
Original Article

Autism parents & neurodiversity: Radical translation, joint embodiment and the prosthetic environment

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Abstract It has become increasingly common to view and discuss autism as a form of difference, rather than a disorder. Moreover, the autism spectrum has generated new possibilities for personhood and social inclusion. These developments have typically been ascribed to the recent work of autistic autobiographers and autistic self-advocates associated with the neurodiversity movement, who are providing a sort of linguistic infrastructure to support autistic personhood. Drawing on historical and ethnographic research, this article makes the complementary and analogous claim that parents of autistic children have used autism therapies to create a technical infrastructure to support autistic personhood. The article follows an earlier genealogical thread to argue that parents have used the techniques and technologies of behavioral therapies (sometimes said to be incommensurable with neurodiversity's philosophy) in ways that have actually helped establish this autism-as-difference view. They have done so by translating their child's behaviors and utterances and engaging in forms of 'joint embodiment' with her to create enabling 'prosthetic environments' where her unique personhood can be recognized. Through an ethnographic focus on 'prosaic technologies' and the politics of everyday practice, the article also provides a thicker and more grounded account of what Ian Hacking calls the "looping effect of human kinds".

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Introduction

Conceptions of autism and autistic personhood have changed dramatically in the 70 years since Leo Kanner's initial landmark description. Extreme isolation and rigidity marked early portrayals (Eisenberg and Kanner, 1956). The prototypical image was of a child rocking incessantly, trapped in his own impenetrable world. The inner lives of autistic people were said to be at worst 'thin', at best inexpressible. In his foreword to autistic author Temple Grandin's (1995) book, *Thinking in Pictures*, Oliver Sacks noted this earlier perception: "It had been medical dogma for forty years that there *was* no 'inside', no inner life, in the autistic, or that if there was, it would be forever denied access or expression" (p. 11). These

earlier views of autism continue to surface in certain contemporary advocacy campaigns and expressions of parental despair. But they have also been joined by a greatly enriched understanding of autistic personhood and experience, replete with emotional and cognitive depth where actions are saturated with meaning and intention. Along this shift in view, autism has come to be seen in some quarters more as a form of difference than a disease or disorder.¹

Most observers consider this autism-as-difference view a new arrival, brought on by the emergence of ‘autistic autobiographies’ (Hacking, 2009a), autistic self-advocates and the neurodiversity movement (Bumiller, 2008; Orsini, 2009; Ortega, 2009; Antze, 2010).² As previous scholars have noted, autistic self-advocacy associations organically emerged in the 1990s from encounters at conferences and through pen pal lists run by autism parent associations (Sinclair, 2005). When trying to establish their own advocacy outfits, however, pioneering autistic self-activists often faced intense resistance from certain parent associations. Indeed, over the years there has been much friction between parent and self-advocacy associations, and people with autism have had to struggle to make their voices heard (Chamak, 2008; Bagatell, 2010). Today’s neurodiversity movement grew out of the efforts of these early autistic self-advocates. It consists of people with autism and kindred neurological diagnoses, joined by some like-minded parents and professionals (Armstrong, 2010). They challenge what they see as a tyranny of ‘neurotypical’ (read: non-autistic) forms of sociality and communication that fail to recognize autistic personhood, and they correctly point out that this sort of devaluation has led to serious abuses. They offer wittily contrapuntal slogans, like ‘eye contact is overrated’, and produce astute socio-political analyses (for example, Broderick and Ne’eman, 2008; Ne’eman, 2010) and innovative scientific research (for example, Dawson *et al*, 2007). Many self-advocates agree that autism is a kind of disability, and that autistic people are ‘wired differently’ than neurotypicals (Ortega, 2009; Kapp *et al*, 2013). But they draw on disability studies critiques to argue that it is the discriminatory neurotypical world – not the neurodiverse brain – that is disabling (Dubin, 2010; Savarese and Savarese, 2010). A flurry of new books, films and blogs present the virtues of neurodiversity’s libratory philosophy,³ and a growing chorus of scholars and journalists has rightly registered the movement’s impact on political and ethical debates (Bumiller, 2008; Antze, 2010). Such scholars often report – and here is where I depart from them – that the movement’s philosophy is irreconcilably opposed to behavioral therapies, especially Applied Behavioral Analysis (ABA), and the parents who use them to treat their autistic children.⁴ These therapies, they say, aim to bring children in line with dominant, neurotypical norms, while neurodiversity is an argument for freedom from them (Hacking, 2007; Bumiller, 2008).

This article follows an earlier genealogical thread and examines a more subterranean route to trace the recent shifts in conceptions of neurobiological difference. Drawing on historical

1 For the broader history of changing ideas and definitions of autism, see Eyal *et al*, 2010; Feinstein, 2010; Grinker, 2007; Hacking, 2007; Nadesan, 2005; Silverman, 2011.

2 I will not recapitulate the history of neurodiversity in detail here. The basic origin story has been somewhat standardized and can be found in a number of accounts by scholars, journalists or activists themselves (see Sinclair, 2005; Bumiller, 2008; Silverman, 2008; Solomon, 2008; Orsini, 2009; Ortega, 2009; Cascio, 2012).

3 For films, see *Loving Lampposts*, *Wretchers and Jabberers* and *Neurotypical*.

4 See Chew’s contribution to Savarese *et al*, 2009 for an argument for the compatibility of ABA and neurodiversity.

research, I argue that early parent advocates paved the way conceptually for self-advocates. They posed autism as a form of radical difference or alterity and situated it above all within a problematic of translation. Contemporary parents, I argue, inherited an ethical imperative to translate and advocate for their autistic child, and to include him or her in ordinary daily life. Through ethnographic research in the United States and Morocco, I found that some parents of ‘low-functioning’ autistic children use behavioral therapies – seemingly incommensurable with neurodiversity – in order to advocate for their child’s full personhood, thereby achieving neurodiverse ends. In doing so, they implicitly promote a richer image of autistic personhood and experience. Indeed, perhaps the most significant aspect of the history of autism is that parents and others have come to know and advocate for people who were previously institutionalized or considered ‘mentally deficient’ and ‘socially incapable’. In the process, a whole new realm of possibility opened up.

Looping and Prosaic Technologies

To understand how categories of *kinds of people* (like autism) are transformed over time, scholars have used Ian Hacking’s theories of *making up people* and the *looping effect*.⁵ *Making up people* refers to the way sciences and their practitioners create new categories of *kinds of people* that did not previously exist. People fitting the criteria for autism can be found throughout history, but ‘autistic’ did not become a way to be a person – a way to experience oneself and to live in society – until after Kanner’s (1943) article transformed autism from a symptom into a syndrome (Grinker, 2007). *Looping* refers to the dynamic interactions that occur between the classification and the actual people labeled. Once a new kind of person is ‘made up’, knowledge is developed, institutions are founded, people are diagnosed, social practices are elaborated and experts emerge. Through complex processes across multiple levels, the kind of person ultimately becomes a ‘moving target’ as people, ideas and the category’s definition shift over time (Hacking, 2007). In the case of autism, such shifts can easily be read in the successive changes to the American Psychiatric Association’s DSM (Diagnostic & Statistical Manual; APA, 1980, 1987, 2000, 2013). The category autism was broadened in successive iterations, and additional categories, like Asperger syndrome, were added and later removed. Scholars widely agree that these shifts contributed to the emergence of the neurodiversity movement and the autism epidemic. However, as looping theory implies, such changes are themselves often secondary to and derivative of broader social processes (Eyal, 2012).

Hacking’s own account of looping in relation to autism offers insight into why ideas about autism have shifted. Focusing on the relatively new and flourishing genre of ‘autistic autobiography’, he argues that autistic authors have refigured what it means to be autistic (Hacking 2009a). They have done this, in part, by providing ‘thicker’ pictures of autistic experience. “Neurotypicals and severely autistic people”, Hacking (2009b) argues, “do not initially share a form of life because the bedrock is lacking”; neither one can plainly tell what the other is thinking, feeling, or intending simply by looking at his or comportment, “and so an artificial platform must be constructed” (p. 56). By giving ordinary language

⁵ See Hacking, 1986, 1994, 1995, 2007, for theoretical reflections and empirical applications of these concepts. See Draaisma, 2009; Eyal *et al.*, 2010; Nadesan, 2005; Orsini, 2009; Ortega, 2009; Ortega and Choudhury, 2011; Murray, 2008) for engagements with them in studies of autism.

descriptions of their sensory experiences, autistic authors help neurotypicals understand seemingly strange autistic behaviors.⁶ Autistic autobiographies thus provide a linguistic infrastructure for making sense of what people with autism are doing in daily life.

As Hacking (2002) notes, his looping accounts, like most others, are based on texts:⁷ “I should warn that my concern is philosophical and abstract; I look more at what people might be than what they are. I imagine a philosophical notion I call dynamic nominalism, and reflect too little on the ordinary dynamics of human interaction” (p. 100). As a result, such accounts capture only one stretch of the loops, so to speak, one segment of a dynamically interacting ensemble of forces. What is ultimately left out are the quotidian, ‘capillary’ practices (Foucault, 1995[1977]) through which actual subjects inhabit and exhibit these new forms of personhood (see Hacking, 2004). This article uses ethnographic research within the contexts of daily life to make an argument that is analogous and complementary to Hacking’s. I claim that autism therapies and their prosaic technologies have helped create an ‘artificial platform’ and equipped people with autism, their families and broader communities with tools for living together and sharing ‘forms of life’ (see also Reno, 2012). Just as autistic autobiographers provided a linguistic infrastructure, autism therapies have provided a *technical* infrastructure for establishing a ‘thicker’ image of the interior lives and personhood of people with autism.

My focus on autism therapies and everyday practice departs from recent studies of looping and autism in other important ways. Previous scholarship focuses on cutting-edge biogenetic and neurological research aiming to ‘prevent’ or ‘cure’ autism and the critical reactions it incites (Nadesan, 2005; Orsini, 2009; Pellicano and Sears, 2011). Within social studies of biomedicine more broadly, scholars have invented a host of anthropological neologisms to capture the resultant broad-based social processes: “biosociality” (Rabinow, 1992), “bio-availability” (Cohen, 2004), “biocapital” (Sunder Rajan, 2005), “biobureaucracy” (Korhman, 2005), “biomedicalization” (Clarke *et al*, 2010) and so on. The wealth of bio-prefixes indicates an emphasis on technoscientific biomedicine’s ability to create and organize novel social worlds. Yet, by studying sciences exclusively at their biomedical cutting edge, might we be overlooking the importance of increasingly common ‘minor’ forms of non-medical expertise about health problems, especially as they contribute to looping?

In fact, ‘bio-’ concepts have limited purchase on several salient human afflictions. Autism, alcoholism, eating disorders and gambling addictions, for example, are all subject to biomedical explanations and speculative research programs. But they are still diagnosed and treated primarily with low-tech non-medical techniques carried out by paraprofessionals, patients and their kin. How might the anthropology and sociology of science, technology and medicine look if they focused more on these ‘prosaic technologies’ (Silverman, n.s.) and ‘minor’ forms of expertise?

An ethnographic focus on the fine-grained details of local worlds and prosaic technologies like behavioral therapies has an important theoretical payoff. It gives us a thicker, more grounded understanding of looping effects. While the public pronouncements of advocates

6 Hacking (2009a, 2010a, b) develops this line of thought in several articles.

7 Some path-breaking scholars have used ethnographic methods to study autism (for example, Ochs *et al*, 2001; Park, 2008; Solomon, 2010; Solomon and Bagatell, 2010), although not to study the broader sociological processes through which the category autism is made and remade and new ideas about autism emerge and circulate (see Ochs *et al*, 2004, p. 174).

and experts have a powerful impact on public policies, multi-million dollar research budgets and legal precedents (see Orsini and Smith, 2010), research that focuses on such statements alone sometimes overstates or oversimplifies the terms of debate. Similarly, structured or semi-structured interviews and surveys typically set the terms and topics of conversation in advance, leading respondents in particular directions (Bernard, 2005). The arguments of this article, by contrast, largely emerged over the course of participant observation research. Observing and participating in everyday life allows the researcher to notice and track the performative and political dimensions of everyday practice (Das and Addlakha, 2001). Focusing on the politics of practice, we see that something altogether different is at stake for participants from what appears in public debates. In fact, we find that everyday therapeutic and domestic practices do not fix identities into place like self-conscious identity politics do. Rather, they leave them suspended while working on other levels: habits, bodies and minute interactions. At these levels, abstract goals like ‘curing autism’ or ‘becoming normal’ and even abstract concepts like ‘autism’ become practically irrelevant.⁸ Further, such an approach allows us to attend to the unremarked ways that simple therapeutic procedures are folded into the fabric of everyday domestic and social life and sometimes put to unexpected uses. Combining this approach to the politics of practice with a longer historical view, I suggest that these mundane scenes of daily family life might be key nodes in the subterranean routes through which the category autism is transformed over time. Quotidian parental practices of advocacy and translation, I suggest, provided the material rails on which novel ideas about autism have been circulating since the late 1960s.

To make this argument, I introduce three interlinked concepts: *radical translation*, *joint embodiment* and *prosthetic environment*. The first two grew out of my own ethnographic fieldwork; the third is taken from writings on behavioral therapies. By *radical translation*, I mean that parents translate and frame their child’s behaviors and utterances in ways that index a complex – if difficult-to-access and radically different – inner world. By *joint embodiment*, I am referring to an improvised social choreography whereby parents and child prompt each another verbally, gesturally and physically as they together move through the social world. In this way, the child’s personhood is co-performed by the parent–child duo. Indeed, many of the parents I met did not use behavioral therapies to cure their child, or mask his or her weirdness, or even to make him or her normal. Rather, the therapies allowed them to become part of an enabling *prosthetic environment* that facilitated his or her inclusion in a range of settings – strange behavior, atypical communication and all.

This article is based on nearly 4 years of ethnographic fieldwork in schools, homes and clinics in the United States and Morocco. Specifically, I conducted 9 months of participant observation in the American Midwest on the use of complementary and alternative treatments for autism in conjunction with behavioral therapies (2004–2005). As part of a larger project on autism expertise, I spent 9 months conducting participant observation 1 day a week in an ABA-based autism school on the East Coast of the United States and conducting participant observation with families in their homes (2007–2008). Finally, I conducted 20 months of participant observation research with families of autistic children in urban Morocco

8 See Landsman, 2009 for a similar argument, and Haldane and Crawford, 2010 for an autoethnographic account.

(2010–2012). The research included in-depth life history interviews with 22 US parents of autistic children and 40 Moroccan parents, and extensive archival research on the history of American autism diagnosis, treatment and parent advocacy.

The three different portions of research – American Midwest, East Coast and Moroccan – were each separate from one another and were not designed to be comparative. Rather, each project built on the insights of the prior one, and the concepts and arguments presented in this article were developed over the course of all three projects. While the American and Moroccan contexts differ dramatically, and comparing the two is beyond this article's scope, I found some strikingly similar practices among parents in both places. This is partly explained by the fact that the Moroccan parents I worked with drew on a North American model of autism education and activism. They watched YouTube videos, read manuals, consulted experts and ordered materials from abroad in order to implement behavioral therapies for autism, like ABA. Further, the fact that I found these same neurodiverse practices among parents in Morocco, where the neurodiversity movement has almost no presence, further supports the idea that autism therapies can serve as vehicles for neurodiverse ideas.

Polarizing Debates

The contemporary field of public discourse about autism is deeply fractured and politically charged. Two camps, seemingly archenemies, sit at either end. They appear to disagree fundamentally about where and how to locate the person in relation to autism in both space and time. This article uses ethnographic research to burrow underneath, so to speak, contemporary debates, illuminating their complementary and common elements. Before doing so, however, allow me first to rehearse a caricatured, but commonly articulated, sketch of the battle lines.

On one side are parents of 'low-functioning' children who consider autism a disorder that should be remedied, treated, cured or 'defeated'. For them, seemingly meaningless autistic behavior is a sort of 'veil' that renders the child's inner world incomprehensible, and cuts him off from the social world. From this side, we hear statements that figure autism as a disorder of personhood itself, where therapeutic intervention "can bring out the real person inside" (Niemark, 2007). Therapy becomes a rescue mission, a sort of hostage situation where parents and experts (some of whom are parents themselves) are hailed to heroically recover the 'authentic' child from the clutches of his or her autism. Personhood is both buried underneath autism and deferred to some future moment. Let us call this the *autism-as-disorder* view. To parents promoting this view, neurodiversity activists are mere high-end-of-the-spectrum pretenders with no right to speak in the name of their much more severely disabled children (for example, Lutz, 2013).

On the other side is a band of articulate 'high-functioning' autistic self-advocates who see autism as one among many types of human difference – like gender or race or deafness – which should be respected, even celebrated, but certainly not 'cured' or muted through medical or behavioral treatments. Autistic people are not *disconnected* from the social world, they announce, but *differently* connected to it. They lead rich emotional lives; but they experience, cope with and express their feelings in idiosyncratic ways. There is, they argue, a logic to the seeming enigma of autistic behavior. The 'real person' is not hidden beneath their autism, but

can and should be found precisely amidst all that seemingly crazy rocking, rubbing, spinning, buzzing, squealing, humming, tapping and hand flapping. The ‘veil’ of autism, then, is more like static in the transmission resulting from the fact that autistics and non-autistics communicate on different frequencies and experience the world in radically divergent ways. Let us call this the *autism-as-difference* view. To these advocates, parents are doubly damaging their autistic children: first, by trying to squeeze them into ill-fitting normative boxes and; second, by inadvertently communicating a wish that they not be as they are, perhaps even that they should not exist at all (Sinclair, 1993).

Several observers have noted that things are not so cut and dry. Some parents support self-advocacy movements; some autistic adults denounce neurodiversity (Orsini, 2009; Ortega, 2009; Bagatell, 2010; Silverman, 2011). In fact, a recent internet survey by Kapp *et al* (2013) found substantial overlap between parents, autistic adults and people aware of the neurodiversity movement; the authors argue that many autistic adults and people aware of neurodiversity hold a ‘deficit-as-difference’ conception of autism that transcends the “false dichotomy between celebrating differences and ameliorating deficits” (Kapp *et al*, 2013, p. 66; see also Savarese *et al*, 2010). Similarly, in my own fieldwork, I found that families regularly crisscrossed rifts between opposed discourses or ideologies in their everyday lives: books about behavior modification and ‘yeast-free’ diets leaned up against autistic autobiographies on family shelves; parents used behaviorist principles to toilet train their child one moment, then lay loose-boned on the floor imitating her vocalizations to try to spark a sort of interaction the next. Some parents do promote certain methods with evangelical fervor. But most are therapy omnivores.⁹ In fact, two families I interviewed used facilitated communication (FC) at home, a method often preferred by neurodiversity activists, while sending their children to ABA-based schools.

Further, people sympathetic to the neurodiversity movement do not always and only celebrate the differences associated with autism. Some self-advocates have reaffirmed the autism-as-disorder model by paradoxically reifying and pathologizing the impairments of lower functioning people on the spectrum. Such sentiments surfaced in recent debates about the newly revised *Diagnostic and Statistical Manual*, which collapsed several categories, including autistic disorder and Asperger’s disorder, into the more encompassing designation “autism spectrum disorder”. Michael John Carley, executive director of the New York-based autistic self-advocacy group GRASP (Global and Regional Asperger Syndrome Partnership), noted, “I personally am probably going to have a very hard time calling myself autistic”. Asperger syndrome was often valorized as a sign of extreme intelligence and popularly associated with figures like Albert Einstein. The new DSM, Carley said, would now place him on a spectrum with “somebody who might have to wear adult diapers and maybe a head-restraining device. This is very hard for us to swallow” (Hamilton, 2010).

Additionally, we see principles and practices often associated with behavioral therapies in the context of certain methods associated with the neurodiversity movement. The film *Wretches & Jabberers*, for instance, presents a neurodiversity view of autism-as-difference,

⁹ Recent surveys support this finding. A survey of 176 families in Alberta Canada found that 93.8 per cent of children with autism in that area are being treated with complementary or alternative medicine, with the average family trying nine different treatments (Gibbard, 2005). Green *et al* (2006) found that parents in the United States, Canada and Australia use 111 different types of treatments in total, with a mean number of current treatments of 7.

documenting the experience of two adult autistic men who have learned to type with light assistance from their aides using the method FC.¹⁰ In the film, we see that a certain amount of mutual conditioning, analogous to behavioral therapies, is required in order to get through daily life and to use FC. We see the two men being prompted by their neurotypical aides to finish typing, to slow down and focus, and to behave in specific, culturally suitable ways throughout their travels.

In sum, the battle lines of the so-called ‘autism wars’ dissolve in light of the messy particulars of day-to-day life and on both sides we find a certain ambivalence. In the sections that follow, I go beyond recognizing such heterogeneity, ambivalence and overlap. I begin by tracing the way a group of parents established autism as a problem of radical difference or alterity and positioned parents as translators and advocates for their autistic children in the crucial transitional moment of deinstitutionalization.

Citizenship in translation¹¹

The practices of radical translation and joint embodiment have roots in the 1960s and 1970s. This was the time when people with developmental disabilities were becoming citizens and autism parents were transforming themselves into ‘experts on their own child’ (Eyal and Hart, 2010). Institutionalization had reduced legions of those deemed ‘socially incapable’ to legal and moral non-persons (Schwartzberg, 2005). With deinstitutionalization, they were returning (or staying) home. But the very nature of their disabilities made it difficult for them to inhabit available forms of citizenship or personhood. Many lacked adequate means of communication and thus could not represent themselves or their interests. Their communities offered few adaptations and special education was not yet guaranteed for people with autism (see Akerley, 1979). In the field of mental retardation activism, the solution to this conundrum was to pair up each “retardate” (*sic*) with his or her own personal ‘citizen advocate’ who would represent and seek to fulfill his or her physical, economic and emotional needs (Novak, 1971). The parents who founded the American National Society for Autistic Children (NSAC) made the parent the ultimate ‘citizen advocate’ and established autism parenting as something akin to an ethical vocation. Among other things, this vocation involved advocating and translating on a daily basis for a child who could not speak for herself (Lapin and Donnellan-Walsh, 1977, p. 191).

At NSAC’s fourth annual conference in 1972, psychiatrist Lorna Wing, a renowned autism parent, made comments that established autism as a problem of *alterity*, not simply pathology, and parents as natural translators. She told parents and professionals that autism was not, as Kanner had suggested, rooted in a profound lack of affective contact. To make her case, she emphasized the same aspects of autism as do today’s self-advocates: differences in sensory and perceptual experience and linguistic expression. Against the idea that autism was a form of ‘aloneness’, Wing (1973) drew on the studies of Hermelin and O’Connor: “they came to the conclusion that autistic, meaning ‘socially withdrawn’, is a completely inappropriate label to apply to these children. They believe (as I do) that autistic children have all the normal emotions appropriate for their mental age, but are severely handicapped in showing them” (p. 111). If autism is a problem of alterity, Wing (1973) continued, the parents who care for autistic children daily and serve as co-therapists in behavioral therapy programs are organic

10 Thanks to Joshua Reno for pointing out this example and suggesting I discuss this ambivalence.

11 This section draws on and expands arguments we make elsewhere (Eyal *et al.*, 2010; Eyal and Hart, 2010).

translators: “Many parents who have learned the *special language* of their own autistic child are of the same opinion” (p. 111: my emphasis). Others articulated the same view at this time. When discussing a ‘comprehensive’ educational program for autistic children, for example, a professional at the same meeting said, “we cannot over-emphasize the mother’s help in ‘translating’ the symbolic, verbal, and non-verbal language of her child” (Johnson, 1973, p. 84: quotes in original).

I want to invite you to think of it as a radio. It is not that autistics are not transmitting. With autism, each child is just on his or her own frequency, and it takes a committed and engaged parent to tune in and receive the message, to decipher the child’s own ‘special language’ and translate it for others. Now compare this with a statement made by prominent self-advocate, Sinclair (1988), and note the resonance.

I could write pages of suggestions for relating to an autistic person, but the most important theme is: DON’T TAKE ANYTHING FOR GRANTED. Don’t assume you can interpret the person’s behavior by comparing it with your own or other people’s behavior; you have to learn to recognize that particular person’s unique signals.

Wing and Sinclair’s comments dovetail with a certain adage in today’s autism community: if you know one autistic child, you know one autistic child. The idea is that each child is so particular as to have his or her own idiolect, or ‘special language’. This language is not only verbal; it includes seemingly cacophonous gestures, vocalizations and ritualistic behavioral patterns.

Before the 1970s, medical and psychiatric professionals held a near interpretive monopoly on autism. This was the era when some experts argued that unloving parents caused their child’s autism. But in the pivotal historical moment of deinstitutionalization, parents were taking over the task of translation. In doing so, they were also altering it. It was no longer the deep interpretation of psychoanalysis, drilling down like an archeologist into the child’s or parent’s past to find autism’s cause; theirs was more ethnographic, operating precisely on the surface of day-to-day interactions. It consisted in the everyday translation, across radically different experiential worlds, of the give and take of daily emotional travails. And it was always tentative and inferential. Rather than unearthing the ‘authentic’ autistic subject beneath the ‘veil’ of autism, parents came to find it on the very surface of their behaviors, utterances and comportment. Behavioral therapies, and the practice of everyday care, encouraged, even obliged parents to work on that very surface and to watch it for subtle changes over time. The idea was that autistic people have rich emotional experiences but the trick is to learn how to decode the seeming cacophony of their behaviors and utterances.¹²

The 1960s and 1970s parent advocacy that established parents as translators shared an elective affinity with the deinstitutionalization philosophy of normalization. On the surface, normalization, with its emphasis on normative behaviors, appears at odds with the autism-as-difference view. Indeed, normalization is at the heart of today’s debates about behavioral therapies and changing ideas about autism. Hacking (2007) believes that normalization is “not where the action is” (p. 311). He argues that the imperative “to normalise” is important to looping only insofar as it spurs the people classified – in this case, autistic people – to “reclaim their identity” (Hacking, 2007, p. 306). In other words, it is productive because it

12 See Chew (2013) for an astute insider’s analysis of the “task of the translator” in autism.

incites a counteraction on the part of people with autism themselves. But normalization, and behavioral therapies for autism, do not *necessarily* amount in practice to making “unfavorable deviants as close to normal as possible”, as Hacking (2007) suggests (p. 311).

One explanation for this can be found in the original, most basic meaning of normalization philosophy: to provide disabled citizens with social lives that are as ordinary as possible by increasing their access to typical contexts of social life (Wolfensberger and Nirje, 1972). As Wolfensberger (1970) writes, “Normalization means that a person should live a normal routine of life”, with an ordinary rhythm of work, education, recreation, vacation and so on (p. 294). “Normalization also dictates”, he continues, “that a person should be as independent, free to move about, and empowered to make meaningful choices as are typical citizens of comparable age in the community” (Wolfensberger, 1970, p. 295). For parents this means simply going out into the world with one’s child, taking him into social situations within which his or her weirdness may be unwelcome. Consider what mother and blogger Kristina Chew said when interviewed for a recent film promoting neurodiversity.

If there is any activism in me, it is that I take [my son] Charlie everywhere I can possibly think of. Ok, he sniffs the sushi sometimes. You know, he runs up and down the aisles. He’s as tall as I am and he acts like a much younger child. But, I feel like Charlie has the right to go out in public, and people can handle it.

(*Loving Lampposts*, 2011)

Taking her son with her wherever she goes, and implicitly asking others to accept or at least tolerate his inclusion, Chew notes, is itself a form of activism. I am arguing that, as practiced by parents like Chew and many others, the practice of normalization actually works in the counterintuitive direction. Rather than trying to bring everyone in line with norms, it ultimately alters what can be recognized as normal and who can be seen as possessing the fundamental qualities that make us human. Indeed, as Rapp and Ginsburg (2011) have recently shown, the experience of living with a disabled child, and finding one’s experience out of joint with one’s expectations, has led many parents to become “philosophers of human diversity” and to produce novel narratives and practices of family life, thereby generating a “new kinship imaginary”.¹³ In the case of autism, the confluence of deinstitutionalization, normalization and the ethical imperative to translate for one’s autistic child led parents to a productive contribution: under the sign of trying to normalize their children’s experience, parents learned to communicate with their children, to appreciate their singular personalities and to advocate on their behalf in the context of everyday life and sometimes beyond it. Thus, under the sign of normalizing autistic children they actually began a dialectical process of radical acceptance of their differences.¹⁴

Everyday advocacy and translation

Contemporary autism parents inherited the task of translation and advocacy from earlier parent advocates who were responding to the historical necessities of deinstitutionalization. As Lapin and Donnellan-Walsh (1977) argued, “parents of an autistic child collided head-on

13 See also Rapp and Ginsburg, 2001 on the “unnatural histories” and “visions of lives lived against the grain of normalcy” in new disability narratives.

14 I would like to thank one of the anonymous reviewers for suggesting this lovely formulation of one of this article’s main points.

with the responsibility to ‘speak for’ their child early on” (p. 191); this issue was common among the handicapped, but particularly salient in the case of autism. “Because the problems of autism are so pervasive”, they added, “parents of autistic children function as advocates on a daily basis” (ibid.). This kind of advocacy is a major aspect of what it currently means to be an ‘autism parent’. This often amounts to a sort of proxy citizenship in dreadful battles with school districts over hours of therapy and assistance (see Fish, 2008). Through ethnographic study, I found that many parents also implicitly advocate for their children’s personhood in more mundane social interactions by drawing on behavioral therapies, and translating and framing the child’s behaviors in particular ways. The kind of personhood they are advocating for is remarkably similar to what neurodiversity advocates are demanding.

In the epistemic murk surrounding autism, the child’s body is a dense site of indeterminate signs. Take ‘hand flapping’, a prototypical autistic trait that can be translated many ways: sign of distress, need for sensory input, physical discomfort or meaningless autistic behavior. Each translation harbors a tacit image of autistic experience and a tacit theory of what autism is, respectively: handicap of emotional expression, sensory processing problem, gut–brain disturbance or hardwired neurological disorder. Further, each indexes a particular model of autistic subjectivity and personhood. In the context of this indeterminacy and the tension between these different views, struggles ensue. These typically hinge on whether a particular utterance or behavior should be considered a meaningful sign.¹⁵ Indeed, in continuity with the ethical vocation of autism parenting, some American parents and therapists translate the child’s behaviors or utterances (seemingly unintelligible to outsiders) as meaningful signs. They do so in ways that index a complex – if difficult-to-access – subjectivity, replete with emotions and intentions.

Let me give an ethnographic example from the sleepy suburbs of Long Island. Rebecca was just returning home from a day at her ABA school. Her father held her hand as she stepped off the bus. At the threshold, she lurched through the door, sloughed off her backpack and skip-hopped through to the kitchen, her hands flapping rhythmically. “Whoa, girlie”, her dad said, picking up her bag. “A little emotional discharge?” He added, eying me. “What’s up?” He looked into her daily notebook for clues about her day from her teachers’ notes. By calling his daughter’s hand flapping ‘emotional discharge’, rather than writing it off as a hardwired autistic behavior best extinguished through therapy, James links the behavior to what he imagines was a particularly stressful day at school.

In my research in Morocco, I witnessed a number of similar moments. For example, one Sunday morning, I sat around a table in Youssra’s family living room. I was sitting with Mounir, her non-verbal autistic teenage son, his sister, a behavioral therapist and a speech therapist. The speech therapist was new, and she asked why certain therapeutic programs introduced years ago had stalled out. Just then, Mounir laughed loudly. His mother laughed too and added, “he’s responding to you, saying, ‘oh, you guys don’t know why it’s not working?’” Youssra’s interpretation established Mounir as an active, understanding participant in the interaction. She considered his laugh meaningful, even sardonic. Instead of considering Mounir as too disabled to benefit from therapy, Youssra’s interpretation positioned him as a cunning resistor of therapeutic intervention. Youssra in Morocco and James in Long Island, as well as many other parents I met, often translated their children’s

15 This is what Kockelman (2005) calls, in a different context, “semiotic strain” (p. 261).

strange behaviors or garbled utterances as meaningful or indicative of an emotional state, and they did so in ways that affirmed a passionate conviction of the reality and richness of their child's inner world.

I want to suggest that by translating their child's actions and utterances in these ways, parents implicitly aim to make the child's behavior at least somewhat legible to unfamiliar others and to seek recognition for their child's personhood. At the very least, they demand that their child's utterances and gestures deserve an interpretation, even if they appear totally illegible. Through interactions like these, they perhaps can, in a sense, convert others to this view of the child as a full person. Indeed, we can say that autism literally *is* something different when a parent is translating 'hand flapping' as emotional expression than when a professional therapist is 'extinguishing' that same behavior, and that these struggles are a sort of 'ontological politics' (Mol, 2002). Importantly, these struggles over the meaningfulness of the child's behaviors and utterances can have ramifications at broader societal levels. In short, they are integral parts of the loops that remake autism, and shifts in the category are likely produced and propagated at this very level of struggles over interpretation of seemingly strange autistic behaviors. The same can be said for the practices of joint embodiment, which I turn to now.

A Role for ABA and the Prosthetic Environment

In addition to the task of translation, parents also engage in *joint embodiment* as they become part of what one ABA expert called the *prosthetic environment* (Holmes, 1990). Both concepts – *joint embodiment* and *prosthetic environment* – relate to behavioral therapies like ABA that, paradoxically, play a central role in the history of establishing this autism-as-difference view. How could these therapies, seemingly at odds with the neurodiversity movement, play a role in establishing this other, emotionally 'thicker' view of autism?

Let me be clear. This is not an appraisal of ABA's efficacy in treating autism, and I am not arguing that behavioral therapies are successfully treating autism in ways that lead us to revise previously held ideas or reshape the clinical course of autism.¹⁶ Rather, I am concerned with shifts in understandings and conceptions of autism. The point here is that behavioral therapies – seemingly incommensurable with neurodiversity – have been used to achieve what I consider neurodiverse ends. Parents often use them to advocate for their child's unique and complex personhood and to include him or her in a range of social settings. This micropolitics of recognition, I suggest, is an important aspect of the looping processes that have given us a richer view of autistic personhood and experience.

Educators, therapists and parents use behavioral therapies to teach developmentally disabled children and adults everything from making eye contact, to dressing themselves, to short division and much more. In the 1960s and 1970s, parents were among the major promoters and developers for behavioral treatments for autism (Eyal *et al*, 2010; Silverman, 2011). In recent decades, there has been a proliferation of behavioral therapies with new

16 Some researchers have noted that the 'natural' course of autism is changing in response to autism therapies. See Catherine Lord's discussion of the recent history of autism in relation to the debates in advance of about the forthcoming DSM-V's release <http://www.youtube.com/watch?v=up4sP1l1BMw>, last accessed, August, 2012.

methods constantly being invented or adapted. Over the past few decades, ABA has become the *de facto* gold standard (Silverman, 2011, p. 114).

ABA has many faces. It is used in homes and schools, throughout all the public and private scenes of everyday life. The standard image of ABA looks like this: a child sits at a table across from his or her teacher. The teacher gives instructions and, if necessary, prompts the child to carry them out. Through rote and repetition, the child builds various types of skills. In school settings and some family homes, children spend much time in this format. But ABA does not solely involve such skills-building sessions or principled conditioning and reinforcement, and I am not interested here in at-the-table ABA.

In theory, the *telos* (or ultimate goal) of ABA is the vision of the modern subject: fully autonomous, independent, communicating and learning spontaneously. The founder of modern ABA, (Lovaas, 1987), famously argued that 47 per cent of autistic children receiving early intensive ABA therapy would develop to be “indistinguishable” from their peers. This ‘success rate’ is a main fundament of support for ABA, though some contest its veracity (Dawson, 2004). Nonetheless, both ABA’s critics and defenders focus on this 47 per cent and the goal of becoming indistinguishable from typical students. But I would like to turn our attention to the other 53 per cent (or perhaps more, if critics are correct) who never come to approximate the ideal modern subject.

Consider the simple technology at the heart of ABA: prompting. To teach a new skill – say, putting on a shirt – therapists or parents will usually run a ‘baseline’ trial to assay the child’s initial ability.¹⁷ If the task is particularly difficult, teaching begins with hand-over-hand physical prompting, where the therapist’s hands literally act as a second skin to the child’s. Over time, as the child becomes more able, prompts are ‘faded out’. Perhaps a nudge on the elbow or simply pointing will suffice. Ideally, the prompts will be faded out completely as the student learns to put on a shirt independently. While doing fieldwork among severely affected children and adults it appeared to me that something else altogether was being taught or cultivated through ABA.

In many cases the *goal*, it seemed to me, was not so much full autonomy but rather *promptability* itself. Indeed, ABA is often discussed as a method of teaching children to learn how to learn. Almost invariably, teachers begin with basic pre-academic skills. They implement programs to teach the child incrementally through repetition to sit, stand, wait and follow a host of other simple instructions. At the same time, the students learn to engage in social interactions and to perform everyday tasks in concert with their teachers or parents. This is often glossed as ‘cooperation’ or ‘rapport’. The child learns to respond to the parent’s subtle cues and to carry an activity through to its end.

Interestingly, promptability is a two-way street. In prompting their child, parents learn to respond to the child’s cues and gain an up-close perspective on his or her experience. They learn the textures of the sensory environment that attract or repel their child, and the clues that indicate a changing mood. Thus, prompting can become a technology that allows autistics and their companions to find their way around in the world together, to create the shared ‘forms of life’ that Hacking notes were initially missing. Like the child’s ‘special language’, these worlds are, ideally, tuned to each child’s singularity. As one New Jersey mother remarked to me, “we live on planet Jesse”. A Moroccan mother named Kaoutar, who lives with her 31 year-old son

17 I use ‘child’ here, but the same procedures are used with adults.

Hakim in Rabat, told me that he had elaborated a whole referential universe distinctly his own, a sort of *idioglossia*. He had novel names for objects and special ways of asking for things, and she had come to speak to him in his idiosyncratic language. Like so many parents I met, she also interpreted subtle signals in his speech and demeanor as indexes of change in his mood; these prompted her to act in particular ways, just as she often prompted him. Importantly, parents do not only use prompting to create shared domestic ‘forms of life’ with their children, but also to include their child in the public sphere. Allow me to give another example from my fieldwork in New York.

I watched one morning as a mother escorted her 14 year-old son Albert onto his school bus. “Say ‘hello’ to the driver”, she said. Her son mumbled something, looking askance. She pulled his shoulder lightly to orient him toward the driver. “Say ‘hello’”, she prompted him – “Heyo”, he said. The driver replied cheerily, “Hi Albert” – “Okay. Give him your backpack”, she told her son. He slid the straps off his shoulders and held the bag out. Reaching behind his back she gently touched her son’s elbow, moving his arm until the bag was within the driver’s reach. Throughout my fieldwork, I watched as parents guided their children to write words on blackboards, to say ‘hello’ or ‘goodbye’ to strangers or teachers, to make eye contact, to request a specific toy or food, to tell an aunt or uncle ‘I love you’.

However, parents also used prompting in ways that went beyond ordinary interactions, like greetings, that could be glossed as neurotypical or normative conventions. Indeed, many families prompted their child through social interactions that are by no means normative, but rather neurodiverse. Take the example of 16 year-old Robert, who loves it when people cough. He positions himself to feel the vibrations, presses his eager hand flat on the cougher’s Adam’s apple. When he met his parents’ friend Dan for the first time, they said hello, shook hands, then seemed unclear about what to do next. Robert’s parents relied on an old trick: they prompted the two through a coughing exchange as an icebreaker. “Do you think Dan can cough?” his mom asked her son. She prompted his polite but garbled request – “I want cough, please”. She pulled back on his arm so he did not press Dan’s throat too hard. At the same time she prompted Dan to cough loudly, and with flair. Robert squealed with delight and Dan smiled, seemingly pleased with himself. Scenes like this one were not at all unusual among the families of autistic children I met throughout my fieldwork.

In Morocco, I met families using behavioral therapies in similar ways. At a café, Selma prompted her non-verbal daughter, Dounia, to kiss the waitresses on their cheeks and to order her tea and cookies using her Picture Exchange Communication System (PECS).¹⁸ Omar, an educator with a 9 year-old autistic son who attends an ABA-based school outside Rabat, often prompted me and other people to engage his son Aziz in unusual games of call-and-response word play. Aziz often created pairs of phrases or words that Omar told me were like “poetic couplets”. For instance, he would tell me to say, “Obama”, and his son would reply “president of the crisis!” (*ra’is al-azma!*). By prompting such interactions, Omar and Youssra, albeit in different ways, invite others to engage their child and, in doing so, to recognize his or her unique personhood.

By prompting, engaging in joint embodiment and translating for their child in such ways, parents become instrumental components of a *prosthetic environment*. Prosthetic

18 See Reno, 2012 for more on PECS.

environments include everything from ‘sensory toys’, to picture-based daily planners, to adaptive spoons with thick, easy-to-grasp handles. The therapies and their technologies, I am arguing, provide an ‘artificial platform’ and a technical infrastructure for the public establishment of autistic personhood. People with autism are being equipped with a range of prosaic technologies that can help ease their insertion into social worlds not built to their specifications. *In the process, these worlds are themselves being reconfigured.* We now have ‘sensory friendly’ movies in the United States where the barrage of sound is dampened for the sake of those with auditory sensitivities. Autistic people make requests in restaurants by exchanging pictures for items, typing out words on small computers, tapping out requests and responses on iPads or letter boards, or having their garbled speech translated by a parent, caregiver or companion.

Note that this is not so different from ordinary parenting. We often prompt typical children to say please and thank you, to stop fiddling with a toy and look up when someone is talking to them. We prompt one another to tell certain stories to others who have not seen us perform them. The irony in all this is that autism, supposedly a disorder of relationality and personhood, lays bare the relational and social roots of personhood writ broadly.

Like the neurodiversity advocates mentioned at the start, the prosthetic environment recasts the locus of disability. It shifts the object of therapeutic intervention from a disabled body – as in the ‘medical model’ – to an individual-within-an-environment; rather than simply trying to change the disabled person, one makes accommodations at the environmental level. Regardless of one’s situation, it is always possible to structure an environment within which one is enabled, and then gradually seek to extend it. The idea of the ‘prosthetic environment’ is, thus, in a sense paradoxical. Therapies may in theory work toward the adaptive goal of helping individuals to ‘pass’ as normal or to ‘camouflage’ their autism. But at the same time they also reconfigure what counts as normal and how someone can pass as such. ABA may aim for maximum independence, autonomy, agency and sociability – all the trappings of the modern subject. But these are often achieved through hybrid arrangements involving therapists and parents who prompt the child or translate his or her utterances and behaviors, and whose own emotional and imaginative worlds have been expanded in the process of learning to do so.

The concept of joint embodiment I am introducing here builds on Rouse’s (2004) concept of “embodiment-by-proxy”. Drawing on the recent work on embodiment and the materiality of signification, Rouse argues that dispositions in the world are made through symbol-laden interactions. She demonstrates the way two poor African American formerly crack-addicted, recently converted Christian parents use a variety of metaphors and symbols in order to shape the dispositions of medical professionals charged with caring for their comatose daughter in order to keep her on life support. Rouse’s analytic stance is especially helpful because it sidesteps questions of identity politics and bioethics and draws us into the intersubjective world where orientations toward individuals with disabilities are dynamically and relationally produced in real time.

However, joint embodiment, while serving similar aims, differs from Rouse’s formulation in that the child is implicated in the scene; he or she actively participates in the action. Not merely parents projecting symbols onto the child, or showing lovability by expressing love for him: it is through brokered interactions and joint movement through the world that the child’s sociability or ‘thickness’ is established. The child’s personhood is, in fact, co-performed by the parent–child duo.

Conclusion

In a very different context, Calvinist conversion in Indonesia, Keane (2007) has theorized the role of the materiality of signification in relation to the dissemination of ideology. Semiotic forms themselves, he shows, harbor certain visions of proper relationships between words, persons and things. Keane (2007) argues that everyday missionary practices “were supposed to provide [Indonesians] *concrete ways of inhabiting new kinds of personhood* ... [with] a certain vision of language and its speakers” (p. 207, my emphasis). In his case, these forms worked toward the purification of the human subject and stipulated that the true seat of agency was an inner immaterial human essence. As a semiotic form, *joint embodiment* works in the opposite direction. It embodies hybridity and quotation, muddying the boundary between persons and radically challenging conventional ideas about individual intentionality and agency.¹⁹ As such, it constitutes a sort of micropolitics of recognition. Rather than molding autistics into ‘normal’ modes of sociality, it seeks recognition for adapted performances or unusual requests. These scenes of recognition, I am suggesting, are key sites within which novel ideas about autistic experience and autistic subjects circulate and gain traction. These practices amount to techniques of conversion because they provide concrete ways of inhabiting and recognizing autistic personhood. They can be used to convert others to a particular view of an autistic person by inviting them to see an agent where they might not have done so before, to see a complex emotional being amidst seeming disconnection and disorganization. All this is remarkably similar to the current aims of the neurodiversity movement and aligns with the autism-as-difference view outlined above.

Ideas about autism have shifted dramatically in the past several decades, perhaps most importantly in terms of the way we view, imagine and engage with the interior lives of autistic people. In place of the earlier image of inaccessibility, extreme aloneness and a lack of affective contact, we now have a richer picture of autistic experience and personhood. Previous scholars have rightly pointed out that neurodiversity activists and autistic autobiographers have helped establish this new autism-as-difference view. However, observers focusing on textual analysis and the public pronouncements of advocates and experts have tended to considered behavioral therapies like ABA and the parents who practice them as promoting an autism-as-disorder view, at odds with autistic self-advocates. The therapies and parents are said to be working to make ‘unfavorable deviants as close to normal as possible’ and, in doing so, enforcing a hierarchy of modes of sociality and communication that fails to recognize the ways in which people with autism are in fact always already social, communicative and interactive. A number of recent scholars have pointed out that the dichotomy between treating autism and celebrating it is a false one (Savarese and Savarese, 2010; Kapp *et al*, 2013). By taking a ‘view from below’ and focusing on the politics of practice, this article builds on that insight and offers a novel interpretation of the way that some parents have long used behavioral therapies and their attendant technologies. By attending to everyday micropolitics of recognition, I show how some parents are enmeshed in behavioral therapies in ways that achieve neurodiverse ends. By taking a longer historical view, I suggest that parents have

19 In this way, it resembles the controversial therapy facilitated communication (FC) championed by some neurodiversity activists, where an autistic person types words while in physical contact with an aide whose role is to stabilize him or her physically and emotionally. See (Reno’s, 2012) outstanding article on PECS, FC and semiotic ideologies.

contributed to establishing and propagating an alternative conception of autism and opening up new ways for autistic subjects to be recognized as full persons, by acting as the child's personal translator, engaging in joint embodiment and creating prosthetic environments.

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