DSM-5* would influence institutional arrangements, service provision, and legal protections became a widespread concern among autistic self-advocates, as well as parents and service providers.⁷¹ Numerous organizations mobilized around the issue, and the Autistic Self Advocacy Network emerged as particularly effective in influencing the debate with a pair of policy briefs.⁷² The briefs were widely cited in no small part because Ari Ne’eman and co-author, fellow self-advocate Steven Kapp, demonstrated impressive understanding of the relevant conceptual issues and research literatures, as well as familiarity with ground-level practical realities of the role autism diagnoses play in people’s lives.

By reframing the revisions primarily in terms of disability rather than in terms of symptoms of pathology, Ne’eman and Kapp not only laid out a persuasive case for their proposed changes, but also succeeded in articulating the stakes in such a way that even pro-cure parent organizations almost couldn’t help but follow their lead. Two points they

⁷⁰ Kupfer also said in a previous interview, “We have to do something about the rising rates of several childhood psychiatric disorders and this is an important adjustment to decrease the level of children with autism...” Verhoeff, “Drawing Borders of Mental Disorders”; Harmon, “As Specialists Debate Autism, Some Parents Watch Closely.”

⁷¹ While the Volkmar study is obviously flawed, it remains uncertain how consequential the revised criteria will be in its effects on service provision or for epidemiological research. A 2014 review of multiple studies concludes that the new criteria could significantly reduce the number of individuals receiving an autism spectrum diagnosis. Kulage, Smaldone, and Cohn, “How Will DSM-5 Affect Autism Diagnosis?”. McPartland, Reichow, and Volkmar, “Sensitivity and specificity of proposed DSM-5 diagnostic criteria for autism spectrum disorder.”

⁷² Ne’eman and Kapp, *What Are the Stakes? An Analysis of the Impact of the DSM-5 Draft Autism Criteria on Law, Policy and Service Provision*; Kapp and Ne’eman, *ASD in DSM-5: What the Research Shows and Recommendations for Change*.

made stand out in particular: first, that the role of diagnosis in determining eligibility for disability-related services and legal protections should be the over-riding factor in *DSM-5* revisions; and, second, that ASD criteria should be aligned with recently passed disability legislation, which they argued instructed the judicial branch to interpret the definition of disability more broadly.⁷³ While not all of their suggestions made it through to publication, they were remarkably successful in harnessing shared anxieties about loss of services to make a broader case about autism being more disability-like than disease-like, at least in so far as DSM categories become institutionalized in public policy, education practices, and social welfare programs. The Autistic Self Advocacy Network and the Autism Society, the oldest national parent organization, issued a joint statement calling on the *DSM-5* Task Force to devise criteria that would ensure that all those who qualified for diagnosis with *DSM-IV* criteria would continue to do so under *DSM-5*.⁷⁴

As Swedo's presentation at the 2009 IACC meeting showed, she assumed her role as chair of the Neurodevelopmental Disorders Work Group firmly ensconced in the NIMH biomedical paradigm and institutional culture. She also viewed herself as aligned with autism parents concerned about increasing environmental toxins and immunological dysfunction among the pediatric population. It was further clear that initially she considered the autism spectrum to have become overly broad and inclusive. Then, abruptly, Swedo had found herself under attack in the course of her responsibilities as chair precisely for those same professional and personal commitments. The positions she

⁷³ For a concise description of the Americans with Disabilities Act Amendments Act of 2008, see Equal Employment Opportunity Commission, "Questions and Answers on the Final Rule Implementing the ADA Amendments Act of 2008."

⁷⁴ Ne'eman and Badesch, "Joint Statement of the Autism Society and Autistic Self Advocacy Network on the DSM-5 and Autism."

had staked out quickly became decidedly uncomfortable for her and, as she told an audience in 2012, “It hurt like hell that newspapers were accusing us of trying to hurt kids by denying them services.”⁷⁵ Swedo remained responsible to the same institutional imperatives as before, but she now had to contend with ways that the disease defining and treating role of psychiatric diagnosis was in tension with all sorts of other social purposes the autism category served.

Swedo indicated that she already realized her work group’s predicament when she reported on their progress to the IACC in April 2010. She spoke about the problem of “artificially” high and climbing prevalence rates, as well as how the work group was struggling with the ambiguity created by using “clinical significance” as a diagnostic threshold and how they might go about “moving cut points.” Then Swedo asked, rhetorically, “The difficulty, though, is then where do you set that threshold?” She moved on rather haltingly, concluding, “However, we don’t want to lose any of the folks who should be within that spectrum, and so you can’t draw the line too strictly, and we absolutely don’t want to be taking services away from individuals who are benefitting from them.” During the Q&A period, Ari Ne’eman, who had become a member of the IACC earlier in the year, asked a probing question about how the work group planned to address the issue of “severity.” Swedo took the opportunity to thank him, especially, because he and his colleagues had been “very influential in this process in terms of opening our eyes to some of these questions.”⁷⁶ It had not taken her long to realize that

⁷⁵ Singer, “Diagnosis.”

⁷⁶ One can get a sense of how self-advocate expertise manifests through the hybridization of rhetorical skill, theoretical facility, and experiential familiarity with the way Ne’eman formulated his question. He asked how the work group’s proposed severity scale might “recognize the change that can occur over the lifespan as people develop new skills,” adding that there are also autistic people who “have

Ne’eman and other self-advocates could contribute something important to the revision process. She recognized then that they did so both conceptually and experientially, but when controversy erupted later she benefitted from how their innovative use of a disability framework helped strategically steer the criteria to a point where both the Autistic Self Advocacy Network and Autism Speaks could endorse the changes, with caveats of course.

Space does not allow me to address exactly how nimbly self-advocates finessed the existing draft criteria to better reflect their own concerns, as well as to foreground what every parent advocacy group had to acknowledge was *the* overarching concern about autism in *DSM-5*: who was at risk of being kicked off the spectrum, losing their diagnosis and access to disability-related services and legal protections. There are two points especially relevant to my analysis. First, the “severity scale” originally posted on the dsm5.org website in 2009 would be significantly reoriented away from individual impairment (i.e. severe, moderately severe, less severe, subclinical symptoms, normal variation) to a very different sort of continuum that focuses on different levels of support needs, with numerous references to contextual factors. The second intervention, which also has far reaching implications that I am not sure are widely recognized yet, individuals may now meet each domain in the criteria either “currently or by history.” In

severe challenges in one domain and mild challenges in another domain.” He elaborated: “My concern is that there are certainly autistic traits like encompassing preoccupations, which in some contexts are disabling, and in some contexts may be strengths, as well as traits like hand-flapping or other forms of stimming which serve a definite purpose. And if you’re defining a trait – severe as having a lot of these traits and less severe as having less of these traits – how do you intend to avoid the risk that clinicians will take that as guidance to eliminate non-harmful autistic traits that may serve an important purpose for the individual?” Swedo was clearly in the process of becoming persuaded that that was a very good question, indeed. She responded that the workgroup was currently struggling with the issue and there was now some question of whether there would be a severity scale in *DSM-5* at all.

other words, autistic “symptoms” need not be in evidence at the current time as long as they manifested at some point during development.

The significance of the second point may not be immediately apparent. Basically, without addressing these terms directly, the addition of the words “currently or by history” simultaneously make the diagnosis work more in a disability rather than disease register and also suggest the potential disarticulation of high-functioning versus low-functioning, as well as mild versus severe, as meaningful labels for individuals or disorders outside of their social contexts.

During another presentation to the IACC in July 2012, Swedo explained that the change to “currently or by history” originated in some of the superb advice her group received from advocates, who pointed out that symptomatically autistic behaviors do not necessarily manifest when an individual is surrounded by a supportive environment. However, without intervention and supportive environment, the problem behaviors would return once more. The appropriate conclusion, which Swedo accepted as logical because it is hard to argue with – it *is* logical – was that individuals “shouldn’t lose their diagnosis, and therefore, lose their services” just because they were no longer, currently, manifesting “symptoms.” Swedo recognized the logic by way of analogy. She told the IACC gathering, "I think the example that was given to us, if you need a crutch to be able to walk, but you walk perfectly fine with that crutch, you don't want to, then, say you don't need the crutch anymore." It’s brilliant, really, and even if one wants to problematize the analogy, the message is clear – don't take away our support! The next step in the logical sequence is manifestly obvious as well: do not take away the diagnosis when we are doing well because that is how we are able to get the supports we need.

During the Q&A at the meeting, Swedo immediately came under attack from two newly appointed IACC members, one an autistic self-advocate and the other a parent-advocate. In truth, I found both of their questions difficult to follow. I think Swedo did too, initially. But judging by how she began to speak over both advocates, Swedo recognized their hostility and realized she was being interrogated more quickly than I did. Tensions were running high since this was just a few months after the article on the Volkmar research appeared in the *New York Times*.

Although neither the self-advocate nor the parent-advocate articulated their questions very clearly, it was the combination of the two that prompted Swedo to explain the origin and significance of the four word intervention, “currently or by history.” I find this significant for several reasons. First, the presence of the two advocates made an important difference in the unfolding situation, i.e. prompting Swedo to elaborate, only in part because of what they were able to articulate, but also simply because of how they are positioned *vis-à-vis* autism and institutional power. Part of the difference made was simply a result of self-advocates and parent-advocates both being included on the IACC. Second, the exchange shows just how much the *DSM-5* controversy had the effect of making the concerns of self-advocates and parent-advocates come more closely into alignment. At that point in time, the access of autistic individuals and their families to disability-related services really was the most important fact of the diagnosis.

I am emphasizing the convergence of a number of significant developments. Self-advocates had a powerful effect on the revised *DSM-5* autism spectrum diagnosis, which included making the criteria more attentive to social context and support, as well as less emphatic about the pathological nature of individual impairments. Self-advocates’

use of a disability framework combined with the threat of losing access to disability-related services, prompting parent-advocates and others to focus much more attention on autism's disability-likeness, rather than what had recently been a public discourse relentlessly focused on an autism epidemic and the search for a cure. Observing these developments, I was impressed by how well self-advocates organized and articulated their position, as well as the way Sue Swedo, parent-advocates, and others became more response-able to self-advocates by virtue of how they were becoming re-positioned in relation to the situation, which itself was being re-configured in significant and multiple ways by large-scale institutional realignments.

I consider these emergent differences among stakeholders to be significant, but at the same time, I view their convergence as meeting at a crossroads. It is not at all clear to me whether the path forward will be more in keeping with what I describe as acceptance of important parts of autism's disability-like presence or a path more defined by the emergent clinical neuroscience and the powerful impulse to cure or prevent that which is (and those who are) difficult and seen as undesirable. In keeping with my own admiration for the work done to make these differences meaningful, which cohabitates with my uncertainty about whether they will prove durable and robust, I will point out three problems I see with the way I have characterized these events – a bit of a reality check by way of listening to Sue Swedo.

The first problem is that it is very hard to reconcile certain things Swedo has said with what I have described as her working hard to listen and respond to self-advocate concerns, as well as her insistence that the Neurodevelopmental Disorders Work Group had no intention of redefining the autism spectrum in such a way that would reduce its

prevalence. For example, she told an audience at the annual meeting of the American Psychiatric Association in 2012, “Aspies don’t actually have Asperger’s Disorder, much less Autism Spectrum Disorders.” She said Aspies were simply “Norwegian bachelor farmers, just a little awkward... but we consider them to have a normal variation.”⁷⁷ My point is not to prove duplicity but rather to suggest complexity and to recall that Swedo’s productive relationship with the Autistic Self Advocacy Network emerged precisely because she was put into a position where she had to negotiate competing institutional imperatives and ontological commitments that are in tension. Strategically positioned actors have to wrestle with the myriad ways torque affects people, institutions, and categories over time and across difference.⁷⁸

I realized another *spectrum* problem while listening to Swedo present the finalized criteria for the first time to an audience at the 2013 annual meeting. She remained true to her word that she considers it her responsibility to make sure people pay attention to the addition of the key phrase, “currently or by history.”⁷⁹ It was something else she also emphasized that gave me a sinking feeling:

⁷⁷ Greenberg, *The Book of Woe*, 324–327.

⁷⁸ Another thing she said at the 2012 APA meeting reinforces my sense that we should take seriously the possibility that Swedo’s seemingly contradictory statements (there are others), nevertheless, may reflect simultaneously genuine and incompatible ontological commitments. When asked what role the provision of services played in the revision, she told the audience a story about a field trial clinician who sent her a note which said, “My patient did not meet criteria for autism, but I know he has it, so I gave him the diagnosis anyway.” Swedo then gave the audience her perspective: “I think this is actually quite appropriate. If the clinician’s gut feeling is that the patient has the disorder, it’s appropriate for them to get [the diagnosis], to give them the services, the treatment, whatever needs to happen...the purpose of the DSM is to provide clinicians with a road map. We’re not driving the car.” Ibid.; Bowker and Star, *Sorting Things Out: Classification and Its Consequences*.

⁷⁹ She said at IACC meeting in 2012, prior to publication, that the phrase would be placed “at the very top [of the criteria], and if we have to, we will put it in every single line in here, ‘currently or by history.’” While the criteria does not include the phrase in every single line, of course, Swedo did use red text to emphasize the point in her presentation to the APA. Swedo, “Neurodevelopmental Disorders in DSM-5.”

Please, please, please pay attention to the final criterion. ‘These disturbances are not better explained by intellectual disability or global developmental delay.’ My psychologists tell me that they are now spending half of their time un-diagnosing autism among their patients who are given the diagnosis when what they actually have is a global developmental delay. Autism Spectrum Disorder is a very specific behavioral condition that is characterized by very specific and unique deficits in social communication as well as by the presence of RRBs [restrictive and repetitive behaviors]. It is not a global developmental disorder.

This is how you would go about lopping off individuals on the flip-side of the spectrum, opposite Norwegian bachelor farmers who are just a little awkward but a normal variation. If ‘aspies’ don’t really have an autism spectrum disorder because they are a normal variation, or phrased differently too high-functioning, then ‘intellectual disability’ and ‘global developmental delay’ are reserved for those deemed to be at core intellectually deficient, or too low-functioning. These two categories are assigned to cases where prospects for further development appear minimal, and they still carry stench of mental defect.⁸⁰

I then realized that all of the media coverage, as well as the Autistic Self Advocacy Network *DSM-5* briefs, were entirely focused on how the revised criteria might exclude individuals with diagnoses of Asperger’s and PDD-NOS, used for those judged high-functioning with mild symptoms. There were reasons, not least of which, because people with Asperger’s and PDD-NOS appeared at risk of ending up without any diagnosis at all and finding themselves completely without support services. The risks for those at “the low end” of the spectrum are different. An autism diagnosis garners a much higher grade of much more expensive services. The behavioral and pedagogical

⁸⁰ The point is not so much what *intellectual disability* and *global developmental delay* are *vis-à-vis* autism but the detrimental effects that result from being severed from the spectrum. The severity scale for intellectual disability in *DSM-5*, for instance, retains ranked impairment levels: Mild, Moderate, Severe, Profound.

interventions are costly because they are labor intensive. They are provided because, despite all we hear about how autism is devastating, it is a diagnosis given to those for whom hope is reserved.

Which brings me to the final problem, the way that I have interpreted the significance of the words, “currently or by history.” I have no reason to doubt that Swedo meant what she said, and what self-advocates intended, for the words to prevent autistic individuals from losing support services simply because they benefit from them. However, the *DSM-5* still operationalizes criteria in terms of “symptoms,” despite the new emphasis on social support and prosthetic environment which seemingly helps reframe autism spectrum disorder more within a ‘social model’ of disability. The *DSM-5* does not recognize an autistic person to be functioning well within a particular, perhaps modified and carefully choreographed, situation. Instead, the criteria allow for an individual to qualify for diagnosis although they may not be currently exhibiting symptoms, having become asymptomatic.

It is that last word, *asymptomatic*, yet still diagnosable, which gives away the problem, because I can see how “currently or by history” could be made to work not in a disability framework but, instead, be repurposed to function in the emergent vision of a clinical neuroscience.⁸¹ That’s what RDoC is designed to do, generate biomarkers and measurable thresholds so that brain diseases can be diagnosed asymptotically and preventatively. This is biomedicine as risk management, what Robert Aronowitz has

⁸¹ Furthermore, the very idea that *symptoms* – defined in terms of behaviors and deficits – might be “manifested...currently or by history” begins to appear contradictory when combined with a diagnostic threshold defined as “clinically significant impairment in social, occupational, or other important areas of current functioning,” which *DSM-5* relies on.

called the preventative revolution: if a health risk can be reduced, it should be.⁸² Down this path is where pharmaceutical interventions lie, as well as prenatal screening and other methods for dealing with unwanted presences.

⁸² Thinking of cholesterol management, Dumit describes it as prevention without illness, where “...some sort of screening test determines whether or not that person has crossed a line and needs to be treated.” But screening tests tend to function differently with neurodevelopmental disorders. Cited in Dumit, *Drugs for Life: How Pharmaceutical Companies Define Our Health*, 13.

Chapter Four

Critical Studies of Autism, Or: How I Learned to Stop Worrying and Love Neuro-essentialism

Trying to make someone ‘normal’ isn’t always the best way to improve their life.

Ari Ne’eman
*Wired Magazine*¹

I truly pray for the day to come when my daughter can blog or self advocate. She still has a long way to go in overcoming significant cognitive challenges.

Alison Singer
*Autism Science Foundation Blog*²

Autism is a very big continuum that goes from very severe -- the child remains non-verbal -- all the way up to brilliant scientists and engineers... It's a continuum of traits. When does a nerd turn into Asperger, which is just mild autism? I mean, Einstein and Mozart and Tesla would all be probably diagnosed as autistic spectrum today.

Temple Grandin
*TED Talk*³

In this chapter, I examine how the mobilization for autistic rights, identity, and culture began to be channeled into a movement to accept and affirm “neurodiversity,” or varieties of neurological configuration. In particular, I focus on why claims to an autistic identity and the articulation of autistic community values in terms of neurodiversity have been criticized in academic literatures, as well as in popular media and advocacy arenas. Both an emerging “Critical Autism Studies” and critical writing on the topic of

¹ Silberman, “Neurodiversity Rewires Conventional Thinking About Brains.”

² Singer, “Speaking Out About ‘Autism Every Day’.”

³ Grandin, *Temple Grandin*.

cerebralized subjectivity in light of the increasing influence of neuroscience reflect an enduring preoccupation of “critical” academic discourses with the problem of essentialism and complicated histories of political movements rooted in and routed through “identity.” I argue that a move away from an analytic mode of critique is necessary to gain a better understanding of the autism spectrum, neurodiversity, and the movement to affirm autistic-ness as problematics in need of exploration. In the process, I adopt what I consider an “anti anti-essentialist” position, which is not the same as an uncritical embrace of essentialism.

Even efforts to take the autistic rights and neurodiversity movements seriously must address persistent anxieties about reinforcing essentialist divisions, such as autistic/neurotypical and biological/social. At the same time, critics tend to reinforce other binaries prevalent in the public autism discourses under scrutiny, such as low-functioning versus high functioning, nonverbal versus verbal, pathology versus difference. Writers in the academy struggle to navigate the ambiguities and conundrums evident in autism as spectrum and the real-imaginary of differences in social functioning.

I am critical of this critique of autistic identity politics due to the kind of doubt it raises about the validity and value of emergent autistic identities, communities, and cultures - assemblages, which I myself might, at key junctures, attempt to recast in terms of identifications and objective-self fashioning, co-productions and social worlds. But I have grown increasingly open to the notion that these autistic identities, communities, and cultures – and even neurologically different human kinds – can be productively engaged with and in their own terms. I have seen the new potentialities that emerge through these individual and collective formations as they are enacted and practiced,

through inter-active and intra-active dynamics. I am suggesting that the critique of essentialism and reductionism is of limited theoretical value for understanding autism and autistic worlds. Critique makes it more difficult to explore the important new sense-making, re-mattering, and re-worlding that are always already underway.

While there is something particular in how critical analysis in the humanities and social sciences sometimes reproduces enduring post-Enlightenment Great Divides, I suggest that a possible path for more productively thinking through these issues with autism worlds is to pay careful attention to how autism parents and autistic self-advocates are themselves active participants in academic and critical studies of autism. Just as parent-advocates and autistic self-advocates seek to influence the direction of academic scholarship, critical studies of autism plays a mutual, co-constituting influence on “neurodiversity” and autistic rights movements. Academic discourses provide another public forum where the politics of autism and neurodiversity play out and potentially become a valuable opportunity to open up a new ecology of care and new opportunities for engagement with dissimilar understandings of autism, as well as to make generous space for *autistic* understandings.

Authenticity, Representatives, and Representativeness

It is risky to begin the chapter, as I have, by quoting Temple Grandin’s view of the autism spectrum as a continuum, running from severe and nonverbal to brilliant scientists and engineers all the way through to transcendent genius. It’s risky because it does not represent the view of the spectrum endorsed by the autistic self-advocates I am writing about, nor my own understanding of autism as a disability and experiences with autistic difficulty. It’s risky because of Grandin’s historical and ongoing outsized role as

representative for a certain type of autistic, but also because many self-advocates have grown tired of how Grandin has been positioned, and positions herself, in that role.⁴ In fact, I include the quote from Grandin precisely because she is a poor stand-in for what some call radical neurodiversity activists. Nevertheless, Grandin articulates a popular view of the autism spectrum, as a continuum with severely afflicted, nonverbal (child) at one end and high-functioning genius (adult) at the other.

The spectrum that I am writing about is not one that runs in a straight line from individuals such as I worked with in the public schools to the exemplars of intellectual brilliance such as Einstein and Mozart and Tesla cited by Grandin. At the same time, the spectrum also needs to be wrestled with in terms of the constellation of symptoms which define it diagnostically as a combination of social and communication impairments, along with narrow range of interests and circumscribed behavior. I am interested here in a broad conceptualization of autistic thinking, but most particularly in how self-advocates use their positioning *vis-à-vis* being autistic to disrupt the strict ranks of functioning, intelligence, and social worth. So, despite her role as the first widely recognized autistic self-advocate, Grandin is more of a counter-example to the rethinking that the rise of the autistic self-advocacy movement invites.

While Grandin is no longer a singular representative of autistic success in public life, she remains far and away the most cited example of “high-functioning” autism and autistic potential in popular representations. She has become a celebrated public figure, but that certainly was not the case early in her career. When her first book, *Emergence:*

⁴ For example, Lydia Brown lists as number fourteen of fifteen things never to say to an autistic person: "Have you ever heard of Temple Grandin? Her books are really amazing!" Brown, "Autistic Hoya."

Labeled Autistic, was published there was initial speculation about whether Grandin's co-author was the *real* author.⁵ In Oliver Sacks' introduction for the re-publication of *Emergence*, he wrote that Grandin herself was "unprecedented because there had never before been an 'inside narrative' of autism; unthinkable because it had been medical dogma for forty years or more that there was no 'inside', no inner life, in the autistic."⁶ Early on, numerous experts weighed in on the validity of her diagnosis and evaluated the authenticity of her self-representation.

As with the prior chapter, I draw on the words of Ari Ne'eman to help articulate autistic self-advocates' investment in a politics of neurodiversity and the words of Allison Singer to express pro-cure parent advocates' worries about the movements influence. An individual's prominence and their choice to put themselves into the spokesperson role provide a rationale to analyze their representation and representativeness, but such analysis is a risky proposition and there are always counter-arguments. The autism diagnosis of Jim Sinclair and other activists have come under attack when they began to express views that ran contrary to those of established experts or parent advocacy groups. Amanda Baggs was subjected to a virulent campaign to discredit her following appearances in the media, and she went so far as to post her medical records online at one point to 'prove' her diagnosis. But it needs to be noted that self-advocacy communities such as the one organized around Autreat explicitly reject medical diagnosis as the basis for determining who is and is not autistic.

Former Vice President of Autism Speaks Allison Singer came under attack by

⁵ Grandin and Scariano, *Emergence, Labeled Autistic*.

⁶ Cited by Hacking

autistic self-advocates for comments she has made about her daughter.⁷ Both her appearance in the video “Autism Every Day” and autistic activists’ response have received an extra-ordinary amount of critical attention.⁸ Singer continues to position herself in the role of representative for autism parents’ concerns about the politics of neurodiversity as well as advocate for the needs of children with severe autism. She stands out among autism parents who are put in the position and position themselves as advocates for autistic children “who cannot speak for themselves.” Ne’eman, too, has been a controversial figure.

Ne’eman, who has played a leading role in establishing the Autistic Self Advocacy Network’s position as the leading non-profit organization “run by and for autistic people,” incorporates the disability rights movement slogan, “nothing about us without us,” into every one of his frequent public appearances and presentations.⁹ Nonetheless, critics accuse Ne’eman of being on record suggesting that success for “autistics and other neuro-diverse citizens” depends on society coming to view their “quirks and eccentricities” as “just as legitimate as the social skills of the mainstream.”¹⁰ Writing as a teenager in 2006, Ne’eman did use precisely this language in his piece,

⁷ See Chapter Three for the specific comment that proved inflammatory, as well as the quote below where Singer says, “It is hard to consider her ‘differently abled’ because she is not ‘abled.’”

⁸ Criticism of both Singer’s comments and self-advocates’ responses to them have appeared in academic and popular writing about the politics of neurodiversity. The criticism is hardly one sided, alternately focusing on Singer and self-advocates. For an example of the latter, Andrew Solomon writes: “The neurodiversity people have had a picnic with this; Ne’eman drew a connection between these comments and the killing of autistic children, saying that Autism Speaks was “morally complicit in these murders.” It’s disrespectful toward Singer and Jenny Nash and other mothers like them to suggest that their struggles are anything less than passionately loving. Autistic children seem frequently, by virtue of the extra care they require, to inspire a desperate, enormous welter of adoration, fantastically powerful even when it is striated with frustration and sorrow. The love predicated on hope is as profound as that predicated on acceptance. The balance is infinitely difficult.” Solomon, “The Autism Rights Movement.”

⁹ “About ASAN.”

¹⁰ Ne’eman, “Difference Is Not a Disease.”

“Difference is Not a Disease,” published in *Jewish Weekly*.¹¹ It is suggested, sometimes subtly and often overtly, that outspoken self-advocates such as Ne’eman do not believe autism is a disability at all, but only difference to be celebrated.

There are aspects of the early “Difference is Not a Disease” essay that run parallel to the way Ne’eman has spoken about the spectrum and neurodiversity in subsequent years – i.e. he still admonishes that autism is neither disease, defect, nor inferiority; that the rhetorics of cure and misdirected attempts at normalization are harmful and counterproductive; that autistic ways of thinking and perceiving are worthy of respect and accommodation; and that the basic acceptance of neurological difference offers the most promising avenue to autistic success, allows the engagement of preferred learning modalities, and promotes the tapping of unrecognized potential. Another constant has been Ne’eman’s opposition to abuse and use of involuntary restraints, aversive conditioning, and seclusion in institutional settings.¹² He continues to frame spectrum individuals in terms of a minority group identity, insisting that autistic individuals have something valuable to offer society, but due to misconception and stigma they are, in numerous ways, denied access to opportunity and paths to achievement. In his view, access and the removal of barriers go hand-in-hand with a shift toward recognizing the legitimacy of autistic perspectives, rights, and dignity.

While Ne’eman wrote in 2006 that “difference is not disability,” such a statement

¹¹ Ibid.

¹² Ne’eman filed a letter along with a Minority Report condemning the use of “restraints and aversives” attached to the New Jersey Special Education Review Commission’s 2007 report, which was co-signed by three fellow committee members: “It would have been our preference to find a solution in the main document to this issue. However, owing to numerous compromise proposals having been rejected, including one as basic as requiring parental consent prior to the utilization of these techniques, we feel it incumbent upon us to file a minority opinion.” “Special Education Review Commission Report.”

does not directly contradict his later advocacy, but it also does not adequately reflect the extent to which the framework of a social model of disability would become central to Ne’eman and the Autistic Self Advocacy Network, which emphasizes a political theory of stigma, discrimination, and access barriers as the source of disablement.¹³

Self-Advocacy and the Functioning Divide

It is often asserted that pro-neurodiversity advocates are exclusively Asperger’s adults or individuals on the high-functioning end of the spectrum, as well as claimed that severely affected individuals are incapable of self-advocacy. While she was Senior Vice President for Autism Speaks, Alison Singer published an open letter addressed to autistic self-advocates, entitled “*Cure* is not a four-letter word.” In it, she wrote,

... I am certainly glad that persons with Asperger Syndrome are becoming able to access support and services if they feel they need them. But the “differing abilities” of persons with Asperger Syndrome are nothing like my daughter’s autism. When we at Autism Speaks use the word *cure*, we are most often focused on the people at the lower end of the spectrum. I have not met a person with Asperger Syndrome who seemed anything like my daughter. None of these persons, however, has ever met my daughter because it is so hard to take her out of the house. It is hard to consider her “differently abled” because she is not “abled”. She is sweet and loving and works harder than anyone I know, but she does not have any areas of strengths that I fear squashing through medication, intervention or cure.¹⁴

The move Singer makes is to paint all self-advocates as uniformly high-functioning and

¹³ Ne’eman acknowledges that he did not initially emphasize the idea that autism is a disability, citing his experience of being denied access to an appropriate and challenging academic curriculum while he was assigned to a segregated special education program. In 2008, Ne’eman told Education Week, “We have much more of a cross-disability focus,” and in another interview the same year, Ne’eman said, “Autism is a disability insofar as we’re disabled by society. A society that is often very hostile to our ways of communicating, to our ways of being that often is structured in such a way that makes it difficult for us to access places of public accommodation and services and countless other things. It creates an education system where autistic people are often abused and do not have our communication and other needs met. In that sense, yes it is a disability. It can be very disabling. But is it something that we want to eliminate? No. What we want to do is we want to eliminate those societal obstacles that are the true barriers in our lives...” Samuels, “In Advocacy Realm, Specific Disabilities Gain in Prominence.” Edelson, “Abnormal Ambitions.” “Interview Transcript for Ari Ne’eman.”

¹⁴ Singer, “Cure Is Not a Four-letter Word.”

therefore uninterested in the harder parts of autism.

There are autistic individuals and self-advocacy groups such as the Global and Regional Asperger's Syndrome Partnership (GRASP) and Aspies for Freedom who have at times actively promoted the high- vs. low-functioning distinction, as well. Some of those who at one time emphasized the distinction have changed their language and views over time but others have not. However, in the lineage of self-advocacy, autistic rights, and use of the term neurodiversity that I follow, traceable from Autism Network International through to the Autistic Self Advocacy Network, there has been a concerted effort to problematize and contest the conceptualization of individuals as devisable along a temporally stable and decontextualized line of functioning.

The desire to maintain an autism hierarchy with Asperger's at the pinnacle does not reflect the views commonly shared among members of both Autism Network International and the Autistic Self Advocacy Network, and resistance to such tendencies to rank autisms and autistic individuals has long been explicitly incorporated into these organization's literature. A clear statement of this position appeared in an open letter posted on *autistics.org* in 2004, which reads, "Most of us who call ourselves 'autistics' are not proclaiming our superiority, merely our lack of inferiority and the fact that autism *even with all of its associated difficulties* is inseparable from the rest of us."¹⁵ The authors then proceed to dismantle any simplistic notion that autistic rights advocates belong on the high-functioning end of a spectrum. One section provides a long list of

¹⁵ Emphasis in original. The People At Autistic.org, "In Support of Michelle Dawson and Her Work."

bullet points to address “areas commonly cited by parents trying to claim we aren't autistic or at least aren't ‘like their children,’” which I quote in part:¹⁶

- We have all been institutionalized, although for one of us it was a brief period during early childhood.
- None of us are fully toilet-trained, two of us have required adult diapers on a regular basis.
- None of us have communicative speech all the time, one of us has none. Two of us use augmentative communication devices sometimes, one uses one all the time. Sometimes even language isn't possible.
- Between us, we have accrued labels from professionals like mental retardation, low functioning, unsalvageable, non-communicative, in our own worlds, and aloof. Some of us still risk those labels when we go out in public alone.
- Two of us receive significant amounts of state-funded services due to lack of self-care skills, the other sorely needs them but such things don't exist where that person lives.
- All of us either self-injure or have self-injured in the past, including in measures that go beyond the standard descriptors of severe self-injury in autistic people.
- Two of us have been significantly violent in the past, as described by others. The other has been considered to have "scary" behavior.
- All of us have at some point been described as incapable of communicating, thinking, and/or making decisions for ourselves. All of us are still in danger of being described that way in certain situations.
- We flap, finger-flick, rock, twist, rub, clap, bounce, squeal, hum, scream, hiss, and tic.

Amanda Baggs, in particular, is an outspoken critic of the hazardous situation created by emphasis on a continuum of functioning and “Aspie supremacy.” She was joined by a concerted effort among both autistic and autism parent bloggers to counter media reports quoting president of GRASP, John Michael Carley, as saying he has a hard time calling himself autistic because of the social stigma attached.¹⁷

¹⁶ Ibid.

¹⁷ Reportedly Carley indicated that he preferred to maintain distance between Asperger's and at the other extreme, "somebody who might have to wear adult diapers and maybe a head-restraining device. This is very hard for us to swallow." In a response posted on her blog, Square 8, Bev wrote: “Welcome to the concept of Stigma folks, you don't like it do you? Well neither does any body else,

At the same time, the high-functioning autistic has become a central figure in autism narratives, reflected in a fascination reflected in popular accounts, and to a lesser extent in scientific research, about what are variously described as strengths, talents, and skills associated with Autism Spectrum Disorders diagnoses (e.g. eye for detail, pattern recognition, systematizing, etc.) But these strengths do not divide neatly between the categories of Autistic Disorder and Asperger's Disorder, and the distinction has become further complicated with the proliferation of the "not-otherwise-specified" diagnosis. Fundamentally, however, the neuro-developmental expanses defined as the autism spectrum are not really about the boundaries between disorders or even low-/high-functioning distinctions. Or rather, I should say, the manner in which severity and functioning divisions are drawn, presumably in an effort to identify the specific needs of autistic individuals, provide poorly drawn boundaries and guidelines for further action. And yet, clearly, contested ideas about functioning and dis/ability are central to understanding the emergent politics of neurodiversity.

From Alison Singer's perspective, the politics of autistic rights and neurodiversity do not directly address the needs of individuals such as her daughter and do not properly recognize the truly disabling aspects of autism. She was quoted in 2013 as saying that high-functioning individuals were opposed to medical research, which "they don't need, but my daughter does. If she were able to function at their level, I would consider her cured."¹⁸ The implication drawn from Singer's comments and heard from other critics is

which is why some folks stand for the dignity of Autism, all of it." Hamilton, "Asperger's Officially Placed Inside Autism Spectrum"; Bev, "Angry Aspies, Please Go Away"; Carey, "Dismay at Aspie 'Hate'"; Baggs, "Aspificating Snobbery over the DSM All over Again"; Baggs, "Aspie Supremacy Can Kill."

¹⁸ Lutz, "Is the Neurodiversity Movement Misrepresenting Autism?"

that neurodiversity advocates have trivialized the challenges and obstacles faced by the many individuals diagnosed with autism, who possess substantial deficits and impairments which, according to this logic, “high-functioning” self-advocates do not.

Nevertheless, Ari Ne’eman has continued to influence policy discussions and garner support as well as criticism. President Barack Obama’s appointment of Ne’eman to the National Council on Disability was confirmed in 2010 after months of delay due to an anonymous hold in the U.S. Senate, which led to speculation that opponents exerted political pressure behind the scenes.¹⁹ Jonathon Shestak, co-founder of Cure Autism Now, told the *New York Times*, “Why people have gotten upset is, he doesn’t seem to represent, understand or have great sympathy for all the people who are truly, deeply affected in a way that he isn’t.”²⁰ In a similar vein, Swedo and Insel suggested at the 2009 IACC meeting described in Chapter Three that the autism research agenda should primarily focus on the needs of more severely affected, lower functioning individuals. Nevertheless, Ne’eman was announced as one of five new members appointed by the Secretary of Health and Human Services to the Interagency Autism Coordinating Committee in 2010, side-by-side with Autism Speaks’ chief science officer Geraldine Dawson.²¹

The above highlights a number of significant tensions – there are real divisions within autistic communities over the validity and desirability of using functioning-level

¹⁹ Diament, “White House Remains Steadfast In Support Of Disability Council Nominee”; Diament, “Senate Confirms Controversial Autism Self-Advocate To National Disability Council.”

²⁰ In contrast, the director of Autism Society of America, Lee Grossman, told the *Times*, “We have this community out there frustrated and bewildered and reaching out for any assistance, and that makes us battle-hardened,” Mr. Grossman said. “We need to reframe the discussion. From our perspective, it’s great to have a person on the spectrum being nominated to this committee.” Harmon, “Nominee to Disability Council Is Lightning Rod for Dispute on Views of Autism.”

²¹ “Secretary Sebelius Announces New Members of the Interagency Autism Coordinating Committee.”

distinctions; there really is an assumption among many who encounter the claims of autistic self-advocates and the rhetoric of neurodiversity that ‘acceptance’ of autism, or acceptance of neurological difference in general, celebrates ‘natural variation’ but diverts attention from the needs of those who are more significantly impaired and dependent; and there is the practical reality that there really are different degrees (and varying kinds) of need in terms of accommodation, care, and support.

As Dana Lee Baker and Lila Walsh point out, “In policy contexts, spectrums have the power to create conundrums.”²² Indeed, autistic activists often focus on public efforts to define them as dysfunctional and more-or-less ‘functioning’ for very pragmatic reasons. Those designated as low-functioning are constantly in danger of losing opportunities for independence, self-expression, and respect. And those judged high-functioning are in danger of losing support, services, and acknowledgment of their areas of difficulty.

Institutional infrastructures of all sorts – ranging from educational and therapeutic service provision to the distribution of welfare benefits – rely on the affixation of diagnostic labels and the assignment of individuals to disability categories. Baker and Walsh argue that even when there is recognition of the role played by social and political infrastructures in the creation of disability, “the design of most disability policy still turns on the identification of a particular individual as (more or less permanently) having a disability or not.” Spectrums mismatch because, “this reality can be difficult to match to the concept of a spectrum, in that it requires established definitions and agreed-upon cutoff points with regard to what constitutes having a disability.” Furthermore, just as

²² Baker and Walsh, “Divided or Opposed?: The Level-of-Functioning Arguments in Autism-Related Political Discourse in Canada,” 214.

institutions rely on the assignment of disability status, so to do disabled individuals and their care-networks.

The latter point became abundantly clear when the American Psychiatric Association made public their intention to de-list Asperger's from official disorder status in 2010. A range of constituent groups raised anxious questions about whether and how currently diagnosed "autism spectrum" individuals would be included in the new *DSM-5* rubric of consolidated Autism Spectrum Disorder. It re-surfaced the extent to which some who have been diagnosed with Asperger's Disorder are indeed invested in the designation by experts that it is as a form of high-functioning autism, as well as Asperger's relative distinctiveness as an identity associated with technical skill or even genius.²³ At the same time, the prospect of Asperger's or those deemed "high-functioning" no longer qualifying for a *DSM-5* autism spectrum diagnosis made apparent the extent to which many parents of diagnosed children are heavily invested in the disability services model and may have been somewhat less engaged by the cure and disease discussion. It remains to be seen just how much the ground has shifted.

One approach to understanding the emergence of autistic self-advocates as a constituency then, which cannot be easily ignored, would be to locate neurodiversity activists as just another group of combatants in the Autism Wars described in Chapter Two. That sort of offensive and counter-offensive positioning is certainly at work among pro-cure and pro-acceptance/neurodiversity constituencies. According to Singer, "Neurodiversity advocates have definitely succeeded in implementing their agenda... You

²³ See Singh 2011 for a discussion of the salience of the Asperger's diagnosis as basis for positive identity formation and Aspies' anxieties about how sharing the ASD label "with people at the lower end of the spectrum" could create "stigma by association." Singh, "The Vanishing Diagnosis of Asperger's Disorder," 253.

can see it in the strategic plan [of the IACC]—there are more studies focused on higher-functioning adults and the services they need, such as finding employment.” She portrays the distribution of attention and resources as a zero-sum game, “...because we’re reallocating money, not increasing the budget, that means shifting funds away from the needs of lower-functioning children, who need treatments, for example, to help them control self-injurious behaviors.”²⁴ Singer distinguishes between lower-functioning children as necessarily within the sphere of medical intervention and higher-functioning adults as outside, properly in the domain of service allocation and employment support.

Ne’eman can be, at times, decidedly adversarial in his political strategy and rhetoric, as well as adroit in cultivating strategic alliances. Ne’eman’s views may not always appear entirely consistent in the ebb and flow of constant maneuvering and in the extent to which various projects and interventions address the needs and interests of all autistic people equally. But that is not really a reasonable standard with which to evaluate whether his efforts and the work of the Autistic Self Advocacy Network are relevant to individuals throughout the autistic spectrum. To see that the organization seeks to be inclusive of the needs of those considered low-functioning as well as high one need look no further than the wide range of support services advocated, the emphasis on adaptive communication technologies for non-speaking individuals, and the persistent effort to reduce abusive practices in schools and residential institutions.

The problematic of functioning is central to understanding the autism spectrum and the various agendas of autistic self-advocates. But, the problem is, the high-functioning versus low-functioning distinction helps produce an impoverished

²⁴ Lutz, “Is the Neurodiversity Movement Misrepresenting Autism?”.

understanding of the functioning problematic, and it hinders a more nuanced and productive focus on how to address and think well with individuals on the spectrum in ways relevant to their particular, varying circumstances and environments. Just as dominant parent advocacy organizations try to make it appear that a desire for cure is *the* parent position, universally shared, the high- vs. low- distinction is used by pro-cure advocates to make it seem that low-functioning autism must be understood as a disease, often with the implication that high-functioning autistics should be sent on their way to feel satisfied in their difference.

Here, the slip-‘n-slide of *disability* comes into play, with the term used very differently by different actors. Pro-cure advocates see disabling medical conditions affecting individuals, and self-advocates see unjust social conditions and disabling environments. This is the terrain where the distinction between a medical versus social model of disability continues to do important work. While sometimes polarizing, the either/or divisions implicit in social versus medical definitions of disability highlight genuine political and ontological differences regarding how to approach problems of individual and situational functioning.

Neurodiversity: Definitions and Origins

I have only harsh words for those in the media, government, doctors' offices, universities and on blogs and sites who'd have us believe we are bad parents for wanting to wipe away our children's autism to reveal the child underneath. Who think we are simply ignoring the good and the gifts of autism. My girls are gifts. My girls are good. Their autism is a noose around their necks. I've no patience for those who might *tisk tisk* and beg for acceptance...

Kim Stagliano

The Huffington Post, 2012 ²⁵

It's the usual stereotype, "natural variation good, disability bad." Well anyone who believes that, wake up! What you call disability *is* part of natural human variation and always has been. People with easily recognized Aspie skills, or whatever they are called these days, are not the only people of value on this planet... Let me be clear: When I talk about neurodiversity, I mean all neurodiversity.

Amanda Baggs
Ballastexistenz, 2006 ²⁶

When parent-run autism groups appeal to policy makers and research funding bodies, they make frequent reference to "the autism community" as part of their appeal for a seat at the table. At Autreat in 2007, by way of contrast, Ari Ne'eman made a point to draw a sharp distinction between the *autistic* community, composed of individuals on the spectrum, and the "traditional autism community of parents, professionals, and educators."²⁷ In a presentation, entitled "Neurodiversity and the Autistic Community," Ne'eman examined the potential of neurodiversity as both conceptual framework and political opportunity for the autistic community. In his words, "The essence of neurodiversity, or neurological diversity, is the idea that the paradigm of acceptance extends towards racial, religious and other similar differences apply to neurology as well." Ne'eman pointed out that the emergent autistic community had readily adopted Jim Sinclair's earlier assertion that "autism was not an external factor that removed or masked parts of a normal human being, but an intrinsic part of a different kind of human being." And he emphasized the ways that autistic activists had "developed an identity

²⁵ Stagliano, "Autism Sucks and Then We Die."

²⁶ "Temple Grandin Devalues Us Again, In Print This Time."

²⁷ Ne'eman, "Neurodiversity and the Autistic Community."

that should be exceptionally familiar in today's multi-cultural society: a minority group.” Ne’eman described the autistic community’s minority group identity formation as demonstrating strong parallels with deaf culture and post civil rights movement political struggles.

According to Ne’eman, while the basis for neurodiversity lies in the notion of acceptance for neurobiological differences, its political bases emerge from minority group identity and culture forged in the face of stigma and inequality. The most powerful similarities and shared principles exist with the disability rights movement, which Ne’eman asserted, continues to be a more marginalized group compared to the relative empowerment attained by women and ethnic and religious minorities over recent decades. Neurodiversity advocates, at least its autistic proponents, share with the larger disability movement that their struggle for equal rights, as well as their minority group identity, has been inextricably tied to their opposition to the medicalization of their bodies, minds, and identities as damaged individuals. Citing Neurodiversity.com, Ne’eman maintained, “The idea behind ‘curing’ autism is fundamentally opposed to the idea of the autism spectrum and those on it as a natural variation of ‘the variety of human wiring.’” He suggested that since the autistic community had rejected a traditional support group model associated with diseases and chosen a model more associated with cultural and ethnic identities, the stage was set for “a fundamental clash with mainstream autism thinking.”

Thus, the concept of neurodiversity is deeply intertwined with the emergence of autistic identity, culture and community. The autistic community has come to define itself as both distinctive and new but also, in numerous respects, sharing many

experiences and objectives in common with recent histories of collective struggle for individual rights, self-representation, and equal status. In the early 1990s self-advocates developed new ways to connect with each other, increasingly so as the internet became more widely accessible. In 1997, Harvey Blume wrote in *The New York Times*, “In cyberspace, many of the nation’s autistics are doing the very thing the syndrome supposedly deters them from doing – communicating.”²⁸ The formation of autistic culture, at least the specific origins of ANI’s community, occurred offline in the years just prior to the popularization of the World Wide Web. Nevertheless, by all accounts autistic culture really took off and spread rapidly on internet Usenet groups and grew exponentially with the advent of instant messaging, chat rooms, and blogs.²⁹

While the concept of neurodiversity may have first appeared in online discussion groups, Australian Judy Singer introduced the term to academic discourse. Singer at one point claimed to have coined the term neurodiversity while a student at the University of Sydney in her 1998 honors thesis, “Odd People In: The Birth of Community Amongst People on the ‘Autistic Spectrum’: A Personal Exploration of a New Social Movement Based on Neurological Diversity,” in which she uses her family history (with Singer’s

²⁸ Blume, “Autistics, Freed from Face-to-face Encounters, Are Communicating in Cyberspace.”

²⁹ The significance of online communication in the emergence and maintenance of autistic identity, community and culture has received a great deal of attention: Blume, “Autism & The Internet or It’s The Wiring Stupid”; Kenway, “Blessing or Curse?”; Hacking, “Autism Fiction”; Brownlow and O’Dell, “Constructing an Autistic Identity”; Brownlow, “The Construction of the Autistic Individual: Investigations in Online Discussion Groups”; Davidson, “Autistic Culture Online: Virtual Communication and Cultural Expression on the Spectrum”; Kidney, “Involvement in the Online Autistic Community, Identity, Community, and Well-being”; Bertilsdotter Rosqvist, Brownlow, and O’Dell, “Mapping the Social Geographies of Autism: Online and Off-line Narratives of Neuro-Shared and Separate Spaces”; Bierer, “Online Community Building by Autistic Adults.”

mother, daughter, and herself on the spectrum) to theorize new forms of biosociality.³⁰

Subsequently in an essay appearing in the volume *Disability Discourse*, she wrote:

For me, the key significance of the "Autistic Spectrum" lies in its call for and anticipation of a politics of "Neurodiversity". The "Neurologically Different" represent a new addition to the familiar political categories of class / gender / race and *will augment the insights of the social model of disability*.³¹

Singer marked neurodiversity for inclusion along with the category of disability in keeping with “the social model.” At the time of Singer’s writing during the late 1990s, Disability Studies was still early in the process of constituting itself as a recognizable academic field. Singer echoes a claim widely heard in ‘disability theory’ at the time, namely, disability belonged among what was sometimes referred to as the holy trinity of race, class, and gender.³²

Singer’s introduction of neurodiversity to academic discourse is even more visibly a product of that particular moment by how she locates the concept within the post-modern turn. She writes:

The rise of Neurodiversity takes post-modern fragmentation one step further. Just as the post-modern era sees every once too solid belief melt into air, even our most taken-for-granted assumptions: that we all more or less see, feel, touch, hear, smell, and sort information, in more or less the same way, (unless visibly disabled) are being dissolved.³³

³⁰ The precise origins are not entirely clear, as Ortega notes: “The term also appeared in Jane Meyerding’s 1998 ‘Thoughts on finding myself differently brained’, and Singer herself wrote, ‘I am not sure if I coined this word, or whether it’s just “in the air”, part of the zeitgeist (quoted in Meyerding, 1998).’

Singer, “Odd People In: The Birth of a Community Amongst People on the ‘Autistic Spectrum’”; Ortega, “The Cerebral Subject and the Challenge of Neurodiversity,” 431.

³¹ Emphasis added. Singer, “Why Can’t You Be Normal for Once in Your Life? From a ‘Problem with No Name’ to the Emergence of a New Category of Difference.”

³² Arguably ‘sexuality’ was more successfully introduced to critical theory than was the case with ‘disability’ during the 1990s, and included more thoroughly as an axis for thinking “intersectionality.”

³³ Singer, “Why Can’t You Be Normal for Once in Your Life? From a ‘Problem with No Name’ to the Emergence of a New Category of Difference.”

Singer asks whether autism may be the metaphoric disease of the internet age or, more provocatively, not really a “disease” at all but simply another category open to contestation by those who have been *othered* for thinking and perceiving differently. She likened the invention of the internet as having significance for autistic culture similar to sign language for deaf culture. Singer’s formulation of neurodiversity in terms of post-modernity, which she defined as the dissolution of belief and fragmentation of taken-for-granted assumptions, is clearly locatable within a particular discursive moment, which was hardly confined to the halls of the academy.

Harvey Blume’s 1998 write-up in *The Atlantic*, entitled simply “Neurodiversity,” is commonly cited as among the earliest uses of the term.³⁴ Blume anchors the piece with a description of a website he had recently come across, “The Institute for the Study of the Neurologically Typical.” The site describes the neurotypical – or “normal” – person as if they are diseased. Neurotypicals harbor symptoms which can be “characterized by preoccupation with social concerns, delusions of superiority, and obsession with conformity.” The architect of the site, who goes by the moniker of Muskie, explains at the top of the page, “Note: The content of this site is a parody. It is not to be taken literally,” and provides a link that reads, “Help with understanding the humor.” At the other end of the link, there is further explanation for autistic people and others who might be reading the parody with an overly literal filter, indicating that the point is to show how, “by selecting and twisting the facts, medical researchers can portray autistics, who have a *difference* with *positive* as well as negative attributes, as defective individuals and genetic mistakes.” Blume describes the ISNT as an example of the ascendance of

³⁴ Blume, “Neurodiversity: On the Neurological Underpinnings of Geekdom.”

“Information Age geekdom,” asserting, “The site gives geeks space to emerge from the neurological closet and declare themselves to be high-functioning autistic (HFA) as opposed to neurologically typical (NT).” At the time, just prior to the popping of the late-1990s Internet Bubble, it might have been tempting to dismiss Blume’s take on the ISNT as techie froth, geek chic, and the concept of neurodiversity as a facile and fleeting offshoot of “celebrate diversity” pluralism.

However, rather than focusing on multiculturalism as the model for neurodiversity, Blume turned to the biological realm where biodiversity offers the promise of resilience and efflorescence. He concludes, “Neurodiversity may be every bit as crucial for the human race as biodiversity is for life in general. Who can say what form of wiring will prove best at any given moment? Cybernetics and computer culture, for example, may favor a somewhat autistic cast of mind.” The idea that ‘autism genes’ carry evolutionarily significant traits, contributing to hyper focused, systemizing minds, has proven to have a wide appeal, including for many scientists studying the condition.³⁵

A 2001 *Wired* article, “The Geek Syndrome,” developed Blume’s thesis into an investigation of Asperger’s and autism in Silicon Valley, complete with expert scientific

³⁵ The entry for *neurodiversity* on Wikipedia provides a useful overview of neurodiversity as both a concept and social movement: “Neurodiversity is an approach to learning and disability which suggests that diverse neurological conditions appear as a result of normal variations in the human genome. This term was coined in the late 1990s as a challenge to prevailing views of neurological diversity as inherently pathological, and it asserts that neurological differences should be recognized and respected as a social category on a par with gender, ethnicity, sexual orientation, or disability status. Neurodiversity is also an international online disability rights movement which has been promoted primarily by the autistic self-advocate community (though other disability rights groups have joined the neurodiversity movement). This movement frames neurodiversity as a natural human variation rather than a disease, and its advocates reject the idea that neurological differences need to be (or can be) cured, as they believe them to be authentic forms of human diversity, self-expression, and being. These advocates promote support systems (such as inclusion-focused services, accommodations, communication and assistive technologies, occupational training, and independent living support) that allow those who are neurologically diverse to live their lives as they are, rather than being coerced or forced to adopt uncritically accepted ideas of normalcy, or to conform to a clinical ideal.” “Neurodiversity.”

opinion and statistics showing elevated rates of autism diagnosis among children living there, drawing on the hypothesis that the tech-centric environment fosters assortative mating among hyper-systemizing brain types.³⁶

Formal definitions of neurodiversity are making their way into clinical and research literatures. For instance, the *British Medical Journal* describes neurodiversity thus, “The term neurodiversity refers to the variety of non-debilitating neurological behaviours and abilities exhibited by the human race.”³⁷ The concept of neurodiversity is generally described in terms of the need for society to recognize “atypical neurological wiring” as a normal and acceptable part of human difference that is worthy of respect, inclusion, and even cultivation. Increasingly it has been used to encompass a broader range of conditions outside the autism spectrum, including conditions like epilepsy, Tourette's syndrome, dyspraxia, ADHD and dyslexia. The website *Neurodiversity Now* defines the concept as the inclusion of neurological diversity as a category of human difference: “The term Neurodiversity is an inclusive concept... everybody is part of diversity, whether they are in the majority or the minority, the 'normal' or the 'special'. There are no accidents in nature... only possibilities.”³⁸ Neurodiversity may or may not prove to be a term that endures the test of time, but just like the concept of the autism spectrum it is now part of both public and academic discourses.

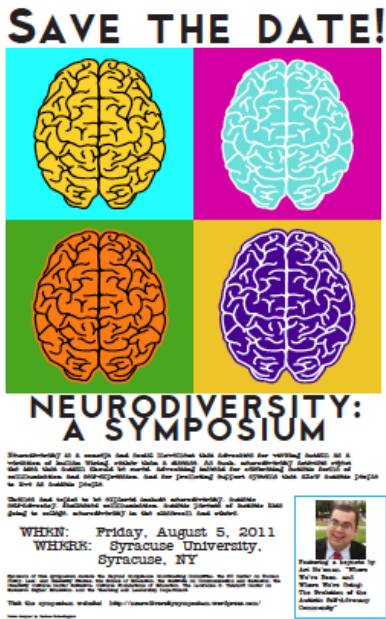
In 2011, Syracuse University held the first in a planned conference series, entitled The National Symposium on Neurodiversity. Promotional material suggested that neurological differences are to be recognized and respected in the same manner as any

³⁶ Silberman, “The Geek Syndrome.” See also Baron-Cohen and Hammer, “Parents of Children with Asperger Syndrome”; Baron-Cohen, “The Hyper-systemizing, Assortative Mating Theory of Autism.”

³⁷ “Minerva.”

³⁸ Cited in “Neurodiversity, the Concept.”

other human variation: “Neurodiversity is a concept and social movement that advocates



for viewing autism as a variation of human wiring, rather than a disease. As such, neurodiversity activists reject the idea that autism should be cured, advocating instead for celebrating autistic forms of communication and self-expression, and for promoting support systems that allow autistic people to live as autistic people.”³⁹

In conjunction with the text, the poster art seems to dance along a neuro-imaginary where color re-coded brain scans promise revelation of different human

kinds, which, unfortunately, have been misconstrued as pathological by biomedicine. Ari Ne’eman’s image appears in the lower right corner to advertise his participation as keynote speaker.

As can be seen in the text and imagery, there is a strong emphasis on the legitimacy of autistic difference as a form of natural variation in human wiring. On the other hand, while generally used to describe atypical neurologies, the concept of neurodiversity is also routinely employed to denote an ethos of acceptance more generally, often with lesser emphasis on a notion of specific, or fixed, biological configuration. The neurodiversity described in the Syracuse Symposium is recognizably the same concept and movement described by Judy Singer and Harvey Blume more than a decade prior. However, notably, despite explicit reference to promoting support systems for autistic people the framework of disability goes unmentioned. The question

³⁹ “National Symposium on Neurodiversity at Syracuse University.”

is, does this reflect an omission by the university organizers or by the “neurodiversity activists” they seek to represent and include at the conference? Or, alternately, is disability’s near total absence here a reflection of the way neurodiversity problematizes a common sense that keeps the category of disability separate from (normative) notions of positive difference?

Neurotalk and Critique

“The interest in the neurological basis of individual and social behaviour has... generated a considerable number of 'neurologisms' — new terms for the complex and varied phenomena arising at the intersection of brain science and society — including neuroethics, neuromyths, neurorealism, neuromarketing and neurotalk. Some of these terms, such as neurotalk and neuroethics, bring ideas for a dedicated new practical and scholarly effort to the foreground. Others, such as neurorealism and neuromyths, highlight how the seductive allure of neuroscience explanations can confer an unwarranted sense of objectivity based on the general hype that surrounds contemporary science and technology.”

Judy Illes et al.,
Nature Reviews Neuroscience ⁴⁰

In academic literatures, the autistic rights movement, and neurodiversity advocates in particular, face criticism of two principal varieties, raised both as grounds for concern and grounds for dismissal: 1) self-advocates are deemed to be engaged in a bio-centric, essentializing discourse and/or to have followed overly narrow (or misguided) goals and aspirations associated with identity politics; and, 2) the supposed lack of consideration for the needs of low-functioning individuals diagnosed with autism, combined with the suggestion that high-functioning autism reflects an illegitimate outgrowth of an overly-inclusive spectrum. As shown above, criticism from both parents and experts immersed in autism biopolitics tend to focus on the latter point. Concerns

⁴⁰ Illes et al., “Neurotalk.”

about biological essentialism and identity politics more often emerge from scholarly assessment of the political and ethical stakes.

For example, Chloe Silverman explains that self-advocates define their experience as significantly divergent from that of neurotypicals, using language that suggests profound differences to a degree that gives the impression that autistics might be akin to a distinct and foreign species or, at minimum, a human kind clearly distinct from the neurologically typical. Silverman notes that a biopolitics of neurological diversity is subject to criticism similar to that leveled at essentializing discourses, generally. She argues that, if taken to an extreme, neurodiversity positions autistics “as members of a distinct species of human to which our obligations and responsibilities might be different. We need to be careful to pay attention to the ways that ideas about the biology of autism are reproduced and reinforced through medical literature, clinical and self-help books, and even support groups.”⁴¹ Theoretical and ontological stakes of a certain sort become central when autistic identities and neuro-politics are defined in terms of their potential for re-enforcing essentialism and biologism.

The work of Francisco Ortega and Suparna Choudhury illustrate how the efforts of autistic self-advocates have been characterized as reproducing an essentializing and positivistic neurobiological discourse. In particular, they are skeptical of the manner in which activists have found that “the prestige of the neurosciences supports their positive judgment about autistic neurodiversity as a value and as a scientific fact.”⁴² They use neurodiversity as a negative case example for what can emerge from a new

⁴¹ In my view, autistic community and culture long ago overflowed the bounds of the more narrowly defined formulations of “self-help” and “support groups.” Silverman, “Fieldwork on Another Planet: Social Science Perspectives on the Autism Spectrum.”

⁴² Ortega and Choudhury, “‘Wired up Differently’,” 335.

“neurorealism” and “neuro-essentialism,” or, the equation of subjectivity with the brain and brain-based knowledge about “true selves.”⁴³ They argue that neurological explanations have been mobilized in order to “obliterate differences within the autistic movement” and “to homogenize the entire autistic identity,” as well as to erect artificial barriers to set themselves apart from the neurotypical population. They express dismay about “the typologizing of brain difference” and the negative effect of understanding themselves as “kinds of brains,” which Ortega and Choudhury view as a new form of identity politics that both naturalizes difference and erects “identity frontiers.” According to this critical reading, both identity frontiers and emphasis on bodily differences are at minimum suspect.

Ortega and Choudhury do not seek to cast blame, necessarily, and explain that social legitimacy and, particularly in the US political economy of health care, access to services depend on the status afforded to a particular illness’s somatic basis. And while they acknowledge that self-advocates have employed neuroscientific discourse to counter stigma, to resist being pathologized, and as a basis for new forms of social community, they critique the manner in which self-advocates articulate “the neurologization of autism.” They worry at some length about self-advocates’ enthusiasm for redefining autism “in terms of a *real* cerebral difference,” and how “neurological explanations are mobilized by some radical activists to foster a radical identity politics.” Near the conclusion, they warn, “However, it is worth asking if, even though seeing oneself as a

⁴³ Neurodiversity activists and discourses are contrasted with the views of adolescents who are, according to the authors, more reluctant to accept “neurological identities” or neuroscientific figurations of ‘the adolescent’ and the idea of “the teen brain” as a monolithic entity. Adolescents and autistic self-advocates are contrasted as “two categories of people who constitute important objects of study in current work in cognitive neuroscience and psychiatry” which often are “using the same experimental paradigms pertaining to executive functions and social cognition.” Ibid.

cerebral subject bolsters one's sense of identity and helps erase the social stigma often associated with mental pathology, whether, on the other hand, it somewhat solipsistically narrows the notion of what it is to be a person." In a prior article, Ortega characterized the neurodiversity movement as engaged in "reductionist identity politics," employing "a solipsistic and reductionist ideology that turns humans into cerebral subjects."⁴⁴ It is clear that the neurodiversity example is presented mostly as a cautionary tale.⁴⁵

The second thrust to the criticisms leveled at neurodiversity activists is that the movement is composed entirely (or mostly) of high-functioning adults, who do not address the needs of more severely autistic people, especially children, and frequently, the implication that self-advocates are *not really* autistic or genuinely disabled. Ortega and Choudhury write:

Neuroscience serves not only to erect a real barrier between autistic and non-autistic populations. The flipside is that this brain discourse is also mobilized by self-advocates to homogenize the entire autistic identity, in spite of the fact that autism is increasingly understood as a spectrum consisting of low- and high-functioning autistic traits and present not just in 'diagnosed' individuals but in the whole population.⁴⁶

⁴⁴ Ortega, "The Cerebral Subject and the Challenge of Neurodiversity," 242.

⁴⁵ Ortega and Choudhury approvingly cite Judy Singer, the early proponent of neurodiversity, who later denounced the term for contributing to "the dark side" of identity politics, neglecting to mention that she does so on the basis of a decidedly neuroessentialist vision of autism's "dark side." Singer speculates about "autistic villains" and "autistic bad guys," expressing that "not all Nature's experiments are inherently good," and "that there may be innate neurological causes" for the existence of "people who are not wired for empathy." She includes a list of autism-like symptoms for Hitler, Eichmann, and Neitsche (sic.). In this light, it would seem Singer's later reflections on "neurodiversity" are more supportive of a critique of the dangers of excessive reliance on neurological explanations for human behavior in general, rather than for how they are used to support an identity politics, per se. But Ortega and Choudhury cite Singer in a way that casts autistic self-advocates in a fairly damning light, writing, "While adolescents focus on the 'darkness' – the homogenizing effect, the negative characteristics and the removal of their sense of responsibility, the autistic self-advocates tend to neglect such tensions and the fact that, as Singer (2007) points out, 'not all is for the best in this brave new world that the "neuroscience revolution" delineates'." Ortega and Choudhury, "'Wired up Differently,'" 336. Singer, "Light and Dark: Correcting the Balance."

⁴⁶ Ortega expresses the critique more forcefully in the 2009 article, where he criticizes "the aggressive identity politics advanced by the radical activists of the autistic movement, who appropriate the right to speak in the name of every person diagnosed with autism... It would be hypocritical to subsume all

Part of the concern here is that difference is flattened within the spectrum, just as too firm a boundary is drawn between autistic and neurotypical populations, as part of a “reductionistic identity politics.” But the quote also suggests the most pervasive and enduring criticism – persistent across social scientific, biomedical, and advocate analyses of the emergence of autistic self-advocacy – namely that autistic rights claims and activists’ adoption of a model of neurodiversity are significantly weakened, or only narrowly relevant, due to the over-representation of high-functioning individuals and their supposed disregard for the needs of severe, low-functioning autistic individuals. Ortega and Choudhury continue: “For the self-advocates the homogenization within the spectrum of autism constitutes an important political move that would counter the critiques of parents and professionals who accuse them of speaking in the name of ‘all’ the autistics and of forgetting that they are at the high-functioning end of the spectrum.”⁴⁷ There appears to be here, and commonly found elsewhere, the hasty assumption that self-advocates, collectively, are strategically “forgetting” their place on the spectrum in order to speak for all autistics – without adequate attention to what autistic rights activists have actually been saying, nor the ways in which the autism spectrum and autistic functioning resist easy divisions, whether considered as a conceptual matter or biological substrate or the conditions of everyday living.

Bioethicists, too, have weighed in with similar concerns. For example, Jaarsma and Welin evaluate the claims of neurodiversity activists in terms of their legitimacy as a

forms of the autistic continuum under the ‘high-functional’, and then happily consider that autism is a lifestyle.” Ortega, “The Cerebral Subject and the Challenge of Neurodiversity,” 427.

Ortega and Choudhury, “‘Wired up Differently’,” 232.

⁴⁷ Ortega and Choudhury, “‘Wired up Differently’,” 232.

basis for depathologization and how they measure up as a minoritized group.⁴⁸ Taking up the comparison between the potential depathologization of autism with the analogy of the depathologization of homosexuality, they write:

In a homophobic society nearly all homosexuals will appear pathological. The cure for these problems has simply been a wider acceptance of homosexuality. We should expect that many autists in a similar way have psychiatric and psychological problems due to the “autism-phobic” character of present society. In similarity with homosexuals most of the problems for high-functioning autists may be due to social conditions. To say that these people have a mental disorder because of the consequences of their condition is in a sense blaming the victim. The consequences of their condition are perhaps for a very important part the result of society’s reaction to their condition.⁴⁹

Jaarsma and Welin are fairly accurate in their portrayal of how the analogy of the struggle for gay rights has been used as the basis for civil rights claims and in their characterization that autistic self-advocates view social stigma and institutional bias as hostile to their way of being and behaving. They are also correct when they claim, “...if autists have an IQ in the normal range (or above), they usually are said to have high-functioning autism (HFA).”⁵⁰ The division above and below an IQ of 70 remains standard practice for the low-functioning versus high-functioning distinction both in the categorization of research subjects and for epidemiological purposes. IQ continues to be a powerful psychometric instrument that reinforces the common-sense of a singular continuum bisected by a high-functioning/low-functioning division.

⁴⁸ For critiques of self-advocate claims for the integrity of autistic identity, see for example: Fenton and Krahn, “Autism, Neurodiversity and Equality Beyond the ‘Normal’”; Barnes and McCabe, “Should We Welcome a Cure for Autism?”; Sorell, “Disability Without Denial”; Barnbaum, *The Ethics of Autism*; Russell, “Reflections on ‘Autistic Integrity’.”

⁴⁹ Jaarsma and Welin, “Autism as a Natural Human Variation: Reflections on the Claims of the Neurodiversity Movement.”

⁵⁰ Ibid.

Jaarsma and Wellin, however, make the common mistake of claiming that autistic self-advocates as a group reject the idea that autism is a disability.⁵¹ They assert the following:

The high-functioning autists that do not need care live happily in the knowledge that they are freed from the burden of having a deficit and may have a better life with non interference. But it may not be so good for low-functioning autists or even high-functioning autists that do need care. Acceptance does not ‘cure’ difficulties with social relationships, social communication, rigidity and sensory issues.⁵²

On these grounds the authors support only a “narrow version of the neurodiversity claim,” because, “It is clear that people with low-functioning autism are extremely vulnerable and their condition justifies the qualification ‘disability.’” On the other hand, they find that, “in the case of high-functioning autists, society should not stigmatize these persons as being disabled,” which they equate with deficit-based labeling.⁵³ In other words, the authors miss the point self-advocates make about the way disability and stigma work entirely. And thus, bioethicists add their voices to the critical assessment of self-advocates’ claims to legitimacy, self-definition, and social worth as they appropriate and subvert both research findings and popularized neurotalk.

⁵¹ The authors struggle with how to conceptualize the role of social environment and the stigmatizing effects associated with notions of pathology, disability, deficit, difference, and natural variation. For example, they parenthetically note: “(Lower-functioning autism is also part of natural variation but may rightly be viewed as a disability.)” Nevertheless, they ultimately conclude: “It is not fair to place the locus of the problem solely on the autistic individual. What also is needed is a discourse about the detrimental effects of an autism-incompatible and autism-phobic society on the well-being of autists. Therefore, in the case of high-functioning autists, society should not stigmatize these persons as being disabled, or as having a disorder or use some other deficit- based language to refer to these people.”

Ibid.

⁵² Ibid.

⁵³ Ibid.

Critical Autism Studies

The co-editors of *Worlds of Autism*, Michael Orsini and Joyce Davidson introduce the volume as a way of articulating an emerging “critical autism studies.”⁵⁴ Nadesan’s *The Social Construction of Autism* published in 2005 is identified as a forerunner for what has become a domain of study. The literatures that I describe above as critical of biological essentialism influence Nadesan’s work as well as my own. What I am marking here is the particular way that the majority of writing originating from the humanities and social sciences since Nadesan, expresses concern about how autistic people have embraced a biological discourse to emphasize genetic and neurological difference. Nadesan argued that such a model “is simultaneously divisive and affirmative in its representation of autistic difference.”⁵⁵ A worry expressed consistently is that it is somehow unfortunate that autistic actors tend to essentialize themselves as “ontologically different beings,” with self-knowledge undergirded by the neurological foundations of behavior and rooted in *biological facts* or “facts,” with varying degrees of emphasis on the scare quotes and italics.⁵⁶

Michael Orsini has written insightfully about autistic subjectivities and their productive tension with theories of biological citizenship. Similar to the analytic take I

⁵⁴ When it is useful to refer to a body of work, I prefer the more general frame of “critical studies of autism,” rather than naming a new domain of study as Critical Autism Studies in its own right. I think the stakes are different than for the broader domain of Disability Studies, which is after all still an emerging field. Davidson and Orsini, *Worlds of Autism*.

⁵⁵ Nadesan, *Constructing Autism: Unravelling the “Truth” and Understanding the Social*, 208.

⁵⁶ *Ibid.*, 209. See for example: Baker, “Neurodiversity, Neurological Disability and the Public Sector: Notes on the Autism Spectrum”; Bagatell, “Orchestrating Voices: Autism, Identity and the Power of Discourse”; Boundy, “Are You Sure, Sweetheart, That You Want to Be Well?: An Exploration Of The Neurodiversity Movement”; Bumiller, “Quirky Citizens: Autism, Gender, and Reimagining Disability”; “From Cure to Community”; Caruso, “Autism in the U.S.”; Straus, “Autism as Culture”; Brownlow, “Re-presenting autism”; Baker, *The Politics of Neurodiversity: Why Public Policy Matters*; Barry, “Gray Matters.”

adopt with this dissertation, Orsini places in the foreground how the autistic movement took shape as a “fledgling movement” with strong ties to, but also deep tensions with, an autism movement more shaped by evolving concerns articulated by autism parents, researchers, educators, and clinical professionals. He too examines autistic self-advocacy and self-fashioning as deeply enmeshed in and co-constituted by an over-abundance of discourse focused on “the autism crisis” and “autism epidemic.” Orsini explores the manner in which “the autism wars” have pitted parents of autistic children seeking access to treatment/therapy against autistic self-advocates, as exemplified in a controversial Canadian Supreme Court decision in 2004.⁵⁷

Orsini views biological citizenship as it relates to autistic subjects as “studded with contradictions,” but offers a more generous take, recognizing, “It is at once empowering and affirming to find others who share your neurological distinctiveness, and to build the requisite networks of mutual support.”⁵⁸ In Orsini’s rendering, there is more space for the work autistic subjects are doing to reclaim what Goffman termed a “spoiled identity” and the excessive pathologization of non-normative difference. But Orsini joins Majia Holmer Nadesan in her concern about reification of social divisions *vis-à-vis* biology. However, one gets the impression from some writing in the loosely

⁵⁷ Orsini focuses on the involvement of autistic advocate Michelle Dawson in the case, which overturned two lower court decisions, finding that provincial governments were not required to fund Applied Behavioral Analysis as “a medically necessary” treatment under the principles of the Canada Health Act and the rights enshrined in the Canadian Charter of Rights and Freedoms. Orsini provides a thorough analysis of what is a fascinating case, making ample use of provocative claims made by Dawson, which Orsini draws both from her role as formal “intervener” in the case, as well as from her blog, autismcrisis.blogspot.com. For a period in the mid-2000s, the case and Dawson’s involvement led to numerous flare-ups between autistic rights advocates and parent advocates. Orsini, “Contesting the Autistic Subject: Biological Citizenship and the Autism/Autistic Movement,” 115. See also: Orsini, “Autism, Neurodiversity and the Welfare State: The Challenges of Accommodating Neurological Difference.”

⁵⁸ Orsini, “Contesting the Autistic Subject: Biological Citizenship and the Autism/Autistic Movement,” 127.

defined domain of critical studies of autism, such as Orsini and Nadesan, that they are more attempting to defend self-advocates against the inevitability of the accusation of essentialism.

Francisco Ortega, the major critical analyst of neurodiversity and neurotalk discussed earlier, makes a direct contribution to the formation of a critical autism studies in the *Worlds of Autism* anthology.⁵⁹ Again he focuses on the movement's use of "popularized neuroscientific 'facts'" and the "cerebralization of autistic culture" as an example of the risks associated with "brain-based subjectivization."⁶⁰ He offers illuminating observations about the ways that neuro-discourse has been mobilized and notes its tactical usefulness as a means to challenge "degrading and deficit-focused" constructions of autism and autistic subjectivities. In this version, Ortega makes more room to acknowledge the ways in which self-advocates engage in "a cohabitation of everyday ontologies," where "individuals shift ontological registers, expressing a coexistence of views and practices of the self."⁶¹ However, the primary analytic frame is driven by what he argues is the need to "critique the so-called critical discourses," including "the possible shortcomings of so-called emancipatory discourse within the autistic self-advocacy movement," in order to ward off the recurrent ills of "reductionist forms of identity politics."⁶² In this piece, too, Ortega worries that neurodiversity activists may ultimately "solipsistically constrict what it means to be human" and "solipsistically narrow the notion of what it is to be a person." He remains dubious about

⁵⁹ *Worlds of Autism*, edited by Orsini and Davidson, is probably the most significant humanities and social science anthology to focus on autism since the 2007 publication of *Autism and Representation*. *Worlds of Autism* focuses considerably more attention on autistic self-advocacy and neurodiversity. Osteen, *Autism and Representation*.

⁶⁰ Ortega, "Cerebralizing Autism Within the Neurodiversity Movement."

⁶¹ *Ibid.*, 89.

⁶² *Ibid.*, 76.

the ability of the neurodiversity movement to successfully pursue “collective goals of improving access, accommodations, and acceptance for autistic individuals, as well as to challenge predominant degrading narratives of autism.”⁶³ But I find myself dissatisfied with what is offered as an alternative.⁶⁴

Ortega favors an “anti-identity politics” over “an identity politics that mobilizes brain metaphors to erect and naturalize identity frontiers, stressing the radical heterogeneity of autistic and nonautistic people and contributing to their mutual otherness and alien feeling.”⁶⁵ He argues that autistic identity politics paradoxically reinforces the very biomedical discourses that they seek to criticize and it “draws on neurology to justify and naturalize differences between autistics and neurotypicals, precluding intragroup differences.”⁶⁶ This mode of critique does not encourage further investigation of the many instances where self-advocates are engaged in critical thinking about many of the tensions identified by Ortega. He notes that Jim Sinclair and others have condemned anti-neurotypical prejudice, but moves on quickly to assert that “these identitarian ambivalences are frequently ignored by radical activists.”⁶⁷ The assertion

⁶³ Ibid., 88.

⁶⁴ It should be acknowledged that, despite his misgivings, Ortega seeks to affirm significant aspects of what self-advocates are attempting to accomplish. There are intriguing and critical tensions evident in Ortega’s argument that cannot be addressed adequately here. For example, he raises a number of important questions, such as, “Yet how can autistic people struggle against an oppression based on the category without using the very same category and organizing themselves around it?” Very much to the point. Ibid., 76, 87.

⁶⁵ Ibid., 88.

⁶⁶ Ibid., 86.

⁶⁷ In a footnote, Ortega quotes Amanda Baggs, which he found in another academic text: “I don’t fit the stereotype of autism. But who does?...The definition is so fluid and changing every few years.” Ortega proceeds to say, “It is one thing to state that autism categories and diagnostic labels are changing, problematic, or degrading,” but, he opines, “It is another thing to infer from the first issue that differences across autistic populations do not exist, and to declare autism as an alternative form of life, thereby negating the reality and suffering imposed by the impairment on individuals diagnosed and their families.” It seems to me that there is a leap in logic here, but more importantly, in my view,

may in fact be true on one level, but it does not encourage discovery of how consistently prominent autistic self-advocates have raised concerns regarding out-group hostility, as well as strongly resisted efforts to police in-group boundaries and restrict who is “autistic enough” for inclusion on the neurodiverse spectrum. Ortega suggests autistic identity politics seem to ignore the adage cited regularly by Ian Hacking, “If you know about one autistic person, you know about one autistic person,” without taking enough time to reflect on how such an adage came into common usage to begin with.

Instead, what Ortega advocates is “Hacking’s ‘narrative’ approach [which] draws on self-testimonies and autobiographies to establish a bridge between autistic and neurotypical populations (and to dismantle the ‘alien’ trope used by both autistics and NTs to refer to each other) and to stress the radical heterogeneity within the autistic population.”⁶⁸ The irony is that despite the theoretical contributions derived from Hacking’s “narrative” approach it is built on the backs of autistic self-testimonies and autobiographies but since, to my knowledge, Hacking does not consider himself autistic, what Ortega suggests as an alternative to autistic identity politics is for a non-autistic interpreter to make better use of autistic life stories. The additional irony is that the organization of autistic gatherings and the formation of autistic online use-net groups were spurred in large measure by the tendency for parent led and professional organizations to only make space for autistic voices to be heard as what Sinclair refers to

is that he grossly mischaracterizes the thrust of Baggs’ writing to yoke her statement to this argument in such a manner. *Ibid.*, 85, 87, 90–91.

⁶⁸ Ortega, like Hacking, does not give sufficient credence to the ways the alien trope itself has served as a kind of bridge – and invitation – to understanding across otherness. *Ibid.*, 86.

as “self-narrating zoo exhibits.”⁶⁹ In other words, the trouble Ortega sees with autistic identity politics assumes its current form, in part, because autistic individuals felt the need to create venues where their perspectives and critical thinking would be shared and valued. That history is one of the reasons “we” need to stick with this trouble but there are other reasons as well.⁷⁰

I am laying out my concerns in some detail because in numerous respects these evaluations of cerebral subjectification authored and co-authored by Ortega can be viewed, and have been viewed, as analytically strong and productive; they do raise legitimate concerns and reveal important tensions. To be clear, I am not suggesting that non-autistics should avoid critical analysis of the political potential expressed through the language of neurodiversity or raise questions about the possible harms that can come with particular enactments of neurological subjectification. Not at all. For example, I very much appreciate Ortega’s idea of a cohabitation of everyday ontologies, and I believe it resonates very well with Scott Vrecko’s notion of folk neurologies.⁷¹ However, I want to point out an historical, ethical, and ontological imperative to accept autistic presences as they come, which, to some extent, means that they be allowed (or even encouraged) to redefine, renegotiate, and refashion themselves in their own ontological terms and redefine autistic paths of becoming which better reflect their own choices and sense-making. The emergence of organized self-advocacy and the making of neuro-identity

⁶⁹ Sinclair, “Being Autistic Together”; Sinclair, “Autism Network International: The Development of a Community and Its Culture.”

⁷⁰ There is not sufficient space here for me to disentangle how Ortega’s “anti-identity politics” has both points of overlap and difference with critical analyses of neuro-essentialism and diversity discourses more firmly grounded in disability theory and the multiple histories of disability rights movements. See for example: Mallett and Runswick-Cole, “Commodifying Autism: The Cultural Contexts of ‘Disability’ in the Academy”; Strauss, “Autism as Culture”; Davis, *The End of Normal*.

⁷¹ Vrecko, “Folk Neurology and the Remaking of Identity.”

claims to respect disability as legitimate natural variation, as well as their evolving senses of what it means to be autistic, are of course assumed in relation to and in engagement with the neurotypical world.

Ortega's work is noteworthy not for a failure of critical thinking – quite the contrary. I am focusing on it here because it illustrates a common set of theoretical pre-occupations, which tend to make visible certain possibilities, certain realities, and not others. I am arguing that to approach in a mode of critique limits the conditions of possibility that might enable the hearing of previously unimaginable insights and critical interventions which autistic self-advocates are sharing – sharing with each other and, more often than not, attempting to share with parents, professionals, policy makers, and wider neurotypical publics. Listening carefully to how self-advocates are re-occupying lives on the autistic spectrum does not mean we have to agree with the positions taken in a politics of neurodiversity, but it does require that we do not react judgmentally, including to what some might consider essentializing moves or reductive distinctions based on neurological wiring. I am suggesting, similar to Orsini and Davidson, that a rather more intricate neuro-cultural kaleidoscope is on display.⁷²

Charlotte Brownlow and Lindsay O'Dell's "Autism as a Form of Biological Citizenship" follows Ortega's chapter in *Worlds of Autism*.⁷³ They also examine how

⁷² Davidson has suggested a provocative re-conceptualization of autistic communication differences in Wittgensteinian terms of "language games;" autistic associations and individual identifications as "family resemblances;" and the articulation of 'new' neurological minorities in terms of a new "form (or forms) of life." In a later co-authored piece, Davidson takes up the proposition that autistic actors may actually "travel in parallel" sensory geographies, or at minimum, it is important to "attempt to understand and appreciate sensory diversity in, and on, authors' own terms." Davidson, "Autistic Culture Online: Virtual Communication and Cultural Expression on the Spectrum"; Davidson and Henderson, "'Travel in Parallel with Us for a While'."

⁷³ Elsewhere, Brownlow and O'Dell explore autistic identity and autistic community as a negotiated, interactional formation that takes shape in the context of shared ideas about friendship and kinship, and

self-advocates make use of neurobiological explanations of autism in the context of NT/AS binaries (neurotypical opposite autism spectrum). It is a nuanced analysis of autistic advocates as engaged with the tools of biological citizenship, as well as biopower, which cannot be easily encapsulated here. However, in contrast to Ortega, Brownlow and O'Dell argue, "Rather than framing biology and neurology as a reductionist tool...we propose that the biological and neurological elements *need* to be foregrounded in discussions of the positioning of autism."⁷⁴ They continue, "Constructing NTs as 'strange' and problematic by implication can enable people with autism and their advocates to understand autism in a positive, enabling way."⁷⁵ It is worth taking stock of a few of the authors' important analytic lenses, foci, and emphases, including: their incorporation of observational research from four online discussion groups (two for diagnosed individuals, one for parents, and one for professionals who support families); their stress on how much group discussion focuses on the "strangeness" of NTs and a concomitant challenge to the presumed normalcy of NTs; their engagement with ongoing efforts to retheorize "the social model" of disability, in particular the emphasis on impairment as separate from disability and the biological from the social; and their attention to the frequency with which autistic activists are confronted with accusations of "not being autistic enough."

Brownlow and O'Dell make fine strategic use of relevant theoretical tools, for instance, their incorporation of Rose and Novas's specification of informational

through active social networking in specific spaces of becoming, both online and offline settings for education, care, and work. Bertilsdotter Rosqvist, Brownlow, and O'Dell, "Mapping the Social Geographies of Autism: Online and Off-line Narratives of Neuro-Shared and Separate Spaces."

⁷⁴ Emphasis mine. Brownlow and O'Dell, "Autism as a Form of Biological Citizenship," 101.

⁷⁵ Ibid., 102.

biocitizenship, rights biocitizenship, and digital biocitizenship. Hacking's work is engaged in an unusually productive fashion, particularly the use of a quote, which reads in part, "In a sense, we have more biologies to choose from than we anticipated."⁷⁶ And yet, for my purposes here, it is important to also point out that, amidst all this lively and generous engagement, there is still evidence of a nagging worry about the expediency of conceptualizing autism in terms of NT/AS dualisms. More than once, they link the tendency to designate "dichromatic difference" with the construction of "two separate worlds: the NT world and the AS world." They also distance their analysis from a "biologized understanding," and they insist that they "have drawn on 'biology' and 'neurological functioning' as discursive products rather than inescapable facts."⁷⁷ Of course, as should be clear by now, my point is that these authors are certainly not alone in these pre-occupations.

From my vantage point, I would be more interested in seeing Brownlow and O'Dell trouble the evident but unanalyzed bifurcation of functioning on the autism spectrum, which is in tension with their interest in the potential to breakdown the NT/AS binary through "the construction of a single, neurodiverse world in which everyone falls on a spectrum of neurological functioning."⁷⁸ I am flagging their emphasis on a single world model, even one that defines itself as neurodiverse, as well as their preference for "a singular spectrum of functioning," partly out of concern for the possible explanatory limitations associated with a singular model, but also because of the probability that autistic actors would (still) not have the same ability as neurotypicals to resist the

⁷⁶ Ibid., 110.

⁷⁷ Ibid., 112.

⁷⁸ Ibid., 111.

tendency for certain kinds of neurologies/bodies to get stuck at the less desirable end of the spectrum. In other words, a spectrum of functioning that is conceived as singular, and which is defined in terms of individual brains/capacities, inevitably presents a less limiting problematic for neurotypicals compared to the more tenuous claims to full personhood that are available to people diagnosed with autism.

Parents and Autistics in Academic Spaces: New Critical Perspectives

Writers in the academy both take up the discourse and politics of neurological diversity as an emergent concept and social movement and, understandably, to explore its relevance in relation to their existing theoretical preoccupations. As Chloe Silverman noted in 2008, “The idea of autism – as a metaphor, a neurological disorder, a mental state, an increasingly prevalent diagnostic category, or a species of neurological difference – has an almost ready-made appeal for social scientists, concerned as they are with questions of human identity, difference, perception, and subjectivity within a social and cultural context.” The critical autism literature, perhaps not unlike that of the wider and still-taking-root field of disability studies, draws heavily from the perspectives of those with personal connection to the phenomena being examined. From the outset, many of the most notable contributors have come from parents of autistic children for whom the themes of self-advocacy and neurodiversity resonate (Grinker, Murray, Nadesan, Savarese, Chew, Klar, etc.). Increasingly, autistic writers are also finding ways to contribute to the academic literature, in part as a result of an autism spectrum diagnosis no longer being viewed as incompatible with academic credentials. Important contributions to scholarly journals and anthologies have come from Dawn Prince (formerly Prince Hughes), Phil Shwarz, Jim Sinclair, Dora Raymaker, and Ari Ne’eman

among others. In 2010, a special issue of *Disability Studies Quarterly*, edited by pro-neurodiversity autism parents Ralph and Emily Thornton Savarese, allotted a significant amount of space to sharing autistic voices and autistic thinking, both from individuals with and without formal academic credentials.⁷⁹

I incorporate more contributions of autism parent scholarship elsewhere, but here I will briefly touch on Ralph Savarese's writing, for the reason that he has shown a particular affinity for neurodiversity inspired themes and the rich potentiality (and productivity) of an autistic poetics. A prolific writer himself, Ralph Savarese has embraced the "neuro-" in both neurodiversity and other neurologically-centered discourses. He offers his own interpretations of autism and provides accounts of what he considers personal encounters with an autistic sensorium and processing, which run the gamut from extraordinary difficulty in everyday tasks to what almost feel like moments of transcendence or sublime illumination. In addition, Savarese has made it a priority to enable autistic-self representation, particularly for his son, DJ, and Tito Mukhopadhyay, described as "an Indian writer in America whom the medical community would describe as 'severely' autistic." He seeks to wed somatic and literary domains, where "the neurological other" has much to teach about their distinctive apprehension of their environment.

Since publication of his memoir, *Reasonable People*, Savarese's writing has become occupied with a proliferation of embodied metaphors and the rendering of autistic inspired, neuro-atypical somatizations.⁸⁰ His adoption of a "philosophy of the flesh"

⁷⁹ Savarese and Savarese, "Autism and the Concept of Neurodiversity."

⁸⁰ Savarese, *Reasonable People: A Memoir of Autism & Adoption: On the Meaning of Family and the Politics of Neurological Difference*.

largely takes for granted “the fact that cognition is embodied, which is to say radically conditioned by physiological systems.”⁸¹ While one gets the sense that Savarese does not hesitate to bring his own interests into the work, he is perhaps unmatched in his enthusiasm for autistic lyricism, and his adoption of a neuro-poetics is filled with autistic presence. Here, there is more than tacit acceptance, as he attempts to facilitate for neurotypicals experiences of non-standard embodiment. At its best, Savarese’s writing depicts the everyday reality of living with profound difficulties, as well as shares both a different sense of relationality and a different way with words.⁸²

Kristina Chew is a Classics professor, prolific blogger, and mother of an autistic child named Charlie whom many would characterize as low-functioning. She is a dedicated autism parent-advocate whose elected function of facilitating her dis/abled son’s engagement with the social world suggests a very different project than the pro-cure advocacy discussed in Chapter Two. Chew describes moments when Charlie demonstrates remarkable agility and facility, such as when he swims amid crashing ocean waves, as well as his, and her, extreme struggle moving through difficult days. In *Worlds of Autism*, Chew writes about the importance of the parent’s (esp. mother’s) role as translator for their child who has communication challenges, as well as how channels of communication may broaden, or perhaps thicken, with intimate knowledge of the person

⁸¹ Savarese, “Toward a Postcolonial Neurology: Autism, Tito Mukhopadhyay, and a New Geo-poetics of the Body.”

⁸² Savarese’s work offers an over-abundance of provocative titles, but the following are my favorites: Savarese and Savarese, “Literate Lungs: One Autist’s Journey as a Reader”; Savarese, “River of Words, Raft of Our Conjoined Neurologies”; Savarese, “Literary Autism by Literary Autistics: Beyond the Destructive Presumption and Paternalism of Neurotypicals”; Savarese, “Moving the Field: The Sensorimotor Perspective on Autism (Commentary on ‘Rethinking Autism: Implications of Sensory and Motor Differences,’ an Article by Anne Donnellan, David Hill, and Martha Leary)”; Savarese, “‘Jostled by Difference’: Ralph James Savarese Responds to Len Gutkin.”

and with careful attunement.⁸³ She acknowledges that her translations are on some level “faulty, even false,” but she nevertheless must translate in order to advocate for him, even though she does not and usually cannot “know exactly what he thinks or wants or would prefer.”⁸⁴ She puts that awareness in tension with the idea that, “bad translations arise when the needs – the mode of signification – of the audience ‘blacks out’ the original intent.”⁸⁵ She maintains that despite the difficulty or even impossibility of fully knowing intent, “translators must make the assumption that their own language can somehow convey the meaning of another one, that there is a kinship of languages.”⁸⁶ In working with Charlie, she also assumes, “first, that he wants to communicate and, second, that he is communicating, albeit in unusual, often behavioral or nonverbal ways.”⁸⁷ Chew’s work points to the simultaneous difficulty, limitation, and necessity inherent in the role of translator. There can be no true verification, Chew says, “a translator, especially if she is working across significant difference, can have only a limited sense of the original *intentio* of the author.”⁸⁸ But she believes the above assumptions, along with attentive engagement and humility, are the best she can manage, faced with the imperative to translate and the desire to attempt adequate, and not bad, translations.

Kristina Chew’s perspective is helpful here for numerous reasons; I will highlight four. First, she prompts us to consider the complex challenges and negotiations associated with the role of parent advocate-translator. Second, she suggests that no matter what our perception of individual limitation, we have a responsibility to presume

⁸³ Chew, “Autism and the Task of the Translator.”

⁸⁴ *Ibid.*, 316.

⁸⁵ *Ibid.*

⁸⁶ *Ibid.*, 315.

⁸⁷ *Ibid.*

⁸⁸ *Ibid.*, 314.

“struggles to be known.” Third, in her role as both parent-advocate and nuanced autistic rights, neurodiversity aligned thinker, she encourages us to resist (a possibly declining) tendency to frame neurodiversity politics in terms of a faceoff between parent advocates of low-functioning children and high-functioning autistic self-advocates. And, fourth, Chew’s sustained contributions speak to the many autism parents who have helped reorient studies of autism toward a more positive (and still critical) appraisal of autistic personhood and self-advocacy.

Scholars openly advocating for themselves as autistic and for an affirming autism politics are becoming increasingly visible. Autistic presences bring new experiences and distinct perspectives to academic discourse. Melanie Yergeau and Scott Robertson are noteworthy autistic self-advocates who earned doctoral degrees in 2011 and 2013, respectively. Their published work, along with that of PhD candidate Steven Kapp, suggest some of the ways that newly minted autistic scholars are bringing a paradigm of autism acceptance and respect for neurodevelopmental difference and disability to their academic work.⁸⁹ Scott Robertson’s personal investment as a self-advocate (and co-founder of the Autistic Self Advocacy Network) are evident in his research foci, which examine strategies for the reduction of cyber and face-to-face bullying. Through his writing, he has also offered proposals for implementing a neurodiversity perspective in order to shift wider research priorities toward improving quality of life, addressing real

⁸⁹ There are numerous other autistic writers and thinkers, both inside and outside the academy, who are making important contributions to theories of autistic sociality, and to social theory more generally. I chose Robertson, Yergeau, and Kapp for reasons related to both their thematic emphases and their timeliness.

life challenges in terms of both strengths and difficulties, as well as the need for researchers and professionals to seek collaborative relationships with autistic adults.⁹⁰

Similarly, the contribution of an autistic advocate's perspective can be seen in Steven Kapp's contribution to the design and evaluation of survey research with results which suggest that, 1) "self-identification as autistic and awareness of neurodiversity reduce neither acknowledgment of deficits associated with autism nor support for ameliorative interventions," countering the common assumption that autistic self-advocates reject the idea of intervention of any sort; 2) even autistic individuals who support the ideal of acceptance for neuro-developmental and neuro-behavioral differences associated with neurodiversity claims often recognize the need for adapting to and blending in with the neurotypical world as a practical matter; and 3) often, parents of children diagnosed with autism benefit from learning about the values associated with neurodiversity, finding ways to develop parenting practices that are both accepting of difficulties and affirming of difference, without abandoning their own sense that there are "negative aspects" to autism (which autistic respondents recognized as well).⁹¹

⁹⁰ Robertson and Ne'eman, "Autistic Acceptance, the College Campus, and Technology"; Robertson, "Neurodiversity, Quality of Life, and Autistic Adults"; Nicolaidis et al., "Collaboration Strategies in Nontraditional Community-Based Participatory Research Partnerships: Lessons From an Academic-Community Partnership With Autistic Self-Advocates."

⁹¹ Kapp and co-authors present a framework of overlap between the medical model, conceived as emphasis on elimination and amelioration, and the neurodiversity model, conceived as celebration and amelioration. According to the authors, "This emerging, nuanced understanding of disability may require disentanglement of symptoms and adaptive functioning and care supporting significantly challenged people, including considering the perspectives, abilities, and opportunities of people with disabilities." Citing the published work of several of the autistic and autism parent experts discussed here, they propose to make room for the legitimacy of multiple perspectives and agendas, as well as the spectrum nature of disability: "Scientists, working with the community, can help stakeholders with competing agendas make informed choices between rights, responsibilities, and needs at personal, social, and political levels by affirming that diverse societies respect multiple perspectives, as empathy, communication, and relationship work both ways." "Deficit, Difference, or Both?"

Another autistic self-advocate, Melanie Yergeau begins and ends her experience-full essay, “Clinically Significant Disturbance: On Theorists Who Theorize Theory of Mind,” by describing to the reader how she was involuntarily committed to the university psychiatric ward during her second week as a new faculty member. She recounts, “...at each moment, as I tried and tried to prove my sanity and humanity and rhetoricity, I found myself deeper within a narrative of neurological determinism. Suddenly, doctors were conferring any and all agency to my supposed disembodiment, or my supposed *disenmindment*.” Embracing her own autistic-ness, then, can be understood as part of a strategy for responding to the reality of being someone at risk in institutionally sanctioned narratives of neurological (over-) determinism. She concludes with the following:

I reflect upon it always, sometimes perseveratively, sometimes echolalically, but mostly perseveratively. I recently dreamed that I was forced into a special education class for assistant professors, my three-inch Autistic Pride button affixed to my backpack, bloodstained and visible. This dream was a waking dream, an unrestful dream, a dream filled with groans and body twitches. The button was how I knew I had a body; the wakefulness was how I knew I had a voice. But that is probably just my autism talking.”

Yergeau foregrounds the possible invalidity of her own utterances as what is always already in question and at stake.

Through the essay’s structure and her own predetermined doubt-able rhetoricity, Yergeau illustrates the circularity of Theory of Mind (ToM): “We know that autistic people lack a ToM because non-autistic people have a ToM; we know that non-autistic people have a ToM because autistic people lack a ToM.” She is caught, she already knows, and she also shows, “Autistic being is predicated on un-being.” Her echolalia doubles back on her repeatedly, possibly assisting in undoing her capacity to be heard as

autistic. She is the ultimate unreliable narrator; “Autistic people are hardly described as having the capability to function as rhetors, interlocutors, or any other descriptor that might confer agency, intentionality, or selfhood onto an autistic body.” In other words, if autism is defined as a lack of theory of mind, any possible demonstration of said theory negates one’s status as autistic, and forces non-persons such as Yergeau into the role of “the ultimate unreliable narrator.” She pits her body-mind-rhetoricity against what is still the reigning psychological theory of autism. ToM denies autistics rhetoricity, author-ity and author-ability: “I am writing this essay, but anyone with a ToM can refute it, can refute *me*.”

With her putative lack of capacity as an autistic to cognize and represent others’ mental states or her own, Yergeau actually offers the reader only one of the many tools available to wield in the undoing of her autistic-self: She is too high-functioning. Too creative. Too independent. Misdiagnosed. But, in my mind, she makes a strong case for the necessity of adopting an *anti-* anti-essentialism. Then again, since what she *is* has already been determined by lack, what she says is easily dismissed. It’s simple really. She can’t really be autistic.

She can’t be autistic. Not really.

Not autistic. Enough.

How I Learned to Stop Worrying and Love Neuro-essentialism

The critical interpretations coming out of the academy are alternatively being buttressed, augmented, and contested by the continued proliferation of autism writing and autistic writing being produced in non-institutional contexts. Memoir and autobiographical writing has been a staple narrative form for both autism parent authors

and autistic authors for some time. The publication of two noteworthy anthologies, *The Thinking Parents Guide to Autism* and *The Loud Hands Project*, suggest that both autistic advocates and autism parent writers, as well as often overlooked *autistic* parent advocates, are organizing to bring carefully honed critical interventions into print after their projects' initial inception in online forums. There are many examples in other media such as documentary film and video, but some that have found their way to a receptive audience in the last few years include: *Loving Lampposts*, *Wretches and Jabberers*, as well as notable earlier contributions such as *Autism is a World*. Blogs and online discussion groups (and youtube) are still important venues for sharing ideas and bringing together geographically and/or socially isolated individuals, but they are no longer the only alternative to advocacy organizations and self-help group meetings for people who want to talk and think critically about encounters with autism and autistic encounters.

These developments reflect the evolution of individual and collective common-sense-making about what it means to be autistic and how to get along living with autistic presences. The increasingly visible work of autistic scholars (who are also self-advocates) makes it more difficult to over-simplify the perspectives of actors invested in the autistic rights and neurodiversity movement. And, as a result, it is becoming less tenable to sustain “straw man” arguments based on a caricature of autistic culture as a singular object of study or to ignore self-advocates' own recognition of tensions within the neurodiversity movement. Much of the newer scholarship assumes from the outset that a robust understanding of neurological difference will embrace the validity of human impairments and associated difficulties, while at the same time fostering changes in

social attitudes and lived environments, which necessarily includes attention to therapeutic interventions. What remains at odds and more difficult to reconcile is neurodiversity advocates' insistence that autism and autistic-ness – conceived broadly in terms of experience, thinking style, sensory perception, interactional preferences, and neurological wiring – are not things to be cured or eliminated or even targeted for prevention.

In an increasingly biomedicalized world, more and more neurologized-individuals and neuro-collectives are opting in on quasi-diagnostic identities as material ripe for objective-self fashioning, but with a twist, as “diagnosis” becomes depathologized as fodder for new adaptations and new re-enactments, for new practices and new knowings, and, one hopes, underpinnings for healthily non-normative belonging. Persistent (academic-ized) terms are being wielded like weapons – essentialism, reductionism, determinism. What is at stake in the theoretical and ontological positions being carved out? What looks different through generous engagement with autistic articulation and inhabitation of emergent worlds, where the material-semiotics of nature-cultures are being co-produced and re-processed? On one hand, these re-worldings question the extent to which we have ever been fully autonomous individuals, or even capital “H” human in any essential sense. On the other hand, in the sense-making I am trying to engage, there are encounters when identifications and individuations *happen*, and essences arrive, which is to say these are situations where shared collectivities and inter-personal divisions get done and redone, and are precisely how relational encounters and inter-/intra-personal mattering unfolds.

What if we make the assumption that, rather than repeatedly pointing out the problem of essentialisms no matter where they manifest, it is more important to pay attention to the specific ways that the autistic/neurotypical distinction problematizes what are the relatively unassailable discourses buttressing normativity? Will we be more able to pay attention to how frequently the term neurotypical or “NT” is used to denaturalize and make-strange common-sense divisions between normal and abnormal? And how do self-advocates, gathering both online and off, handle instances when their autistic community veers towards anti-neurotypical space? To what extent are self-advocates’ use of neuro-biological explanations being used to articulate a more expansive and more inclusive understanding of natural (and social) variation? And might neurotypical critical thinkers gain more adequate understandings of autistic self-advocacy with a set of assumptions that are in some way akin to those Kristina Chew adopts in her efforts to translate Charlie’s “struggles to be known,” which she knows is a huge responsibility given her “ever-potential misinterpretation and misrepresentation” of Charlie and, in general, autistic experience, behavior, and words?⁹²

Although individual and collective identities rooted in neurologically defined difference lean toward an emphasis on biological determinism, or at least biological explanations for behavior, this is often not the case. When bio-deterministic framing does occur, there is frequently movement in and out of bio-centric understandings of difference. Evaluating this fluidity requires careful attention on the part of the observer but also recognition that different actors mobilize the discourse differently, some more nimbly than others, and variably according to the situation. At times autism and other

⁹² Davidson and Orsini, *Worlds of Autism*, 316.

forms of neurological difference are positioned as radically distinct from neurotypical neurologies; but deployed by other actors, or the same actors in different contexts, the spectrum of neurological variability is imagined as contiguous across all human biological configurations and hardly grounds for a static social-individual order.⁹³ Similarly, the domain of social and political action relevant to the neurodiversity movement is usually defined in relation to disability, but not always. Analogies are also drawn with the goals and histories of other rights and identity based social justice movements, principally in terms of shared experiences of marginalization. There can be more or less specific allusion to embodied, personalized *differences* that result from having been minoritized, pathologized, or otherwise stigmatized and subjugated.

The social movements most commonly cited as analogous with neurodiversity – rights and identity claims formulated on the bases of race, ethnicity, gender, religion, sexual orientation, and disability – give a sense of how this is very much a biosocial relational field that cannot be easily pinned down (nor pigeonholed) as entirely rooted in biology, culture, or social structure without referencing other frames. While there are articulations of obvious biological essentialism, neurodiversity advocates cannot be fairly characterized as consistent biological reductionists. Neurologically defined difference, and autistic atypicality in particular, as the basis for collective identification and political mobilization is, perhaps surprisingly, ensconced in an ontology of becoming that resists disentanglement of factors, variables, or definitions as purely biological, social, cultural, or historical. This, despite emergence in a milieu heavily infused by and co-constituted

⁹³ Beyond the realm of the human, analogies are sometimes drawn between the neurological wiring of cats and autistic people, while dogs' wiring for sociality is likened to neurotypicality or ADHD. For example, see Hoopmann, *All cats have Asperger Syndrome*; Hoopmann, *All dogs have ADHD*.

with newly formulated and increasingly influential neuroscientific and biomedical knowledge systems.

While neurodiversity is not necessarily my preferred idiom, for reasons I will elaborate, I do think that the densely layered yet fluid articulations reflect its original application as a highly strategic, political discourse employed by individuals and collectives who share their identification with dis-enfranchisement and dis-enablement. It also speaks to the extent to which biological and psychiatric knowledge production struggles with complexity – in part because getting a grasp on an unfolding world (or worlds) is difficult and inevitably partial – but also because biomedical research and scientific explanations more generally are caught between, on the one hand, a “translational imperative” (to apply, to publish, to bring to market) in conjunction with an audience that holds onto an onto-epistemic model which prizes clear-cut distinctions and strict causal explanations, and on the other hand, an undertaking (and uptaking) by at least some research-practitioners, of an openness to emergent understandings which require subtle attentional shifts and careful attunement of apparatuses to evolving, multivalent encounters with inter- and intra-actional events, which defy long-standing efforts to hold the constituent parts separate in fixed and distinct categories.

The ways neurodiversity folk practice and re-theorize interpersonal relations and connectivity with their physical environment are innovative and distinctive cultural phenomena. For the parents whose experience of autism is that it is an unwanted affliction, the ideas of acceptance and accommodation are at times framed in a way that come across as Pollyanna-ish and vapid, even hostile and dangerous for what is portrayed as the truer, majority, “low-functioning” autistic population. It is certainly the case that

acceptance in autism worlds is a truly multi-dimensional concept, which cannot be realized outside specific situations.

Making a difference for people on the spectrum requires more than just a code switch where behaviors/personalities that are currently denigrated as negative and difficult are suddenly transformed into a laudatory positive type. Self-advocates and others who insist that autism ought not be considered in a disability framework at all are not as vocal as they were five or ten years ago during the initial wave of popular interest in autistic culture; and, in any case, are not the actors that primarily motivate my interest. The ideas embedded in “autism acceptance” that I find theoretically distinctive and politically compelling – found in children’s literature like *The Autism Acceptance Book* and through foundations like The Autism Acceptance Project – articulate around real life difficulties, as well as possibilities, experienced in complex, often ambiguous, encounters.⁹⁴

Re-coding autism is part of the story, but it is a process continually *done* through unfolding negotiations, rather than universally applicable or settled once and for all. A good enough and coherent enough conceptualization of the autistic spectrum means coming to terms with an entire range of actors and their collective, as well as individual, needs and desires. Neurodiversity as a term may indeed become overburdened as a popular buzzword that deemphasizes all that is difficult with autism. However, autism re-cast as a spectrum and autistic as a meaningful identification, with all the multivalent implications, will likely endure as lasting innovations.

⁹⁴ Klar, “The Joy of Autism.” Sabin, *The Autism Acceptance Book*.

Conclusion

Situated Functioning: Facilities and Difficulties

Spectrum. Functioning. Autistics. Care. The dissertation taken as a whole is an examination of the social worlds and conditions which these words problematize. It reflects my own commitment to pay attention: to specific histories, presents, and imagined futures; to the institutional structuring and ordering of biosocial entanglements, individual difficulties, and neuro-developmental differences; and to the concerns, commitments, and interests of a variety of differently situated actors. These title words and core problematics are intertwined in the new historical turn I am pointing to here. In the conclusion I begin to move on toward a focus on *functioning* especially as a way to think about how autistic self-advocates and the category of autism itself can be understood to be opening up an alternate future in contrast to or at least alongside the one imagined as manageable through “clinical neuroscience.” I also revisit how parents are beginning to give more recognition to self-advocates. More and more, parents are joining with self-advocates to express concern about a mental health and care paradigm in the process of being reconsolidated around biomedical interventions which are directed toward the goals of cure and prevention, individual perfectibility and corporate profit, social order and technoscientific control.

The idea of spectrum is being used very differently by different actors and across different settings. How individuals and communities come to care deeply with and in autism worlds is importantly determined by how they are positioned *vis-à-vis* autism,

which is co-produced by how concerns and commitments come to be articulated, defined, and mobilized by actors in a particular time and place for a specific purpose. Autistics, in particular, have taught me to think critically about how we all come to inhabit our social worlds with moments of both fluency and trouble. And they helped me to think differently *with* the concept of social and intellectual functioning rather than to simply critique functionalism without anything to offer as an alternative.

Sea Change

In 2010 blogger abfh, “autistic bitch from hell,” announced in 2010 that the blog *Whose Planet Is It Anyway?* had reached the end of a five year mission to work toward promoting understanding and acceptance of autistic people in terms of neurodiversity.¹ While there was more work to be done, abfh said autistic perspectives had now at least become visible in mainstream media, public policy circles, local autism societies, and researchers’ consideration of ethical concerns and practical needs. This state of affairs stood in stark contrast to the site’s beginning in 2004, when “finding a new self-advocate website or a parent site that wasn't doom and gloom was like discovering an oasis in a vast scorching desert of intolerance.”² I took note of the posting because of what abfh believed had been accomplished, but also because she cited battle fatigue and infighting among self-advocates that had led to the “implosion of the Autism Hub.” The Autism Hub had been an influential neurodiversity oriented webring which morphed into an online community.³ What struck me as significant was the sense that the Hub’s

¹ ABFH, “Roses.”

² Ibid.

³ ABFH wrote: “The implosion of the Autism Hub, although it marks the end of an exciting time when the blogs were at the forefront of a major cultural shift, was not a defeat for autistic civil rights or for

“implosion” was somehow simultaneously precipitated by and allowable because the internal autistic community controversies had centered on the dramatic emergence of Amanda Baggs and Ari Ne’eman as representatives for neurodiversity and autistic rights in the mainstream media, as well as by Ne’eman’s appointments to the Interagency Autism Coordinating Committee and the National Council on Disability. It seemed that autistics’ arrival on the national stage had made possible a moment of reflection, as well as realignment and schism, with the implication that a new generation was taking the lead for a new stage of self-advocacy.

Other events in 2010 indicated that, according to Stuart Murray, “the tide [had] turned on the anti-vaccine movement,” at least in so far as questions about vaccine safety would no longer dominate every public conversation about autism.⁴ *The Lancet* retracted the 1998 paper that had generated so much anxiety regarding the MMR vaccine, and the lead author Andrew Wakefield was censured and barred from practicing medicine in Britain.⁵ In addition, the US Autism Omnibus Proceedings issued the last of its rulings on three test cases related to thimerosal, finding no causal relationship.⁶

In 2011 and 2012, other participant-observers began talking about a “sea change” in public perceptions of autism. Steve Silberman, author of “The Geek Syndrome” and a

the concept of neurodiversity. On the contrary, it's now clear that we won the first battle. We made people understand that they were looking at human beings, not at monsters or changelings. We did an effective job of consciousness-raising in the autistic community.” Ibid.; Leitch, “The Autism Hub.”

⁴ The relationship between public discourse and rates of vaccination is complicated because local “opt out” policies and other factors influence how infectious disease outbreaks tend to cluster. Murray, *Autism*, 87; Archana Chatterjee M. D., “The Controversy That Will Not Go Away”; Brown, “CDC Reports on U.S. Vaccination Rates, Recent Measles Outbreaks”; Kollipara, “How the Anti-vaccine Movement Is Endangering Lives.”

⁵ The Editors of *The Lancet*, “Retraction—Ileal-lymphoid-nodular Hyperplasia, Non-specific Colitis, and Pervasive Developmental Disorder in Children.”

⁶ Haertlein, “Immunizing Against Bad Science”; Kirkland, “The Legitimacy of Vaccine Critics: What Is Left After the Autism Hypothesis?”

forthcoming book on neurodiversity, nominated *The Thinking Person's Guide to Autism* as his book of the year. He said it was representative of a new creed for “parent-warriors,” who are, “prolific bloggers and tweeters on the war-torn autism frontier every day: battling misinformation and quackery, standing up for science and evidence-based medicine, and crucially, building mutually beneficial alliances between parents and self-advocates.”⁷ A year later, one of the book’s editors, science writer Emily Willingham, pointed to evidence of a sea change in the inclusion of Ari Ne’eman and Michael John Carley on a panel testifying before Congress. Following campaigns mobilized by supporters and members of their organizations, the Autistic Self Advocacy Network and the Global and Regional Asperger Syndrome Partnership, the two self-advocates sat alongside representatives of pro-cure parent groups Autism Speaks and SafeMinds, as well as spokespersons for the CDC and NIH.⁸

Another sign that currents are flowing differently was the reaction to “Autism Speaks to Washington – A Call to Action,” a public letter posted on Autism Speaks’ website and distributed as a press release to publicize the organization’s “policy and action summit” in late 2013.⁹ Many autism parents seemed to be in agreement with self-advocates that Autism Speaks was failing to foster a vision of hope for autism families. Letters were published criticizing co-founder Suzanne Wright for her “letter to Washington” which described the horrible lives lived with autism, stating over and over, “this is autism.” Wright now seemed out of step when she wrote:

⁷ Silberman, “Book of the Year.”

⁸ Hopefully the fact that Autreat will not be held in 2014 does not become an indicator that the venue’s role in fostering autistic community and culture has past. Willingham, “Autism Congressional Hearings: Bingo, Vaccines, and Some Baby Steps Forward.”

⁹ Wright, “Autism Speaks to Washington - A Call for Action.”



“These families are not living. They are existing. Breathing – yes. Eating – yes. Sleeping – maybe. Working – most definitely – 24/7... Life is lived moment-to-moment. In anticipation of the child’s next move. In despair. In fear of the future.”

Many parents responded to say that this was not their family and not the autism they knew. Some parents joined a movement to boycott Autism Speaks, including the editor

of *Autism Parenting Magazine*, who wrote a letter to readers explaining her growing disillusionment, invited a self-advocate to comment, and featured a cover article, entitled “Exposing Autism Speaks.”¹⁰

I described in Chapter Three how the *DSM-5* revision process helped bring together self-advocates and parent-advocates on matters of widely-shared concern, helping disability-based services and legal protections to re-emerge as the central issue for families affected by autism. In particular, I focused on the successful effort by self-advocates to harness a disability framework to articulate a compelling alternative to the vision of autism as disease, an effort which had a profound influence on the final text of the *DSM-5* as well as shifting the general tenor of public discourse. Self-advocates successfully positioned themselves to be recognized as integral to defining goals for autism policy and research, and their message became increasingly appealing to parent-

¹⁰ Burby, “Issue 14 – Exposing Autism Speaks.”

advocates and others, including educators, therapists, and even some biomedical researchers.

There was already something provocative and innovative in the way autistic rights claims were interwoven with the ideal of acceptance for non-normative behavior and atypical sensory processing. This ideal was increasingly promoted through autistic community and culture, and articulated in terms of neurological diversity and natural human variation. But it was the sense-making work *vis-à-vis* autism as a disability category that really turned *autism acceptance* into a vision compelling enough to register as both broadly desirable and sufficiently rational to become a viable alternative to cure and prevention focused biomedical treatment and disease management. During the *DSM-5* process, parents began to realize (again) how much their families stood to lose if autism were fully transformed into disease category. As a result, it became unmistakable that autism conceptualized as disability was both institutionally useful and pragmatically necessary.

In what follows, I take acceptance further into the realm of assessment, proposing a new idiom for understanding disabilities and difference. Here, functioning becomes “situated” within its inevitably relational contexts. My thinking has been influenced by key autistic self-advocates whose mode of analysis is an embodied and situated way of engaging with the world. Such a way of articulating both possibilities and limitations offers a more generous way to do assessment within expanding notions of care, while suggesting a more generative approach for developing tools and locating resources that improve functioning.

Situated Functioning: *Facilities, Difficulties, and Problems of Living*

The experiences of people on the autistic spectrum highlight the fact that our current conceptions of intelligence and functioning need to be reexamined. We need to think carefully about how current key terms and conceptual frames institutionalized in assessment apparatuses steer us in certain directions, and how thinking differently about what is being assessed can open new possibilities for both autistic functioning and care.

For the past several years I have been developing the concept of ‘situated functioning’, an idiom that allows a more nuanced and comprehensive understanding of an autistic – or any – person’s possibilities for growth and accomplishment, with an emphasis on the re-articulation of the co-producing environment’s critical contributions. This way of thinking has been informed by my learning from autistic self-advocates. I am also indebted to Donna Haraway’s theorizing of ‘situated knowledges’ and relational encounters, as well as to the contributions of Dan Goodley and Griet Roets in rethinking impairment, learning difficulties, and developmental disabilities.

Situated functioning works both with and against the structuring of limitations in terms of high-functioning and low-functioning, and metrics routinely imposed on people on the spectrum. I began presenting these ideas in an invited guest lecture to teacher credential students at Cal State Hayward in 2008. The formulation became clearer in a paper presented at the annual meeting of the Society for Disability Studies in 2009 and again at a workshop at Autreat in the summer of 2011. I was then invited by a parent and disability education specialist to give a keynote at the 2012 annual meeting of AutCom, an advocacy organization dedicated to social justice for autistic people and their families. The present discussion is adapted from the presentation at Autreat.

The concept of intelligence underpins the practice of dividing people into “high-functioning” vs “low functioning.” I want to challenge the deeply rooted practice of imagining and assessing people as if they were individuals in isolation, without resources and devoid of context; to see how these current ways of thinking lead the behavior of autistic persons and others to be interpreted in particularly limiting ways. Labeling autistic persons as either "high functioning" or "low functioning" limits real future possibilities for functioning. A different approach could expand the possible futures available to autistic people.

At the 2010 Autreat conference, a group presentation by Drew Morton Goldsmith, Amanda Baggs, and Morton Anne Gernsbacher raised concerns about the widespread use of functioning labels to describe individuals on the autism spectrum.¹¹ Drew’s short film, “Grading People,” reviewed the historical practice of dividing “subnormal” humans into the classifications of *moron*, *imbecile*, and *idiot*, with further distinctions made on whether an individual ranked as high grade, medium grade, or low grade moron/imbecile/idiot.¹² The film then went on to point out:

The Internet abounds with autistic people labeling themselves high functioning and sometimes labeling others as low functioning – with the terms ‘high functioning’ and ‘low functioning’ being used to indicate status, quality, and even perceived worth just like the historical terms ‘high grade’ and ‘low grade.’

I am advocating for an understanding of functioning that is “situated” to suggest that we need to evaluate functioning as situation-dependent and to incorporate how other people are functioning and behaving in a given situation. My approach locates individual dis/ability within specific physical and social environments. In every conceivable

¹¹ Baggs, Goldsmith, and Gernsbacher, “The Ethical, Scientific, and Societal Implications of Grading Autistic People.”

¹² Goldsmith, *Grading Autistic People*.

situation, mutually attuned social relationships facilitate accomplishment, enable it really, as do concrete tools, strategies, and techniques. By using an idiom of situated functioning we highlight the situation-contingent and interpersonal nature of functioning. This shift in perspective helps work against what Dan Goodley describes as “discourses that position disability in the realm of individual pathology, personal problem and individual incapability.”¹³

Current language of ‘functioning’ and intellectual disability (i.e. mental retardation, etc.) taps into our culture’s taken-for-granted understanding of intelligence, but it does so somewhat inconsistently. The term ‘functioning’ becomes very slippery, a floating signifier that seems to capture something vital to individual development, social cohesion, and the performance of narrow, circumscribed roles within institutional structures. In practice, *high-* and *low-functioning* tend to play out at the crudest level: high-functioning = intelligent; low-functioning = retarded. Although the division is not always so explicit now, traditionally the division has been that the LF label is assigned for an IQ below 70 and HF label for an IQ above that cutoff.

But what does it mean to function well or poorly – at a high level or low level? In her article, “Defining Autistic Lives,” Cal Montgomery describes sliding back and forth across an ill-defined divide between being high-functioning and low-functioning at various times during her life. She writes, “The high/low distinction seems very often to be a fight over the kinds of lives made available to autistic people.”¹⁴ She points out that

¹³ Dan Goodley, "'Learning Difficulties', the Social Model of Disability and Impairment: Challenging Epistemologies," *Disability & Society* 16, no. 2 (2001). 222.

¹⁴ Montgomery, “Defining Autistic Lives.”

as someone with an IQ under 85, she is by definition considered to be incapable of benefiting from formal education. She goes on to say:

I've watched people -- mostly people who consider themselves to be supporters of disability rights -- react to me as my ability to control my body deteriorated again and I slowly slipped across whatever lines they were using to mark the boundary between "high-functioning" and "low-functioning." A lot of them can't handle it. If they're very polite they make some kind of excuse, but either way most of them are no longer in my life. Given that those lines are there I am grateful I had a chance to be regarded as fully human for awhile; because it bolsters my own sense that I am indeed fully human and possess the same basic human rights as other people. But I am more grateful for the people whose friendship has not recognized the lines at all; and I wish that together the disability communities could erase all of these lines and value us all.

Montgomery points to the ways discourses of *functioning* and *intelligence* can divide people and movements on the very terrain we hope to transform. The autism diagnosis confounds the idea of knowing an individual's global "functioning level." I would say, productively so. The ambiguities create both problems and possibilities; however, it is the possibilities I will focus on in the concluding part of my dissertation.

'Co-Morbid' Autism and Mental Retardation: The Entanglements of NeuroDevelopmental Disorder and Intellectual Disability

It is a productive offshoot of the spectrum concept, and largely due to the intervention of autistic self-advocates, that there is now a framework and willingness on the part of some scientific researchers to explore cognitive strengths among the autistic population. Furthermore, there is something about the diagnostic profile and narrative descriptions of autism that persistently disrupts easy categorization. For example, general unevenness in performance across contexts and skill sets has in the eyes of many observers – as far back as the initial identification of "autistic disturbances" by Kanner

and Asperger – suggested cognitive potential. Early descriptions of autism report profound unevenness across domains; and autistic “islets of ability” and “splinter skills” have long fascinated observers in the cognitive sciences. The image of the autistic savant has especially engendered wonder and endless speculation about the relationship between intelligence and social-cognitive functioning.

But it is not the search for the link between autism and “genius” that interests me. What I am intrigued by is another striking development – in the world of autism, who precisely counts as *retarded* or *intelligent* has slipped its moorings. Recently, the statistics for the co-morbidity of autism and mental retardation have been turned upside down. The medical establishment has been forced to question what was formerly considered fact – that the majority of autistic people are mentally retarded. Both the third and fourth editions of the *Diagnostic and Statistical Manual of Mental Disorders (DSM)* claimed that 70-75% people diagnosed with autism were also mentally retarded. The revised fourth edition of the *DSM* changed tack and claimed that “most” people diagnosed with autism were also mentally retarded, which *DSM-5* attenuated further to read, “autism spectrum disorder is *frequently associated* with intellectual impairment.”¹⁵ Recent research indicates a pattern of shoddy citational practices and the outright unsubstantiated fabrication of “facts” about the “co-morbidity” of autism and mental retardation.

A 2006 article by Meredyth Goldberg Edelson asked, “Are the Majority of Children With Autism Mentally Retarded?,” and set out to evaluate the evidence. The

¹⁵ Emphasis added. American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders*, 1980; American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders*, 1994; American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders, Text Revision*.

author reviewed hundreds of articles published over the past seventy years and found that three quarters of all claims about the correlation of autism and retardation were not based on empirical research. In fact, close to half could not be traced back to any source whatsoever, and furthermore, the empirical research that had been conducted was already several decades old. As a result, in the past few years, articles appeared suggesting that the actual rate of retardation among autistics is probably closer to 25%. The swing from 75% to 25% is fascinating, although I am not suggesting that 25% is right and 75% is wrong.¹⁶ Something much more complicated and potentially exciting is happening here if we explore the implications of how these categories of autism and mental retardation are being ripped apart and reconfigured.

In a similar vein, a 2007 article entitled “The Level and Nature of Autistic Intelligence” by Michelle Dawson, an autistic woman working with colleagues at a major research lab in Montreal, argues that commonly used IQ tests rely too heavily on oral prompts and are therefore inappropriate for use with most autistic subjects. Dawson and her co-authors argue that another test, the Raven’s Progressive Matrices, is the more appropriate measure of autistic intelligence, and provides evidence that autistics actually outperform neurotypicals in some areas.¹⁷ They conclude that the intelligence of autistic

¹⁶ The study reveals the tenacity of embedded assumptions about the nature of intelligence and intellectual impairment, but also points to a complex and dynamic history. Interest in Asperger’s work helped open up the possibility for seeing autism among people who might also be considered intelligent and actively participating in public life. As a result, changes in diagnostic criteria have helped produce a different profile for the autistic population. Edelson, Meredyth Goldberg, “Are the Majority of Children with Autism Mentally Retarded? A Systematic Evaluation of the Data.” *Focus on Autism and Other Developmental Disabilities*, 21:2, Summer 2006, 66-83.

¹⁷ Dawson et al., “The Level and Nature of Autistic Intelligence.”

people has been underestimated due to the use of particular testing instruments, and claim, essentially, that researchers have simply been giving the wrong tests.¹⁸

It is genuinely important to learn that certain tests do a much better job of showing what autistic people *can* do. This important research has revealed, in aggregate, enhanced perceptual processing across several domains, including: locally oriented visual and auditory perception and greater autonomy of “low-level” information processing toward “higher-level” operations.¹⁹ But I don’t believe that translates into a claim that this other test shows the true nature and level of autistic intelligence. Certainly the difference in performance across various sub-sections of the test is worthy of further investigation. Nevertheless it is striking how the framework and instruments for recognizing (and doling out) both *intelligence* and *retardation* continue to be stuck in the muck of either/or claims, or at best, movement along a linear continuum. Again, from low to high. What choice do autistic people have but to want to be nearer the top and recognized for their “native” intelligence? What choice does *anybody* have but to compete for recognition of their own innate intellectual ability? This is the core predicament caused by this thing we call intelligence.

For some people, both autistics and others who care about them, articles such as these provide grounds to elevate the status of autism – to insist that autistic people have something valuable to offer. The evidence has provided some autistic communities a place to stake a claim of worth – and, of course, that is a hugely important claim to make. But I think we need strategies that don’t leave others behind, others who it is presumed

¹⁸ We know something interesting is going on when a major research lab has given a prominent position to an un-credentialed autistic person, and I don’t think Dawson is merely a token figure – she appears to have had a profound impact on the direction of the research done in the lab.

¹⁹ Mottron et al., “Enhanced Perceptual Functioning in Autism.”

really are mentally retarded, as currently conceived – where mental retardation or intellectually disabled continues to serve as a category for people incapable of learning and personal growth, those without potential.²⁰

The binary divisions of high/low functioning and intelligent/retarded are pervasive. It is not enough to emphasize what people *can* do and to celebrate areas where individuals can be embraced for being intelligent. We need a theoretical and strategic language that radically re-frames areas of intellectual difficulty, as well. Recognizing “cognitive strengths” alone and in isolation does not get us through this morass.

Intelligence is an unhelpful, discriminatory concept and has been used systematically to deny rights and personhood to entire categories of people and has been closely tied to eugenic thinking. The conception is that *intelligence* is a thing people have; the deeply ingrained assumption is that, yes, social context and environment are important, but underneath it all there are individuals with bodies and biologies that if they could just be removed from their location and circumstances would reveal themselves to be innately intelligent to greater or lesser degrees, and that their native intelligence could and would emerge in any setting or environment.

This decontextualized way of thinking – where individuals are imagined in isolation with only fixed capacities – sets us down the wrong path. It is by thinking in terms of situating individuals in their specific social and material conditions, in their

²⁰ I initially thought the concept of mental retardation could be reframed/reclaimed/rearticulated, but my thinking has changed, because I think the idea of retarded minds is too tightly coupled with the paternalistic image of intellectually disabled people as ‘forever children,’ which inhibits their ability to lead full and multidimensional adult lives. I prefer the model endorsed by British self-advocates, which frames intellectual disability as ‘intellectual difficulties’ because everybody still has the potential to learn and acquire new skills. For example, Goodley and Rapley report one self-advocate’s preference for the term “learning difficulties,” because, “...then they know that people want to learn and to be taught how to do things” Goodley and Rapley, “How Do You Understand ‘Learning Difficulties’?,” 229.

everyday interactions and intra-actions, that we can see how functioning occurs in dynamic negotiation with others and in a shared environment, albeit one where individuals have uneven access to power and resources. An analysis of situated, interpersonal functioning points toward ways that social dynamics could be altered to meet particular goals so that many kinds of barriers would be removed from the environment to provide increased access for disadvantaged groups. It also points to ways those deemed intellectually competent already benefit from numerous ‘invisible’ social and technical support systems.

How I Came to Know and Value Autistic Functioning

I return now to experiences I had while working as a credentialed substitute and summer school teacher in a ‘community access and transition’ program for young adults geared toward providing work and independent living skills. How did the standard, not-situated concept of functioning work in this context? As the teacher, my own functioning basically went unquestioned. Maybe I would be judged to be a good or bad teacher or I might conceivably be deemed incompetent, if I really floundered, but because of my position of authority and my credentials, it is highly unlikely that there would ever be any consideration of my performance in terms of functioning. In general, the language of functioning is used in medicalized settings and for “diagnosed” populations – a reminder that schools intersect with clinical spaces in important ways.

Several experiences with students during my years teaching in the transition program were important in seeding my thinking about functioning. As I describe the social dynamics of different situations in what follows, it is clear I am thinking of functioning as collective, and an individual’s functioning to be intertwined with the

functioning of other people. I think that with a little tweaking the concept of situated functioning can be productively applied to anyone active in a particular setting, regardless of whether they carry a diagnosis or experience the world in a more or less typical way. It is who is present, influencing, and/or benefiting from a given situation that matters.

During two of my summers teaching in the transition program, there was an autistic student who kept track of all things logistical. On his own initiative he would provide reports as the buses arrived in the morning and left in the afternoon, who hadn't arrived yet and which buses we were still waiting for, as well as which student needed to get on which bus in the afternoon. All this was done with one or two word statements. He also kept a record on the whiteboard of how students and teaching assistants would be grouped for the day and where they would be going – on most days to a number of different locations as there were fewer jobs continuing during the summer and more time for recreational activities. I really depended on him because I struggled with the shifting bus schedule. There were five or six buses, and which student rode on which bus changed each week and was different in the am/pm, due to the disorganized structure of summer school and the fact that only certain campuses remained open. This student rode public transportation independently to and from school; so he arrived early each morning and, in the afternoon, he waited until the last of the school buses departed (one or two were regularly quite late) before he said goodbye and walked to the public bus stop. The entire class benefited from his special facilities and willingness to contribute.

Another summer, there was an autistic student who knew the entire public transportation system, and in fact could draw a map of the entire city, block by block.

He was authorized by the city to provide directions to tourists – he even had an official jacket to wear. But the prime tourist location near the school is privately owned and the security guard made us leave on our second day there. To be honest, I would have needed more training and experience to help facilitate interactions with tourists effectively in any case. Even together we only managed to relay helpful information to a few of the many people we engaged. But what a useful service he could have provided at this major tourist and transportation hub! ²¹

I had believed that another student who I worked with over multiple years could only communicate by speaking single words in response to direct questions. Then one day, I saw him carrying on a conversation with the regular teacher by writing out short but complete sentences on a notepad. It would have been nice to have known all along about his facility with writing!

It would be easy to criticize the handling of the situations with each of these students, casting blame on someone, in part because doing so would play into popular narratives about the failings of public schools. But a more fruitful approach is to think in terms of responsibility – how to make each participant more *response-able* – in order to think creatively about ways the situation might work better. For example: the regular teacher could have told me that the last student communicates well with writing; and I could have taken it upon myself to learn that sometimes autistic people have greater

²¹ Unfortunately, here I can only footnote one of the ways the idiom of situated functioning needs to work with a variety of different problematics. Relevant to this student’s extra-ordinary facility with maps and spatial logic, for a variety of reasons a more generous functioning discourse cannot primarily serve to identify “use value.” Situated functioning needs to simultaneously mobilize acceptance of difficulties, no matter how extreme, and to draw forth facilities, no matter how minimal. But, at the same time, those who are *both* unable and not-yet-enabled to demonstrate what others recognize and value must not be put ontologically at risk of being left behind as mere ballast and burden. Nothing whatsoever must be *proven* with this pragmatic idiom of inclusion.

facility with writing or typing than with oral speech. I would then have had a better idea of how to ask good questions; or perhaps the student could have taken out a pencil and pad without prompting; or better yet, the school district could have instituted a policy that would help enable the communication of students who *do* need prompting by making the practice with effective communication systems central to the everyday functioning of all educational programs.²²

The student in my first example, who kept track of buses and daily activities, also did not have a communication system in place at school. By this point in my teaching I knew more about autism and varying facilities with different modes of communication, so we experimented with typing together over the summer. While much of the time he responded to my questions with repetitious echolalia-like sentences, there was also real communication.²³ I learned for example that he had an assistive communication device at home but didn't bring it to school because it was so expensive! And I found out that he wanted to go to the dance on Friday with his friends!

Of the three I describe here, student number two might have had a chance to be labeled high-functioning in certain settings, largely because of his use of spoken language rather than his (idiot) savant-like memorization of the city map. But as autistic self-advocates point out, real problems come along with being labeled high-functioning, beyond the obvious risk of losing access to needed services and supports. As a brief example, my student was nearly arrested twice for shoplifting during our first week out in

²² As a result of lobbying by self-advocates there was a presentation on assistive communication devices at the 2009 IACC meeting discussed in Chapter Three. It offered an early look at how relatively inexpensive and “cool” mobile devices were beginning to transform the market for adaptive and assistive communication technologies (AAC). More recently, mainstream media has been reporting the story. For example, Westervelt, “iPads Allow Kids With Challenges To Play In High School’s Band.”

²³ And I likely did not yet know how to glean more from what I understood to be *only* echolalia.

the community together – once at bookstore when he slipped an expensive map book into his backpack and then at a convenience store when he shoved several pieces of chocolate into his pockets as we passed the cash register.²⁴

Autistic people know about obstacles and how the right supports can make all the difference, making all kinds of new actions and engagements possible. I'm offering my journey to this realization to illustrate the distributed and situated nature of functioning – that what matters most is how we function together in a particular time and place. With each of these students, I learned how each had facilities to draw from to help them participate with and perhaps to contribute to the community, both the classroom and the broader city community. When I think of facilities, I include skills *and* abilities, even how someone draws on things like technological assistance and social supports, things that make tasks easier to accomplish. The point of identifying the facilities of my former students is not to try to determine whether they are acquired skills or innate ability, but rather, to nurture the conditions that would help them draw on their facilities more effectively. Assessment of this sort could help in the development of rich, fulfilling lives and the identification of strategies for wrestling with difficulties they face along the way.

Two of the dictionary definitions for the word “facility” give a sense of why I have come to pair *facilities* with *difficulties* to articulate a situated understanding of functioning:

²⁴ In another incident, he jumped into an “empty” seat on a busy MUNI bus when a young boy momentarily stood up to say something to his father. The boy and, more so, the father were visibly upset and tried to make the student move. I don't know how the confrontation would have ended if I had not been there to intervene. But, it should be noted, I was unable to get the student to move either. The father gave up in part because he saw me, the teacher, unable to convince the student to comply with socially expected behavior.

facility [F. *facilité*, *facilis* easy: see FACILE and -ITY.]

1. The quality, fact, or condition of being easy or easily performed; freedom from difficulty or impediment, ease; an instance of the same. Often in phrase *with (great, much, more) facility*.
2. Unimpeded opportunity for doing something. Means, resources, and favorable conditions, for the easier performance of any action.²⁵

It is evident that opportunity – and the means, resources, and favorable conditions to complete a given task or to achieve a particular goal – do not reside solely within the individual. Every person, whether child or adult, employs strategies acquired through lived experience to engage in dynamic interplay with the social environment and the available institutional infrastructure (or work with ways that institutional infrastructure is accessible or not). Interactions matter; accessible design and the availability of resources matter, too.

Autistic organizer and thinker Jim Sinclair has identified important developments in autistic people’s facilities for social processing that became possible with the emergent resources available through autistic social space:²⁶

Most autistic people who have never experienced autistic space have never meaningfully experienced "social rules." And until there was such a thing as autistic space there were no such things as autistic social rules. But once autistic space came to be autistic people began doing kinds of social processing that we had never done before. As a result of this authentic autistic social processing authentic autistic social rules began to emerge. Autistic social rules evolved in accordance with autistic processing and meanwhile autistic social processing was *able to further develop because of the facilitative environment* created by the autistic social rules. Thus autistic social rules develop synergistically with autistic processing both online and in real space.

²⁵ *OED Online*.

²⁶ Emphasis added. Sinclair writes both about the social space of Autreat’s annual gathering and online communities here. As described elsewhere in the dissertation, many have been impressed by how online space became a powerful resource for autistic people. Sinclair, “Being Autistic Together.”

Further, xe describes how the social space of “being autistic together” has opened new vistas of opportunities, included richly theoretical experimental praxis, and ignited all kinds of possibilities previously unimagined:

For people who have never been "allowed" to acknowledge autistic difficulties or to ask for support, this freedom, even encouragement, to express needs and request accommodations can present surprising and previously unimagined possibilities. People may begin to envision, and consider, and experiment with, doing things they'd never thought they could possibly do, or would ever want to do. Trying new things opens opportunities to experience new successes — and also opportunities to experience new failures and frustrations. Often people don't even know what kind of assistance and accommodations would help them. Finding out what works is a process of trial and error, disappointment and discovery.²⁷

Terminology Matters

The concept of the autism spectrum – and even how it gets split into low-/high-functioning and intelligence/retardation – is simultaneously tricky and richly generative. For example, consider two widely read authors – Temple Grandin, autistic scientist and celebrity cited in Chapter Four, and Roy Richard Grinker, an anthropologist with an autistic daughter whose work has influenced my own. My point is not to single out Grandin or Grinker for criticism. People on all sides of debates about autism get stuck with the descriptive language of intelligence, retardation, and bifurcated functioning – individuals almost inevitably become defined as *either* intelligent *or* retarded, high-functioning *or* low-functioning.

Grinker, who has written what is in many ways a very fine book, writes that the autistic spectrum is confounding because it includes individuals ranging from

²⁷ As noted in the introduction to the dissertation, Sinclair prefers a set of gender neutral pronouns which online “wictionary” sources credit xem with developing.

“exceptionally intelligent to profoundly retarded.”²⁸ Many have suggested that the spectrum verges on incoherence or possibly has become too broad to be useful. But that view misses something important about these descriptive categories and the possibilities which a non-linear spectrum model opens up.

The binary functioning split violently divides autistic populations. For example, Temple Grandin frequently draws the distinction between (good) "high-functioning" and (bad) "low-functioning" autism. For example, in *Thinking in Pictures*, Grandin writes:

A little bit of the autism trait provides advantages but too much creates a low-functioning individual who cannot live independently. The paradox is that milder forms of autism and Asperger's are part of human diversity but severe autism is a great disability. There is no black-and-white dividing line between an eccentric brilliant scientist and Asperger's. In an ideal world the scientist should find a method to prevent the most severe forms of autism *but allow the milder forms to survive*. After all, the really social people did not invent the first stone spear. It was probably invented by an Aspie who chipped away at rocks while the other people socialized around the campfire. Without autism traits we might still be living in caves.²⁹

Autistic and disability rights advocate Amanda Baggs emphatic response to Grandin was quoted in part in Chapter Four. I offer it again at more length because it reveals what is at stake in this conceptualization of functioning:

The really problematic part is, yet again, her view that so called low functioning non independent non-verbal autistics are useless... She draws a distinction between natural human variation and disability. It's the usual stereotype, "natural variation good, disability bad".

Well anyone who believes that, wake up! What you call disability *is* part of natural human variation and always has been. People with easily recognized Aspie sklllz, or whatever they are called these days, are not the only people of value on this planet...

Let me be clear: When I talk about neurodiversity, I mean all neurodiversity. Not just the people that Temple Grandin happens to find worth in. I am fighting for a

²⁸ Grinker, *Unstrange Minds: Remapping the World of Autism*.

²⁹ Emphasis mine. Grandin, *Thinking in Pictures*, 122.

world in which there is a place for every single one of us and our value is not even questioned...

I honestly think Temple Grandin owes an apology to the many, many autistics she has used her position as the most famous autistic person on the planet to devalue. But more than an apology, she owes us a serious attitude change. Not, mind you, just because of our “feelings”: It’s our very *existence* she could help eliminate in the future.

Grandin sees no clear dividing line between a brilliant scientist and Asperger’s and yet readily embraces the idea that a line *can* be drawn between mild and severe forms of autism. Her own autobiography belies the notion that “severity” is stable, context-independent, and readily discernible across domains. She indicates that she herself was considered low-functioning or “classic Kanner type” autism in her younger years. As Baggs reminds us, allowing intelligence and developmental potential for some and disavowing it in others has life-and-death-consequences. These are the things life trajectories are made of.

Groups like Autism Network International and Autistic Self Advocacy Network generally do an excellent job of maintaining an emphasis on the rights of all autistic people. They regularly point to the conceptual failings inherent in global functioning labels. They stress that the high/low division simply doesn’t hold up under scrutiny, that autism and disability more generally are more complex than a linear continuum allows. But functioning labels and the high/low divide clearly do create ongoing tension among autistic communities and in their interaction with the broader world of parent advocates, medical practitioners, educators, etc.

The Twining of *Facilities* with *Difficulties*

I have suggested that the terms *difficulties* and *facilities* can help us articulate a more flexible, nuanced, and generous conception of *situated functioning*. I like the word-concept ‘facilities’ better than *intelligence* for a number of reasons. Whereas *facilities* seem flexible and dynamic, *intelligence* appears intractably rigid and fixed. *Intelligence* is awkward in the plural and resists calls for generosity.³⁰ As a noun, *facility* is the inverse of *intelligence*, and it is awkward in the singular. It is really an adjective-like noun to describe mental processes at work and in motion: *facility* begs to be multiplied into *facilities*. And it is more pliable than alternatives like *strength*, *acuity*, *faculty* or *aptitude*. Still, nouns seem so fixed and self-contained. A deeper sense of the term becomes apparent when *facility* is used adjectivally, as in “thinking with facility.” *Facilitate* is the most readily available verb form, and I very much like the gerund form, *facilitating*.

The absence or lack of *facility* is a very different proposition when compared with the absence or lack of *intelligence*. *Difficulty* comes to mind easily and without violent implications. Nobody is automatically denied capabilities; and facing difficulties is not nearly so disparaging or disheartening as being labeled *unintelligent*, *retarded*, or *incompetent*. The source of difficulties remains very much open to question; for example, they could be more or less individual, social, or environmental. *Facilities* are something we may all hope and strive for, but *difficulties* are generally easily

³⁰ For example, Howard Gardner’s notion of “multiple intelligences” has both helped stimulate generative educational theory and pedagogic practice, but it also imposes real limitations on how student potential is perceived. Gardner, *Frames of Mind: The Theory of Multiple Intelligences*.

recognizable as part of self as well as other. One's own difficulties are not something to deny or reject out of hand; and there is value attached to hard-won achievements.

With an idiom of situated functioning, self-advocacy skills become a resource for developing and activating other facilities. Jim Sinclair is widely recognized as a pioneer in autistic self-advocacy and, occasionally, disability theory. Infrequently acknowledged in academic literatures, he earned a B.A. in Psychology and a graduate degree in Rehabilitation Counseling subsequent to entering the politicized world of self-advocacy. Sinclair now articulates both autistic difficulties and facilities in a nuanced way:

Being autistic in shared autistic space may be easier than being autistic in NT space or in one's own personal space – or it may be harder. People sometimes come to autistic space expecting a kind of utopia where there will be no interpersonal or environmental difficulties. In actuality it simply has some *different* difficulties... Leaving our familiar personal spaces to come together in autistic physical space is not always easy or comfortable. Those of us who make the effort to come together (at least those who keep coming back) do it not because it's easy and problem-free, but because the benefits we get from it are worth the difficulties and discomforts.³¹

Furthermore, *facilities* and *difficulties* in and between relationships intuitively make sense. And neither *difficulties* nor *facilities* presuppose an automatic bad or good-in-itself. Definition two, “unimpeded opportunity for doing,” clearly indicates *facilities* exist outside, socially with, rather than only contained within, the person; it suggests opportunity may emerge through material support and the potential for technological adaptation.

I believe more flexible, generous, and relational thinking is possible with terms like *facilities* - and the corollaries of *facilitate*, *facilitating*, *facilitation*, and

³¹ Emphasis in original. It almost seems as if because Sinclair's autistic advocacy is filled with political import, his credentialed expertise goes unmentioned by academic investigators. For more on Sinclair's professional work, see Golubock and Sinclair, “Conferences and Workshops.” Sinclair, “Being Autistic Together.”

thinking/doing *with facility* – juxtaposed with *difficulties* – finding creative approaches to doing the things that need doing. That is to say, doing and accomplishing both with facility *and* with difficulty.

Situating real-world problems of living

For autistic individuals, a “situated functioning” approach offers tools for self-assessment and personal advocacy – for identifying and explaining one’s abilities and disabilities, areas of strength and weakness, or in the idiom of my presentation, tasks and situations where one tends to encounter more or less facility and difficulty in accomplishing specific goals. As an approach to self-advocacy and allies’ advocacy, situated functioning is a political language that is useful for confronting stereotypes and recalibrating expectations, whether too low or too high. By insisting that both one’s ability and disability be recognized, accommodated, and affirmed in all their complex and specific manifestations, the idiom resists assimilation into uses that tend to reductively summarize and make static by way of all-encompassing, but ill-defined, functioning labels.

For autistic people and members of their families, thinking in terms of situated functioning could be used to enhance relationships and interpersonal communication. It can help identify life activities where support may be needed to work through difficulties, as well as highlight ways that an autistic person actively taps their own resources to meet goals. Situated functioning, as both idiom and approach to understanding, encourages family members to look for ways to remove obstacles that hinder their loved one’s ability to function well in a particular environment. Properly situated, functioning can help in considering ways that the physical environment and social interaction are generally set up

to enhance the smooth functioning of neurotypicals but how those same arrangements can create problems for people on the spectrum. The question then becomes: how can the facilities of each family member, i.e. their ways of doing that come to them more easily, be drawn on effectively?

I am also interested in how a situated functioning approach might influence the work of educators, clinicians, and service providers. The assessment of needs and designation of goals – whether they are clinical, educational, or service related – assume a different character when social interaction, physical environment, and assistive technology are all essential components to be considered when determining what (and who) is functioning poorly or well. At core, the idea is to meet the needs and desires of autistic people and those who care *with* them by addressing specific problematic situations and social arrangements. Caring with means striving for an aligned, mutual process which is different from caring for. The approach illustrates the poverty of a deficit approach, where a myopic focus on what an individual supposedly *cannot* do simply serves to perpetuate the circumstances that establish what is already misunderstood as individual incapacity in the first place. What might professional expertise look like without power-laden diagnostic labels? Can good functioning be approached as a *collaborative encounter*?

The goal is not to define exactly which aspects of functioning are universally important. The point of situating functioning is precisely to refuse the concept of functioning when used in a de-contextualized way – outside of particular situations and what inevitably are complexly and collectively choreographed social encounters. Those with the authority to designate and label others as dysfunctional have an obligation to

provide a good account of what may or may not be functioning well in the context of a particular environment. The assessors, therefore, bear a special responsibility.

We should ask a lot of questions whenever we hear somebody say that someone is low-functioning, perhaps at times making explicit our indignation:

Hey, what do you mean when you say that person is low-functioning?

How are you defining the situation where xe functions?

Does what you are labeling as “functioning” vary at different times and in different contexts?

What adaptive strategies and supports are you including in your hypothetical scene?

In an educational environment, for example, we can ask: Who is doing what? Where? What else is going on in that space? Can you be specific about the nature of the difficulties the student is experiencing? What techniques and tools are facilitating the student’s ability to reach their goals? How are goals and success being defined? How could we alter the situation to provide the appropriate level of challenge, enhance functioning and enable success?

Thinking with the idiom of situated functioning offers us a path toward a better understanding of how we get on together – and how we can get along together better. In the autistic world as well as any other social arena, people become entangled in messy moments of cooperation and conflict. These situations can be seen as inevitably embedded in relationships of uneven power which generate friction or, and maybe even simultaneously, rearticulated toward more dynamic support and mutually successful outcomes.

By thinking about my experience with my students, and about myself as a teacher and a student, I find that ability and disability are complex phenomena. In particular, I find that the particulars of a given situation matter greatly – that the circumstances in which one tries to function, and in which one is expected to function in particular ways and according to specific criteria, which may be explicit or tacit, might (in theory at least) be set up and configured differently. We collectively determine the conditions for survival through social arrangements, by shaping material environments and by incorporating assistive technologies – through an extensive web of relations, extending beyond our line of vision and awareness, with other humans and with nonhuman others (companion animals, ecologies, and knowledge systems).

We cannot fully describe the sort of complex, dynamic relationality that I am reaching for, just as we cannot really know the individual self in the abstract, removed from the social world. We need to approach both selves and situations as being in a state of “becoming” to remind ourselves that each of us lives and develops in process, in the midst of change. Therefore, to better understand our collective human situation, we must not mis-conceive a mode of assessment – intellectual, functioning, brain bio-marking, or any other – which assumes that we have removed our objective-selves from social worlds. By designating our selves and our others as ‘becoming with,’ we articulate a state of flux and entanglement, as well as the unfinished work of our situated knowledges and conjoint functioning.

References

- “Advertisement.” *USA Today*, April 6, 2006.
- “Autism Has High Costs To US Society.” *Medical News Today*, April 27, 2006. <http://www.medicalnewstoday.com/releases/42260.php>.
- “Autism Testing - Division of Genetics: Autism 16p11.2 Deletion / Duplication,” 2008. <http://www.childrenshospital.org/clinicalservices/Site1925/mainpageS1925P9.html>.
- “CHARGE Publications and Presentations.” *CHARGE (Childhood Autism Risks from Genetics and the Environment)*. Accessed February 15, 2014. <http://beincharge.ucdavis.edu/presentpublish.php>.
- “Four Dads’ Passion Leads to New University-Based Institute for Treating Autism and Other Disorders.” UC Davis Health System | Newsroom, March 19, 1999. <http://www.ucdmc.ucdavis.edu/publish/news/newsroom/2566>.
- “Interview Transcript for Ari Ne’eman.” *CBC News - Positively Autistic*, October 26, 2009. <http://www.cbc.ca/news/interview-transcript-for-ari-ne-eman-1.822409>.
- “Minerva.” *BMJ* 328, no. 7451 (May 29, 2004): 1326.
- “National Autism Leader Peter Bell Named President & CEO Of Eden Autism Services.” *PR.com*, December 5, 2013. <http://www.pr.com/press-release/531256>.
- “National Symposium on Neurodiversity at Syracuse University.” Accessed December 24, 2013. <http://neurodiversitysymposium.wordpress.com/>.
- “Neurodiversity, the Concept.” *Neurodiversity.com*. Accessed August 27, 2009. <http://www.neurodiversity.com/neurodiversity.html>.
- “Neurodiversity.” *Wikipedia, the Free Encyclopedia*. Accessed December 24, 2013. <http://en.wikipedia.org/wiki/Neurodiversity>.
- “Special Education Review Commission Report.” Garden State Coalition of Schools, April 10, 2007. http://www.gscschools.org/gsc/Special%20Education%20Funding%20Issues/Special%20Education%20Review%20Commission%20Report%20submitted%20April%202007.html/_top.
- “The Wright Era: Q&A with Bob Wright Television Legend Hangs Up His NBC Hat, Moves on to New Challenges.” *TV Week*, April 2007. http://www.tvweek.com/news/2007/04/the_wright_era_qa_with_bob_wri.php.
- “UC Davis M.I.N.D. Institute Launches Largest Biomedical Assessment of Children with Autism,” March 8, 2006. <http://www.ucdmc.ucdavis.edu/newsroom/releases/archives/mind/2006/phenomeproject3-2006.html>.

- ABFH. "Roses." *Whose Planet Is It Anyway?*, May 31, 2010. <http://autisticbfh.blogspot.com/>.
- Alan, Michael. *I Wish My Kids Had Cancer: A Family Surviving the Autism Epidemic*. PublishAmerica, 2008.
- Alma Avla, As Next Friend Of Amber N. Avila vs Johnson & Johnson et al. (In Risperdal/Seroquel/Zyprexa Litigation; Superior Court of Middlesex County, New Jersey, 2010).
- Althusser, Louis. "Ideology and Ideological State Apparatuses (Notes Towards an Investigation)." In *Lenin and Philosophy and Other Essays*, 127-186, Aakar Books, 1971.
- American Psychiatric Association, A.P.A. *Diagnostic and Statistical Manual of Mental Disorders*. Vol. DSM-III. Washington DC: American Psychiatric Association, 1980.
- . *Diagnostic and Statistical Manual of Mental Disorders*. Vol. DSM-III-R. Washington DC: American Psychiatric Association, 1987.
- . *Diagnostic and Statistical Manual of Mental Disorders*. Vol. DSM-IV. Washington DC: American Psychiatric Association, 1994.
- . *Diagnostic and Statistical Manual of Mental Disorders*. Vol. DSM-IV-TR. Washington DC: American Psychiatric Association, 2000.
- . *DSM 5*. American Psychiatric Association, 2013.
- . *Draft Criteria for Autism Spectrum Disorder*. DSM-5 Development, 2012. www.dsm5.org.
- . "Highlights of Changes from DSM-IV-TR to DSM-5." American Psychiatric Publishing, 2013.
- Archana Chatterjee M. D., Ph D. "The Controversy That Will Not Go Away: Vaccines and Autism." In *Vaccinophobia and Vaccine Controversies of the 21st Century*, edited by Archana Chatterjee, 181–211. Springer New York, 2013.
- Asperger, Hans. "Die 'Autistischen Psychopathen' Im Kindesalter." *European Archives of Psychiatry and Clinical Neuroscience* 117, no. 1 (1944): 76–136.
- Autism Network International. "About Autreat," n.d. <http://www.autreat.com/aut09.html#INTRO>.
- Autism Speaks. "Press Release | Autism Speaks Withdraws Support for Strategic Plan for Autism Research, Decries Unexpected Change in Final Approval Process," January 15, 2009. <http://www.autismspeaks.org/about-us/press-releases/autism-speaks-withdraws-support-strategic-plan-autism-research-decries-unexp>.
- . Autism Speaks. "NBC Networks to Focus on Autism." Accessed June 11, 2009. http://www.autismspeaks.org/inthenews/naar_archive/nbc_networks_focus_on_autism.php.

- . “New Study Reveals Autism Prevalence in South Korea Estimated to Be 2.6% or 1 in 38 Children | Press Release.” Autism Speaks, May 9, 2011. <http://www.autismspeaks.org/about-us/press-releases/new-study-reveals-autism-prevalence-south-korea-estimated-be-26-or-1-38-chil>.
- . “Dan Smith to Lead Discovery Neuroscience.” Autism Speaks, May 22, 2012. <http://www.autismspeaks.org/science/science-news/dan-smith-lead-discovery-neuroscience>.
- . “Autism Speaks Names Robert Ring to New Position of Vice President of Translational Research | Press Release.” Autism Speaks, July 25, 2012. <http://www.autismspeaks.org/about-us/press-releases/autism-speaks-names-robert-ring-new-position-vice-president-translational-re>.
- . “New Research Finds Annual Cost of Autism Has More Than Tripled.” Autism Speaks, March 28, 2012. <http://www.autismspeaks.org/about-us/press-releases/annual-cost-of-autism-triples>.
- . “Robert H. Ring, Ph.D. Named Chief Science Officer of Autism Speaks.” *Autism Speaks*, June 13, 2013. <http://www.autismspeaks.org/about-us/press-releases/robert-h-ring-phd-named-chief-science-officer-autism-speaks>.
- . “Autism Speaks Names Paul Wang, M.D., Senior Vice President and Head of Medical Research | Press Release.” Autism Speaks, September 30, 2013. <http://www.autismspeaks.org/about-us/press-releases/autism-speaks-names-paul-wang-md-senior-vice-president-head-medical-research>.
- Autistic Self Advocacy Network. “About ASAN.” Autistic Self Advocacy Network. Accessed November 20, 2013. <http://autisticadvocacy.org/about-asan/>.
- Bagatell, Nancy. “Orchestrating Voices: Autism, Identity and the Power of Discourse.” *Disability & Society* 22, no. 4 (2007): 413–426.
- . “From Cure to Community: Transforming Notions of Autism.” *Ethos* 38, no. 1 (2010): 33–55.
- Baggs, Amanda M. “The Validity of Autistic Opinions.” *Autism Information Library*, 2003. <http://archive.autistics.org/library/autopin.html>.
- . “Help! I Seem to be Getting More Autistic!” *Autism Information Library*, May 13, 2005. <http://archive.autistics.org/library/more-autistic.html>.
- . “Neurodiversity... but not quite.” *Ballastexistenz*, December 28, 2005. <http://ballastexistenz.wordpress.com/2005/12/28/neurodiversity-but-not-quite/>.
- . “The Meaning of Self-Advocacy.” *Autism Information Library*, 2005. <http://archive.autistics.org/library/autopin.html>.
- . “Temple Grandin, Displaying Near-Textbook ‘HFA/AS Elitism.’” *Ballastexistenz*, January 8, 2006. <https://ballastexistenz.wordpress.com/2006/01/08/temple-grandin-displaying-near-textbook-hfaas-elitism/>.

- . “Suicide and Autism ’Severity.’” *Ballastexistenz*, March 28, 2006. <http://ballastexistenz.autistics.org/?p=60>.
- . “Temple Grandin Devalues Us Again, In Print This Time.” *Ballastexistenz*, April 27, 2006. <http://ballastexistenz.wordpress.com/2006/04/27/>.
- . “Politics, Ethics, and Mental Widgets.” *Ballastexistenz*, January 11, 2007. <https://ballastexistenz.wordpress.com/2007/01/11/politics-ethics-and-mental-widgets/>.
- . “No Good Guys or Bad Guys Here.” *Ballastexistenz*, June 28, 2007. <https://ballastexistenz.wordpress.com/2007/06/28/no-good-guys-or-bad-guys-here/>.
- . “Aspie Supremacy Can Kill.” *Ballastexistenz*, March 7, 2010. <https://ballastexistenz.wordpress.com/2010/03/07/aspie-supremacy-can-kill/>.
- . “Aspificating Snobbery over the DSM All over Again.” *Ballastexistenz*, February 13, 2010. <http://ballastexistenz.wordpress.com/2010/02/13/aspificating-snobbery-over-the-dsm-all-over-again/>.
- . “Up in the Clouds and Down in the Valley: My Richness and Yours.” *Disability Studies Quarterly* 30, no. 1 (2010).
- . “Love, Devotion, Hope, Prevention, and Cure.” *Autism Information Library*, n.d. <http://archive.autistics.org/library/love.html>.
- . “The World I Want To Live In.” *Autism Information Library*, n.d. <http://archive.autistics.org/library/want.html>.
- Baggs, AM, Phil Schwarz, Joel Smith, Laura Tisoncik. “Who Can Call Themselves Autistic?” *Autism Information Library*, n.d. <http://archive.autistics.org/library/whoisautistic.html>.
- Baggs, Amanda, Drew Morton Goldsmith, and Morton Ann Gernsbacher. “The Ethical, Scientific, and Societal Implications of Grading Autistic People.” presented at the Autreat 2010: Living the Autly Way, Bradford, PA, June 29, 2010.
- Baird, Gillian, Emily Simonoff, Andrew Pickles, Susie Chandler, Tom Loucas, David Meldrum, and Tony Charman. “Prevalence of Disorders of the Autism Spectrum in a Population Cohort of Children in South Thames: The Special Needs and Autism Project (SNAP).” *The Lancet* 368, no. 9531 (2006): 210–215.
- Baker, Dana Lee. “Neurodiversity, Neurological Disability and the Public Sector: Notes on the Autism Spectrum.” *Disability & Society* 21, no. 1 (2006): 15–29.
- . *The Politics of Neurodiversity: Why Public Policy Matters*. Lynne Rienner Publishers, 2011.
- Baker, Dana Lee, and Lila Walsh. “Divided or Opposed?: The Level-of-Functioning Arguments in Autism-Related Political Discourse in Canada.” In *Worlds of Autism: Across the Spectrum of Neurological Difference*. University of Minnesota Press, 2013.

- Baker, J. P. "Mercury, Vaccines, and Autism: One Controversy, Three Histories." *American Journal of Public Health* 98, no. 2 (2008): 244.
- Balintfy, Joe. *Transcript: NIH Podcast*. Mp3. NIH Research Radio. Accessed September 10, 2013. <http://www.nih.gov/news/radio/podcast/2009/e0090.htm>.
- Barad, Karen. *Meeting the Universe Halfway: Quantum Physics and the Entanglement of Matter and Meaning*. Duke University Press, 2007.
- . "On Touching—The Inhuman That Therefore I Am." *Differences* 23, no. 3 (January 1, 2012): 206–223.
- Barnbaum, Deborah R. *The Ethics of Autism: Among Them, but Not of Them*. Indiana University Press, 2008.
- Barnes, R. Eric, and Helen McCabe. "Should We Welcome a Cure for Autism? A Survey of the Arguments." *Medicine, Health Care and Philosophy* 15, no. 3 (August 1, 2012): 255–269.
- Baron-Cohen, Simon, and Jessica Hammer. "Parents of Children with Asperger Syndrome: What Is the Cognitive Phenotype?" *Journal of Cognitive Neuroscience* 9, no. 4 (July 1, 1997): 548–554.
- Baron-Cohen, Simon. "The Hyper-systemizing, Assortative Mating Theory of Autism." *Progress in Neuro-Psychopharmacology and Biological Psychiatry* 30, no. 5 (2006): 865–872.
- Barry, Kevin. "Gray Matters: Autism, Impairment, and the End of Binaries." *San Diego Law Review* 49 (2012): 161.
- Bascom, Julie, ed. *Loud Hands: Autistic People, Speaking*. Autistic Self Advocacy Network, 2012.
- Bayer, Ronald, and Robert L Spitzer. "Neurosis, Psychodynamics, and DSM-III: A History of the Controversy." *Archives of General Psychiatry* 42, no. 2 (1985): 187.
- Bayer, Ronald. *Homosexuality and American Psychiatry-The Politics of Diagnosis*. Princeton University Press, 1981.
- Becchio, Cristina, and Umberto Castiello. "Visuomotor Resonance in Autism Spectrum Disorders." *Frontiers in Integrative Neuroscience* 6 (2012): 110.
- Bell, Peter. "Autism - From Denial to Hope." *Behavioral Healthcare: The Business of Treatment and Recovery*, July 1, 2006. <http://www.behavioral.net/article/autism-denial-hope>.
- Bell, Peter, and Sallie Bernard. *Fulfilling Our Vision: Cure Autism Now, 2005 Annual Report*, 2005.
- Berr, Jonathan. "How Autism Can Cost Families Millions." *MSNMoney*, March 25, 2013. <http://money.msn.com/now/post.aspx?post=00d9751b-dad1-4d2a-b3ea-01287216ce21>.

- Bertilsson Rosqvist, Hanna, Charlotte Brownlow, and Lindsay O'Dell. "Mapping the Social Geographies of Autism: Online and Off-line Narratives of Neuro-Shared and Separate Spaces." *Disability & Society* 28, no. 3 (2013): 367–379.
- Best, Joel. "The Problems with Moral Panic: The Concept's Limitations." In *The Ashgate Research Companion to Moral Panics*, 67–78. Ashgate Publishing, Ltd., 2012.
- Bettelheim, Bruno. "Individual and Mass Behavior in Extreme Situations." *The Journal of Abnormal and Social Psychology* 38, no. 4 (1943): 417.
- . *The Empty Fortress: Infantile Autism and the Birth of the Self*. New York: Free Press, 1967.
- Bev. "Angry Aspies, Please Go Away | Square 8." *Square 8: Squawk About Disability and Society*, February 13, 2010. <http://aspergersquare8.blogspot.com/2010/02/angry-aspies-please-go-away.html>.
- Bérubé, Michel. "Equality, Freedom, and/or Justice For All: A Response to Martha Nussbaum." In *Cognitive Disability and its Challenge to Moral Philosophy*. John Wiley & Sons, 2010.
- Bierer, Lydia Nicole. *Online Community Building by Autistic Adults*. Ph.D. diss, University of Texas, Austin, 2013.
- Biklen, Douglas. *Autism and the Myth of the Person Alone*. New York University Press, 2005.
- Blumberg, Stephen J, Matthew D Bramlett, Michael D Kogan, Laura A Schieve, Jessica R Jones, and Michael C Lu. "Changes in Prevalence of Parent-reported Autism Spectrum Disorder in School-aged US Children: 2007 to 2011–2012." *National Health Statistics Reports* 65 (2013): 1–11.
- Blume, Harvey. "Autism & The Internet or It's The Wiring Stupid." *Media In Transition - MIT*, July 1, 1997. http://web.mit.edu/m-i-t/articles/index_blume.html.
- . "Autistics, Freed from Face-to-face Encounters, Are Communicating in Cyberspace." *New York Times*, June 30, 1997. <http://www.nytimes.com/1997/06/30/business/autistics-freed-from-face-to-face-encounters-are-communicating-in-cyberspace.html>.
- . "Neurodiversity: On the Neurological Underpinnings of Geekdom." *The Atlantic*. Accessed May 11, 2007. <http://www.theatlantic.com/magazine/archive/1998/09/neurodiversity/5909/>.
- Boundy, Kathryn. "Are You Sure, Sweetheart, That You Want to Be Well?: An Exploration Of The Neurodiversity Movement." *Radical Psychology: A Journal of Psychology, Politics & Radicalism* 7, no. 2 (2008): 2–2.
- Bowker, Geoffrey C., and Susan Leigh Star. *Sorting Things Out: Classification and Its Consequences*, 1999.
- Brady, Michael T, Carrie L Byington, H Dele Davies, Kathryn M Edwards, Mary P Glode, Mary Anne Jackson, Harry L Keyserling, Yvonne A Maldonado, Dennis

- L Murray, and Walter A Orenstein. "Recommended Childhood and Adolescent Immunization Schedule—United States, 2013." *Pediatrics* 131, no. 2 (2013): 397–398.
- Braff, Laura, and David L Braff. "The Neuropsychiatric Translational Revolution: Still Very Early and Still Very Challenging." *JAMA Psychiatry* 70, no. 8 (August 1, 2013): 777–779.
- Bragesjö, Fredrik, and Margareta Hallberg. "Dilemmas of a Vitalizing Vaccine Market: Lessons from the MMR Vaccine/Autism Debate." *Science in Context* 24, no. 01 (2011): 107–125.
- Bresnahan, Michaeline, Guohua Li, and Ezra Susser. "Hidden in Plain Sight." *International Journal of Epidemiology* 38, no. 5 (October 1, 2009): 1172–1174.
- Brown, Eryn. "CDC Reports on U.S. Vaccination Rates, Recent Measles Outbreaks." *Los Angeles Times*, September 12, 2013. <http://articles.latimes.com/2013/sep/12/science/la-sci-sn-cdc-measles-vaccines-20130912>.
- Brown, Lydia. "15 Things You Should Never Say To An Autistic." *Autistic Hoya*, February 24, 2012. <http://www.autistichoya.com/2012/02/15-things-you-should-never-say-to.html>.
- Brownlow, Charlotte Louise. "Constructing an Autistic Identity: AS Voices Online." Edited by Steven J. Taylor. *Mental Retardation* 44, no. 5 (October 2006): 315–321.
- . *The Construction of the Autistic Individual: Investigations in Online Discussion Groups*. Ph.D. diss, University of Brighton, 2007.
- . "Re-presenting Autism: The Construction of 'NT Syndrome'." *The Journal of Medical Humanities* 31, no. 3 (September 2010): 243–255.
- Brownlow, Charlotte, and Lindsay O'Dell. "Autism as a Form of Biological Citizenship." In *Worlds of Autism: Across the Spectrum of Neurological Difference*. University of Minnesota Press, 2013.
- Bumiller, Kristin. "Quirky Citizens: Autism, Gender, and Reimagining Disability." *Signs* 33, no. 4 (2008): 967–991.
- Burby, Leslie. "Issue 14 – Exposing Autism Speaks." *Autism Parenting Magazine*, January 2014. <http://www.autismparentingmagazine.com/issue-14-asd-options-living-independently/>.
- Bush, Marc. "Constructing an 'Autistic Pathology': Hans Asperger, Austria & the Profession of Psychiatry, 1900-1945." presented at the Gender, Health, and Medicine in Historical Perspective Conference, University of Exeter, July 6, 2008.
- Carey, Allison C. *On the Margins of Citizenship: Intellectual Disability and Civil Rights in Twentieth-century America*. Temple University Press, 2009.

- Carey, Benedict. "McCain Steps Into Debate Over Cause of Autism." *New York Times*, March 3, 2008. http://www.nytimes.com/2008/03/03/us/politics/03cnd-autism.html?_r=1&adxnnl=1&oref=slogin&adxnnlx=1204936543-FzDWPPtNw3+iHwN4veDQ9Q.
- . "New Definition of Autism May Exclude Many, Study Suggests." *The New York Times*, January 19, 2012. <http://www.nytimes.com/2012/01/20/health/research/new-autism-definition-would-exclude-many-study-suggests.html>.
- Carey, Matt. "Dismay at Aspie 'Hate'." *Left Brain Right Brain*, February 15, 2010. <http://leftbrainrightbrain.co.uk/2010/02/15/dismay-at-aspie-hate/>.
- Caruso, Daniela. "Autism in the U.S.: Social Movement and Legal Change." *American Journal of Law & Medicine* 36, no. 4 (2010): 483–539.
- Centers for Disease Control. "Prevalence of Autism Spectrum Disorders --- Autism and Developmental Disabilities Monitoring Network, 14 Sites, United States, 2002." *Morbidity and Mortality Weekly Report*. CDC, February 9, 2007. <http://www.cdc.gov/mmwr/preview/mmwrhtml/ss5601a2.htm>.
- . "Telebriefing Transcript: Media Briefing on Vaccines and Child Health," July 19, 2005. <http://www.cdc.gov/od/oc/media/transcripts/t050719.htm>.
- . "Prevalence of Autism Spectrum Disorders --- Autism and Developmental Disabilities Monitoring Network, United States, 2006." *Morbidity and Mortality Weekly Report*. CDC, December 18, 2009. <http://www.cdc.gov/mmwr/preview/mmwrhtml/ss5810a1.htm>.
- . "Prevalence of Autism Spectrum Disorders — Autism and Developmental Disabilities Monitoring Network, 14 Sites, United States, 2008." *Morbidity and Mortality Weekly Report*. CDC, March 30, 2012. http://www.cdc.gov/mmwr/preview/mmwrhtml/ss6103a1.htm?s_cid=ss6103a1_e
- . "Data and Statistics, Autism Spectrum Disorders - NCBDDD." Accessed September 19, 2013. <http://www.cdc.gov/ncbddd/autism/data.html>.
- . "CDC Estimates 1 in 68 Children Has Been Identified with Autism Spectrum Disorder." Press Release | CDC Online Newsroom | CDC, March 27, 2014. <http://www.cdc.gov/media/releases/2014/p0327-autism-spectrum-disorder.html>.
- Chamak, Brigitte, and Béatrice Bonniau. "Changes in the Diagnosis of Autism: How Parents and Professionals Act and React in France." *Culture, Medicine, and Psychiatry* 37, no. 3 (2013): 405–426.
- Chamak, Brigitte, Béatrice Bonniau, Lila Oudaya, and Alain Ehrenberg. "The Autism Diagnostic Experiences of French Parents." *Autism* 15, no. 1 (2011): 83–97.
- Chaste, Pauline, and Marion Leboyer. "Autism Risk Factors: Genes, Environment, and Gene-environment Interactions." *Dialogues in Clinical Neuroscience* 14, no. 3 (September 2012): 281–292.

- Chew, Kristina. "Autism and the Task of the Translator." In *Worlds of Autism: Across the Spectrum of Neurological Difference*, edited by Joyce Davidson and Michael Orsini. University of Minnesota Press, 2013.
- Clarke, Adele. *Situational Analysis: Grounded Theory After the Postmodern Turn*. Sage, 2005.
- Clarke, Adele, and Susan Leigh Star. "The Social Worlds Framework: A Theory/methods Package." In *The Handbook of Science and Technology Studies*, edited by Edward J Hackett, Olga Amsterdamska, Michael Lynch, and Judy Wajcman, 113–139, 2008.
- Clarke, Adele E., Janet K. Shim, Laura Mamo, Jennifer Ruth Fosket, and Jennifer R. Fishman. "Biomedicalization: Technoscientific Transformations of Health, Illness, and U.S. Biomedicine." *American Sociological Review* 68, no. 2 (April 1, 2003): 161–194.
- Clarke, Adele E., Laura Mamo, Jennifer Ruth Fosket, Jennifer R. Fishman, and Janet K. Shim. *Biomedicalization: Technoscience, Health, and Illness in the U.S.* Duke University Press, 2009.
- Clifford, James. "Feeling Historical." *Cultural Anthropology* 27, no. 3 (2012): 417–426.
- Clinton, Hillary. "Hillary Clinton's Plan to Help Children And Families Affected By Autism" (February 8, 2008). <http://www.hillaryclinton.com/news/release/view/?id=4342>.
- Collins, Harry. "Actors' and Analysts' Categories in the Social Analysis of Science." In *Clashes of Knowledge*, edited by Peter Meusburger, Michael Welker, and Edgar Wunder, 101–110. Knowledge and Space 1. Springer Netherlands, 2008.
- . "The Third Wave of Science Studies: Developments and Politics." *Japan Journal for Science, Technology & Society* 20 (2011): 81–106.
- Conrad, Peter. *The Medicalization of Society: On the Transformation of Human Conditions into Treatable Disorders*. JHU Press, 2008.
- Cure Autism Now. "Board Spotlight: Peter Bell." *Advances*, Winter 2003-2004.
- Das, Veena, and Ranendra K. Das. "Pharmaceutical in Urban Ecologies: The Register of the Local." In *Global Pharmaceuticals: Ethics, Markets, Practices*, edited by Adriana Petryna, Andrew Lakoff, and Arthur Kleinman, 171–205. Durham: Duke University Press, 2006.
- Davidson, Joyce. "Autistic Culture Online: Virtual Communication and Cultural Expression on the Spectrum." *Social & Cultural Geography* 9, no. 7 (2008): 791–806.
- Davidson, Joyce, and Michael Orsini. *Worlds of Autism: Across the Spectrum of Neurological Difference*. University of Minnesota Press, 2013.

- Davidson, Joyce, and Victoria L. Henderson. "‘Travel in Parallel with Us for a While’: Sensory Geographies of Autism." *Canadian Geographer / Le Géographe Canadien* 54, no. 4 (2010): 462–475.
- Davis, Lennard J. *Enforcing Normalcy: Disability, Deafness, and the Body*. London; New York: Verso, 1995.
- . *The End of Normal: Identity in a Biocultural Era*. University of Michigan Press, 2013.
- Dawson, Geraldine, Sara Webb, Gerard D. Schellenberg, Stephen Dager, Seth Friedman, Elizabeth Aylward, and Todd Richards. "Defining the Broader Phenotype of Autism: Genetic, Brain, and Behavioral Perspectives." *Development and Psychopathology* 14, no. 03 (2002): 581–611.
- Dawson, M., I. Soulieres, M. A. Gernsbacher, and L. Mottron. "The Level and Nature of Autistic Intelligence." *Psychological Science* 18, no. 8 (2007): 657–662.
- De la Bellacasa, María Puig. "‘Nothing Comes Without Its World’: Thinking with Care." *The Sociological Review* 60, no. 2 (2012): 197–216.
- Decker, Jeni, and Peter Sekirin. *I Wish I Were Engulfed in Flames: My Insane Life Raising Two Boys with Autism*. Skyhorse Publishing Inc., 2012.
- Desmet Trumbull, Raissa. *A Liquid World: Figuring Coloniality in the Indies*. Ph.D. diss, University of California, Santa Cruz, 2013.
- Despret, Vinciane. "The Becomings of Subjectivity in Animal Worlds." *Subjectivity* 23, no. 1 (July 2008): 123–139. 33
- . "Responding Bodies and Partial Affinities in Human–Animal Worlds." *Theory, Culture & Society*. 30, no. 7-8 (2013): 51-76.
- DeWeerd, Sarah. "Funding Agency Shifts Focus Away From Diagnostic Groups." *Simons Foundation Autism Research Initiative*, May 27, 2013. <http://sfari.org/news-and-opinion/news/2013/funding-agency-shifts-focus-away-from-diagnostic-groups>.
- Diament, Michelle. "White House Remains Steadfast In Support Of Disability Council Nominee." *Disability Scoop*, March 29, 2010. <http://www.disabilityscoop.com/2010/03/29/neeman-nomination/7473/>.
- . "Senate Confirms Controversial Autism Self-Advocate To National Disability Council." *Disability Scoop*, June 22, 2010. <http://www.disabilityscoop.com/2010/06/22/neeman-confirmation/9133/>.
- Dingfelder, Sadie F. "A Shift in Priorities at NIMH." *Monitor on Psychology*, February 2004. <http://www.apa.org/monitor/feb04/shift.aspx>.
- Dobbs, Michael. "Fact Checker - Dr. Obama and Dr. McCain." Accessed August 27, 2013. http://blog.washingtonpost.com/fact-checker/2008/04/dr_obama_and_dr_mccain.html.

- Dodds, Klaus, and Philip Kirby. "It's Not a Laughing Matter: Critical Geopolitics, Humour and Unlaughter." *Geopolitics* 18, no. 1 (2013): 45–59.
- Dominus, Susan. "The Crash and Burn of an Autism Guru." *The New York Times*, April 20, 2011. <http://www.nytimes.com/2011/04/24/magazine/mag-24Autism-t.html>.
- Dumit, Joseph. *Picturing Personhood: Brain Scans and Biomedical Identity*. Princeton University Press, 2004.
- . *Drugs for Life: How Pharmaceutical Companies Define Our Health*. Duke University Press, 2012.
- Edelson, Mat. "Abnormal Ambitions." *UMBC Magazine*, Winter 2009. <http://www.umbc.edu/magazine/winter09/>.
- Edelson, Stephen M., and Bernard Rimland. *Treating Autism: Parent Stories of Hope and Success*. Autism Research Institute, 2003.
- Elsabbagh, Mayada, Gauri Divan, Yun-Joo Koh, Young Shin Kim, Shuaib Kauchali, Carlos Marcín, Cecilia Montiel-Nava, et al. "Global Prevalence of Autism and Other Pervasive Developmental Disorders." *Autism Research* 5, no. 3 (2012): 160–179.
- Epstein, Steven. *Impure Science: AIDS, Activism, and the Politics of Knowledge*. University of California Press, 1996.
- . "Patient Groups and Health Movements." In *The Handbook of Science and Technology Studies*, edited by et al. Edward J. Hackett, 3rd:499–539. Cambridge, Mass: MIT Press, 2008.
- Equal Employment Opportunity Commission. "Questions and Answers on the Final Rule Implementing the ADA Amendments Act of 2008," n.d. http://www.eeoc.gov/laws/regulations/ada_qa_final_rule.cfm.
- Eyal, Gil. "For a Sociology of Expertise: The Social Origins of the Autism Epidemic." *American Journal of Sociology* 118, no. 4 (January 1, 2013): 863–907.
- Eyal, Gil, Brendan Hart, Emine Onculer, Neta Oren, and Natasha Rossi. *The Autism Matrix: The Social Origins of the Autism Epidemic*. Cambridge, U.K.: Polity, 2010.
- Feighner, John P, Eli Robins, Samuel B Guze, Robert A Woodruff Jr, George Winokur, and Rodrigo Munoz. "Diagnostic Criteria for Use in Psychiatric Research." *Archives of General Psychiatry* 26, no. 1 (1972): 57.
- Feinstein, Adam. *A History of Autism: Conversations with the Pioneers*. John Wiley & Sons, 2010.
- Fenton, A., and T. Krahn. "Autism, Neurodiversity and Equality Beyond the 'Normal'." *Journal of Ethics in Mental Health* 2, no. 2 (2007): 1–6.
- Fisher, James. "No Search, No Subject? Autism and the American Conversion Narrative." In *Autism and Representation*. Psychology Press, 2007.

- Fitzgerald, Des. *Tracing Autism: Ambiguity and Difference in a Neuroscientific Research Practice*. Ph.D. diss, The London School of Economics and Political Science, 2012.
- . “The Affective Labour of Autism Neuroscience: Entangling Emotions, Thoughts and Feelings in a Scientific Research Practice.” *Subjectivity* 6, no. 2 (July 2013): 131–152.
- Fombonne, E. “Epidemiology of Autistic Disorder and Other Pervasive Developmental Disorders.” *Journal of Clinical Psychiatry* 66 (2005).
- Foucault, Michel. *The Birth of the Clinic: An Archaeology of Medical Perception*. Vintage Books, 1994 (1973).
- . *Abnormal: lectures at the Collège de France, 1974-1975*. Picador, 2004.
- Gardner, Howard. *Frames of Mind: The Theory of Multiple Intelligences*. Basic books, 1985.
- Gernsbacher, Morton Ann. “Toward a Behavior of Reciprocity.” *Journal of Developmental Processes*, 2006.
- Gernsbacher, Morton Ann, Michelle Dawson, and Hill Goldsmith. “Three Reasons Not to Believe in an Autism Epidemic.” *Current Directions in Psychological Science* 14, no. 2 (2005): 55.
- Ginsburg, Faye, and Rayna Rapp. “Disability Worlds.” *Annual Review of Anthropology* 42, no. 1 (2013): 53–68.
- Goldberg, Carey. “Under Suspicion: Researchers Now Believe That Autism Can Be Caused by Genes in Combination with Environmental Triggers. The Question Is, What Are Those Triggers?” *The Boston Globe*, August 13, 2007.
http://www.boston.com/news/globe/health_science/articles/2007/08/13/under_suspicion/?page=full.
- Goldsmith, Drew Morton. *Grading Autistic People*, 2010.
- Golubock, Susan J., and Jim Sinclair. “Conferences and Workshops.” *Making Sense of Autism*. Accessed June 12, 2014. <http://www.siautism.net/>.
- Goodey, CF. “What Is Developmental Disability? The Origin and Nature of Our Conceptual Models.” *Journal on Developmental Disabilities* 8, no. 2 (2001): 1–18.
- Goodley, Dan. “‘Learning Difficulties’, the Social Model of Disability and Impairment: Challenging Epistemologies.” *Disability & Society* 16, no. 2 (2001): 207 – 231.
- Goodley, D., D. Armstrong, K. Sutherland, and L. Laurie. “Self-Advocacy, ‘Learning Difficulties,’ and the Social Model of Disability.” *Mental Retardation* 41, no. 3 (2003): 149–160.
- Goodley, Dan, and Geert Van Hove. *Another Disability Studies Reader?: People with Learning Difficulties and a Disabling World*. Garant, 2005.

- Goodley, Dan, and Griet Roets. "The (be)comings and Goings of 'Developmental Disabilities': The Cultural Politics of 'Impairment'." *Discourse: Studies in the Cultural Politics of Education* 29, no. 2 (2008): 239–255.
- Goodley, Dan, and Mark Rapley. "How Do You Understand 'Learning Difficulties'? Towards a Social Theory of Impairment." *Mental Retardation* 39, no. 3 (June 2001): 229–232.
- Goodley, Dan, Bill Hughes, and Lennard Davis. *Disability and Social Theory: New Developments and Directions*. Palgrave Macmillan, 2012.
- Gowen, Emma. "Imitation in Autism: Why Action Kinematics Matter." *Frontiers in Integrative Neuroscience* (2012): 117.
- Grandin, T., and M. Scariano. *Emergence, Labeled Autistic*. Academic Therapy Publications, 1986.
- Grandin, Temple. *Thinking in Pictures: And Other Reports from My Life with Autism*. Random House Digital, Inc., 2006.
- . *The World Needs All Kinds of Minds*. Video on TED, 2010. http://www.ted.com/talks/temple_grandin_the_world_needs_all_kinds_of_minds.html.
- Greenberg, Gary. *The Book of Woe: The DSM and the Unmaking of Psychiatry*. Blue Rider Press, 2013.
- Grinker, Roy Richard. *Unstrange Minds: Remapping the World of Autism*. Basic Books, 2007.
- . "Commentary: On Being Autistic, and Social." *Ethos* 38, no. 1 (2010): 172–178.
- Grob, Gerald N. "Origins of DSM-I: A Study in Appearance and Reality." *The American Journal of Psychiatry* 148, no. 4 (April 1991): 421–431.
- . "The Transformation of American Psychiatry." In *History of Psychiatry and Medical Psychology*, 533–554. Springer, 2008.
- Gross, Jane, and Stephanie Strom. "Autism Debate Strains a Family and Its Charity." *The New York Times*. June 18, 2007. <http://www.nytimes.com/2007/06/18/us/18autism.html>.
- Gross, L. "A Broken Trust: Lessons from the Vaccine–Autism Wars." *PLoS Biol* 7, no. 5 (2009): e1000114.
- Hacking, Ian. *The Social Construction of What?* Cambridge: Harvard University Press, 1999.
- . "Kinds of People: Moving Targets." *Proceedings of the British Academy* 151, Oxford University Press, 2007.
- . "Autistic Autobiography." *Philosophical Transactions of the Royal Society B: Biological Sciences* 364, 2009.

- . “How We Have Been Learning to Talk About Autism: A Role for Stories.” *Metaphilosophy* 40, no. 3–4 (2009): 499–516.
- . “Autism Fiction: A Mirror of an Internet Decade?” *University of Toronto Quarterly* 79, no. 2 (2010): 632–655.
- Haertlein, Lauren L. “Immunizing Against Bad Science: The Vaccine Court and the Autism Test Cases.” *Law and Contemporary Problems* 75 (2012): 211.
- Hall, Stuart. “Gramsci and Us.” In *Antonio Gramsci: Critical Assessments of Leading Political Philosophers*, 227–238, 2002.
- . “Signification, Representation, Ideology: Althusser and the Post-structuralist Debates.” *Critical Studies in Media Communication* 2, no. 2 (1985): 91–114.
- Hall, Stuart, Charles Critcher, Tony Jefferson, John Clarke, and Brian Roberts. *Policing the Crisis: Mugging, the State, and Law and Order*. London: Macmillan, 1978.
- . *The Changing Shape of “Panics.”* Open University Press: Maidenhead, 1978.
- Hamilton, Jon. “Asperger’s Officially Placed Inside Autism Spectrum.” *NPR.org*, February 10, 2010. <http://www.npr.org/templates/story/story.php?storyId=123527833>.
- Happé, Francesca. “Criteria, Categories, and Continua: Autism and Related Disorders in DSM-5.” *Journal of the American Academy of Child & Adolescent Psychiatry* 50, no. 6 (2011): 540–542.
- Haraway, Donna. “Situated Knowledges: The Science Question in Feminism and the Privilege of Partial Perspective.” *Feminist Studies* 14, no. 3 (October 1, 1988): 575–599.
- . “The Promises of Monsters: a Regenerative Politics for Inappropriate/d Others.” *Cultural Studies* (1992): 295–337.
- . *Modest_Witness@_Second_Millennium. FemaleMan_Meets_OncoMouse: Feminism and Technoscience*. Routledge, 1997.
- . “The Biopolitics of Postmodern Bodies: Determinations of Self in Immune System Discourse.” In *Feminist Theory and the Body: a Reader*. Taylor & Francis, 1999.
- . *When Species Meet*. University of Minnesota Press, 2007.
- Harmon, Amy. “How About Not ‘Curing’ Us, Some Autistics Are Pleading.” *The New York Times*, December 20, 2004, sec. Health. <http://www.nytimes.com/2004/12/20/health/20autism.html>.
- . “Nominee to Disability Council Is Lightning Rod for Dispute on Views of Autism.” *The New York Times*, March 27, 2010. <http://www.nytimes.com/2010/03/28/health/policy/28autism.html>.
- . “As Specialists Debate Autism, Some Parents Watch Closely.” *The New York Times*, January 20, 2012, sec. U.S. <http://www.nytimes.com/2012/01/21/us/as-specialists-debate-autism-some-parents-watch-closely.html>.

- Harris, Gardiner, and Anahad O'Connor. "On Autism's Cause, It's Parents Vs. Research." *The New York Times* (2005): A1.
- Hayward, Eva. "Sensational Jellyfish: Aquarium Affects and the Matter of Immersion." *Differences* 23, no. 3 (January 1, 2012): 161–196.
- Herbert, Martha R. "Contributions of the Environment and Environmentally Vulnerable Physiology to Autism Spectrum Disorders." *Current Opinion in Neurology* 23, no. 2 (April 2010): 103–110.
- Hoopmann, Kathy. *All Cats Have Asperger Syndrome*. London; Philadelphia: Jessica Kingsley Publishers, 2006.
- . *All dogs have ADHD*. London; Philadelphia, PA: Jessica Kingsley, 2009.
- Hu, Valerie W. "From Genes to Environment: Using Integrative Genomics to Build a 'Systems-Level' Understanding of Autism Spectrum Disorders." *Child Development* 84, no. 1 (2013): 89–103.
- Hughes, Bill. "Civilising Modernity and the Ontological Invalidation of Disabled People." In *Disability and Social Theory: New Developments and Directions*, edited by Dan Goodley, Bill Hughes, and Lennard Davis. Palgrave Macmillan, 2012.
- Hughes, Virginia. "Video: NIH Director Has Big Plans for Autism Research — SFARI.org - Simons Foundation Autism Research Initiative." *SFARI: Simons Foundation Autism Research Initiative*, October 19, 2009. <https://sfari.org/news-and-opinion/conference-news/2009/society-for-neuroscience-2009/video-nih-director-has-big-plans-for-autism-research>.
- Hyman, Steven. "Psychiatric Drug Development: Diagnosing a Crisis." *Cerebrum*, April 2, 2013. <http://dana.org/Cerebrum/Default.aspx?id=39489>.
- Interagency Autism Coordinating Committee. *IACC Report to the Congressional Appropriations Committee on the State of Autism Research*. HHS, NIH, NIMH, April 2004. <http://iacc.hhs.gov/reports/2004/report-to-the-congressional-appropriations-committee-april.shtml#asd>.
- . "IACC Charter." *Interagency Autism Coordinating Committee*. Accessed October 28, 2013. <http://iacc.hhs.gov/about/charter-2009.shtml>.
- . "IACC Public Comment." *Interagency Autism Coordinating Committee*. Accessed October 28, 2013. <http://iacc.hhs.gov/public-comment/index.shtml>.
- Illes, Judy, Mary Anne Moser, Jennifer B. McCormick, Eric Racine, Sandra Blakeslee, Arthur Caplan, Erika Check Hayden, et al. "Neurotalk: Improving the Communication of Neuroscience Research." *Nature Reviews Neuroscience* 11, no. 1 (January 2010): 61–69.
- Immunization Safety Review Committee. "Immunization Safety Review: Vaccines and Autism." *Washington, DC, USA: Institute of Medicine, National Academy of Science* (2004).

- Insel, Thomas R. "Disruptive Insights in Psychiatry: Transforming a Clinical Discipline." *The Journal of Clinical Investigation* 119, no. 4 (April 1, 2009): 700–705.
- . "Next-Generation Treatments for Mental Disorders." *Science Translational Medicine* 4, no. 155 (October 10, 2012): 155ps19–155ps19.
- . "Transforming Diagnosis." *NIMH | Director's Blog*, April 29, 2013. <http://www.nimh.nih.gov/oca.ucsc.edu/about/director/2013/transforming-diagnosis.shtml>.
- Insel, Thomas R., and Remi Quirion. "Psychiatry as a Clinical Neuroscience Discipline." *JAMA : the Journal of the American Medical Association* 294, no. 17 (November 2, 2005): 2221–2224.
- Insel, Thomas R., and Bruce N Cuthbert. "Endophenotypes: Bridging Genomic Complexity and Disorder Heterogeneity." *Biological Psychiatry* 66, no. 11 (2009): 988–989.
- Insel, TR, V Voon, JS Nye, VJ Brown, BM Altevogt, ET Bullmore, GM Goodwin, RJ Howard, DJ Kupfer, and G Malloch. "Innovative Solutions to Novel Drug Development in Mental Health." *Neuroscience & Biobehavioral Reviews* 37, no. 10 (2013): 2438–2444.
- Iroegbu, Osita. "A 'Sweet Victory' in the Fight Against Autism." *Legal Times: Law and Lobbying in the Nation's Capital* (December 18, 2006). <http://www.law.com/jsp/article.jsp?id=900005469287>.
- Jaarsma, P., and S. Welin. "Autism as a Natural Human Variation: Reflections on the Claims of the Neurodiversity Movement." *Health Care Analysis* (2012): 1–11.
- Jardine, Cassandra. "Should We Want to Cure Autism?" *Telegraph.co.uk*, October 22, 2008. <http://www.telegraph.co.uk/health/3356688/Should-we-want-to-cure-autism.html>.
- Jasanoff, Sheila. "The Idiom of Co-Production." In *States of Knowledge: The Co-Production of Science and Social Order*. New York: Routledge, 2004.
- Johnson, Jenell. "Negotiating Autism in an Epidemic of Discourse." *Disability Studies Quarterly* 33, no. 2 (March 28, 2013). <http://dsq-sds.org/article/view/3716>.
- Jutel, Annemarie. "Sociology of Diagnosis: A Preliminary Review." *Sociology of Health & Illness* 31, no. 2 (2009): 278–299.
- Kalb, Claudia. "Erasing Autism." *Newsweek Magazine*, May 16, 2009. <http://www.thedailybeast.com/newsweek/2009/05/15/erasing-autism.html>.
- Kanner, Leo. "Exoneration of the Feebleminded." *American Journal of Psychiatry* 99, no. 1 (July 1, 1942): 17–22.
- . "Autistic Disturbances of Affective Contact." *Nervous Child* 2, no. 2 (1943): 1.

- Kapp, Steven K., and Ari Ne'eman. *ASD in DSM-5: What the Research Shows and Recommendations for Change*. Policy Brief, Autistic Self Advocacy Network, June 2012.
- Kapp, Steven K., Kristen Gillespie-Lynch, Lauren E. Sherman, and Ted Hutman. "Deficit, Difference, or Both? Autism and Neurodiversity." *Developmental Psychology* 49, no. 1 (2013): 59–71.
- Kata, Anna. "A Postmodern Pandora's Box: Anti-vaccination Misinformation on the Internet." *Vaccine* 28, no. 7 (February 17, 2010): 1709–1716.
- . "Anti-vaccine Activists, Web 2.0, and the Postmodern Paradigm – An Overview of Tactics and Tropes Used Online by the Anti-vaccination Movement." *Vaccine* 30, no. 25 (May 28, 2012): 3778–3789.
- Kaufman, Sharon R. "Regarding the Rise in Autism: Vaccine Safety Doubt, Conditions of Inquiry, and the Shape of Freedom." *Ethos* 38, no. 1 (2010): 8–32.
- Kendell, Robert, and Assen Jablensky. "Distinguishing Between the Validity and Utility of Psychiatric Diagnoses." *American Journal of Psychiatry* 160, no. 1 (January 1, 2003): 4–12.
- Kennedy, Robert F. "Deadly Immunity." *Rolling Stone*, 2005.
<http://www.rollingstone.com/politics/news/deadly-immunity-20110209>.
- Kennedy Jr, Robert F, and David Kirby. "Autism, Vaccines and the CDC: The Wrong Side of History." *The Huffington Post* (2009).
- Kennedy, Robert Foster. "The Problem of Social Control of the Congenital Defective: Education, Sterilization, Euthanasia." *American Journal of Psychiatry* 99, no. 1 (July 1, 1942): 13–16.
- Kenway, Ian M. "Blessing or Curse? Autism and the Rise of the Internet." *Journal of Religion, Disability & Health* 13, no. 2 (2009): 94–103.
- Kerr, Margaret Anna. *The Autism Spectrum Disorders/Vaccine Link Debate: A Health Social Movement*. PhD diss, University of Pittsburgh, 2009.
- Kidney, Colleen Anne. *Involvement in the Online Autistic Community, Identity, Community, and Well-being*. M.A. Thesis, Portland State University, (2012).
- Kim, Young Shin, Bennett L. Leventhal, Yun-Joo Koh, Eric Fombonne, Eugene Laska, Eun-Chung Lim, Keun-Ah Cheon, et al. "Prevalence of Autism Spectrum Disorders in a Total Population Sample." *American Journal of Psychiatry* 168, no. 9 (September 1, 2011): 904–912.
- King, Marissa, and Peter Bearman. "Diagnostic Change and the Increased Prevalence of Autism." *International Journal of Epidemiology* 38, no. 5 (October 1, 2009): 1224–1234.
- Kirby, D. *Evidence of Harm: Mercury in Vaccines and the Autism Epidemic: A Medical Controversy*. St. Martin's Griffin, 2006.

- . “The Autism-Vaccine Debate: Anything But Over.” *The Huffington Post* (November 30, 2007). http://www.huffingtonpost.com/david-kirby/the-autismvaccine-debate_b_74853.html.
- . “Last Night’s Autism Debate -- Who Will Win the Special Needs Vote?” *Huffington Post*. October 16, 2008. http://www.huffingtonpost.com/david-kirby/last-nights-autism-debate_b_135256.html.
- . “Rising Autism Numbers -- Leading Federal Official Says ‘No Question’ That Environmental Exposures Are A Factor.” *Huffington Post*, December 21, 2009. http://www.huffingtonpost.com/david-kirby/rising-autism-numbers_b_397978.html.
- Kirkland, Anna. “Credibility Battles in the Autism Litigation.” *Social Studies of Science* 42, no. 2 (2012): 237–261.
- . “The Legitimacy of Vaccine Critics: What Is Left After the Autism Hypothesis?” *Journal of Health Politics, Policy and Law* 37, no. 1 (2012): 69–97.
- Kittay, Eva Feder. *Love’s Labor: Essays on Women, Equality, and Dependency*. Routledge, 1999.
- . “When Caring Is Just and Justice Is Caring: Justice and Mental Retardation.” *Public Culture* 13, no. 3 (2001).
- Kittay, Eva Feder and Licia Carlson, eds. *Cognitive Disability and Its Challenge to Moral Philosophy*. John Wiley & Sons, 2010.
- Klar, Estée. “The Joy of Autism.” Accessed May 12, 2011. <http://joyofautism.blogspot.com/>.
- Kollipara, Puneet. “How the Anti-vaccine Movement Is Endangering Lives.” *The Washington Post*, May 5, 2014. <http://www.washingtonpost.com/blogs/wonkblog/wp/2014/05/05/how-the-anti-vaccine-movement-is-endangering-lives/>.
- Kras, Joseph F. “The ‘Ransom Notes’ Affair: When the Neurodiversity Movement Came of Age.” *Disability Studies Quarterly* 30, no. 1 (February 22, 2010). <http://dsq-sds.org/article/view/1065/1254>.
- Krinsky, Charles. *The Ashgate Research Companion to Moral Panics*. Ashgate Publishing, Ltd., 2013.
- Kulage, Kristine M., Arlene M. Smaldone, and Elizabeth G. Cohn. “How Will DSM-5 Affect Autism Diagnosis? A Systematic Literature Review and Meta-analysis.” *Journal of Autism and Developmental Disorders* (February 2014): 1–15.
- Kutchins, Herb, and Stuart A. Kirk. *Making Us Crazy*. Simon and Schuster, 2003.
- Lai, Meng-Chuan, Michael V. Lombardo, Bhismadev Chakrabarti, and Simon Baron-Cohen. “Subgrouping the Autism ‘Spectrum’: Reflections on DSM-5.” *PLoS Biol* 11, no. 4 (April 23, 2013): e1001544.
- Lakoff, Andrew. “Adaptive Will: The Evolution of Attention Deficit Disorder.” *Journal of the History of the Behavioral Sciences* 36, no. 2 (2000): 149–169.

- . *Pharmaceutical Reason: Medication and Psychiatric Knowledge in Argentina*. Cambridge: Cambridge University Press, 2005.
- . “The Right Patients for the Drug: Pharmaceutical Circuits and the Codification of Illness.” In *The Handbook of Science and Technology Studies*, edited by Edward J. Hackett, Olga Amsterdamska, Michael Lynch, and Judy Wajcman, Third:742–759. Cambridge: The MIT Press, 2008.
- . “Autism and Its Milieu.” *BioSocieties* 7, no. 3 (2012): 331–333.
- Landecker, Hannah, and Aaron Panofsky. “From Social Structure to Gene Regulation, and Back: A Critical Introduction to Environmental Epigenetics for Sociology.” *Annual Review of Sociology* 39, no. 1 (2013): 333–357.
- Landrigan, Philip J. “What Causes Autism? Exploring the Environmental Contribution.” *Current Opinion in Pediatrics* 22, no. 2 (2010): 219–225.
- Lappé, Martine D. *Anticipating Autism: Navigating Science, Uncertainty, and Care in the Post-Genomic Era*. Ph.D. diss, University of California, San Francisco, 2012.
- Latour, Bruno. *Pandora's Hope: Essays on the Reality of Science Studies*. Harvard University Press, 1999.
- . “Why Has Critique Run Out of Steam: From Matters of Fact to Matters of Concern.” *Critical Inquiry* 30, no. 2 (2004): 225–248.
- . *Reassembling the Social: An Introduction to Actor-Network-Theory*. Oxford University Press, USA, 2005.
- . “An Attempt at a “Compositionist Manifesto.” *New Literary History* 41, no. 3 (2010): 471-490.
- Lau, Kimberly J. “The Political Lives of Avatars: Play and Democracy in Virtual Worlds.” *Western Folklore* 69, no. 3-4 (2010): 369-394.
- Law, J., and K. Hetherington. “Materialities, Spatialities, Globalities.” In *Knowledge, Space, Economy*, 34–49. London: Routledge, 2000.
- Law, John, and John Hassard. *Actor Network Theory and After*. Wiley, 1999.
- Lehner, Thomas. “NIMH: Center for Genomic and Phenomic Studies in Autism,” 2006. <http://www.nimh.nih.gov/research-funding/grants/concept-clearances/2006/center-for-genomic-and-phenomic-studies-in-autism.shtml>.
- Leitch, Kevin. “The Autism Hub.” *Left Brain Right Brain*, May 7, 2010. <http://leftbrainrightbrain.co.uk/2010/05/07/the-autism-hub/>.
- Liu, Ka-Yuet, Marissa King, and Peter S Bearman. “Social Influence and the Autism Epidemic.” *AJS; American Journal of Sociology* 115, no. 5 (2010): 1387.
- Lock, Margaret. “Genomics, Laissez-Faire Eugenics, and Disability.” In *Disability in Local and Global Worlds*, 189–211, 2007.

- Luscombe, Richard. "Charity Chief Quits over Autism Row." *The Guardian*, January 24, 2009, sec. Society. <http://www.guardian.co.uk/lifeandstyle/2009/jan/25/autism-mmr-vaccine>.
- Lutz, Amy S. F. "Is the Neurodiversity Movement Misrepresenting Autism?" *Slate*, January 16, 2013. http://www.slate.com/articles/health_and_science/medical_examiner/2013/01/autism_neurodiversity_does_facilitated_communication_work_and_who_speaks.single.html.
- Mallett, Rebecca, and Katherine Runswick-Cole. "Commodifying Autism: The Cultural Contexts of 'Disability' in the Academy." In *Disability and Social Theory: New Developments and Directions*, 33, 2012.
- Martin, Emily. *Flexible Bodies: Tracking Immunity in American Culture from the Days of Polio to the Age of AIDS*. Beacon Press, 1994.
- . *Bipolar Expeditions: Mania and Depression in American Culture*. Princeton University Press, 2007.
- Mayes, Rick, and Alan V. Horwitz. "DSM-III and the Revolution in the Classification of Mental Illness." *Journal of the History of the Behavioral Sciences* 41, no. 3 (2005): 249–267.
- McGann, P.J., and David J. Hutson. *Sociology of Diagnosis*. Emerald Group Publishing, 2011.
- McGuire, Anne. "Representing Autism: A Sociological Examination of Autism Advocacy." *Atlantis: Critical Studies in Gender, Culture & Social Justice* 35, no. 2 (2012): 62–71.
- . *The War on Autism: On Normative Violence and the Cultural Production of Autism Advocacy*. Ph.D. diss, University of Toronto, (2013).
- McNamara, Damian. "FDA Approves First Agent for Treating Autism Symptoms: Risperidone Approval Called 'Breakthrough.'" *Clinical Psychiatry News*, 2006. <http://linkinghub.elsevier.com/retrieve/pii/S0270664406718562>.
- McNeil, Donald G.. "3 Rulings Find No Link to Vaccines and Autism." *The New York Times*, March 12, 2010. <http://www.nytimes.com/2010/03/13/science/13vaccine.html>.
- McPartland, James C, Brian Reichow, and Fred R Volkmar. "Sensitivity and specificity of proposed DSM-5 diagnostic criteria for autism spectrum disorder." *Journal of the American Academy of Child and Adolescent Psychiatry* 51, no. 4 (April 2012): 368–383.
- McRobbie, A., and S.L. Thornton. "Rethinking 'Moral Panic' for Multi-mediated Social Worlds." *British Journal of Sociology* 46, no. 4 (1995): 559–574.
- Mitchell, Ellen. "Not All Sold on Pill for Autism." *Los Angeles Times*, November 20, 2006. <http://articles.latimes.com/2006/nov/20/health/he-autismdrug20>.

- Mnookin, Seth. *The Panic Virus: a True Story of Medicine, Science, and Fear*. Simon and Schuster, 2011.
- Mol, Annemarie. *The Body Multiple: Ontology in Medical Practice*. Duke University Press, 2002.
- . “Mind Your Plate! The Ontonorms of Dutch Dieting.” *Social Studies of Science* 43, no. 3 (June 1, 2013): 379–396.
- Monastersky, Richard. “Is There an Autism Epidemic?” *The Chronicle of Higher Education*, May 11, 2007.
- Montgomery, Cal. “The Tactics of Survival.” *Ragged Edge Online*, 1998.
- . “Critic of the Dawn.” *Ragged Edge Online*, 2001.
- . “Tangled in the Invisibility Cloak.” presented at (In)Visibility, Recognition, and Marginalization: Queers with Non-apparent Disabilities, San Francisco State University, June 2-3, 2002.
- . “Defining Autistic Lives.” *Ragged Edge Online*, June 30, 2005. <http://www.ragged-edge-mag.com/reviews/ckmontrubin0605.html>.
- . “Buying Sickness.” *Ragged Edge Online*, July 28, 2005.
- . “Autistics Speak.” *Ragged Edge Online*, December 16, 2005.
- Mottron, Laurent, Michelle Dawson, Isabelle Soulières, Benedicte Hubert, and Jake Burack. “Enhanced Perceptual Functioning in Autism: An Update, and Eight Principles of Autistic Perception.” *Journal of Autism and Developmental Disorders* 36, no. 1 (February 2006): 27–43.
- Murray, Stuart. *Representing Autism: Culture, Narrative, Fascination*. Liverpool University Press, 2008.
- . “On Autistic Presence.” *Journal of Literary & Cultural Disability Studies* 2, no. 1 (May 1, 2008): 1–10.
- . “Autism Functions/The Function of Autism.” *Disability Studies Quarterly* 30, no. 1 (January 12, 2009). <http://dsq-sds.org/article/view/1048>.
- . *Autism*. Routledge, 2011.
- Nature Neuroscience. “Silencing Debate Over Autism.” *Nature Neuroscience* 10 (2007): 531.
- Nadesan, M. H. *Constructing Autism: Unravelling the “Truth” and Understanding the Social*. Routledge, 2005.
- . “Constructing Autism: A Brief Genealogy.” In *Autism and Representation*, edited by Mark Osteen. Routledge, 2009.
- . “Autism and Genetics: Profit, Risk, and Bare Life.” In *Worlds of Autism: Across the Spectrum of Neurological Difference*. University of Minnesota Press, 2013.
- Ne’eman, Ari. “Difference Is Not a Disease.” *The Jewish Week*, March 2006.

- . “Neurodiversity and the Autistic Community.” presented at the Autreat: Living Life the Autly Way, Autism Network International, location undisclosed except to attendees, June 26, 2007.
- Ne’eman, Ari, and Scott Badesch. “Joint Statement of the Autism Society and Autistic Self Advocacy Network on the DSM-5 and Autism.” *Autism Society*, January 31, 2012. <http://www.autism-society.org/news/in-the-news/the-joint-statement-of-the.html>.
- Ne’eman, Ari, and Steven K. Kapp. *What Are the Stakes? An Analysis of the Impact of the DSM-5 Draft Autism Criteria on Law, Policy and Service Provision*. Autistic Self Advocacy Network, June 2012.
- Neumärker, K J. “Leo Kanner: his years in Berlin, 1906-24. The roots of autistic disorder.” *History of psychiatry* 14, no. 54 Pt 2 (June 2003): 205–218.
- Newschaffer, Craig J. “Investigating Diagnostic Substitution and Autism Prevalence Trends.” *Pediatrics* 117, no. 4 (April 1, 2006): 1436–1437.
- Newschaffer, Craig J., and Laura K. Curran. *Autism: An Emerging Public Health Problem*. Public Health Reports, 2003.
- Newschaffer, Craig J., Lisa A. Croen, Julie Daniels, Ellen Giarelli, Judith K. Grether, Susan E. Levy, David S. Mandell, et al. “The Epidemiology of Autism Spectrum Disorders.” *Annual Review of Public Health* 28, no. 1 (2007): 235–58.
- Nicolaidis, C., D. Raymaker, K. McDonald, S. Dern, E. Ashkenazy, C. Boisclair, S. Robertson, and A. Baggs. “Collaboration Strategies in Nontraditional Community-Based Participatory Research Partnerships: Lessons From an Academic–Community Partnership With Autistic Self-Advocates.” *Progress in Community Health Partnerships* 5, no. 2 (2011): 143.
- National Institute of Mental Health. “Prevalence of Parent-reported Autism.” *Science News*, March 20, 2014. <http://www.nimh.nih.gov/oca/news/science-news/2013/prevalence-of-parent-reported-autism.shtml>.
- Obama, Barack. “Health Care.” 2008 campaign, n.d. <http://www.barackobama.com/issues/healthcare>.
- Ochs, Elinor, and Olga Solomon. “Autistic Sociality.” *Ethos* 38, no. 1 (2010): 69–92.
- Ochs, Elinor, Tamar Kremer-Sadlik, Olga Solomon, and Karen Gainer Sirota. “Inclusion as Social Practice: Views of Children with Autism.” *Social Development* 10, no. 3 (2001): 399–419.
- Offit, Paul A. *Autism’s False Prophets: Bad Science, Risky Medicine, and the Search for a Cure*. Columbia University Press, 2008.
- Orr, Jackie. “Biopsychiatry and the Informatics of Diagnosis: Governing Mentalities.” In *Biomedicalization: Technoscience, Health and Illness in the US*, edited by Adele E. Clarke, Laura Mamo, Jennifer Ruth Fosket, Jennifer R. Fishman, and Janet K. Shim. Duke University Press, 2009.

- Orsini, Michael. "Contesting the Autistic Subject: Biological Citizenship and the Autism/Autistic Movement." In *Critical Interventions in the Ethics of Healthcare: Challenging the Principle of Autonomy in Bioethics*, edited by Stuart J. Murray and Dave Holmes. Ashgate Publishing, Ltd., 2009.
- . "Autism, Neurodiversity and the Welfare State: The Challenges of Accommodating Neurological Difference." *Canadian Journal of Political Science* 45, no. 04 (2012): 805–827.
- Ortega, Francisco. "The Cerebral Subject and the Challenge of Neurodiversity." *BioSocieties* 4, no. 4 (2009): 425–445.
- . "Cerebralizing Autism Within the Neurodiversity Movement." In *Worlds of Autism: Across the Spectrum of Neurological Difference*. University of Minnesota Press, 2013.
- Ortega, Francisco, and Fernando Vidal. *Neurocultures: Glimpses into an Expanding Universe*. Frankfurt am Main; New York: Peter Lang, 2011.
- Ortega, Francisco, and Suparna Choudhury. "'Wired Up Differently': Autism, Adolescence and the Politics of Neurological Identities." *Subjectivity* 4, no. 3 (September 2011): 323–345.
- Osteen, Mark. *Autism and Representation*. Psychology Press, 2007.
- Park, Clara Claiborne. *The Siege: The First Eight Years of an Autistic Child: With an Epilogue, Fifteen Years After*. Boston: Little, Brown and Company, 1967.
- Park, Melissa. "Beyond Calculus: Apple-apple-apple-ike and Other Embodied Pleasures for a Child Diagnosed with Autism in a Sensory Integration Based Clinic." *Disability Studies Quarterly* 30, no. 1 (December 14, 2009). <http://dsq-sds.org/article/view/1066>.
- . "Pleasure, Throwing Breaches, and Embodied Metaphors: Tracing Transformations-in-Participation for a Child With Autism to a Sensory Integration-Based Therapy Session." *OTJR Occupation Participation and Health* 32, no. 1 (2012): S34.
- Perez, Victor W. "The Rhetoric of Science and Statistics in Claims of an Autism Epidemic." *Advances in Medical Sociology* 11 (April 21, 2010): 203–221.
- Petryna, Adriana, Andrew Lakoff, and Arthur Kleinman. *Global Pharmaceuticals: Ethics, Markets, Practices*. Durham: Duke University Press, 2006.
- Pickersgill, Martyn D. "Psyche, Soma, and Science Studies: New Directions in the Sociology of Mental Health and Illness." *Journal of Mental Health* 19, no. 4 (2010): 382–392.
- . "From 'Implications' to 'Dimensions': Science, Medicine and Ethics in Society." *Health Care Analysis* 21, no. 1 (2013): 31–42.

- Pickersgill, Martyn D., et al. "Mapping the New Molecular Landscape: Social Dimensions of Epigenetics." *New Genetics and Society* 32, no. 4 (2013): 429-447.
- Posner, Tamar Judith. *Dyscalculic in the Making: Mathematical Sovereignty, Neurological Citizenship, and the Realities of the Dyscalculic*. ProQuest, UMI Dissertation Publishing, 2011.
- Prince, Dawn. "The Silence Between: An Autoethnographic Examination of the Language Prejudice and its Impact on the Assessment of Autistic and Animal Intelligence." *Disability Studies Quarterly* 30, No. 1 (2010).
- . "An Exceptional Path: An Ethnographic Narrative Reflecting on Autistic Parenthood from Evolutionary, Cultural, and Spiritual Perspectives." *Ethos* 38, no. 1 (2010): 56-68.
- Prince-Hughes, Dawn, ed. *Aquamarine blue 5: Personal Stories of College Students with Autism*. Ohio University Press, 2002.
- . *Songs of the Gorilla Nation: My Journey Through Autism*. Radom House, 2004.
- Rajan, Kaushik Sunder. *Lively Capital: Biotechnologies, Ethics, and Governance in Global Markets*. Duke University Press Books, 2012.
- Rapp, Rayna. "Chasing Science: Children's Brains, Scientific Inquiries, and Family Labors." *Science, Technology & Human Values* 36, no. 5 (2010): 662-684.
- Rapp, Rayna, and Faye Ginsburg. "Enabling Disability: Rewriting Kinship, Reimagining Citizenship." *Public Culture* 13, no. 3 (2001): 533.
- Rapp, Rayna, Deborah Heath, and Karen-Sue Taussig. "Standing on the Biological Horizon," in progress.
- Regier, Darrel A. "Mental Disorder Diagnostic Theory and Practical Reality: An Evolutionary Perspective." *Health Affairs* 22, no. 5 (October 2003): 21-27.
- Regier, D, et al. "Evolution of the DSM Conceptual Framework: Development, Dimensions, Disability, Spectra, and Gender/Culture." presented at the 162nd Annual Meeting of the American Psychiatric Association, San Francisco, California, May 18, 2009.
- Reardon, Jenny. *Race to the Finish: Identity and Governance in an Age of Genomics*. Princeton University Press, 2009.
- . "The Democratic, Anti-Racist Genome? Technoscience at the Limits of Liberalism." *Science as Culture* 21, no. 1 (2012): 25-47.
- . "On the Emergence of Science and Justice." *Science, Technology & Human Values* 38, no. 2 (2013): 176-200.
- Rimland, Bernard. *Infantile Autism the Syndrome and Its Implications for a Neural Theory of Behaviour*. Taylor & Francis, 1964.
- . "Is There an Autism Epidemic." *ARRI* 9 (1995): 3.

- . “The Autism Explosion.” *Autism Research Review International* 13, no. 2 (1999): 3.
- . “The Autism Epidemic, Vaccinations, and Mercury.” *Journal of Nutritional and Environmental Medicine* 10, no. 4 (2000): 261–266.
- . “The Autism Increase: Research Needed on the Vaccine Connection.” *Autism Research Review International* 14, no. 1 (2000): 3.
- . “The MMR/Autism Controversy: Should We Believe the IOM?” *Autism Research Review International* 15, no. 2 (2001): 3.
- Ring, Robert. “Autism Spectrum Disorders: Challenges and Opportunities in Medicines Development.” presented at the NeuroDevNet: 2013 Brain Development Conference, Vancouver, British Columbia, September 30, 2013. <http://www.neurodevnet.ca/events/conference/2013/program>.
- Robertson, Scott M., and Ari D. Ne’eman. “Autistic Acceptance, the College Campus, and Technology: Growth of Neurodiversity in Society and Academia.” *Disability Studies Quarterly* 28, no. 4 (August 12, 2008). <http://dsq-sds.org/article/view/146>.
- Robertson, Scott Michael. “Neurodiversity, Quality of Life, and Autistic Adults: Shifting Research and Professional Focuses onto Real-Life Challenges.” *Disability Studies Quarterly* 30, no. 1 (December 14, 2009). <http://dsq-sds.org/article/view/1069>.
- Rodier, Patricia M. “Science Under Attack: Vaccines and Autism.” *BioScience* 59, no. 5 (May 1, 2009): 440–441.
- Roets, Griet, and Dan Goodley. “Disability, Citizenship and Uncivilized Society: The Smooth and Nomadic Qualities of Self-advocacy.” *Disability Studies Quarterly* 28, no. 4 (November 24, 2008). <http://dsq-sds.org/article/view/131>.
- Rollens, Rick. *Russell’s Story, One Child Every Three Hours, the Ultimate Betrayal*, 2002. <http://www.vaccinationnews.com/DailyNews/January2002/RollinsTestimonyCalifornia.htm>.
- Rosa, Shannon Des Roches, et al. *Thinking Person’s Guide To Autism*. Deadwood City Publishing, 2011.
- Rose, Nikolas. *Inventing Our Selves: Psychology, Power, and Personhood*. Cambridge University Press, 1998.
- . *The Politics of Life Itself: Biomedicine, Power, and Subjectivity in the Twenty-first Century*. Princeton University Press, 2007.
- Rose, Nikolas, and Carlos Novas. “Biological Citizenship.” In *Global Assemblages: Technology, Politics, and Ethics as Anthropological Problems*, edited by Aihwa Ong and Stephen J. Collier, 439–463. Blackwell Publishing Ltd, 2008.
- Rose, Nikolas, and Joelle M. Abi-Rached. *Neuro: The New Brain Sciences and the Management of the Mind*. Princeton University Press, 2013.
- Russell, B. “Reflections on ‘Autistic Integrity’.” *Bioethics* (2012).

- Rutter, Michael. "Epidemiological Methods to Tackle Causal Questions." *International Journal of Epidemiology* 38, no. 1 (February 1, 2009): 3–6.
- Sabin, Ellen. *The Autism Acceptance Book: Being a Friend to Someone With Autism*. 1st ed. Watering Can Press, 2006.
- Sacks, Oliver. *The Man Who Mistook His Wife for a Hat and Other Clinical Tales*. Simon and Schuster, 1985.
- . *An Anthropologist on Mars: Seven Paradoxical Tales*. Vintage Books, 1995.
- Samuels, Christina A. "In Advocacy Realm, Specific Disabilities Gain in Prominence." *Education Week*, September 17, 2008. http://www.edweek.org/ew/articles/2008/09/17/04autism_ep.h28.html.
- Sanua, V D. "Leo Kanner (1894-1981): the man and the scientist." *Child psychiatry and human development* 21, no. 1 (1990): 3–23.
- Savarese, D. J. "Communicate with Me." *Disability Studies Quarterly* 30, no. 1 (January 12, 2009). <http://dsq-sds.org/article/view/1051>.
- Savarese, Ralph J. *Reasonable People: A Memoir of Autism & Adoption: On the Meaning of Family and the Politics of Neurological Difference*. Other Press, 2007.
- . "Toward a Postcolonial Neurology: Autism, Tito Mukhopadhyay, and a New Geo-poetics of the Body." *Journal of Literary & Cultural Disability Studies* 4, no. 3 (2010): 273–289.
- . "Literary Autism by Literary Autistics: Beyond the Destructive Presumption and Paternalism of Neurotypicals," 2012.
- . "River of Words, Raft of Our Conjoined Neurologies." *Fourth Genre: Explorations in Nonfiction* 14, no. 1 (2012): 43–52.
- . "Moving the Field: The Sensorimotor Perspective on Autism (Commentary on 'Rethinking Autism: Implications of Sensory and Motor Differences,' an Article by Anne Donnellan, David Hill, and Martha Leary)." *Frontiers in Integrative Neuroscience* 7 (2013).
- . "'Jostled by Difference': Ralph James Savarese Responds to Len Gutkin." *Leviathan* 15, no. 2 (2013): 37–40.
- Savarese, Emily Thornton, and Ralph J Savarese, eds. "Autism and the Concept of Neurodiversity." *Disability Studies Quarterly* 30, no. 1 (2010).
- . "Literate Lungs: One Autist's Journey as a Reader." *Research and Practice for Persons with Severe Disabilities* 37, no. 2 (2012): 100–110.
- Schopler, Eric, Stella Chess, and Leon Eisenberg. "Our Memorial to Leo Kanner." *Journal of Autism and Developmental Disorders* 11, no. 3 (September 1, 1981): 257–269.
- Schrader, Astrid. "Responding to Pfiesteria Piscicida (the Fish Killer): Phantomatic Ontologies, Indeterminacy, and Responsibility in Toxic Microbiology." *Social Studies of Science* 40, no. 2 (April 1, 2010): 275–306.

- Sedgwick, Eve K. *Touching Feeling: Affect, Pedagogy, Performativity*. Duke University Press, 2003.
- Sell, David. "J&J to Pay \$2.2B for Improper Promotion of Risperdal." *Philly.com*, November 6, 2013. http://articles.philly.com/2013-11-06/news/43696907_1_invega-antipsychotic-drugs-nursing-homes.
- Shattuck, Paul T. "Diagnostic Substitution and Changing Autism Prevalence." *Pediatrics* 117, no. 4 (2006): 1438.
- Shostak, Sara. "Marking Persons and Populations at Risk: Molecular Epidemiology and Environmental Health." In *Biomedicalization: Technoscience, Health and Illness in the US*, edited by Adele E. Clarke, Laura Mamo, Jennifer Ruth Fosket, Jennifer R. Fishman, and Janet K. Shim. Duke University Press, 2010.
- Silberman, Steve. "The Geek Syndrome." *Wired* 9, no. 12 (2001).
- . "Book of the Year: Thinking Person's Guide to Autism." *NeuroTribes*, December 19, 2011. <http://blogs.plos.org/neurotribes/2011/12/19/book-of-the-year-thinking-persons-guide-to-autism/>.
- . "Neurodiversity Rewires Conventional Thinking About Brains." *Wired Magazine*, April 16, 2013. <http://www.wired.com/magazine/2013/04/neurodiversity/>.
- Silverman, Chloe. *A Disorder of Affect: Love, Tragedy, Biomedicine, and Citizenship in American Autism Research, 1943-2003*. Ph.D. diss, University of Pennsylvania, 2004.
- . "Fieldwork on Another Planet: Social Science Perspectives on the Autism Spectrum." *BioSocieties* 3, no. 03 (2008): 325–341.
- . *Understanding Autism: Parents, Doctors, and the History of a Disorder*. Princeton University Press, 2012.
- Sinclair, Jim. "Don't Mourn for Us." Toronto: Autism Society of America, 1993. http://www.autreat.com/dont_mourn.html.
- . "Autism Network International: The Development of a Community and Its Culture." *Autreat.com: History of ANI*, January 2005. http://www.autreat.com/History_of_ANI.html.
- . "Medical Research Funding." Accessed November 12, 2007. <http://replay.web.archive.org/20081016043322/http://web.syr.edu/~jisincla/research.htm>.
- . "Bridging the Gaps: An Inside-Out View of Autism." Accessed May 11, 2011. <http://replay.web.archive.org/20080919074006/http://web.syr.edu/%7Ejisincla/bridging.htm>.
- . "Person First Language." Accessed May 11, 2011. http://replay.web.archive.org/20090210190652/http://web.syr.edu/~jisincla/person_first.htm.

- . “Is Cure a Goal?” Accessed May 12, 2011. <http://replay.web.archive.org/20090331054458/http://web.syr.edu/~jisincla/cure.htm>.
- . “Being Autistic Together.” *Disability Studies Quarterly* 30, no. 1 (February 22, 2010). <http://www.dsqsds.org/article/view/1075/1248>.
- Singer, Alison. “Cure Is Not a Four-letter Word” (2006). www.graspfiles.org/ning/media/print/ArtUnTSinger.doc
- . “Speaking Out About ‘Autism Every Day’.” *Autism Science Foundation Blog*, September 9, 2009. <http://autismsciencefoundation.wordpress.com/2009/09/09/speaking-out-about-autism-every-day/>.
- . “Understanding Autism.” *Yale University*: Accessed March 9, 2014. <http://autism.yale.edu/guest-bios/alison-singer>.
- Singer, Emily. “Diagnosis: Redefining Autism.” *Nature* 491, no. 7422 (November 1, 2012): S12–S13.
- Singer, Judy. “Odd People In: The Birth of a Community Amongst People on the ‘Autistic Spectrum’.” Honours Thesis, University of Technology, Sydney, 1999.
- . “Why Can’t You Be Normal for Once in Your Life? From a ‘Problem with No Name’ to the Emergence of a New Category of Difference.” In *Disability Discourse*, 59–67, 1999.
- . “Light and Dark: Correcting the Balance.” Accessed April 16, 2008. <http://www.neurodiversity.com.au/lightdark.htm>.
- Singh, Iliana. “Human Development, Nature and Nurture: Working Beyond the Divide.” *BioSocieties* 7, no. 3 (September 2012): 308–321.
- . “Brain Talk: Power and Negotiation in Children’s Discourse About Self, Brain and Behaviour.” *Sociology of Health & Illness* 35, no. 6 (2013): 813–827.
- Singh, Jennifer S. *Autism Spectrum Disorders: Parents, Scientists, and the Interpretations of Genetic Knowledge*. Ph.D diss, University of California, San Francisco, 2010.
- . “The Vanishing Diagnosis of Asperger’s Disorder.” *Sociology of Diagnosis* 12 (2011): 235–257.
- Singh, Jennifer, Joachim Hallmayer, and Judy Illes. “Interacting and Paradoxical Forces in Neuroscience and Society.” *Nature Reviews Neuroscience* 8, no. 2 (February 2007): 153–160.
- Singh, Jennifer, Judy Illes, Laura Lazzeroni, and Joachim Hallmayer. “Trends in US Autism Research Funding.” *Journal of Autism and Developmental Disorders* 39, no. 5 (May 1, 2009): 788–795.
- Solomon, Andrew. “The Autism Rights Movement.” *New York Magazine*, June 2, 2008. <http://nymag.com/news/features/47225/>.

- . *Far From the Tree: Parents, Children and the Search for Identity*. Simon and Schuster, 2013.
- Solomon, Olga, and Mary C. Lawlor. “‘And I Look down and He Is Gone’: Narrating Autism, Elopement and Wandering in Los Angeles.” *Social Science & Medicine* (2013).
- Solomon, Olga. “What a Dog Can Do: Children with Autism and Therapy Dogs in Social Interaction.” *Ethos* 38, no. 1 (2010): 143–166.
- Sorell, Tom. “Disability Without Denial.” In *Principles of Health Care Ethics*, edited by Richard E. Ashcroft, Angus Dawson Senior Lecturer in Ethics and Philosophy, Heatheraper Reader in Biomedical Ethics, and John R. McMillan Senior Lecturer, 415–420. John Wiley & Sons, Ltd, 2007.
- Sousa, Amy C. “From Refrigerator Mothers to Warrior-Heroes: The Cultural Identity Transformation of Mothers Raising Children with Intellectual Disabilities.” *Symbolic Interaction* 34, no. 2 (2011): 220–243.
- Spitzer, Robert L, Jean Endicott, and Robins. “Research Diagnostic Criteria: Rationale and Reliability.” *Archives of General Psychiatry* 35, no. 6 (June 1, 1978): 773–782.
- Stagliano, Kim. “Autism Sucks and Then We Die.” *Huffington Post*, October 1, 2012. http://www.huffingtonpost.com/kim-stagliano/autism-research_b_1926901.html.
- Star, Susan Leigh. *Ecologies of Knowledge: Work and Politics in Science and Technology*. State University of New York Press, 1995.
- . “The Ethnography of Infrastructure.” *American Behavioral Scientist* 43, no. 3 (1999): 377–391.
- . “This Is Not a Boundary Object: Reflections on the Origin of a Concept.” *Science, Technology & Human Values* 35, no. 5 (September 1, 2010): 601–617.
- Stevenson, Jennifer L, Bev Harp, and Morton Ann Gernsbacher. “Infantilizing Autism.” *Disability Studies Quarterly* 31, no. 3 (2011).
- Stobbe, Mike. “CDC Finances Study Into Causes of Autism.” *The Washington Post*, October 7, 2006. <http://www.washingtonpost.com/wp-dyn/content/article/2006/10/06/AR2006100601146.html>.
- Stratton, Kathleen, Alicia Gable, Padma Shetty, and Marie McCormick. “Immunization Safety Review.” *Committee, Board on Health Promotion and Disease Prevention* (2001).
- Strauss, Joseph N. “Autism as Culture.” In *The Disability Studies Reader*, edited by Lennard J Davis. Fourth Edition. Routledge, 2013.
- Suchman, Lucy. *Human-Machine Reconfigurations: Plans and Situated Actions*. Cambridge University Press, 2007.
- Swedo, Susan. “Neurodevelopmental Disorders in DSM-5.” presented at the APA Annual Meeting, May 18, 2013.

- Swedo, Susan E., Henrietta L. Leonard, and Louise S. Kiessling. "Speculations on Antineuronal Antibody-Mediated Neuropsychiatric Disorders of Childhood." *Pediatrics* 93, no. 2 (February 1, 1994): 323–326.
- Tabor, Holly K., and Martine D. Lappé. "The Autism Genetic Resource Exchange: Changing Pace, Priorities, and Roles in Discovery Science." In *Achieving Justice in Genomic Translation: Re-Thinking the Pathway to Benefit: Re-Thinking the Pathway to Benefit*, 56, 2011.
- Tapper, Jake. "John McCain Enters the Autism Wars," February 29, 2008. <http://blogs.abcnews.com/politicalpunch/2008/02/john-mccain-ent.html>.
- Taussig, Karen-Sue, Rayna Rapp, and Deborah Heath. "Flexible Eugenics: Technologies of the Self in the Age of Genetics." In *Anthropologies of Modernity*, edited by Jonathan Xavier Inda, 194–212. Blackwell Publishing Ltd, 2008.
- The Editors of The Lancet. "Retraction—Ileal-lymphoid-nodular Hyperplasia, Non-specific Colitis, and Pervasive Developmental Disorder in Children." *The Lancet* 375, no. 9713 (February 2010): 445.
- The People at Autistic.org. "In Support of Michelle Dawson and Her Work." *Autism Information Library*, 2004. <http://archive.autistics.org/library/dawson.html>.
- Thompson, Charis. *Making Parents: The Ontological Choreography of Reproductive Technologies*. 1st ed. The MIT Press, 2007.
- Treffert, D. A. *Extraordinary People*. Black Swan, 1990.
- Treichler, Paula A. "AIDS, Homophobia and Biomedical Discourse: An Epidemic of Signification." *Cultural Studies* 1, no. 3 (1987): 263–305.
- . *How to Have Theory in an Epidemic: Cultural Chronicles of AIDS*. Duke University Press, 1999.
- Tremain, Shelley Lynn, ed. *Foucault and the Government of Disability*. University of Michigan Press, 2005.
- Trent, James W. *Inventing the Feeble Mind: A History of Mental Retardation in the United States*. University of California Press, 1995.
- US Congress. *Individuals with Disabilities Education Act (Education of the Handicapped Act Amendments)*. Pub Law No. 101–476, 1990.
- US Congressional Hearing. *Autism: Present Challenges, Future Needs—Why the Increased Rates?*, 2000.
- . *The Autism Epidemic: Is the NIH and CDC Response Adequate?*, 2002.
- U.S. Department of Health & Human Services. "Secretary Sebelius Announces New Members of the Interagency Autism Coordinating Committee." April 30, 2010. <http://www.hhs.gov/news/press/2010pres/04/20100430a.html>.
- Veenstra-VanderWeele, Jeremy, Susan L. Christian, and Edwin H. Cook, Jr. "Autism as a Paradigmatic Complex Genetic Disorder." *Annual Review of Genomics and Human Genetics* 5, no. 1 (2004): 379–405.

- Verhoeff, Berend. "Drawing Borders of Mental Disorders: An Interview with David Kupfer." *BioSocieties* 5, no. 4 (December 2010): 467–475.
- . "What is This Thing Called Autism? A Critical Analysis of the Tenacious Search for Autism's Essence." *Biosocieties* 7, no. 4 (2012): 410-432.
- . "The Autism Puzzle: Challenging a Mechanistic Model on Conceptual and Historical Grounds." *Philosophy, Ethics, and Humanities in Medicine* 8, no. 1 (2013).
- . "Autism in Flux: A History of the Concept from Leo Kanner to *DSM-5*." *History of Psychiatry* 24, no. 4 (2013): 442-458.
- Vrecko, Scott. "Folk Neurology and the Remaking of Identity." *Molecular Interventions* 6, no. 6 (December 1, 2006): 300–303.
- Wadman, Meredith. "Autism's Fight for Facts: A Voice for Science." *Nature News* 479, no. 7371 (November 2, 2011): 28–31.
- Wakefield, AJ, SH Murch, A Anthony, J Linnell, DM Casson, M Malik, M Berelowitz, et al. "Ileal-lymphoid-nodular Hyperplasia, Non-specific Colitis, and Pervasive Developmental Disorder in Children." *The Lancet* 351, no. 9103 (February 28, 1998): 637–641.
- Waltz, Mitzi. "From Changelings to Crystal Children: An Examination of 'New Age' Ideas About Autism." *Journal of Religion, Disability & Health* 13, no. 2 (2009): 114–128.
- . *Autism: A Social and Medical History*. Palgrave Macmillan, 2013.
- Ward, Steven C. *Modernizing the Mind: Psychological Knowledge and the Remaking of Society*. Greenwood Publishing Group, 2002.
- Weaver, Harlan. "Monster Trans: Diffracting Affect, Reading Rage." *Somatechnics* 3, no. 2 (2013).
- Westervelt, Eric. "iPads Allow Kids With Challenges To Play In High School's Band." *NPR.org*, June 11, 2014. <http://www.npr.org/blogs/ed/2014/06/11/320882414/ipads-allow-kids-with-challenges-to-play-in-high-schools-band>.
- Weller, Kris. *Defining Human: Species, Sanity and Legal Subjecthood*. Ph.D. diss, University of California, Santa Cruz, 2010.
- Whalen, Jeanne, and Betsy McKay. "Fifteen Years After Autism Panic, a Plague of Measles Erupts." *Wall Street Journal*, July 19, 2013. <http://online.wsj.com/article/SB1000142412788732330000457855453881252798.html>.
- Willingham, Emily. "Autism Congressional Hearings: Bingo, Vaccines, and Some Baby Steps Forward," November 30, 2012. <http://www.emilywillinghamphd.com/2012/11/autism-congressional-hearings-bingo.html>.
- Wing, Lorna, and Judith Gould. "Severe Impairments of Social Interaction and Associated Abnormalities in Children: Epidemiology and Classification." *Journal of Autism and Developmental Disorders* 9, no. 1 (1979): 11–29.

- Wing, Lorna. "Asperger's Syndrome: A Clinical Account." *Psychological Medicine* 11, no. 1 (1981): 115–129.
- . "Reflections on Opening Pandora." *Journal of Autism and Developmental Disorders* 35, no. 2 (2005): 7.
- Wolf-Meyer, Matthew. "Therapy, Remedy, Cure: Disorder and the Spatiotemporality of Medicine and Everyday Life." *Medical Anthropology* 33, no. 2 (2014): 144-159.
- Wolf-Meyer, Matthew and Karen-Sue Taussig. "Extremities: Thresholds of Human Embodiment." *Medical Anthropology* 29, no. 2 (2010): 113-128.
- Woods, Rima, and Janine M. LaSalle. "Epigenetic Epidemiology of Autism and Other Neurodevelopmental Disorders." In *Epigenetic Epidemiology*, edited by Karin B. Michels, 321–342. Springer Netherlands, 2012.
- Wright, Suzanne. "Autism Speaks to Washington - A Call for Action." *Autism Speaks*, November 11, 2013. <http://www.autismspeaks.org/news/news-item/autism-speaks-washington-call-action>.
- Yan, Jun. "APF Convenes Unique Pipeline Summit." *Psychiatric News: From the American Psychiatric Association*, April 6, 2012. <http://psychnews.psychiatryonline.org/newsArticle.aspx?articleid=1096598>.
- Yates, Scott, Simon Dyson, and Dave Hiles. "Beyond Normalization and Impairment: Theorizing Subjectivity in Learning Difficulties - Theory and Practice." *Disability & Society* 23, no. 3 (2008): 247 – 258.
- Young, Allan. *The Harmony of Illusions: Inventing Post-Traumatic Stress Disorder*. Princeton University Press, 1997.
- Zachar, Peter. *Psychological Concepts and Biological Psychiatry: A Philosophical Analysis*. John Benjamins Publishing, 2000.
- Zachar, Ph.D., and M.D. Kendler. "Psychiatric Disorders: A Conceptual Taxonomy." *American Journal of Psychiatry* 164, no. 4 (April 1, 2007): 557–565.
- Zukang, Sha. "Global Awareness of Autism: Challenges, Responsibilities and Actions." presented at the United Nations - Office of the Under-Secretary-General - Statements, April 2, 2008. http://www.un.org/esa/desa/ousg/statements/2008/20080402_autism_awareness.html.