"No One Has to Be Your Friend": Asperger's Syndrome and the Vicious Cycle of Social Disorder in Late Modern Identity Markets

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Abstract   The past 40 years have seen a significant increase in diagnoses of autism spectrum disorder (ASD), a condition characterized by social impairments and restricted or repetitive behaviors. This increase has been particularly marked in the United States, where prevalence estimates have risen from 1 in 2,500 children in 1987 to 1 in 88 today (Baio and Centers for Disease Control and Prevention 2012; Ritvo et al. 1989). I argue that changing social environments are one factor contributing to this increase by altering trajectories of social development, particularly among those with social-cognitive vulnerabilities in the absence of comorbid intellectual impairment. In a sociocultural milieu in which friendships and other extra-familial relationships are increasingly determined by individual choice, with affiliations formed around likeability and the negotiation of mutual positive affect, those who are slower to develop nonverbal awareness, perspective taking, and emotional self-regulation are often excluded from the flow of social life. Such exclusion results in the rapid amplification of characteristics considered to be deviant, thus perpetuating worsening cycles of exclusion and atypical development. [autism, Asperger's syndrome, mental health, friendship]

How and why do certain kinds of societies produce certain kinds of people? The way that particular forms of social organization interact with individual characteristics to produce patterns of experience, beliefs, and behavior is a long-standing concern at the heart of psychological anthropology. These questions are of particular importance in the case of mental illness. Psychological anthropologists have long sought to elucidate the varied pathways through which organic factors, culture-specific expectations, explanations, behavioral repertoires, and individual processes of meaning making intersect to create clusters of experiences that are understood as discrete illnesses (i.e., Chapin 2008; Hinton et al. 2002; Kleinman and Kleinman 1985; Simons 1985). Such pathways can be seen particularly clearly in moments when new conditions emerge or when they become salient or prevalent in a new way or in a new context (Bordo 1985; Hacking 1998; Herman 1992; Young 1995).

We are facing such a moment in the United States, as we struggle to make sense of the extraordinary rise in autism spectrum disorders. Once thought of as a rare disorder, prevalence estimates for autism in the United States has risen from 4 per 10,000 in studies conducted in the 1980s (Burd et al. 1987; Ritvo et al. 1989), to 1 in 155 in 2007, to 1 in 88 at the time of this writing (Baio and Centers for Disease Control and Prevention 2012; Matson

and Kozlowski 2011). This rise is consistent with a global trend towards increased diagnosis of autism spectrum disorders; however, the highest levels of ASD's have consistently been measured in the United States and the United Kingdom, with similar patterns found across Northern Europe and lower prevalence rates found outside of those countries (Elsabbagh et al. 2012; Zaroff and Uhm 2012). Many factors undoubtedly contribute to these international differences in prevalence rates, including pronounced differences across countries in case ascertainment, treatment infrastructures, behavioral expectations, symptom presentation, and symptom interpretation (Grinker and Cho 2013; Matson et al. 2011). The outcome of all of these factors (and their interactions) is an historical moment in which disorders of sociality itself are suddenly extremely prominent within certain societies. Much attention has been paid to the question of why there suddenly seem to be so many more people who behave in a repetitive, rule-bound way, who have difficulty engaging in reciprocal, flexible social interactions, and who seem incapable of forming successful relationships and thus incapable of succeeding at home, school, or the workplace.

Explanations for the increase fall into two camps. Some (i.e., Grinker 2008; Taylor 2006) believe the increase is an artifact of expanded diagnostic criteria and increased awareness of a condition that has historically been misdiagnosed or overlooked. Others, however, believe that in addition to these diagnostic changes, there has also been a "true" increase, where "true" connotes a biological change in the bodies of developing children, most likely caused by exposure to environmental toxins (i.e., Blaxill 2004; Herbert 2008). While there has been increasing acknowledgment that both environmental and diagnostic changes may be contributing to the increase (i.e., Insel 2012), historically these camps have been deeply polarized, with those who believe there is no true increase criticizing those who disagree for causing unnecessary panic (i.e., Gernsbacher et al. 2005), and those who argue for a true increase denouncing those who study social context for their failure to acknowledge and respond to an emerging public health crisis (i.e., Weintraub 2011).

Amidst this controversy—between the autism increase as "real" and thus biologically determined and the autism increase as socially determined and thus "unreal"—a third possibility has been overlooked: contributing factors to the increase could be both social and real. In this article, I will describe one mechanism through which changes to the social environment shift developmental trajectories and thus contribute to a genuine increase in social impairments among individuals whose cognitive style makes them particularly vulnerable. When social affiliations are organized primarily by voluntary choice and contingent upon sustained mutual satisfaction, those who are slower to develop the kinds of competencies necessary to form and maintain such relationships are also systematically denied opportunities to develop them. The experiences of social exclusion and interpersonal violence that result from being socially unskilled, in a context wherein inclusion is contingent upon the display of certain social competencies, results in the amplification of characteristics considered to be deviant, perpetuating ongoing cycles of exclusion and atypical development. Such a social setup is a recipe for rapid increases in social developmental disorder.

I focus here on those individuals on the expanding diagnostic borderlands of the autism spectrum: people who display the debilitating social impairments and rigidity characteristic of ASD, without comorbid intellectual impairment or other significant developmental disabilities. These individuals occupy a contested classificatory grey area between personality difference and pathology (Baron-Cohen 2000; Nugent 2009). Whether they receive a diagnosis often depends less on the presence or absence of characteristics symptomatic of ASD and more on the extent to which these characteristics produce clinically significant impairment in daily life (Atwood 2007). I argue here that the vicious cycles of social exclusion and social incompetence described by many of my informants may be sufficient to cause some individuals to cross the line from subthreshold eccentricity into difficulties in living that register as clinically significant. At a time when the detection and diagnosis of autism spectrum disorders is a major emphasis of public health initiatives, such a process of "threshold crossing" could be one contribution to the rising number of ascertained cases.

The cases presented here are drawn from two research studies of the life experiences of individuals with Asperger's Disorder. Asperger's Disorder (more frequently referred to as Asperger's Syndrome) is a diagnostic category that was added to the Diagnostic and Statistical Manual of Mental Disorders in 1994 as one of the Pervasive Developmental Disorders that comprise the autism spectrum. Individuals diagnosed with Asperger's show the restricted or repetitive behaviors and social impairment typical of autism, without intellectual impairment or delay in acquiring spoken language (American Psychiatric Association 1994). In the newly revised DSM-5, all the Pervasive Developmental Disorders have been combined into a single category, Autism Spectrum Disorder, thus codifying the trend toward including individuals fitting the criteria for Asperger's under the umbrella of autism (American Psychiatric Association 2013).

The first of these two studies consists of interviews with 16 young adults across the United States diagnosed with Asperger's Syndrome, focusing on their experience of the transition from adolescence into adulthood. Participants were recruited through organizations serving individuals with Asperger's. Each participant was interviewed three times, either in person or via email; the in-person interviews lasted approximately one hour each. The second is a multisite ethnography investigating how people affected by autism spectrum disorders draw upon broader discourses of biomedicine and identity to make sense of this emerging diagnostic category. This project consisted of two years of participant observation and 130 semistructured interviews, conducted in sites where these meanings were being negotiated and put into practice in consequential ways: classrooms, support groups, psychiatric clinics, and summer camps, as well as a bowling league for adults on the autism spectrum and a science fiction convention. All were located in an urban area and nearby rural community on the East Coast of the United States.[1]

The impact of voluntaristic and preference-based norms of affiliation on social development was thus not an initial focus of either of the studies from which these data are drawn. Rather, the observations I share here have emerged from 10 years of somewhat open-ended explorations of life on the autism spectrum in the North American cultural context; they

are also informed by my clinical practice as a psychotherapist working with individuals on the autism spectrum and their families. The stories told in this piece, of pervasive exclusion from social roles where access is contingent on personal characteristics and of consequently worsening social impairment, are representative of those I have heard many times in both clinical and research contexts, from both people on the autism spectrum and from parents and practitioners who care for and about them. This pattern appears to play out among both males and females and among both the more and less well-off; the specific impact of gender and socioeconomic background on social inclusion among youth with ASD is an important topic for future research.

The theoretical sample of accounts I have chosen to illustrate these processes are from individuals who spontaneously shared well-formed causal narratives of their own social and psychological development; for this reason they are among the more verbally articulate of the individuals I have formally interviewed. However, their strong intellectual and verbal abilities, broadly middle-class background, and significant difficulties in social and occupational functioning are typical of my overall research sample.

Making causal arguments, particularly arguments about change over historical time, is a challenge when using qualitative data, especially that which is gathered over a shorter time period than the one under discussion. As Maxwell observes, the close observation of small numbers of cases, including individuals' narratives of their own experience, can allow us a more direct (though never fully transparent) view of the processes through which phenomena are linked. Making such inferences, however, requires us to carefully articulate our epistemological assumptions about the nature of causation itself. Following Nagel, Maxwell suggests that causal accounts of psychological phenomena often rely on "an understanding based on the 'fitting together' of pieces of evidence in a way that elucidates how a particular result occurred rather than the demonstration that a statistical relationship exists between particular variables" (2004:250). The argument I am making here relies on the fitting together of three pieces: a psychological mechanism, prior observations of social context, and autobiographical narratives.

First, in making my own causal inferences about psychosocial development in sociocultural context, I am drawing on a body of existing theory from psychology and anthropology that highlights the importance of interpersonal relationships for developing social competencies. A number of traditions within psychology including relational-cultural theory (Jordan 2000, 2009; Walker and Rosen 2004), psychodynamic psychology (most relevantly Sullivan 1953; see also Benjamin 1990), and attachment theory (Ainsworth 1979; Bowlby 1988; Mikulincer and Shaver 2012) suggest that it is through relationships with others, both in infancy and throughout life, that we learn to recognize and regulate our own feelings, as well as to attend to those of others, tuning in to their rhythms and taking their perspective. While parent-child relationships are crucial for acquiring basic relational abilities, learning to negotiate adult relationships characterized by intimacy and mutuality is facilitated by experience with relationships with peers that are less determined by power imbalances (Buhrmester 1998; Hartup and Sancilio 1986; Sullivan 1953). Anthropological literature on socialization

shows that specific settings and social roles also require the acquisition of specific behavioral repertoires. These repertoires are learned through participation, often initially guided and facilitated by cooperative insiders (Davis and Davis 1989; Rogoff 2003; Rogoff et al. 2007; Whiting and Whiting 1975). The extent to which repertoires from one setting can be successfully applied to another depends greatly on the similarity between these settings, with status hierarchy being a particularly salient dimension (Whiting 1980). Skills learned in situations of significant status difference (such as parent-child or teacher-student) may not generalize well to relationships (such as with friends, romantic partners, and sometimes even coworkers) that are expected to be at least ostensibly egalitarian (Atwood 2007). Opportunities to participate in such relationships as a novice are thus an important way to gradually gain greater competence.

The second piece of evidence I draw on here is previous work from sociology (i.e., Beck 1992, 2002; Bellah et al. 1985; Côté 2000, 2002; Giddens 1991; Putnam 2000), suggesting that over the past half-century, in a number of societies including the United States, there have been changes in the conditions of access to such opportunities. This work documents an "identity market" (Côté 1996) driven by an increasing emphasis on the free choice of interactional partners, and by the increasing centrality of personal characteristics and mutual positive affect as the motivation for sustained interaction, in the absence (or through the devaluing) of extrinsic parameters structuring social interaction. Consequently, a relatively high degree of initial competence is required in order to win and maintain access to social roles—and thus, I argue, to the kind of guided participation necessary for a more comprehensive induction into these roles.

The third piece of evidence that "fits" between these micro- and macrolevels of analysis consists of first-person accounts from individuals living under these conditions. These accounts ground hypotheses about developmental and social processes in autobiographical narratives of lived experience, allowing us to observe the unfolding of these interacting phenomena over time.

The claim I make based on these three pieces and their fit is fairly circumscribed. I do not claim that changing patterns of social affiliation are single-handedly causing the rise in autism spectrum disorders but merely that this is one of many contributing factors, as it results in worsening social difficulties of the sort that get caught in the diagnostic net of ASD. Though limited, this claim is significant because it opens up an understudied area in autism research. In the midst of debates over whether the rise in autism is a biological reality or a social artifact, our failure to acknowledge the robust reality of specific sociohistorical affordances and their impact on developmental trajectories leaves a consequential gap in our collective conceptualization of the autism spectrum. Failing to examine patterns of social interaction as mechanisms that facilitate and constrain social development forecloses opportunities for intervention that are opened up when we engage with these levels of analysis. Furthermore, abstracting ASD from its relational, developmental, and sociological contexts in favor of an exclusively neurobiological understanding leaves people who have an ASD diagnosis without

an explanatory language for conceptualizing the temporal and relational dimensions of their experience. I will conclude with a discussion of both these implications.

Friendship in a Preference-Driven Society

> Parents come to me and they say: my child has no friends. And I ask them: what are you doing about it? And they say: Nothing! What can we do? They don't like him!

Martina Grace is a developmental psychologist who heads up a clinic serving children with Asperger's Syndrome in a major city within the United States. She tells this story a lot— at her public lectures, to the families she works with, to me when I interview her for my dissertation research. The purpose of the story is to call attention to a taken-for-granted assumption and thus to destabilize it. When parents say "what can we do?" they intend this as a rhetorical question, with the implied answer being *nothing*. After all, the other kids don't like him. But Dr. Grace suggests things they *can* do: plan awesome playdates. Make brownies. Buy the cool new game that no one else has yet. She encourages parents to do whatever they need to do to make sure their kid has at least one other person he or she can talk to, play with, interact with in an informal way on a regular basis. Otherwise, that child will never learn the skills necessary to form relationships with other people. *Just one friend*, she goes on to say. *Pay someone if you have to!* This last suggestion is often met with shocked laughter. Real friendships are not supposed to be anchored by such instrumental gains.

According to the dominant narrative of friendship in the contemporary United States, friendship is based on choice, choice is based on personal preference, and that personal preference is determined by personality characteristics. The relationship is characterized by "voluntariness, stability and fragility"—the stability coming from the deliberate cultivation of intimacy, trust, and commitment, the fragility coming from the lack of external anchors or obligations to stabilize the association (Wiseman 1986). Authentic friendships are maintained based on the kinds of feelings and subjective experiences provoked by the relationship in the absence of external determinants.

This model of friendship is paradigmatic of what Giddens has identified as the late modern ideal of the "pure relationship," arising in a social milieu within which "partners are voluntarily chosen from a diversity of possibilities" (1991:87). The pure relationship is "not anchored in external conditions of social or economic life—it is, as it were, free-floating." Instead, relationships are formed and maintained through ongoing "reflexive coordination" in which intimacy and trust are worked at and won. "What matters in the building of trust in the pure relationship is that each person should know the other's personality, and be able to rely on regularly eliciting certain sets of desired responses from the other" (1991:96).

But this ideal of freely chosen association, based on the appealing qualities of the other person and unconstrained by any external factors, is in fact only one of many possible modes of social affiliation. Friendships vary significantly across cultures and between historical periods (Bell

and Coleman 1999; Hruschka 2010). The emphasis on voluntarism, autonomy, sentiment, and lack of instrumentality that is thought to be central to friendship in the contemporary American context is to some extent present in most cultures' ideas of friendship but is in no way always so central (Kilick and Desai 2010). For example, Froerer (2010) found that children in Chhattisgarh, India, formed social groups predominantly out of those with whom they shared a *para* (ward within their village) and thus also shared proximity, activities, a daily schedule, and a basic sense of trust arising from shared group membership. Adams and Plaut have observed that in West African settings, "relationships glossed as friendship often take less voluntary forms that admit a greater role for structural affordance, context specificity, institutionalized obligations, and instrumental use of the relationship for practical ends" (2003:335). Even within the United States, Matheson et al. (2007) found that teenagers with intellectual disabilities tend to describe friendship as the sharing of activities over time and across contexts rather than through the intimacy, personal disclosure, and the process of mutual selection more frequently endorsed by their typically developing peers.

The form that friendship takes in the social mainstream of the contemporary United States, on the contrary, is in keeping with a strong cultural emphasis on individual choice, sometimes at the expense of interpersonal or community bonds (Iyengar and Lepper 1999, 2002; Lane 2001; Schwartz 2000, 2004). Furthermore, choice is determined to a great extent by personal preference rather than the desires and expectations of others, interpersonal loyalties, or extrinsic determinants, all of which shape personal choices to a greater extent in societies with a less individualized model of personal agency (Savani et al. 2008). As Giddens has observed, this "plurality of choice can … be connected directly to relations with others" (1991:87) such that affiliative behavior is increasingly driven exclusively by liking. In a striking example from the experimental literature in social psychology, Miller and Bersoff (1998) found that when presented with a series of vignettes in which one person failed to help another (across a variety of relationships) and asked to make judgments about that person's moral responsibility to help, American adults were significantly more likely than Indian adults to take into account how much the people involved liked each other.

The importance of likeability as a determinant of social interaction has also been intensified by a historical shift within the United States, away from external, shared, and stable under-standings that organize and order social life and toward informal, ad hoc negotiations of mutual experience in the moment. Putnam (2000) has thoroughly documented the decreas-ing role of interest-based clubs and community organizations, within which individuals are held together by shared projects that transcend the individual characteristics of participants and the particularities of their interactions, in favor of informal "hanging out" motivated by the pure pleasure of company. Similarly, Bellah et al. observed an increasing "attenuation" of shared understandings about what constitutes moral behavior and a good life, leading to an increased focus on "extending the calculating managerial style into intimacy, home and community, areas of life formerly governed by the norms of a moral ecology" (1985:48).

Meanwhile, elements of the pure relationship have come to organize a wide range of social and vocational spaces, replacing (or obscuring) other logics. For example, Leidner (1993) has

documented how workplace success in an increasingly service-based economy requires employees to inspire positive affect and a pseudo-authentic sense of relational intimacy in both customers and coworkers, concealing the standardization of commercialized interaction. Task competence is no longer sufficient; in many contexts, it is significantly less important than likeability (Casciaro and Lobo 2008).

Appropriate social participation in such spaces requires the ability to navigate ambiguous situations characterized by diverse and locally specific expectations (Larson et al. 2002). In his study of friendships among high schoolers in the United States, Hruschka found that competence in friendship "involves the creative and occasionally idiosyncratic use of conventional knowledge to meet both personal goals and the specific requirements of local relationships and settings" and that "attempting to approximate some broad cultural norm may not only be unnecessary but also maladaptive in the sense that it draws one away from locally relevant models of appropriate friendship behaviors" (2009:205). Navigating this process requires both situation-specific repertoires and broader competencies in negotiation, flexibility, attention to social nuance, and the ability to shift rapidly in response to shifting conditions.

The Role of Individual Vulnerabilities

Not everyone is equally gifted in meeting such demands. As Ochs et al. observed in their in-depth ethnographic study of the social interactions of children with high-functioning autism, it is just this sort of bottom-up improvisational mode of sociality, with members "intuitively formulating strategies for interpreting and participating in emergent yet conventional social situations" that pose the greatest challenge to individuals on the autism spectrum, who function best within top-down "shared, stable symbolic systems and rules of conduct that organize members' orientations" (2004:148). People who receive autism spectrum diagnoses, while differing widely in their degree of impairment and their overall level of intellectual functioning, tend to share a certain set of underlying cognitive characteristics. These characteristics, depending on their severity and context, may or may not be disabling in and of themselves. However, they place even individuals who are intellectually gifted at a distinct disadvantage in forming and maintaining pure relationships of the late modern sort.

People who receive autism spectrum diagnoses, while often good at predicting the behavior of physical objects and detecting fixed patterns, are often slower to develop their capacity for perspective taking and have a harder time correctly inferring the beliefs, desires, intentions, and motivations of others (Baron-Cohen 1995; Frith 2001). They struggle to read and display nonverbal cues, from the nuances of body language to nonliteral language such as sarcasm and teasing (Adachi et al. 2004; Martin and McDonald 2004; Mundy et al. 1986; Myles and Simpson 2001). They often have difficulty recognizing and regulating their own emotions as well, making them prone to sudden outbursts of fear, rage, or sadness (Hill et al. 2004; Laurent and Rubin 2004). They often prefer to stay focused on one thing for a

long time rather than shifting their attention between topics or activities, and they are often more able to function effectively within systematic, predictable, rule-bound systems rather than those that call for flexibility and improvisation (Baron-Cohen et al. 2003; Gilotty et al. 2002; Ozonoff et al. 2006).

Existing in a sociocultural milieu in which one needs certain abilities at a high level in order to form and maintain relationships does not cause these initial differences in information-processing speed and style; however, it does affect the degree to which they are disabling. Failure to meet such demands leads to experiences that rapidly exacerbate these initial difficulties, while also adding new ones. What might, for some more mildly affected, have been an innocuous difference develops into a debilitating disability, sufficient to meet diagnostic criteria for autism.

Social Disorders in the Identity Marketplace

Côté's (1996, 2000, 2002) model of "identity capital" serves as a powerful framework for understanding the cultural and historical context of these developmental difficulties, suggesting a mechanism through which initial differences in processing style develop into significant and intractable impairments. Drawing on observations from sociologists of the life course under conditions of late modernity (i.e., Beck 1992; Furlong and Cartmel 1997), Côté notes that amidst dwindling of both traditional and institutional supports for preestablished trajectories, youth "must organize their own paths through life and they are increasingly left to their own resources to do so" (2002:118). He suggests cultivating "a strategic deployment of 'who one is' on the basis of exchangeable resources like abilities, appearance, and interactional skills. . . . Together these can be used to establish and accumulate certain identity gains, like securing membership in adult communities" (2002:119–120). Such gains increase the value that the person brings to future attempts at social participation. "With such acceptance, the incumbent gains *identity capital*—there has been an increase in some aspect of 'who they are'" (Côté and Levine 2002:143). They are thus more likely to be successful in the future at "securing community memberships that provide identity validation and social capital" such that "over time, the gains made through these efforts can become resources for further exchange" (2002:119–120).

It is important to note that Côté, and I, are not arguing that the current era is intrinsically more difficult than others, nor is it characterized by a greater degree of overall uncertainty than other periods in human history. Like any other, it is characterized by historically specific processes of marginalization, inclusion, and socialization that have differential effects on participants who are differently positioned within it. The freedom to forge one's own pathway through life opens up new possibilities for innovation; the increased salience of personal characteristics in this process may well allow for a greater degree of self-actualization among many who engage in it. Those who do not initially succeed at cultivating a strategically deployable identity, however, are at risk of falling through the cracks of a social world transformed into a competitive marketplace (Beck and Beck-Gernsheim 2002). When

opportunities to participate in society—whether through jobs, friendships, community memberships, romantic relationships, or other sites of engaged interpersonal interaction—must be won on the basis of personal characteristics, and those characteristics can only be attained through prior successes, initial disadvantages are rapidly amplified into significant impairments.

The Vicious Cycle: Exclusion, Dysregulation, Marginality

When I met her, Mara was a graduate student in her mid-twenties, with a quiet voice and a pale, still face that concealed seething emotional turmoil. She had been diagnosed with Asperger's Syndrome several years earlier after seeking professional help for her long-standing inability to make friends and keep jobs. As long as she could remember, Mara had struggled to read the subtle social cues exchanged by her peers. As she described it to me: "I felt like I was surrounded by aliens. Like they were talking, and it was English, but it wasn't making sense in some fundamental way. They were dancing and I didn't know the steps." Negotiating the nuances of social interaction felt like "doing brain surgery with boxing gloves on." Deeply religious, she had attempted throughout her childhood and teens to find friendship in her Christian youth group, but she struggled with a growing awareness of her failure to fit in. "They never acted anything but nice and polite to me," she told me.

> They never toilet papered my house or anything. But at multiple times during my high school career I'd find out that they'd gone and done something without me, without telling me there was something else to do. . . . One of the most unpleasant memories of my high school years was: [the youth group] were all gonna go to dinner, we were all gonna go to a movie, and we're all supposed to dress up, so I did. It turns out that everybody else who was my age, who was in high school, just had not shown up for this, and they were all at somebody else's house. I found out because one of them had a younger brother who lived in a house that was right next to the church. So he walked over, and I said where's David? *David's with everybody else. Didn't you know?*

At first, she was welcome in the formal structure of faith-based fellowship, though excluded from informal socializing. As she got older, the intensity of her distress about being left out compounded her existing difficulties, both in recognizing other people's feelings and in displaying her own before they erupted into conflict. One time someone in her youth fellowship tried to cheer her up by sending her flowers; it went badly.

> I got a couple of anonymous bouquets and I got really mad, which you would think *why would you be mad that somebody sent you flowers*? Well, I was mad because they sent the flowers saying "anonymous" or "love, God'" on them. If you love me you'd tell me who you are. You wouldn't give me things that let you off the hook of having a relationship. And I was mad, because I felt like they were blowing me off.

She tried, unsuccessfully, to convey to the group how the gifts made her feel, but the message didn't get through: the flowers kept coming. Eventually, she figured out who was responsible

and confronted her. The intensity of her anger was shocking, unexpected. She demonstrated it to me during the interview, getting up in my face, whispering.

> I knew who it was. I found out. And I talked to her at the end of class. In public, yelling at a very low volume, "I can't believe you did that to me." And, you know, she was scared—I was so angry. . .

Over time, such conflicts led to her being asked to leave the youth fellowship group.

> The fall of my fifth year, the church leadership said maybe you should move on, you're upsetting people, you're depressing them. . . . It was really difficult. But you know, it happened again and again . . . I've been getting fired from work and having trouble making friends and getting in trouble with my parents for reasons I didn't fully understand my whole life.

When applying for jobs, when doing volunteer tutoring, at numerous settings where Mara thought her efforts would be welcome, the same pattern plays out.

> Yesterday I went to [a temp agency], and I managed to make the woman in charge angry in two minutes. There was a misinformation technological type problem, and I managed to explain who I was and where I was coming from in such a way to make her angry at me. She told me to leave. I tried to be apologetic, but, you know, I don't think there was really any point in going back there. I'll do it because my parents will get mad at me if I don't, but—yeah, and that's really the story of my life.

She's not breaking any explicit rules, her intentions are good, but her puzzling combination of eerie blankness and sudden anger makes people uncomfortable. They avoid her; she intensifies her efforts to connect with them; they get scared at her lack of responsiveness; she is eventually asked to leave and not return, an outcome that, at this point, feels both completely out of the blue and depressingly predictable.

> When I finally got therapy, one of the most important things we came up with is that *no one has to be your friend*. Even if they ought to be your friend, even if they don't try to like you, you can't arrest someone for not being your friend . . . It's like Charlie Brown: the reason he gets hurt so much is he keeps waiting for the girl to play football instead of tackling him. If I stop waiting around to be tackled, well, then I don't get tackled, so that helps in that sense. And then eventually I developed a new problem, which was: well, okay, I can expect not to make friends and that sort of thing, but what do I do with the rest of my life.

Mara's story is an account of gradually coming to terms with the voluntaristic logics of affiliation in her society and its isolating consequences for her own life. She has gone from hopefully showing up to church in her party dress to raging at the attempts of others to be "let off the hook of having a relationship" with her, to eventually realizing that the hook itself is a figment of her wishful imagination. There is no external power structure to appeal to, no grounds on which to "arrest someone for not being your friend," no obligation to try to like her or to include her in the absence of that liking.

Mara's experience of exclusion extends beyond peer friendship, troubling her search for jobs, communities, and other footholds of adult life. In the absence of a sufficiently marketable personality and without a sufficient degree of the "cognitive skills and personality attributes" that make up identity capital (Côté 1996:426), she struggles to figure out what to do with her life: how to secure a place, a purpose, a sense of meaning. "I could volunteer, I could give them my money, my time, but it wasn't going to help," she told me. "They didn't want me. I wasn't worth enough to the community to put up with." The pervasiveness of the pure relationship infiltrates even Mara's anticipation of her afterlife.

> I've had these fantasies of making it to heaven, there's nothing particularly wrong with me, you know—but I would bring heaven *down*. Everyone would be having such a good time until I got there. So [I would be told]: *you know, we understand you tried, but if you could just go sit outside and not bother people that would be great.*

Mara's vision of her afterlife is a poignant summary of the problems plaguing her current one. Even in a space where inclusion is ostensibly governed by a moral logic of rights and wrongs, Mara imagines herself as the eternal exception to such rules. Neither laughing with the sinners nor crying with the saints, she is banished to a place of lonely liminality.

Damaged Goods: The Impact of Interpersonal Violence

For many on the autism spectrum, especially school-age children, social exclusion is enforced through physical violence. Roland was a senior at a private high school for students on the autism spectrum. His mother, a single parent living on government disability support, fought tooth and nail to raise the money for him to attend because it was the only place where he felt safe. He described his elementary school experience to me as follows:

> I stood out—my interests were much different—and as such I was a seeked target. . . . I had once been stomped on as a trampoline, I'd been bitten, I'd been spat on, I had one kid actually threaten to cut my throat for no reason at all, just came up and acted like that. . . . I had once, in school, actually been attacked by two students on the playground, and the teacher, less than twenty feet away, took a look, didn't even bother to help.

When I met him, Roland was a gangly teenager with a fascination for medieval weapons and a very dim sense of when it was inappropriate to discuss the gory details of their use. He had a tendency to pace to and fro while holding forth at great length about the motivations of political dictators; when upset, he burst into dark, agitated murmurs. He's quite bright, but his family and teachers were worried about what would happen to him if he went to college—worried that people around him would be frightened, that he might get in trouble with the police, might get kicked off campus or arrested.

As it happens, Roland is also one of the kindest people I met in my two years of fieldwork. He graciously showed me around his school shortly after I arrived, making me feel immediately

welcome; he takes younger students protectively under his wing and is one of the few who can soothe the tempers of his classmates when they flare. But this sensitivity and warmth is a side that he does not show to everyone. "By the time I was around 13," he told me,

> I was emotionally very different, I was very frightened. Rather than the friendly, happy person, I'd become a very quiet, very withdrawn, and at times very *dark* individual. . . . Just looking at someone, I can tell who would be dangerous to me, who might want to hurt me, and who might not pay attention. It had certainly changed me. When I came to middle school, I was a far different person than I had been in my other schools.

Roland has always been different from those around him. However, the reactions of others to that difference have profoundly shaped the nature of its expression and manifestation over time. The cruelty that he experienced at the hands of others because of that difference and the status it created for him as a "seeked target" has led him to develop characteristics that lead to further social alienation: preoccupation with violence, emotional instability, suspicion of others, social withdrawal. While these differences are associated with, and frequently attributed to, his autism spectrum disorder, the trajectory through which they developed transcends his individual neurology to implicate the world around him.

The story of interpersonal violence leading to profound changes in one's way of relating to the world was perhaps the most consistent narrative I heard from teenagers on the autism spectrum. Students reported spending large portions of the school day in hiding, fearing for their physical safety on a daily basis, contemplating suicide and being encouraged by classmates to attempt it. Such experiences leave lasting differences in a person's psyche; those differences are fairly consistent and predictable in a way that comes to be associated with the Asperger's diagnosis and those who carry it. "They're all such damaged goods" is a refrain I heard all the time, describing students with Asperger's. I heard it from the principal of Valley View, a private school and sort of sanctuary for kids on the autism spectrum, after he had coaxed a student out of his parents' car and into the schoolroom for the first time; prior to coming to Valley View, the student hadn't left his room in six months. I heard it from Martina Grace as she described learning disabilities that worsened, gifts that were uncultivated by disrupted schooling, and social curiosity withering from rejection and lack of social opportunity. It's a phrase used to describe the impact of these students' life experiences on their current ability to function, the way in which vulnerability leads to victimization and victimization leads to greater vulnerability. It's harsh language, perhaps not the nicest way to describe a child—as goods, as damaged—but the phrase evokes something crucial about the relationship between child and environment, as well as illustrating the kind of language that is available to talk about the result of that interaction. The phrase "damaged goods" connotatively captures the way that a person's worth and capacities are understood to be lessened after such interactions with the social environment.

"Without Being Given Experience, I Cannot Get Any": Lack of Access to Adult Roles

Often, such a developmental trajectory results not only in friendlessness, but also in difficulty attaining the kind of "membership in adult communities" necessary for the cornerstone of late modern adulthood: independent living. Individuals on the autism spectrum, even those with significant intellectual gifts, are often unable to find and keep consistent employment and a stable living situation outside of their parents' houses, despite the pervasive expectation that they do so (Barnhill 2007; Howlin et al. 2004). As Green et al. (2000:290) have observed: "Of the social impairments in AS [Asperger's Syndrome] individuals, perhaps the most striking result is their profound lack of ability for independent living, given their intelligence and often good functioning in other areas."

Samuel was diagnosed with Asperger's at 17; his parents had taken him to see a psychiatrist so they could better understand his decision to drop out of high school. At the time I interviewed him, he was working on his second masters' degree, while struggling to keep a low-paying job shelving books at a library. He couldn't afford to rent an apartment alone, but he also couldn't find anyone willing to live with him, so at age 27, he was still living with his parents. Isolated and friendless, he had never had a girlfriend, despite wanting one badly. "Apparently I am subhuman and subhumans are not granted such privileges" he wrote to me. His increasing frustration, loneliness, and thwarted desire were compounding his existing social problems in the workplace, to the point that it threatened his employment.

> I nearly got fired from my job because my employer accused me of harassing a woman. It is true that I talked to her too much, but I did not realize how bad it was and how she would take it. Because I threaten people, that means my dating chances are much lower, my social chances of any kind are lower, and my job prospects are bad. It has very depressing implications for my ability to exist in this society as an independent adult.

Samuel is stuck in a vicious cycle. Not naturally talented at engaging others in relationships characterized by positive affect, mutuality, and trust, he has been utterly unable to win himself the opportunity to develop these interactional skills. "Without cooperation" he pointed out to me,

> it is very hard to get the kind of skills living in the world requires. Without having a roommate, one cannot learn to be a good one. Without dating, one cannot learn to be a good date. Without being given experience, I cannot get any.

Samuel lives in a society where relationships are not governed by broadly shared sets of expectations or anchored in external parameters but instead guided by perpetually renegotiated and idiosyncratic local norms. Being a good friend, a good roommate, or a good date are not roles one can study at a distance but capacities one develops through experience. Samuel recognizes that novices require the support and guidance of supportive insiders to learn the nuances of appropriately performing social roles within given social contexts. "What bothers me," he told me in our first interview,

> . . . is that many areas of self-development are unmet due to both lack of knowledge about how to learn about them and lack of cooperation from peers. Peers feel no responsibility to help in any meaningful way. No one ever invites me for dinner. They are more willing to be abusive and rejecting than to teach the skills necessary to survive.

His attempts to seek relationships through norms of moral or civic obligation provoke not connection but contempt and avoidance in his peers. Socially awkward his whole life, and now consumed by bitterness, resentment, and rage, Samuel is not particularly likeable and is thus perpetually unchosen for social roles: friend, roommate, employee, boyfriend. Consequently, he is unable to develop the "identity capital" that might allow him to access these roles through a more socially appropriate self-presentation, and he simmers in worsening isolation and deepening discontent.

The Transformational Power of Relationships

However, for those who are able to make a connection with another person, the effect can be powerful—in the words of one young man I interviewed—"transformational." Austin was a college student at an elite university who had been diagnosed with autism as a child. For years, he had struggled to recognize and put words to his own feelings, the experiences of others and how those connected. Then, in his last year of high school things changed. He began to keep a journal—and he found a girlfriend. In doing so, he also found himself. He told me:

> I feel like through the journaling, to some extent, and through my girlfriend to perhaps an even greater extent, I developed the ability to feel myself, to be very in tune with what I want and what I feel. More than ever before, when I got a girlfriend, there was the need to—to make myself known.

Studying psychology helped him formulate an understanding of his own transformation.

> I read an interesting book over the summer—*The Transparent Self* is what I think it's called. It's an older book. But it's about how people don't really become aware of who they are until they express it to another person. When you have someone who's as interested in who you are and what you're feeling as a significant other is, naturally you come to realize things within yourself that you'd never thought to question before. . . . It was through the relationship that I became aware of the very, very profound effect that feeling accepted can have on a person. Both by watching myself and by watching my girlfriend. As the relationship progressed and we both felt more or less accepted at various times. It's absolutely transformational.

Through his relationship with his girlfriend, Austin gained new capacities of self-awareness, as well as a new appreciation for the experiences of others. Though he still struggles with severe social anxiety and is often tormented by an intense sensitivity to changes in his environment, he is also a well-respected member of a small circle of friends who consider him to be empathetic and trustworthy; their support bolsters him in turn.

Implications for Intervention: Alternative Social Spaces, Alternative Possibilities

Austin's story contradicts the assumption that worsening social impairment is a foregone conclusion for those with initial vulnerabilities. Different kinds of developmental trajectories can emerge within different relational ecologies. The "pure relationship" is an increasingly pervasive model for social interaction; however, a number of social spaces follow alternative affiliative logics. Such spaces are often located within either therapeutic or subcultural niches; participation in these spaces may, however, help those on the social margins to acquire social experiences and repertoires that are also effective in the broader society.

For example, a wide range of group-based social skills therapies (i.e., Baker 2003; Coucouvanis 2005; Winner 2006) give people on the autism spectrum the opportunity to practice social skills such as maintaining conversations, reading nonverbal cues, cooperating, and compromising with others, with guidance by more experienced facilitators. Participation in these groups has been shown to improve performance on a wide range of tasks designed to measure social skills, including parent-report and self-report measures; it is less clear how and to what extent these skills generalize outside the group setting (Cappadocia and Weiss 2011; Reichow and Volkmar 2010; White et al. 2007).

Attending to the differences between the social organization of these groups and the society for which they are intended to prepare participants can shed light on obstacles to generalization. Social skills groups differ from peer friendships in that participation is generally obligatory rather than voluntary and hierarchical rather than egalitarian. Participants are usually required to attend by caregivers (especially, though not exclusively, among groups targeted toward children and adolescents, which constitute the majority of such groups), and activities and interactions are predominantly dictated by facilitators. Thus, though group interactions provide a pseudo-naturalistic context, social interactions within such groups are both embedded in and determined by sharply unequal power relations, while intended to generalize to peer cultures that are broadly more egalitarian (though also, of course, characterized by their own complex and idiosyncratic hierarchies). Variation along such dimensions of power and status have been found in many contexts to impede the effective generalization of behavioral repertoires from one context to another (Whiting 1980).

A social space organized around a different sort of associational logic can be found in what Gee (2005) calls "affinity spaces," of which he uses the online strategy game *Age of Mythology* as an example. Affinity spaces are characterized by a series of defining features: common interests or endeavors, rather than individual characteristics, shape the terms on which participants relate to one another; the acquisition and spread of knowledge is valued and motivates much social interaction; participants play a role in shaping the basic affordances of the space; and novices mingle freely with experts, with fairly porous boundaries between leaders and followers and multiple routes available for gaining higher status. These spaces are thus voluntaristic, and flexible in their status hierarchies, much like contemporary friendship; however, the conditions of entry (and the conditions of access, for a novice, to those with

greater expertise) are based on interest, commitment, and the kind of capacities that come with sustained effort rather than on innate abilities or personality characteristics.

While "affinity spaces" have been most extensively studied online, such spaces exist in the face-to-face world as well. These same characteristics organized social life at Lunacon, a science fiction convention I attended after having been told on multiple occasions (correctly, as it turned out) that I might find lots of people with Asperger's there. At such conventions, social interactions are motivated not only by personal characteristics but also by the opportunity to share experiences and information related to topics of interest. In a series of focus groups and interviews that I held at Lunacon, attendees told me that this extrinsic motivation for interaction provided them with a sense of social safety that they often contrasted with the rejection they experienced elsewhere. Ann, the mother of a teenager with Asperger's, told me that, from the time her son was very young, he found the greatest amount of acceptance within the game rooms of such conventions.

> It was such a safe space for him. His little social glitches were more tolerated than they would have been in other places I think . . . Because he was playing the game, he knew the rules—that's what mattered.

Such experiences can deepen one's interest in social interaction. Rob was a Lunacon participant who attended one of my focus groups. Before he started attending conventions, he told me,

> My peer group was a complete mystery. I had no clue about my peer group or what made them tick or why I would want to associate with most of them or why I would care what they thought.

Attending conventions taught him that it was "a good thing to interact with people," something he had not previously found intrinsically motivating:

> There's actually something to be gotten out of this. There are fun things that you can do with people. You can talk about these real esoteric things about the Lord of the Rings; there are other people who want to talk about these really esoteric things about the Lord of the Rings.

Disengaged from pure relationships, baffled by associations based only on "wanting to associate," Rob found a more congenial mode of interaction in a setting where interactions are voluntary but also organized in part by shared interest in extrinsic content rather than merely the pleasure of company.

The ethos of behavioral tolerance that characterizes many such spaces can provide a welcome haven for those excluded elsewhere. However, it does not create a social utopia; see, for example, Suileabhain-Wilson (2003) on the destructive consequences of "geek social fallacies" that idealize total acceptance and loyalty at the expense of personal boundaries.

Further research is needed to investigate the impact of participation in such communities on social development among individuals both with and without ASD diagnoses.

These two approaches can also be combined to create communities that facilitate social relationships among people on the autism spectrum and their peers through interactions motivated by shared commitment to a mutually meaningful activity. An example of one such attempt is the summer camp described in Fein (2010), where teenagers on the autism spectrum shared a therapeutic social space organized around their shared enthusiasm for improvisational role-playing games based on popular fantasy narratives. In the interest of creating a good game, which could only be done collaboratively, campers tolerated each other's quirks and attempted to modulate their own. While the program did not conduct a formal outcome study, a number of participants and parents reported lasting positive changes following the program, including strong relationships that formed within and endured beyond it. Shared affinity provided access to a space within which participants developed identity capital, building friendships and developing their interests and social skills.

Looking at the impact of social organization on relational development opens up spaces for intervening thus upon the level of the group, rather than the individual alone, to create interactional spaces that facilitate authentic social and relational connections while teaching flexible social repertoires. Furthermore, recognizing that social development continues throughout the entire life-course (an insight often missing in neurogenetic accounts of disorder and treatment) motivates interventions that can support individuals in all stages of life, from childhood through adulthood.

Implications for Life under the Description of ASD

Recognizing the role of implicit social logics in the development of social capacity and impairment may also make a difference for how people with autism spectrum diagnoses understand themselves and the nature of their distress. It was through reading about the psychology of interpersonal relationships that Austin came to understand the impact of relationships on his own development. However, as Austin himself observes, it was an "older book"—Sidney Jourard's *The Transparent Self* (1964)—that gave him a language for conceptualizing the causal force of these relational experiences. Jourard's work is part of a humanistic tradition within psychology that "is always concerned with man in his interpersonal potential," taking as foundational the tenet that "the unique nature of man is expressed through his always being in relationship with his fellows" (Bugental 1964:6). Neither Austin alone, nor his girlfriend as an isolated variable, brought about his transformation; it emerged in the interaction between the two of them.

In our contemporary understanding of developmental disorders as problems of broken brains, interpersonal relationships are significantly less richly theorized. As a number of scholars have recently observed (Choudhury et al. 2009; Luhrmann 2000; Rose 2003, 2007), the current trend in psychiatry is to define mental disorders as biological pathologies, best conceptualized at the level of the individual body or below (see, for example, Insel and

Quirion 2005).This phenomenon is particularly pronounced in the case of autism. While a growing body of work within the fields of sociology and anthropology attends to the social, cultural, and historical contexts of autism (i.e., Bagatell 2010; Cascio 2012; Daley 2004; Eyal et al. 2010; Grinker 2008; Nadesan 2005; Ochs and Solomon 2010; Orsini 2009; Silverman 2001; Sirota 2010; Sterponi 2004), this work constitutes a small fraction of the broader field of autism research (Daley 2002). As Solomon and Bagatell have observed, "there is less and less attention in autism research to phenomena that cannot be studied at the neurobiological or molecular level, such as human experience, social interaction, and cross-cultural variation" (2010:2).

These construals of autism as fundamentally intrasomatic are taken up by people diagnosed with the condition, as they work to make sense of themselves, other people, and the relationship between. Such an understanding of disordered social interaction as a product of the individual biological body has inevitable consequences for the interpretation and enactment of social life. In some cases, such as within the ideology of the neurodiversity movement, it becomes a point of pride to identify as "differently hard-wired," exemplifying the position of "cerebral subject" that is implacably impervious to the input of a hostile and unsympathetic social world (Fein 2011; Ortega 2009). But for others, understanding "the failure to develop peer relationships appropriate to developmental level" (American Psychiatric Association 1994) as a phenomenon that can be neatly contained within the contours of the individual biological body is a process that is more vexed and less empowering.

Throughout our interviews, Mara struggled to conceptualize a phenomenon for which she had no ready language: her presence seemed to cause normal people to act in abnormal ways. Something goes wrong in the spaces between her intentions and others' responses to her, and she struggled to make sense of the implications of this process for her own sense of agency and moral personhood.

> If I try to be friendly people become afraid of me. If I try to be generous people resent me. If I try to be open and sharing, people get confused and angry at me . . . It's like driving without my turn signals. How can I plan to be a nice person? How can I work on being a welcoming hospitable kind person if my attempts are going to be misinterpreted? No matter what I do, no matter what I try I'm going to make people angry and afraid of me. I can't, I can't say what I mean.

Searching for a way to make sense of interpersonal disorder in fully individualized terms, she mapped the reactions of others back onto her own broken body, reinscribing it as a causal agent without volition. She described herself as radioactive, as a malfunctioning computer, as a car out of control on an icy road. Eventually, she settled on the metaphor of biological disease transmission.

> I oftentimes say—do you know Typhoid Mary, do you know who that is? She was a real person, a cook. It turned out she was a carrier of typhoid, although she never actually had it, but was passing it on to everyone whom she served . . . Eventually they had to imprison her because she was such a threat to public health when in reality she meant well enough. . . . And I feel like that a lot. I make people—obviously not physically ill, but disturbed, upset, angry, even when I'm trying to do my best.

Mara's conceptualization of her problem as contained yet contagious helps her make sense of the paradoxes of her relational life, but at a cost. The metaphor comes with its own baggage and brings its own constraints upon thought and action. In this case, it guides them in a way that is highly consistent with the symptoms of autism spectrum disorder: a withdrawal from the social field, accompanied by an understanding of interpersonal relationships as governed by implacable physical laws. Mara understands her social life to be organized around the deterministic, avolitional interaction of objects: bodies as machines out of control. Beliefs, desires, and intentions become irrelevant to the point of invisibility; one cannot decide not to catch typhoid—or not to spread it. Interventions upon the interactional field are irrelevant. Within such a system, the only way to protect oneself and others is by avoiding proximity, never coming too close. The predominant language available to talk about social inadequacy is itself inadequately social; this conceptual lacuna perpetuates the very problems it describes.

Conclusion

Questions of cause and etiology—of "why?" and "why me?"—are fundamental to meaning-making processes around human suffering. It is thus important to articulate the ways in which sociocultural conditions may be contributing to the developmental outcomes currently being conceptualized as autism spectrum disorder, even if this explains only a small piece of the epidemiological puzzle. In an era when rapid and profound social transformation is so commonplace as to have become cliché, there are likely many pathways through which patterned changes in life experience are leading to patterned changes in subjectivity, behavior, and biology. However, such factors have gone unexplored in current debates about the rise in autism diagnoses. Instead, these debates tend to bifurcate sharply between accounts that raise alarms by positing the biological as fact and those that reassure by casting the social as fiction. This false binary underplays the real causal force of social structures and relational experiences on development. It leads to an impoverished picture of life on the autism spectrum and a limited range of options for supporting people affected by it. Here, I have attempted to open up a space for considering other possibilities about how, and why, we become the people we are.

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Note

1. These projects were approved by the Social Sciences Institutional Review Board at the University of Chicago. All names and other identifying information about sites and participants have been changed.

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