

## The Geneticization of Autism: From New Reproductive Technologies to the Conception of Genetic Normalcy

**O**ver the past fifty years, there has been a dramatic change in the social construction of autism from a psychiatric disorder to a genetic disease (Melendro-Oliver 2004; Nadesan 2005). Both professionals and laypersons saw this new theory of the cause of autism as instrumental in discrediting the insidious mother-blaming in both popular and medical accounts of autistic disorders. By most accounts, this new scientific evidence provided a factual basis to dismiss mythologies about pathological mothers and wild children and to begin a new era in which autism would be treated as a biological disorder. The biological understanding of autism was constituted as a medical truth that could be the basis of remediation therapies and possibly a cure.

This change does not simply concern the discovery of a new truth but rather is reflective of a complex social and political transformation within the medical profession and its growing control over bodies and identities (Clarke et al. 2003; Lock and Farquhar 2007). This shift has been termed “biomedicalization,” the turn toward utilizing science for enhanced control over the body and its internal nature and expanding the reach of medical technologies in everyday life (Clarke et al. 2003). Biomedicalization has led to the production of new knowledge about health, disability, and illness that both affirms the role of scientific and technological innovation and opens up the possibility for patient-based social movements (Clarke et al. 2003). This transformation is clearly evident in the autism field. Once the purview of a few psychiatric specialists, it has now become a research domain for a wide range of behavioral specialists and biomedical scientists, and this domain is now backed by the activism of parents of autistic children.

Feminist scholars have investigated the consequences of biomedicalization and its relation to other illnesses and disabilities. This research has demonstrated the complex negotiations between citizens and the forces of technological power. These relations were first explored in studies that examined how women struggle to maintain their own interests and rec-

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oncilie their reproductive decisions in the context of genetic counseling sessions (Rapp 1999). Feminists have since described how new reproductive technologies and biotechnologies, while manifestly promoting innovation, have also transformed notions of identity and kinship, promoted global social stratification, and facilitated the development of late capitalism (Thompson 2005). Previous research has also emphasized that consumers are not passive in the face of expert knowledge but routinely incorporate technology in ways to meet their own goals (Mamo 2007). These studies have illuminated the powerful ways in which the social construction of biology and technology becomes material to negotiating the interests of citizens, scientific communities, and the state (Petryna 2004; Lock and Farquhar 2007).

The dramatic developments in the field of autism provide an important context in which to examine the interplay between technological innovators and laypersons (in this case, usually parents of children diagnosed as autistic). First, in the case of autism, its designation as a genetic disability is disputed, and these disputes continue despite contrary assertions by government and the mainstream scientific establishment. There is also a high degree of uncertainty about the biological characteristics of autism.<sup>1</sup> This has led to the growth of insurgent responses to the expanding power of new genetic technology. Second, genetic research in this area has continued to develop without resulting in direct benefits for children and families affected by autism. Coupled with the high personal and financial costs of caring for a child with autism, this has created an unusually sharp divide between advocates for genetic research and others who are focused on responding to the immediate concerns of (usually female) caretakers.

The following analysis will show how conflicting views about the biological nature of autism are directly relevant to internal controversies within scientific communities as well as to divergent strategies among activists. These divisive conflicts emerge from biological uncertainties but also reflect deeper issues about the role of biomedical knowledge in shaping our understanding of normality and the potential health consequences of environmental hazards. The genetic definition of autism largely prevails despite these controversies; this has important consequences for scientific

<sup>1</sup> There is disagreement within both expert and lay communities about a series of fundamental issues: Is autism a singular condition or the result of multiple biological causes? What is the role of genetic or environment influences? Is its incidence stable or increasing in epidemic proportions? Is the condition triggered by prenatal or postnatal factors? Is it a manifestation of a genetic trait(s), an immune system response, or an infection? Is it a lifelong condition, or is recovery possible?

research, the creation of public consciousness, and life strategies for coping with disabilities.

### **Genetics and autism**

The term “geneticization” refers to the growth of genetics as a means to account for and explain health and disease and the process by which biological conditions constitute social definitions of normality and abnormality (Lippman 1991, 18). Abby Lippman coined this term in a feminist analysis of the growing influence of genetic determinism on public policies and private practices regarding pregnancy and health care and to emphasize the gender, race, and class implications of this trend. In particular, Lippman identified the need to study how genetic interventions affect health management in a variety of economic and social contexts. Feminist scholars have been wary of the coercive and normalizing power of medical professionals, yet they have also demonstrated the complex implications of biomedical advances. As Donna Haraway has persuasively argued, it makes little sense to be “simply oppositional” in response to this new technological future because we are deeply implicated in scientific progress (Haraway 1997, 3).

The shift in the autism field was first generated by the efforts of parents with autistic children, who were responding to regressive beliefs within the medical field. The scientific and popularized explanation for autism prior to the 1980s perpetuated a theory that implied that pathological mothering was at the root of the disorder. Bruno Bettelheim (1979) is especially noted by critics for his view that childhood disturbances associated with autism did not arise spontaneously but resulted from extremely abnormal mother-child relations. Bettelheim’s understanding of the condition is drawn from the seminal work of Leo Kanner (1943), who distinguished autism from schizophrenia as an innate or inborn disturbance of affective contact but who also thought that the notable coldness and formality of the parents usually had some effect on the development of the condition. The hypothesis that autism can be attributed to a general lack of maternal warmth is called the “refrigerator mother” theory of autism, and it did not come under direct attack until Bernard Rimland criticized it in his 1964 book *Infantile Autism: The Syndrome and Its Implication for a Neural Theory of Behavior*. Both a parent of a child with autism and trained as a physician, Rimland undertook scientific work and activism that played a central role in recasting autism as a medical condition with distinct psychological symptoms that could potentially be remediated through diet and other therapies. In an era when parents of children with

disabilities were beginning to organize and seek legitimacy, parents of autistic children embraced new biological explanations.

This biological understanding of autism was first verified by studies that sought to establish its hereditary basis. Twin studies provided the earliest evidence for the genetic explanation of autism (Folstein and Rutter 1977). This research used what is known as the classical twin method—it compared the concordance rates between identical twins (MZ) and same-sex fraternal twins (DZ)—and found a strong decrease in risk from MZ to DZ twins (Cook 1998). This statistical modeling of autistic populations suggested that two or more genes were acting in concert. Twin studies have concluded that autism is highly inheritable and that relatives show increased rates of having the broader autism phenotype (Micali, Chakrabarti, and Fombonne 2004). The evolving research on autism genetics, however, has produced mixed results; some in the field claim that molecular genetic research is characterized by the striking failure to identify the genes, while others recognize success at finding the broad phenotype of autism disorders.<sup>2</sup> Researchers have concluded that the autism phenotype, like most inheritable conditions, is not attributable to a single gene and that the syndrome results from multiple genes interacting with one another. Much of this research and the scientific dialogue follow the same modality that Adam Hedgecoe (2001) has seen in the presentation of genetic research about schizophrenia. These studies suggest that the “slow [progress] . . . characterized by many false hopes and unreplicated results” of molecular genetics is merely a result of its complex nature (Hedgecoe 2001, 879). In this way, fairly unimpressive evidence is often portrayed as indicative of the complexity (and implicit value) of genetic knowledge about the causes of disease.

Regardless of the inconclusive studies, in both public and professional circles the genetic understanding of autism has taken hold. Efforts to explain genetic interactions have moved scientists toward the techniques of behavioral genetics, in particular, mouse models (Crawley 2007). Behavioral genetics attempts to make a case for the impact of genes on individual differences in development (Rowe 1993). This is extremely challenging and requires creating mouse behavioral measures relevant to the “core behavioral symptoms” associated with autism (Moy et al. 2006, 45). Recently, experts have made a notable discovery regarding an inheritable genetic trait in individuals with autism. Two studies have found a *de novo* deletion on chromosome 16 in approximately 1 percent of the

<sup>2</sup> See Shastry 2003; Happé, Ronald, and Plomin 2006; Autism Genome Project Consortium 2007; Freitag 2007.

subjects studied. In the patients studied, the parents did not have the deletion, which means that the defect originates in the individual (*de novo*) rather than being inherited (Crawley 2007; Weiss et al. 2008)

These most recent genetic findings are described as potentially useful for diagnostic screening of young children for autism.<sup>3</sup> But it remains unclear how genetic knowledge will actually prove to be useful or influence reproductive decisions. When genetic research was initiated, it was assumed to be proceeding toward inheritable genetic modification (IGM), what is commonly referred to as germ-line therapy (Chapman and Frankel 2003). This might involve actually altering the sperm or egg of potential parents to prevent the genetic abnormality in their future offspring or modifying the genetic structure of embryos. The information could also be used for genetic screening (such as encouraging carriers not to become parents) and in preimplantation genetic diagnosis (which would require sorting out affected embryos; Blaese 2003).

Despite these unresolved issues, genetic research has become institutionalized in the creation of large-scale gene banks for autism (e.g., the Autism Genetic Resource Exchange) that support collaborative research as well as in major university research institutes specializing in autism genetics.<sup>4</sup> Another indicator of autism's acceptance as a genetic disability is its inclusion in the March of Dimes's inventory of birth defects (March of Dimes 2007). This establishes autism—despite its dissimilarity in prevention, diagnosis, and treatment to other disabilities on the organization's agenda—as a legitimate concern in public health campaigns focused on promoting the birth of healthy babies.

The publication of new genetic research is treated as a prime opportunity for funding organizations to create publicity and to stress the potential value of biomedical technology. These public relations efforts are closely tied to the image of autism as a puzzle. In this iconography every new piece of genetic information is portrayed as bringing us closer to seeing the complete genetic map and is then readily characterized as a major breakthrough in the search for the causes of autism (for a discussion of iconic representations, see Nelkin and Lindee 1995). Media reports about these findings and other complex genetic disorders create the im-

<sup>3</sup> The Autism Consortium claims: "The discovery of *de novo* gene deletions and duplications has immediate clinical implications. . . . These tests can provide clinicians with important information on the risk of recurrence for subsequent pregnancies, a concern for many parents. The tests are costly and not always covered by insurance. The research teams are already looking for ways to reduce the cost by developing a simpler way of detecting the specific chromosome 16 deletion or duplication" (Autism Speaks 2008).

<sup>4</sup> See the Autism Genetic Resource Exchange Web site at <http://www.agre.org/>.

pression that a single gene has been discovered, and they often fail to explain the complex interactions among genes (Duster 2003b).

As with other diseases in an era of biomedicalization, the notion of the “genetic” has largely replaced the biological (Hughes 2000, 565). As suggested above, the shift to a biological understanding was longed for by activists and concerned parents, who were unconvinced and personally offended by the attribution of blame to the “refrigerator mother.” But, more importantly, it was hoped that a biological definition would lead to the development of treatment methodologies that had demonstrable effectiveness. This expectation has not been realized; the research has produced neither medical nor pharmacological interventions. Since mainstream scientific research has not led to the development of medical treatments, health insurance companies rarely compensate families for the expenses, time, effort, and resources devoted to caring for a child with autism, nor do children or adults with autism qualify for services on the basis of either physiological or mental illness.

While genetic research has not produced any tangible benefits, it has narrowed both professional and lay perspectives. This narrowing of vision is consequential, especially in addressing the autism epidemic, where progress on both a social and scientific level might depend on the full recognition of the multiplicity of the causes and consequences behind autism. Scientists have begun to critique the biological reductionism that has dominated the scientific understanding of autism over the past thirty years. Martha Herbert, a pediatric neurologist and brain development researcher at Massachusetts General Hospital, has persuasively argued that resistance to reductionism is the necessary response to the crisis of autism and the growing use of biotechnologies. She claims that the designation of “genetic” autism has furthered the denial of the epidemic rates of increase and the role of nongenetic factors in creating the increased prevalence. Even though there is no such thing as a “genetic epidemic . . . research continues to focus almost exclusively on studies of brains, screening and genes, as well as denying the increase or disproving the role of controversial environmental triggers, notably vaccines” (Herbert and Silverman 2003). Herbert and Chloe Silverman, her coauthor, also note that many researchers are deterred from investigating nonbiomedical causes of autism because of the small potential for profitability. As researchers further unravel the causal links between genes and genetic diseases, they are beginning to recognize the important influence of environment, metabolism, and postnatal development in the etiology of autism (Lampe and Snyder 2007). These researchers are suggesting that in the face of “environmental changes we need to consider a different role for genes than outright determination of our health”

(Herbert 2006, 20). From this perspective, the desire for genetic explanations is a roadblock to developing effective treatments for affected individuals and responses to the growing epidemic.

### **Genetic citizenship**

The concept of genetic citizenship has been introduced to describe individuals in the age of biomedicalization who engage in a new style of activism related to their inheritable identities and differential embodiment (Heath, Rapp, and Taussig 2004). This concept is most frequently applied to situations in which individuals and family members affected by a genetic disease come together and take an active role in fundraising, advocating, and influencing scientists in the hope of finding a cure. In the past decade numerous disease-specific advocacy organizations have exercised significant influence over research priorities, affected capital allocation, challenged regulatory bodies, pushed for open access to knowledge, sponsored gene banks, and demanded collaboration in the pursuit of real progress for people living with genetic diseases (Terry et al. 2007). This participation also takes advantage of new networking opportunities created by the Internet and the emergence of virtual communities. These citizens are seen as having cast off the role of passive patients to become active consumers of health services. As collectivities they have strived to maximize their influence on the development of new science, technology, and medical knowledge (Rose 2007, 23).

Autism advocacy provides an important vantage point from which to evaluate the presumed desirability of genetic citizenship because its activism is complicated by intense controversies about the significance of the genetic link and about the social identities of autistics. With the expansion of biomedical research in the field, much autism advocacy has shifted from promoting the well-being of affected families and children to searching for a cure. These new organizations, now consolidated under the banner of Autism Speaks, primarily promote biomedical research and are modeled on other fundraising campaigns that draw attention to the plight of people who suffer from rare diseases. By directly funding research centers and academic positions, these organizations attempt to compensate for what they see as the marginal interest in autism in medical science. Some social analysts have described such advocacy projects as exemplars of active citizenship—a model form of activism in which ordinary people become involved in transforming policies and social conditions that have a direct impact on their well-being and health (Petersen and Bunton 2002, 185).

In their publicity, these programs often depict the birth of an autistic

child as a tragedy and frequently characterize autism as a mysterious condition. Autistic persons identifying with the neurodiversity movement have vehemently criticized these characterizations as well as suggestions that genetic research will lead to a cure (Bumiller 2008). Its members have staged a largely underground campaign against the rhetoric of Autism Speaks and raise fears about its eugenic implications. In particular, they object to the impending use of reverse functional genomics to determine the genes responsible for underlying brain malfunctions, knowledge of which could then be used to generate models for the restoration of normal brain functioning (essentially IGM therapies). If applied, they claim, it would likely delete a broad range of the characteristics of autistic persons (since there is no single autism gene), and such procedures would cross a fine line between medical treatment and body enhancement (Elliott 2004). More generally, the neurodiversity contingent is committed to affirming quirkiness and countering what its members see as neurotypical people's obsession with normality. From the perspective of the neurodiversity movement, mainstream autism activism is counterproductive to the cultural acceptance of autism. Both sides engaged in this controversy, however, subscribe to a genetic understanding of autism and downplay the possibility of other complex factors in the etiology of the disorder. While the major advocacy organizations are fully aligned with the medical establishment and the biomedical industry in supporting research to find a cure, the neurodiversity movement is resistant to medicalization in all of its aspects and asserts that autism is a desirable genetic variation.

Prior studies of genetic citizenship have raised concerns about how the victories of new genetic movements may reflect a questionable convergence of individual interests and market forces and have noted how research priorities are driven by profit motives (Duster 2003a). Similar issues arise in the context of autism; much of this research is conducted in collaboration with high-profile genetic laboratories and large biotech corporations such as deCODE Genetics. This research is given priority despite uncertainty about whether and how genetic information will eventually be useful for pre- or postnatal genetic screening, diagnosis, or treatment methodologies. Both the irresolution about the potential benefits of genetic research and the oversimplification of its significance in the media diminish the power of consumers and the general public to either shift priorities or call for more transparency on the part of medical professionals. Moreover, the current focus on instrumental (and uncertain) goals rather than more broadly framed issues of social justice and welfare limits the role of disease-specific advocacy organizations in setting priorities (Stockdale 1999). Specifically in the case of autism awareness, it has been shown



that since public discourse has focused on the medical paradigm—particularly on efforts to find a cure—there has been less focus on the rights and social welfare dimensions of the issue (Baker 2007).

In their efforts to create excitement about new findings and to encourage funding, advocacy organizations make a great effort to project a connection between biomedical research and benefits to families. As Dr. James Gusella, senior science advisor for the Autism Consortium, explained: “The power of the Autism Consortium is our ability to get rapid results by cutting across institutions and connecting families and clinicians with basic researchers. In this case, we were able to immediately verify the clinical importance of a basic research finding, and rapidly use that information to immediately help families” (Autism Speaks 2008). In this way, genetic research is depicted as contributing to and building on the collaborative efforts of researchers, physicians, and patients. These assertions may also be a reflection of considerable anxiety among professionals about how to make genetic knowledge meaningful and material within clinical settings (Gibbon 2006).

This ideal of collaboration increases expectations on families to participate in autism research. Advocacy networks also serve as recruitment vehicles for research subjects, who participate through providing information about family history and supplying genetic information, or sometimes through more intrusive means. This is part of what Troy Duster (2003a) sees as a powerful and subterranean effort to increase pressure on every citizen to contribute to DNA banks. The generalized expectation for self-advocacy is projected as synonymous with a responsibility to contribute genetic information and thus be part of the effort to prevent or cure disease. This is one way in which consumers of genetic services see themselves as being active participants in promoting their own health (Gibbon 2006).

This new standard for participation has broader implications for how citizens are seen as actors in promoting better public health. Public health officials have already established genetic literacy as a twenty-first-century goal. Promoting general knowledge about genetic technology (like prenatal and postnatal screening) is now part of preventative health practice (Catz et al. 2005). From the perspective of health professionals conducting surveys of public attitudes, when individuals show skepticism about new reproductive technologies, it is seen as a symptom of misinformation and resistance to medical care. In terms similar to those used in implementing vaccination strategies, the refusal to make use of genetic technology is treated by public health officials as a compliance problem. Public health workers have begun to identify demographic groups (in terms of race,

ethnicity, and class) that have poor genetic literacy and are therefore likely to resist preventative health measures.

It is likely that patients who already have access to high-quality medical care and research hospitals are more apt to participate in and benefit from the advances in biomedical research and to fulfill these new expectations as citizens. As feminist research of new reproductive technologies has documented, there is dramatic inequality in access to assisted technologies for procreation (Woliver 2002). However, all forms of new genetic technology will not necessarily have a regressive economic impact, which has been the case for reproductive enhancement. Some forms of technology and medicine might be easier to equitably distribute than other goods and services (Rose 2007, 104; see also Farmer 2003), but cost-effective access to new biomedicines may only come about with strict regulation of the industry.

Another factor that could produce inequalities in access and opportunities is the lack of a uniform or widely shared genetic consciousness across class divisions (Kalfoglou et al. 2005). Surveys give us the little evidence we have about how people ascribe value to genetic knowledge. Surveys of scientists working in the field show that most presume the desirability of new technologies but find that this is largely due either to lack of reflection or to overconfidence that difficult questions will be resolved by bioethicists. While surveys of the general population have found that most people have a positive view of genetic advances in the abstract, ethnographic studies of women's experiences with genetic counseling find a more mixed reaction (Beeson and Doksum 2001). Those who experience the impact of new genetic technologies more directly may respond to it in different ways than passive consumers of this new knowledge do. And, critically, people's experience with other forms of control exercised on the individual and social body, especially racism and sexism, may affect how they assimilate their genetic citizenship with other social roles.

The most divisive expression of dissent to geneticization is found among groups that seek to document environmental causes of autism, such as the use of mercury in vaccines. These outsiders, dubbed the "Mercury Moms," are engaged in insurgent activism against the medical establishment and most directly the Centers for Disease Control and Prevention (CDC). They claim that the CDC has perpetuated a cover-up of medical evidence confirming the link between thimerosal (a mercury preservative previously used in many childhood vaccines) and the increase in autism. In stark contrast to professionals, parents, and activists who sub-

scribe to a genetic understanding of autism, the Mercury Moms are frequently characterized as hysterical and antiscience (Kennedy 2007; Desmond 2008). As Ken Plummer (2001) has suggested in his account of what he calls “intimate citizenship,” this kind of very public debate over controversial issues demonstrates that there is something much grander at stake than the validity of scientific research. For the Mercury Moms, their activities fulfill their role as protectors and provide assurance that they have pursued all avenues to help their children. As activists, the Mercury Moms are often marginalized by the media, national autism advocacy groups, and the professional establishment, not only because they dispute official information but also because they amplify the fears of all parents about the possibility of seemingly benign choices, such as complying with childhood vaccination recommendations. Their advocacy is even seen as dangerous because it could lead to widespread rejection of vaccinations that prevent the resurgence of deadly diseases. In part, the marginalization of the Mercury Moms results from their own tendency toward absolutism, but at the same time there is little mainstream recognition of scientific evidence that supports the possibility of links between exposures to toxins and autism (DeSoto and Hitlan 2007).

### **Backdoor eugenics**

The notion of genetic citizenship is based on the belief that in a biomedical age all citizens are given the possibility and have the responsibility to participate in the creation of healthier societies. Disability activists have been vocal in their efforts to reveal the reemergence of eugenic tendencies under conditions of biomedicalization. The eugenic impact of new biomedical advances, termed a “backdoor to eugenics” (Duster 2003a), cannot be easily dismissed, especially when considering the implications of a genetic understanding of disease based on race and disability (Ellison and Jones 2002; Hauskeller 2004; Hacking 2006). The relevance of an identifiable social group in medical research creates the potential for that group to be devalued and perceived as a threat to the well-being of the social order. Dorothy Roberts, in another article in this issue, demonstrates this potential in terms of racial categories (Roberts 2009; see also Roberts 2005). Disability activists have also identified the specious quality of new reproductive technologies; that is, the preselection or the rejection of embryos as disabled presumes that genetic criteria can measure what constitutes a better, or simply more valuable, human being. This geneticism can always be potentially mobilized by ideological programs, whether

instituted by the state or originating from civil society (Savulescu 2005), that see the eradication of some group as essential to a “stronger or better reality” (Arendt 1951, 61).

For disability advocates the issue is often framed in the starkest of terms—that new reproductive technologies are used to prevent people like themselves from being born (Shakespeare 1999). This constitutes, according to the most vehement critics, a justification for genocidal policies directed at eliminating people viewed as low functioning, resource draining, and incapable of enjoying a “normal” life. One of the strongest assertions of this position has been made by activists working for human rights policies that ascribe selection according to impairment the same ethical status as selection according to sex (Wolbring 2005). This analogy is not just theoretical in relation to autism. Since the incidence of autism is highly correlated to gender (possibly as much as a 10:1 male-to-female ratio), either simple sex selection or sex selection in combination with other genetic traits presents itself as a possibility. From a feminist perspective, the prospect of any form of gender-based selection is problematic and potentially reinforces stereotypes about the desirability of gender-based characteristics.

Even if a variant of sex selection never materializes, disability activists have illuminated the implications of wide-scale genetic screening for the devaluing of disabled lives, particularly as the lines between state policy and individual choice are becoming increasingly blurred. Despite the well-established obligation of physicians and genetic counselors to provide nondirective advice, studies have found that patients were given information that imposes professionals’ views about the usefulness of genetic knowledge and the parental responsibility to promote fetal health (Rapp 1999). This research has shown that professionals effectively delivered the message that the only rational choice is to give birth to a “normal” child. Genetic testing is now understood as a necessary component of preventative public health programs, largely as a result of the trend toward universalized testing and mandatory screening of newborns (van den Daele 2006). This shift has transformed prenatal testing from an option individual women are given to lower their risk of having a child with a genetic defect to a system of reducing overall health problems in the population (Ward 2002). This has occurred because prenatal tests have become legitimized as a routine part of prenatal care and through their “favorable preconception” as a form of medical screening (Vassy 2006, 2047). In this way, these initiatives are easily justified as being in the best interest of pregnant women or as preventing mothers from causing fetal harm (Morgan and Michaels 1999). At the same time, clinicians have increased

the number of conditions tested for and have designated a broader scope of at-risk populations (Shuster 2007); for example, cystic fibrosis testing, which was offered only to affected families, has recently been recommended for the wider population.

Biomedical knowledge not only influences decisions about the fate of a woman's pregnancy but also affects how her children are regarded after birth—that is, whether they are seen as “normal” or “disabled” (Landsman 2005). This may make it less likely for pregnant women and mothers of newborns to even perceive genetic testing as a decision. Rather, it has become the beginning point of a continuous flow of decisions that parents make to safeguard the health of their children, each of which functions as a checkpoint to determine if children are out of the normal range. As long as the tests do not indicate that the fetus or newborn is impaired, the parent can assume that their child is “normal.” Shelly Tremain (2006) has argued that testing and screening technologies contribute to the “naturalization and materialization of impairment” (36). She sees this implicit consent as a process of enlisting pregnant women “to facilitate the normalization of the fetal body” (Tremain 2006, 37). In other words, these tests are used to select out fetuses based on “impairments” or conditions that have been defined as disabilities (Lawson 2006). Impairments are socially defined as deficits relative to typically functioning human beings. This means that women accept their fetuses as normal or impaired not only according to information about genetic attributes but also according to whether these genetic markers are seen as precursors of disablement. For example, if the genetic analysis shows that the child is likely to have Down syndrome or an intersexed condition, these fetuses are socially constructed in utero as impaired (Hamamy and Dahoun 2004). This prospect is particularly troubling in the context of autism, where there is a great deal of speculation about the timing of what some scientists call the autistic insult (the event that may trigger autism)—whether it occurs in utero or after birth. It is therefore possible that a genetic makeup that leads to the birth of a “normal” child who is particularly susceptible to environmental insults would be defined as defective, thus blurring the distinction between the genetic origins of disability and environmental causalities.

In the context of new reproductive choices, disability rights activists cite the dangers of a utilitarian calculus in which disabled people are considered more costly and less productive. By this logic, it is assumed that as people exercise more control over the genetic makeup of their children they will be more likely to choose fetuses that portend greater economic and social value. Disability rights advocates with autism fre-

quently make this point—if parents have a choice between giving birth to a normal child and an autistic child who may suffer stigma for being different, then, under current social conditions, there is essentially no choice at all. It also follows that systematic efforts to stop disabled people from being born may influence the treatment and support of the disabled who are already born and are members of our society (for a contrary position, see Raz 2004). Disability activists have drawn needed attention to what is at stake—how the universalizing of genetic screening is instrumental in narrowing our conception of normal personhood as well as in potentially furthering the economic, social, and political marginalization of people with disabilities (Munger et al. 2007).

### **Life optimization**

The research on prenatal counseling has also shown that professionals often frame genetic testing as necessary for socially responsible parenting. One study found that counselors presented prenatal testing as something women need in order to become good parents (Lippman 1991). In this sense, good parenting is about having the knowledge and resources provided by this testing and then following through in a socially responsible fashion. As genetic testing is fully incorporated as a standard of care for pregnant women, the act of refusal is no longer about the assumption of individual risk. Now, the noncompliant woman has failed to take advantage of an important opportunity to maximize the life chances of her child. Such actions are likely to be seen as contrary to good citizenship in the age of biopolitics, where the technologies of biomedicine have created a context in which “biology is not destiny, but opportunity” (Rose 2007, 51) and the desired course of action is to follow a strategy of life “optimization” (6). This strategy, according to Nikolas Rose, is “not eugenics but is shaped by forms of self-government imposed by the obligation of choice, the desire for self-fulfillment, and the wish of parents for the best lives for their children.” He goes on to say that “its logics and its costs deserve analysis on their own terms” (69).

To see this as part of a new regime of choice is to fail to recognize the unintended consequences of life optimization in regard to the regulation of normalcy. A recent ethnographic study on the influence of new genetic knowledge on Belgian insurance companies aptly illustrates this dynamic at work. Ine Van Hoyweghen, Klasien Horstman, and Rita Schepers (2006) investigated how insurers take account of predictive medicine in the process of determining premiums. They describe the companies’ decision making as a process of “making the normal deviant” because when

insurers make judgments “the margin of being normal is actually quite small and the scope for deviation is quite wide” (Van Hoyweghen, Horstman, and Schepers 2006, 1229). They find that when insurers rate people with genetic predispositions they put extra emphasis on how they have managed their health. This reinforces the idea that managing one’s health is an important way in which people can become good citizens. In Belgium it is illegal for insurers to discriminate on the basis of disability, so insurers do not simply increase premiums for individuals with increased genetic risk (as surmised from family history). Rather, the insurers tend to characterize people as risk takers. The actions of these insurers show how in “light of genetic risks, the emphasis on lifestyle and individual responsibility might be extra stressed” (Van Hoyweghen, Horstman, and Schepers 2006, 1233). In this way, insurers impose a greater responsibility for optimally managing one’s health on people with known risk factors. The authors’ conclusions have serious implications for the social costs of life optimization: “Instead of a ‘genetic determinism’, it seems more plausible that we are all subject to different levels of susceptibility. . . . As a consequence, . . . the individual’s lifestyle habits, preventive initiatives and compliant behavior in relation to these susceptibilities could be stressed more” (Van Hoyweghen, Horstman, and Schepers 2006, 1233). The actuarial process imposes a norm that defines suitable lifestyles for people with risky genes. This creates an incentive system for genetic “deviants” to conform to normal expectations of proper lifestyles in order to satisfy social expectations.

With the continued intensification of biomedicalization, these incentives are likely to have a strong impact on disabled people and their care-takers. In a society with a strong ethic of individual self-care, it might be presumed that the lives of the disabled are optimized through a process of accepting genetic markers of deviancy while also functioning as effectively as they can in society, especially in ways that make them appear normal. In this scheme, citizens who see their fate genetically, or have high genetic literacy, benefit when they both accept their deviance and exercise maximum self-control to curb undesirable or dysfunctional attributes linked to their disability. Knowing one’s genetic susceptibilities and being able to document them may in fact become ever more essential to utilizing health resources.

It is also important to consider that life-optimization strategies often rely on women, as mothers, teachers, and professionals in the field, to assure the assimilation of disabled children into society (Saukko 2004). In the context of neoliberal social policy and the retrenchment of the welfare state, families that cannot rely on women’s usually unpaid labor

or that experience other forms of disadvantage encounter harrowing obstacles to creating an ordered life (Baker 2004). The eligibility requirements for social services often discourage eligible people from pursuing claims and shift the burden onto unpaid caretakers. For example, eligibility for Medicare home health services is based on functional incapacities rather than diagnostic categories. As a result, a disabled child is not eligible for services if she or he has high needs but is coping effectively or has care requirements similar to other children of the same age. This reinforces the norm that even extraordinary care should be delivered by mothers rather than by paid workers.

Within social welfare bureaucracies, there is systematic neglect in meeting children's needs, despite the advent of inclusion policies that have promoted the ideal of family empowerment as the best means to support the interests of the child (Feinberg and Vacca 2000). In the United States, there are no government provisions for direct resource allocation of funds to support either children or adults with autism. Families receive benefits through a variety of indirect channels, such as specifications in individual education plans for home-based training or after-school programs and direct services from family support agencies, which may include small stipends for respite. Eligibility for these resources is often restricted, and even when children are eligible, most school districts fail to provide services despite their clear mandate to do so in special education law. Even when provided, family-support monies are delivered through complex state bureaucracies that vary by state due to eligibility requirements and organization structure. Consequently, the most disconcerting implication of an ethos of life optimization is that it creates the presumption that the needs of the disabled can be satisfied in the private sphere, while in reality most people with disabilities like autism require and are unsuccessful at receiving public support.

The concurrent forces of life optimization under conditions of biomedicalization and demands for personal responsibility in a neoliberal welfare regime make the determination of a disabled person's worthiness central to the process of gaining public health resources. The rights afforded to people with disabilities are more available for those who are good genetic citizens and can demonstrate their strict compliance with social norms. For example, special education provisions rely on eligibility and service determinations that are individualized and ad hoc rather than derived straightforwardly from medical diagnosis. As a consequence, parents with poor genetic literacy often have trouble convincing schools that their children's behavior is the result of a biological condition rather than their bad choices as parents. In social security disability determinations,



each case is processed according to subjective criteria used to measure a person's ability to work. Studies show that success in claiming disability depends on a person's ability and willingness to persevere through the application process (Bilder and Mechanic 2003). Since most claims are routinely denied and these denials lead to a lengthy appeals process, only those who are unusually skilled at conveying medical knowledge, or at enlisting the assistance of medical professionals, are likely to have their applications eventually approved.

These systematic processes have the effect of distinguishing between disabled people who are at low risk and those who are at high risk for becoming dependent on the state. Social policies that rely on dividing people up according to risk groups also cut against the organic sense of solidarity that develops among people with disabilities (or among their advocates and caretakers). These systems of classification rely on distinctions that are often contrary to a dynamic and inclusive sense of citizenship among people with disabilities. The overall effect of a person's genetic status interacting with other forms of inequality is to create conditions of "cumulative social and economic disadvantage" and consequently to reduce opportunities to participate in civic life (Kelly 2002, 181).

For people of privilege who become disabled or for caretakers of the disabled, however, certain forms of life optimization may be easily incorporated into their lifestyles. For example, currently available therapies for autism require parents to "retrain" their children, usually through rigorous at-home and in-school programming. Such strategies, which demand the hypercontrol of children and involve participation in costly programs, are not very different from strategies that middle- and upper-class parents employ to enhance the performance of "normal" children (Sandel 2004). Also, the desire to project one's aspirations beyond the future of one's own child and into efforts to find a cure might be seen as a variant of other complex optimization strategies pursued by wealthier families.

### **Conclusion**

Although the initial promise that we would find genes to diagnose, treat, and cure neurobehavioral disorders like autism has not been realized, there has been little professional and public acknowledgement that these disorders are far more complicated than originally conceived by molecular geneticists. This would require a fundamental change in the narratives about genetic identity that have been commonplace in prenatal counseling and in the treatment of such disorders as well as in public recognition of the limitations of a genetic ontology for illness and disability. A shift toward

a much broader understanding of human vulnerability would include seeing how current genetics models obscure the role of the environment—of women's bodies, communities, chemicals, and other organic and inorganic influences (Casper 2003).

Nevertheless, geneticization continues to play a starring role in a master narrative about the causes of and potential responses to the growing incidence of autism. Its cultural power as a narrative may be in large part due to its ability to reserve the possibility that biotechnological innovation has the power to regenerate healthy children (Franklin 2005), an idea that is all the more powerful precisely because many suspect that unknown and difficult to control environmental conditions may lie at the root of its growing incidence rate. Indeed, geneticization is a significant factor in the diffusion of attention from a public health crisis, what many have termed the epidemic of autism. The predominance of a genetic explanation for the disorder has made it hard for activists to raise awareness about possible environmental causes and identify the factors contributing to increasing incidence. Also, the focus on organizing to promote autism-specific biomedical research discourages potential connections among groups concerned about the rising prevalence of other childhood diseases and disabilities with suspected environmental links (Van den Hazel et al. 2006). Most importantly, the presumption of inheritability has a profound impact on how affected families perceive public responsibility in the face of their own and public institutions' (e.g., schools and social services agencies) inability to cope with all the immediate challenges presented by caring for the growing number of autistic children.

A powerful force in the development of autism as a social problem has been the unfortunate history of mother-blaming. This has caused greater acceptance of medical expertise that dismisses psychogenetic causation and has given particular significance to establishing good collaborations between parents and professionals. This does not mean, however, that mothers are attributed less responsibility. Under the new conditions of biopolitics, and particularly in the context of theories of behavioral genetics, caretakers assume the role of assuring the best possible outcome for children given their genetic defects. High expectations are placed on parents to achieve genetic literacy so as to be able to evaluate the best treatment methodologies, educate teachers and other professionals who work with their children, and make good decisions about bearing additional children. Parents are expected to assume these responsibilities despite the high degree of uncertainty about strong genetic causes.

Moreover, genetic citizenship, as it is exercised in the everyday context of child rearing, is likely to reinforce preexisting inequalities. Parents with

more social and economic advantages are able to embrace life-optimization strategies, while less well-off caretakers may not have access to the needed information or project the credibility necessary to advocate effectively. Most recently, the capacity to use the most up-to-date medical understanding of autism is becoming necessary in order to know about and prove eligibility for social services. In this way, geneticization raises the standards for good parenting and places high expectations on parents' ability to utilize medical knowledge. Geneticization has been highly compatible with the retrenchment of government benefits associated with neoliberalism, and the experience of genetic citizenship serves to reinforce the perception that government response is contingent on the exercise of personal responsibility.

For those who become politically active according to the ideal of genetic citizenship, there emerges a complex relationship between advocates for children and the biomedical establishment. In many ways, this elite activism is a reinvention of consumer power, something that is not new to disability activism. After the deinstitutionalization of people with mental illness and disabilities in the 1970s, consumerism emerged as part of the effort for community empowerment. As new programs of community-based care were developed, advocates pushed for patients to be recognized as consumers. In some cases this was a semantic change that merely recognized the partnership between the state and the market, but there are also examples of activist organizations that took advantage of their role as consumer-citizens to advocate for rights, better services, and changes in social attitudes. The potential of citizens as consumers has remained limited as organizations that serve people with disabilities are increasingly subjected to market constraints. Creating competition and incentives to improve the quality of service to disabled populations matters little when these services fail to thrive in a market where service workers are in low supply and inadequately paid.

In the face of this demise of consumer power, the most visible advocates for autism are national organizations mobilizing for a cure. As this article has shown, these organizations closely fit the ideal of genetic citizenship, especially in their efforts to give greater priority to autism research within the medical establishment. There have been unforeseen symbolic consequences from such organized efforts as people with autism reject how they have been characterized by mainstream fund-raising efforts and see themselves as reacting against eugenic impulses. This conflict may deepen, however, especially if an exaggerated notion of genetic determinism draws resources away from more vital concerns about the social and economic welfare of people with autism. The marginalization of the Mercury Moms,

moreover, is indicative of the power differential between consumers and government (and its partners in the pharmaceutical industry), especially when activists threaten what is seen as a vital public health program.

The geneticization of autism provides an illustration of what Lippman describes as the funneling of social concerns into a genetic prism, one that “poses genetics as the source of illumination itself, not merely one of the ways in which it might be refracted” (Lippman 1991, 19). This narrowing of vision is detrimental, especially in addressing the autism epidemic, where it is clear that progress on both a social and scientific level is furthered by the full recognition of the multiplicity of its causes and consequences (see e.g., Roberts et al. 2007). Moreover, the belief that we have more control over our genetic fate than over our social and environmental world may only place a greater burden on people with disabilities and their caretakers (Kerr 2003). The expectation of life optimization imposes new responsibilities in the private sphere and increases expectations for the production of “normal” children, which swings the agenda away from social and environmental issues and ultimately produces an increased reliance on women’s labor and care work.

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