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ARTICLES

Deconstructing Disability and Neurodiversity: Controversial Issues for Autism and Implications for Social Work

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Disability is a socially constructed concept that can be viewed from either a medical or a social perspective. Autism, a developmental disability, can be viewed from the medical model of disability or through a new perspective brought forth by the autistic community and aligning with the social model termed neurodiversity. Using the medical model and a lens of neurodiversity, we can deconstruct the controversial issues surrounding autism and provide insights for social workers and other professionals working with the community of the disabled.

KEYWORDS autism, disability, medical model of disability, neurodiversity, social model of disability

Disability has an indeterminate meaning in United States culture. It can range from deficits associated with aging to injuries sustained in combat to impairments present from birth. The label of disability can invoke pity or sympathy or entitle persons carrying the label to professional services or governmental benefits. A label of disability can be used to desexualize an individual, depoliticize an individual problem, devocalize disability issues, or simply dehumanize the disability experience. In a growing number of instances, the label of disability can empower the individuals who wield it. Characterizing disability is a steady matter of social debate and social construction as human beings constantly seek to define what is "normal" and

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what is "disabled," with a new emphasis on disability as a form of diversity. In addition to cultural meanings and constructions, policies and practices remain in place to subjugate and marginalize disabled people, despite the passage of the Americans with Disabilities Act (ADA, 1990). The ADA simultaneously invited disabled people's voices into U.S. policy and strengthened them with political participation.

History plays an incalculable role in the establishment of political policies and culture. Paul Longmore (1985) writes that "the history of disabled people as a distinct minority remains largely unwritten and unknown" (p. 586). Indeed, the history of disability has been largely excluded from mainstream understandings of American history and cultural experience. Longmore points out that disability is absent in American written history but exists in every time frame and movement once one is looking for it. He uses the example of American immigration policy history to illuminate the exclusion experienced by disabled persons. Immigrants were initially turned away based on ethnic status, but this policy eventually resulted in immigration officials' turning away immigrants with every sort of disability, associating certain ethnicities as inherently disabled. What do such policies reveal about cultural values regarding disability status (Longmore & Umansky, 2001)? The medical perspective that historians commonly assert to examine the experience of the disabled often views disability in terms of individual case histories (usually pertaining to disease) as opposed to a matter of social, cultural, or political substance. A more in-depth look at history calls us to examine the very commonplace nature of disability in American lives, an experience that is variable and changing—disability as a personal and a public experience and disability as a social problem.

CONTRASTING DISABILITY AND IMPAIRMENT

The World Health Organization (WHO, 2011) defines *impairment* as "any loss or abnormality of psychological, physiological, or anatomical structure or function" (p. 305). *Disability* is defined by the WHO (2011) as "any restriction or lack (resulting from impairment) of ability to perform an activity in the manner within the range considered normal for a human being" (p. 303). These distinctions are necessary when examining the fundamental differences between impairment and disability and their construction within social and political contexts. The most important difference between impairment and disability becomes crucial when thinking in terms of how the label of disability can be applied. Impairment, as defined by the WHO, is simply the body's inability to function in a certain way. It does not imply interpreting impairment as a personal tragedy that can create a fear of impairment and a reliance on medical intervention. Such an interpretation can contribute to the fearful attitudes and oppressive actions that disable individuals (Crow, 1996).

Framing impairment as a personal tragedy is merely a social construction. Crow (1996) advocates for an acknowledgment of the relevance of impairment in constructing disability. She identifies three ways to think about impairment: first, the objective concept of impairment as defined by the Union of the Physically Impaired Against Segregation (UPIAS) in 1976. It defines impairment as "lacking all or part of a limb, or having a defective limb, organism or mechanism of the body" (UPIAS, 1976, p. 14); second, an individual's interpretation of the subjective experience of impairment, with which an individual combines his or her own meanings and personal circumstances and the definition of impairment; and third, the impact of the wider social context on impairment "in which misrepresentation, social exclusion, and discrimination combine to disable people with impairments" (UPIAS, 1976, p. 15). Crow (1996) elaborates on four responses to impairment:

> Avoidance/Escape: through abortion, sterilization, withholding treatment from disabled babies, infanticide and euthanasia (medically assisted suicide) or suicide;
>
> Management: in which any difficult effects of impairment are minimized and incorporated into our individual lives without any significant change in the impairment;
>
> Cure: through medical intervention; and
>
> Prevention: including vaccination, health education, and improved social conditions. (p. 61)

CONTRASTING THE MEDICAL MODEL AND SOCIAL MODEL OF DISABILITY

The history of disability in America has been characterized by the progressive development of several models for interpreting disability. The medical model and the social model of disability both provide conceptual frameworks from which we can examine and deconstruct disability and the experience of the disabled. The medical model of disability focuses on disability as an "individual problem tied to the functional limitations of the bodies of people with impairments" (Swain, French, & Cameron, 2003, p. 22). "Within the medical model, the surrounding environment and culture within which impaired individuals are situated is regarded as unproblematic" (p. 23). It reflects the American cultural assumptions of individuality, personal autonomy, and self-determination (Keith, 1994). The medical model relies heavily on diagnosis and treatment using scientifically validated manuals and protocols (e.g., Diagnostic and Statistical Manual of Mental Disorders). Clapton

and Fitzgerald (2004) provide an interesting view of disability from a historical standpoint wherein the doctor and scientist have gradually replaced the priest or religious leader as experts on societal values and processes of healing and have shaped and defined the disability experience within the medial model. Within the modern era, we began to see certain groups of people defined as deviant and incapable on the basis of bodily or cognitive impairments. Based on the constructs of social Darwinism and the evolution of science and the medical model, institutions were established to control and segregate the disabled from society. This was the beginning of the depoliticization and professionalization of disability and the care for the disabled. Although, in more recent years, disability focus has shifted from institutions to a more community-based focus, the medical perspective remains inherently linked to the economy, where personal disability is assessed as incapacity which, in turn, determines a person's eligibility for public assistance. The implication is that disabled people cannot be productive and are thus socially controlled and regulated alongside other oppressed groups (Clapton & Fitzgerald, 2004).

The social model of disability defines impairment in the identical way it is defined by the medical model—as a physical characteristic, except that the social model of disability reconstructs disability as a social and political process. The social model suggests that it is society that disables the individual. One suggested manner of reinforcing disability as a societally induced and socially constructed concept is through using the term *disabled person* as opposed to the term *person with a disability*. Although the American Psychological Association and the National Association of Social Workers (NASW) both promote the use of "person-first" language, this language does not reflect the terms used by disability advocates and it de-emphasizes the role of society in *dis*abling individuals (American Psychological Association, 2010; NASW, 1999). The term *social model of disability* was first coined in the literature by Oliver (1986) as he interpreted the *Fundamental Principles of Disability* written by UPIAS in 1976. But even prior to this interpretation, other groups inferred the sociopolitical nature of disability and the relationship between impairment and disability. The British Council of Disabled People (1981) felt that impairment existed in the real physical world, and disability was a social construct that existed in a realm beyond language within a complex organization of shared meanings, discourses, and limitations imposed by the environment at a particular time and place. Although WHO made clear distinctions between the terms *disability* and *impairment*, they fell short when they claimed, "Disadvantage accrues as a result of [the individual] being unable to conform to the norms of his universe" (WHO, 1980, p. 29). The social model focuses on functioning as an interaction between a person and their environment, emphasizing the role of society in labeling, causing, and/or maintaining disability within that society.

This model often situates itself within a rights-based perspective. Swain, French, and Cameron (2003) maintain that the most central point of the social model of disability is its provision for a critique of the medical model and its ability to give a voice to disabled people so they can argue against social exclusion and oppression. The significant results seen by movements such as the civil rights movement, the gay rights movement, and other minority movements have bolstered confidence in the social model of disability and its ability to allow for a voice for social change. Beginning in the mid-1960s, inspired by the civil rights movement, the disability rights movement became a force. During this time frame, disability came to be understood as a fusion of personal characteristics and social and political infrastructures designed to exclude those who deviated from the norm (Herzog, 2004). Prior to the 1960s, disability was cause for pity, and professional and political solutions often surrounded acts of public charity or medical care (McCarthy, 2003). Preceding the ADA of 1990, the Rehabilitation Act was the most significant piece of legislation for securing rights for the disabled. Its enactment came about after a 1977 sit-in organized by the American Coalition of Citizens with Disabilities. A historical examination through the lens of the social model of disability uncovers key movements in the history of disability as well as the key roles that disabled individuals have played in constructing American history. Longmore and Umansky (2001) argue that "like gender, like race, disability must become a standard analytical tool in the historian's chest" (p. 15).

SCIENTIFIC AND MEDICAL CONSTRUCTIONS OF AUTISM

Autism has become a considerable player in the fixture of disability. Recent reports from the Centers for Disease Control and Prevention (CDC) estimate autism prevalence rates at 1 in 88 children (CDC, 2012), with males four times more likely to be diagnosed than females (Fombonne, 2005). There is some speculation that because of a widened diagnostic continuum, broader diagnostic criteria, and more sensitive diagnostic tools, we are seeing inflated prevalence rates of autism. Although both Kanner (1943) and Asperger (Frith, 1991) first conceptualized the term *autism* in the early 1940s, an autism diagnosis did not appear in the *Diagnostic and Statistical Manual of Mental Disorders (DSM)* until 1980 in its third edition, when it was classified as a Pervasive Developmental Disorder (PDD; American Psychiatric Association, 1980). Prior to this, in the *DSM-II,* several criteria for childhood schizophrenia including "autistic, atypical and withdrawn behavior" perhaps best characterized autistic symptomology (American Psychiatric Association, 1968, p. 35). Conceptualizing autism as a continuum of disorders or autism spectrum disorders (ASDs) did not occur in the *DSM* until 1987. In the *DSM-III-TR,* Asperger syndrome was identified as a separate autism diagnosis. Pervasive developmental disorder not otherwise specified (PDD-NOS) was

also identified as a category for "atypical" autism. Currently, as defined in the *DSM-IV-TR*, autism remains listed under the category of PDDs. The term *autism* is now frequently meant to refer to a continuum of disorders (ASDs), including Rett syndrome, childhood disintegrative disorder, autistic disorder, pervasive developmental disorder not otherwise specified, and Asperger syndrome, all of which meet three diagnostic criteria: social interaction impairment, language/communication impairment, and restricted or repetitive range of interests and activities (American Psychiatric Association, 2000).

Autism would be most accurately described as a syndrome with multiple genetic and nongenetic causes (Malone, 2012). Although researchers are confident that genetics play a significant role in an autism diagnosis, the diagnosis remains behavior based, meaning that clinicians use the *DSM* to diagnose ASDs on the basis of behavior-based criteria versus biology-based medical testing. The only ASD that can be diagnosed based on biological factors is Rett syndrome, for which researchers have identified mutations of the methyl-CpG-binding protein 2 (MeCp2) gene in most diagnosed cases (Muhle, Tretacoste, & Rapin, 2004).

Genetics has been implicated in the diagnosis of ASDs through several research studies; however, there is no clear explanation for the higher prevalence rates in males versus females because male-to-male transmission in a large portion of families rules out X-chromosome linkage. Twin studies have reported 60% concordance for monozygotic (MZ) twins with a much lower concordance for dizygotic (DZ) twins, with the higher concordance for MZ twins, suggesting genetic inheritance as the predominate causative agent (Hallmayer et al., 2011). Recent research studying twin pairs and autism concordance found 88% concordance for MZ twins and 31% concordance for DZ twins. Also, the overall higher functioning, psychiatric comorbidity, and Asperger syndrome concordance among MZ twins suggests differential heritability for different ASDs (Rosenberg et al., 2009).

Oberman et al. (2005) found a group of neurons in human and ape brains that are termed *mirror neurons* and have been implicated in the cause of ASDs. Mirror neurons play a role in the human ability to learn from modeled behavior and, in turn, allow for predictions to be made based on the intentions, actions, and emotions of others, which are key deficits in autism. Data from whole-genome screens suggest interactions of at least ten genes in the causation of autism (Muhle, Tretacoste, & Rapin, 2004); however, significant evidence points to interactions among multiple genes with a combined exposure to environmental modifiers as the key to unlocking the mystery behind the causes of ASDs (Hallmayer et al., 2011; Malone, 2012; Pickles et al., 1995; Risch et al., 1999).

Several researchers and autism advocacy groups have implicated potential environmental toxins in the etiology of ASDs. As early as 1967, psychodynamic theory posited the idea of the "refrigerator mother" as a causative factor in a child's autism diagnosis (Bettelheim, 1967). The

refrigerator mother was a cold and insensitive mother who could not demonstrate love and attention to her child and therefore reared a distant and removed autistic child. As a result, many mothers of autistic children suffered from blame, guilt, and self-doubt. This theory has since been disproven; however, the concept that autism is caused by some outside environmental factor is still being debated.

The most recent environmental toxin implicated in an autism diagnosis is the measles, mumps, and rubella (MMR) vaccination (Furlano et al., 2001; Wakefield et al., 1998). Wakefield's British medical license has since been stripped, and his 1998 study has been retracted by the *Lancet* due to biased research practices, which some media outlets have called fraudulent, namely a business venture with the father of one of his research subjects in which he stood to earn $43 million by monopolizing on a "vaccine scare. Additional studies have not found an association between autism and vaccinations (e.g., DeStefano & Chen, 2001; Fombonne & Chakrabarti, 2001). It is more likely that vaccinations correlate with the onset of autistic symptoms rather than cause autism itself (Doja & Roberts, 2006), and there is far more evidence to support a strong link between genetics and ASDs or a genetic combination with some outside environmental factor.

Less evidenced through research, but still speculated by advocacy groups of all kinds (e.g., People for the Ethical Treatment of Animals), is the role that food allergies may play in autism diagnoses. For example, many parents and advocates claim that autistic children on gluten-free or casein-free diets are better able to control hyperactive and aggressive behaviors.

Treatment for ASD ranges from more experimental treatments such as the above-mentioned dietary restrictions and chelation therapy, which assumes heavy-metals poisoning as the root cause of autism, to pharmacology and behavioral treatments, which have stronger foundation in scientific literature. With the prognosis for autism remaining unclear, anti-psychotic medications such as risperidone and behavioral treatments such as applied behavior analysis therapy have claimed the most scientifically validated successes in managing autistic behaviors. Intensive early intervention specialized for the autistic population has been found to be most effective in raising IQ, enhancing social interaction skills, assisting with language acquisition, and improving transitions and performance in elementary school (McEachin, Smith, & Lovaas, 1993; Sallows & Graupner, 2005).

NEURODIVERSITY AND THE SOCIAL CONSTRUCTION OF AUTISM

The aforementioned text concerning diagnosis, prevalence, causes, and treatment of autism is based primarily on a medical model of understanding disability, where autism is considered a pathology for which a diagnosis and cure should be sought. A new movement spurred by autistic individuals

is termed *neurodiversity*, and it draws its roots from a social model of disability. If disability movements are a part of the latest generation of social movements, then neurodiversity can be considered the latest generation of the disability movement. Just as the social model draws on re-examining impairment and redefining disability, neurodiversity claims distinctions between neurological impairment and neurological diversity.

In support of this argument, Bickenbach, Chatterji, Badley, and Üstün (1999) interpret disablement as an identifiable variation of human functioning. Neurodiversity calls attention to the divide between inclusion and identity as they relate to disability. These new dimensions of diversity are not overtly obvious or inherently collective (Baker, 2006). Proponents of neurodiversity wish to be accepted as they are, with varying degrees of neurological impairment and neurological diversity. But it is argued that these aspects of diversity should be examined and valued similarly to other forms of diversity (e.g., race and sexual orientation). They argue that prejudices are often fueled by recognition of differences that are construed as inherently bad or flawed. Jurecic (2007) suggests that ". . . our transformation of the word 'autistic' into an insult suggests a prejudice fueled by a profound discomfort with and fear of neurological difference" (p. 423). Her insightful essay prompts many questions surrounding the definition of diversity. We can examine autism through the social model of disability using concepts from neurodiversity, which allow for the independence of impairments often associated with autism (e.g., social deficits) from disability itself.

Autistic individuals began speaking out and claiming their disabled identities in the early 1990s. Jim Sinclair (1993), an autistic man, wrote *Don't Mourn for Us* to voice a message to parents of autistic children. His message was clear: parents of autistic children who were advocating for a cure for autism were mourning for the loss of the "normal" child that they did not have. Instead, they had an autistic child with his or her unique deficits and strengths as an individual. Sinclair advocated for an acceptance of the autistic child and identified autism as a pervasive experience that colors every part of the child's world—an inseparable part of identity. "Therefore, when parents say, I wish my child did not have autism, what they're really saying is, I wish the autistic child I have did not exist, and I had a different (non-autistic) child instead" (Sinclair, 1993, p. 1).

The autistic writer Judy Singer first used the term *neurodiversity* in 1996 in her honors thesis. For her, the very idea that autism had been broadened into a spectrum of functioning signified its call for a politics of diversity

> For me, the significance of the autism spectrum lies in its call for and anticipation of a politics of neurodiversity. The neurologically different represent a new addition to the familiar political categories of

> class/gender/race and will augment the insights of the social model of disability. The rise of neurodiversity takes postmodern fragmentation one step further. Just as the postmodern era sees every once-too-solid belief melt into air, even our most taken-for-granted assumptions: that we all more or less see, feel, touch, hear, smell, and sort information in more or less the same way (unless visibly disabled) are being dissolved. (Singer, 1999, pp. 60–61)

Singer coined the terms *aspies, auties,* and *neurotypicals* to describe individuals with Asperger syndrome, autism, and "typical" neurological functioning. Singer (1999) advocated that autistic individuals use the Internet as a "prosthetic social device" (p. 62) to voice their identities and feelings surrounding an autism diagnosis and its implications in society.

Indeed, autistic individuals have taken the reins and used the Internet as a means of publicizing and politicizing their viewpoints through various mediums and blogs (e.g., the Autistic Self Advocacy Network [ASAN] or Autinet). ASAN was founded in the early 2000s by Ari Ne'eman. It now has members throughout the United States who seek to advance the principles of the disability rights movement in the world of autism by giving a voice to autistic people in autism advocacy. "Working in fields such as public policy, media representation, research and systems change, the ASAN hopes to empower Autistic people across the world to take control of their own lives and the future of our common community" (ASAN, 2009). It is important to understand that although autistic self-advocacy groups such as the ASAN are not representative of all people with autism, they do play a critical role in representing the autism community.

Autistic advocates such as Temple Grandin (2006) do not identify as strongly with the movement toward neurodiversity. Grandin acknowledges the inherent discrimination in U.S. society surrounding autistic people and identifies autism as another way of thinking, but she does not fully disagree with the concept of autism as a disability or the movement toward a cure. There is a separate category of autistic people (e.g., Jon Mitchell, Sue Rubin, Raun Kaufman, and Thomas McKean) who identify as "pro-cure," referring to their preference for the medical model of understanding disability and for genetic research aimed at finding a cure for autism. In this understanding, autism is accepted as a pathological condition—an individual problem that does not require society to reframe its view of disabilities but rather requires society to look for cures and treatments to alleviate the suffering that presumably occurs due to an autism diagnosis.

There have been three main arguments posited against the neurodiversity movement. First, pro-cure autistics and advocates argue that the neurodiversity movement takes into consideration only those autistic people who are considered to be high functioning. The term *high functioning* is used in academic literature and in medical diagnosis to refer

to autistic individuals with average to above-average IQs and verbal communication abilities. This argument assumes that low functioning autistic individuals have an inherently poorer quality of life and would thus desire a cure. The fundamental problem with this assumption is that as nonautistic people, we have no method of accurately judging another human being's quality of life without that judgment's being colored by our own experiences, value systems, and the value systems of the society in which we live. Following from this argument, the second most common opposition to neurodiversity is that all proponents of neurodiversity are high functioning. This claim can be nullified for two reasons: (a) not all proponents of neurodiversity are high functioning. Amanda Baggs is one example of an autistic individual who is nonverbal and vehemently against the pejorative effect of the medical model on autistic individuals; and (b) many, if not all, of the anti-neurodiversity proponents are also classified as high functioning. The final dispute between the pro-cure movement and the neurodiversity movement surrounds the use of research and searches for treatments for autistic individuals. Pro-cure autistic people and advocates frequently allege that the neurodiversity movement is disinterested in research and impartial to finding treatments for autistic people. This position is inherently flawed because the neurodiversity movement values both research and the discovery of new treatments for autism. Neurodiversity proponents experience disharmony between the areas of research and treatment because of their strong beliefs surrounding the need to be cautious of genetic research used in support of eugenics and belief in the rights of an autistic person to self-determine the best treatment approach or to decide against treatment.

> We are interested in workshops about positive ways of living with autism, about functioning as autistic people in a neurotypical world, and about the disability movement and its significance for autistic people. We are not interested in workshops about how to cure, prevent, or overcome autism. (Sinclair, 2005, p. 24)

THE CONTROVERSY SURROUNDING A CURE

The debate that surrounds finding a cure for autism is contingent on its presumed underlying cause. There are three sides to this debate: (a) autism is caused by the environment, specifically environmental toxins, and autism should be cured by addressing these pollutants (e.g., anti-vax, or the anti-vaccination community); (b) autism is genetic and should be addressed through the human genome (e.g., supporters of the medical model); and (c) autism is genetic and is therefore a variation of human functioning that should not be impeded (e.g., the neurodiversity movement).

MULTIPLE EPISTEMOLOGIES: WHO SPEAKS FOR AUTISM?

The controversy can be dichotomized by examining the perceptions of autism by the two largest autism advocacy groups in the United States and their correspondence with the ASAN. The largest and wealthiest autism advocacy group in the United States is Autism Speaks, founded in 2005 by Suzanne and Bob Wright, grandparents of a child with autism, which merged with Cure Autism Now (CAN), founded in 1995 by Jonathan Shestack and Portia Iverson, parents of a child with autism. These two organizations together are "dedicated to accelerating and funding biomedical research into the causes, prevention, treatments and cure for autism spectrum disorders; to increasing awareness of the nation's fastest-growing developmental disorder; and to advocating for the needs of affected families" (www.autismspeaks.org). Suzanne Wright (2008) stated in *Parade Magazine* that a goal of Autism Speaks is to "eradicate autism for the sake of future generations. This statement, combined with ads depicting autistic children from a negative vantage point and continued promotion of research investigating a potential link between vaccinations and autism, have led certain individuals to question the underlying motives of the organization. The ASAN has compared the stance of Autism Speaks toward eradicating autism to being eugenic in nature. Meg Evans (2009) of the Central Ohio ASAN wrote a brief paper titled "Why Autism Speaks Does Not Speak for Us," citing several reasons for the group's position, including Autism Speaks's support for James Watson, former Chancellor of Cold Spring Harbor Laboratory, who has advocated genetic augmentation and extermination of individuals with cognitive disabilities. Evans also reminds readers that in contradiction to its name, Autism Speaks does not have, and has never had, one autistic person on its board of directors or in any leadership position, further promoting exclusionary practices for disabled people and promoting oppression by claiming to speak on behalf of a group of people who are not given a voice within the organization.

Groups such as the ASAN and other proponents of neurodiversity fear insensitive genetic research and the potential for prenatal diagnosis of ASDs. Their fears are not unfounded, considering that all too recently in our history we saw the blossoming of the eugenics movement in which several policies were in place to mandate abortion of disabled fetuses, sterilization of disabled persons, marriage restrictions for the cognitively disabled, and the epitome of mass genocide—Nazi Germany during World War II. These policies may now seem outdated and "a thing of the past"; however, disabled people still have relevant concerns about genetic discrimination, the effects of genetic research, and violations of privacy (Stowe, Turnbull, Schrandt, & Rack, 2007).

Stowe, Turnbull, Pence, et al. (2007) asked the important question, "Are persons with disabilities and their families still concerned that discriminatory

attitudes will drive genetic research and the implementation of genetics?" (p. 192). They found that this was indeed the case in their research with several focus groups of persons with disabilities, citing that disability is still largely viewed by society as a burden and that most medical professionals lack knowledge of the real lives of disabled people (Stowe, Turnbull, Pence, et al., 2007). Concerning prenatal genetic testing, several studies have found that 80% to 90% of women terminate their pregnancies after receiving a diagnosis of Down syndrome (Kramer et al., 1998; Rosch, Steinbicker, & Kopf, 2000), giving credence to the fear that increased genetic testing may lead to extermination or abortion of fetuses prenatally diagnosed with autism.

Dr. Joseph Buxbaum, who heads the Autism Genome Project at the Mount Sinai School of Medicine (New York, NY), has predicted a prenatal test for autism within the next ten years (Herera, 2005). The idea that certain genes may be flawed is in itself a social construction and sets up a false dichotomy between "normal" genetics and "flawed" genetics. With the work of the Human Genome Project and its goal of mapping every gene in the human body advancing every day, the social construction of genetics will become increasingly significant, especially for the disabled population. There is an increasing trend toward geneticizing human difference in order to explain physiological and cognitive differences among human beings in terms of their genetic makeup and, more crucially, to attach differing (social) values to embryos, fetuses, and human beings according to the particular configuration of their genetic (and therefore bodily) structure (Drake, 1999, p. 12).

Another large autism advocacy group within the United States is the Autism Society of America (ASA). Perhaps the oldest autism advocacy group, it was founded in 1965 by Dr. Bernard Rimland and Dr. Ruth Sullivan along with several other parents of autistic children. The ASA produces a quarterly journal and hosts a comprehensive yearly national conference for parents and professionals. Although the ASA has stated, "Most of the enlightened world knows that autism is at its root, genetic, and therefore by definition it is not something that can be considered 'curable' or a 'disease'" (www.autism-society.org), following the similar beliefs of the ASAN, they are also like Autism Speaks in that they do not have any members with autism in their leadership. The ASA has been at the forefront of many policy efforts on behalf of autistic persons and their families. Recently the group has participated in legislation aimed at making it unlawful to deny medical insurance to persons with autism. It also supported the Combating Autism Act, which was signed into law on December 19, 2006 and reauthorized in 2011. The Act authorized $693 million in federal funding to combat autism through screening, early intervention, education, research, and expeditious referrals and treatments (Combating Autism Reauthorization Act, 2011).

Although more than 60 disability rights advocacy groups, including the ASAN, have signed a petition condemning Autism Speaks for

their negative advertisement and sponsorship (http://www.ipetitions.com/petition/AutismSpeaks/), the ASAN has remained relatively silent concerning the motives of the ASA, although it would seem fit to argue against the inherent violent and negative language of the Combating Autism Act.

AGREEMENT AND COMPROMISE

Although neither organization has an autistic leader, both Autism Speaks and the ASA have been integral in promoting autism awareness, and they were both started as grassroots efforts by parents and family members of autistic people who had genuine intentions. The ASAN, however, has taken the autism movement one step further—into the disability rights movement, ascribing to the social model of disability. This new movement aims to have the experiences of autism be considered as epistemology. It aims to influence politics, and it aims to have autistic people recognized as true partners (Chamak, Bonniau, Jaunay, & Cohen, 2008). The conflict between parents' associations and autistic people both invigorates the autism movement and weakens it through dichotomy.

Despite considerable disagreement on the different sides of the arguments regarding finding a cure for autism, genetic testing and prenatal testing for autism, and the relevance of parent-run advocacy groups, there is room for agreement and compromise. Roy Richard Grinker (2008), author of *Unstrange Minds*, which he wrote concerning his autistic daughter, points out that whatever side of the epistemological fence one is on in this debate, everyone has suspicion of the motives of scientists. It is this suspicion that will continue to keep pushing researchers to be innovative and mindful of the implications of their research. They are being watched closely by a large community, all of whom are ready and willing to question and dissect their findings.

Temple Grandin (2006), in her autobiography and in several of her published texts, has implied that everyone in the autism world is in agreement that there is confusion about what constitutes sickness and what qualifies as "oddness." As an autistic woman who has not aligned herself with one particular autism advocacy group, this statement speaks to the need for compromise and communication within the autism community. We have seen many diagnoses in the *DSM* change throughout the years (e.g., homosexuality). The diagnosis of autism itself has evolved from a single diagnosis to a wide spectrum. In fact, changes to the *DSM-5*, to be released in May 2013, will completely alter the autism diagnosis from a five-pronged umbrella with separate autism-spectrum disorders to a single diagnosis of autism-spectrum disorder with varying levels of severity. The need for open-mindedness and acceptance of change should be closely fixed with scientific knowledge and multiple epistemologies.

IMPLICATIONS FOR SOCIAL WORK

Professionals and researchers have created an industry surrounding the diagnosis and treatment of ASD. The annual cost to society is estimated at $126 billion, with average lifetime care for an individual with autism costing between $1.4 and $2.3 million in the United States. (Mandell & Knapp, 2012). Very lucrative markets have arisen as a result of the high incidence of autism, including training programs, special diets, behavioral techniques, genetic tests, and many other unique therapies (Chamak et al., 2008). Social workers, as one of the largest groups of professionals working with individuals with disabilities including ASD, need to be ever mindful of their place in this industry. Because of the large social work representation in disability treatment and advocacy (DeWeaver, 1995; NASW, 2006), social workers should be reminded that they play integral roles in helping autistic people establish their identities in a world filled with ableism. The new changes to the *DSM-5* will also raise identity-related concerns for social work practitioners who diagnose and treat ASD because the traditional labels of Asperger syndrome and autistic disorder will be removed, eliminating a label with which some members of the autistic community strongly identify.

The disability rights movement, along with the social model of understanding disability, is not always a comfortable fit with disability treatment because of its differentiation between disability and health statuses (Corker & French, 1999). Social workers are simultaneously encouraged to diagnose individuals with ASD (frequently so they can qualify for service provision) and treat them as having a less than healthful status, while also looking at strengths and valuing diversity. The power differentials and practitioner-as-expert roles that are inherent in service provision, especially in work with disabled people, must be challenged as autistic individuals claim self-determination and an adherence to the beliefs of neurodiversity and the social model of disability. Autistic individuals and their families should be encouraged to examine all of the options for interpreting disability and disabled status in the United States. Social workers and other professionals can use Crow's (1996) understanding of disability to assess clients' responses to impairment and whether those responses mesh with the environmental context and epistemological framework for disability in which each client is embedded.

In line with the person-in-environment perspective and systems theory, social workers must acknowledge barriers to ability constructed within interwoven systems of society. It is not the bodies and minds of disabled individuals that are at fault. The oppressive disabling of individuals takes place within a society that restricts access to resources through prejudice, discrimination, inaccessible environments, and inadequate support. What is more important to consider is that if these problems indeed are created by society, then social workers have an obligation to un-create them. Social

work practitioners can and should advocate for inclusive environments free of discrimination and prejudice for autistic individuals and their families.

Drawing from the concept of universal design, which originated in architecture, all environments should be made accessible and inclusive. This is easy to picture when dealing with an individual's physical environment (e.g., a person who uses a wheel chair for mobility gains accessibility with ramps, elevators, and accessible bathrooms). However, it is less clear how social work practitioners can advocate for inclusive environments for autistic individuals whose impairments lie within the social realm. Popular opinions of autism (e.g., lacking of empathy or inability to love) give the impression that the social impairments of individuals with the autism cause them to function at the boundaries of what is characteristically human, therefore justifying inhumane exclusionary treatment (Kaul, 2003). Focus on the extraordinary skills (e.g., savant qualities) and abilities of some autistic individuals is often used to complement and justify exclusionary practices for "lower functioning" individuals. This is compiled with the mystification concerning the brains of people with autism (e.g., the puzzle-piece symbol for autism awareness, which emphasizes the confusion, complexity, and unsolvable mystery of ASD). Therefore, in the context of neurodiversity, creating an environment that adheres to the concepts of universal design and inclusion, the social work practitioner should make space for the consideration of alternative definitions of disability, disablement, and what it means to be autistic. This includes empowering and giving a voice to autistic individuals, whether that occurs through an augmentative communication device, art, sign language, or verbal speech. Individuals with autism and their families should be encouraged to explore the fullness of community integration through participation in community activities, the workforce, politics, spirituality, and any and all activities that allow for the establishment of an identity that values the inherent worth and dignity of personhood.

As the movement grows, neurodiversity will be a concept that social workers will have to confront in practice. Freshwater and Rolfe (2004), in their understanding of critical reflection and deconstruction, present the idea of an *aporia,* which is described as a difficulty faced when trying to establish a theoretical truth. It is created by the presence of evidence both for and against a claim. Neurodiversity, with its underlying assumption of autism as a form of human diversity, will be cast side by side with the medical model and its assumption of autism as pathology, as recognized by the *DSM.* The challenge for social workers and other professionals will be to establish an epistemology for understanding alongside their clients. Stowe, Turnbull, Schrandt, et al. (2007), in their research on focus groups, found that scientific knowledge alone was not enough to correct the misrepresentation of disability and the quality of life of disabled individuals. Social workers should be effective in communicating accurate knowledge about disability

and ensuring that their own professional attitudes are not leaving their clients vulnerable to discrimination.

The establishment of legislation such as the ADA and Individuals with Disabilities Education Act (1997) and technologies to enhance communication, stress the importance of inclusion in school and community settings. This inclusion reiterates the need for autistic people's voices to be part of the formulation and implementation of such policies. Intervention at these levels will be most helpful when the opinions of those receiving intervention are not only taken into consideration but also are used as a foundation for knowledge building and effective practice.

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