

Neurodiversity and the Future of Autism

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Abstract

This article recognizes autism as an urgent and largely neglected social issue and frames autism in the context of the neurodiversity movement. In comparing the ideology of this school of thought with that of the dominant medical model, this article analyzes the social implications of each. It seeks to promote the notion of self-advocacy among individuals with disabilities and discusses possible applications to policy and intervention. By mobilizing the community to raise awareness of autism-related issues, stronger support systems can be built, and notions of inclusion and diversity can be fostered within society.

Introduction

Autism is currently defined as a developmental condition that typically becomes apparent during the first three years of life through impaired development of learning, social, and communication skills as well as restricted or repetitive behavior. Much still remains unknown about its causes because it manifests itself differently and varies in severity from person to person. Thus termed a “spectrum disorder” by the National Institute of Mental Health, autism is classified among other neurodevelopmental conditions such as Asperger’s syndrome and Rett’s disorder (NIMH, 2011). In recent years, autism has been increasingly addressed by the media as an important sociocultural and public health issue. Its prevalence was estimated to be twenty per ten thousand individuals in the 1970s, but studies conducted by the Centers for Disease Control and Prevention in 2006 reported a prevalence of fifty-five per ten thousand people in the United States (Jurecic, 2007). It remains debatable whether this significant increase can be attributed to a broadened definition of the spectrum that autism encompasses, increased methods of diagnosis, or an increase in the rate of onset of the condition itself. Regardless, the urgency of autism as a social issue and need for raised public awareness and government attention are certain.

Historically and traditionally, autism has been stigmatized as an abnormal difference and a medical condition by the general community which “views disability as a deficit and people with disabilities as individuals who need to be ‘fixed’” (Bagatell, 2010). However, autism advocacy has been on the rise in the past sixty years, and shifting perceptions of disability have catalyzed the emergence of several ideologies that oppose and question the integrity of the medical model. The neurodiversity movement, or autism rights movement, stands as one of the prominent voices in autism advocacy today. Neurodiversity aims to reevaluate the meaning of disability as a social construct and shift social dynamics to encourage the acceptance of autism as a “variation in

functioning” rather than as a condition which needs to be cured (Jurecic, 2007). In his book, *Not Even Wrong: Adventures in Autism*, Paul Collins sums up the philosophy of the neurodiversity movement and related social model of disability: “Think of it: a disability is usually defined in terms of what is missing...but autism...is as much about what is abundant as what is missing, an over-expression of the very traits that make our species unique” (2005). In speaking of autism as a natural aspect of human diversity, neurodiversity identifies judgmental social attitudes at the root of the problematization of autism. As a fairly new but strongly supported affiliation, neurodiversity is quickly gaining command in the world of disability. This article will examine the potential of the growing neurodiversity movement to influence the course of disability policy and the future of autism in general.

Neurodiversity, Reimagining Disability, and Self Advocacy

The neurodiversity movement seeks to encourage an attitude of acceptance and reverse the stigma that has predisposed feelings of social exclusion and identity uncertainty for those affected by autism. Kristin Bumiller (2008) describes this philosophy in her article by saying neurodiversity “has renewed interest in the question of how to promote diversity in all its manifestations and to further a more inclusive society,” identifying its righteous nature as parallel to that of historical and ongoing civil rights and gay liberation movements. Advocates of neurodiversity compare spectrum disorders to any other human variation and assert that a burden has been placed on the autism community by society’s construction of a view of disability that dictates the necessity for a cure.

Through media and organized events, neurodiversity activists seek to promote positive discussion about autism and create a sense of unity among all individuals, regardless of behavioral or social differences. Neurodiversity aims to reconceptualize the idea of disorders like

autism by supporting equal opportunity, changing associated language, dismissing the need for a cure, and encouraging acceptance for unconventional types of autonomy (Jurecic, 2007). Most importantly, this model works to empower affected individuals with the knowledge and ability to manage or deny their course of treatment in the absence of pressure from societal judgments or stigmas. In her article, “From Cure to Community: Transforming Notions of Autism,” Nancy Bagatell (2010) describes a fundamental component of neurodiversity called self-advocacy that encourages people with autism to voice their opinions, make their own decisions, fight for policy change, and essentially take control of their lives. In 1993, Joseph Shapiro qualified the self-advocacy movement as “the parallel cry for self-determination by another group of disabled people rebelling against being long underestimated, deprived of choices, treated as eternal children, and thought to lead lesser lives.” People First, the oldest self-advocacy group, was established in 1974 and voiced the needs of people with autism and other developmental disabilities. At least 505 groups existed by 1994, and these coalitions continue to grow and gain influence by serving as support systems and valuable community resources for individuals with disabilities all over the country (Aull, 2005).

With Regard To Other Models

While the neurodiversity movement serves as the focal point for discussion in this article, it is important to compare its fundamentals with those of other existing models in order to understand its potential to influence the future of autism. The social model proposes many of the same ideas as those of the neurodiversity movement, identifying the root of the problem as the social construction of a “norm” that imposes societal barriers on those who may differ. Some theorists view the neurodiversity movement as a subset of the social model that attributes the unique quality of people with autism to a difference in neurological development. Both models promote

the idea of “equality without sameness” and criticize a community that is unreceptive and, in fact, disapproving and unaccepting of behavioral diversity. The social and neurodiversity models focus their intervention efforts toward changing a society that nurtures a stringent “norm” and identifies anyone who is different as flawed (Jaarsma and Welin, 2012).

The neurodiversity movement stands in greatest contrast to the well-established medical model which targets interventions towards “fixing” the social and behavioral aspects of spectrum disorders deemed abnormal. The medical model views autism as a debilitating illness and thus primarily channels its resources into rehabilitation and cure research. Medical model interventions strive to increase “functionality” of those affected by autism toward the standards of normalcy set by society. Many sources cite the medical model as being more established within the general population, especially with “neurotypicals,” or people without autism. Because autism is such a personal and internal phenomenon, a possibility for distrust of neurotypicals active in disability advocacy arises from the premise that others could not possibly understand the challenges the condition impresses. Jacqueline Vaughn Switzer (2003) wrote about a popular opinion among people with autism that “when others speak for you, you lose” and that neurotypicals “claim to represent [their] needs but don’t really listen.” Additionally, Vaughn Switzer noted that many autism organizations are run by neurotypicals and support the medical model. One can infer that for this reason, self-advocacy is central to neurodiversity and disagreement is inherent between the two models of disability. A major challenge in disability advocacy is then to resolve conflicts between proponents of the medical and social models and between neurotypicals and people with autism in regards to policy change, direction of funds, and legislation in general.

The National Council on Disability

The National Council on Disability, established in 1978 as an amendment to the Rehabilitation Act of 1973, is a federal advisory board designed to represent the disabled population and ensure equal access to opportunities. Under an authorizing mandate, the team of fifteen Senate-confirmed presidential appointees advises the president, Congress, the secretary of education, and other federal groups in regards to “policies, programs, practices, and procedures” in the best interest of the affected population as well as promotes means through which the disabled can achieve maximum independence and full inclusion in society (“NCD”). Common threads of controversy include legislation related to school reform efforts, health care access, and fair employment opportunities. The statutory mandate states that the council will consist of “individuals with disabilities, parents or guardians of individuals with disabilities, or other individuals who have substantial knowledge of experience relating to disability policy or programs” (“NCD”). This particular component of the policy-making process is very important to the neurodiversity movement because it promotes self-advocacy and serves as a medium through which disabled populations can voice their needs and opinions about legislation.

The National Council on Disability drafted the first version of the Americans with Disabilities Act in 1988. Signed by President George H.W. Bush and implemented in 1990, this pivotal piece of legislation blazed a trail for future policy to protect the rights of disabled populations. The Americans with Disabilities Act defines disability as “a physical or mental impairment that substantially limits a major life activity” and illegalizes discrimination against individuals with such disabilities. In 2008, President George W. Bush signed the ADA Amendments Act which aims to give broader protections for the disabled and specifically notes what constitutes a “major life activity” in the original legislation. Today, the National Council on Disability continues to

play an influential role in advising our nation's government authority. Implementing disability policies concerning education, transportation, livable communities, foster youth, and crime victims (Young, 2010) the council shapes policy not only based on their own knowledge and research but also in response to the thousands of e-mails and letters they receive every year from individuals all over the United States ("NCD"). Aside from its policy work, the National Council on Disability serves as a valuable resource for disability-related information, giving interested groups access to articles, reports, and statistics via printed and digital media. Alongside existing self-advocacy groups, the work done by the National Council on Disability helps to ensure disabled individuals and their rights remain well represented in policy deliberation, media, and housing and employment opportunities.

A Continuing Paradigm Shift

In her book, *Disabled Rights: American Disability Policy and the Fight for Equality*, Vaughn Switzer (2003) identified a change in the political atmosphere in the 1970s which allowed for disability policy to rise as a "legitimate issue on the policy agenda," a notion which is radical in the context of history. Vaughn Switzer described a powerful statement made by the National Council on the Handicapped in 1983 that captured the essence of this change, that the disabled were no longer viewed as damaged, flawed, or dependent on government aid. Instead, "the council called on the government to shift to policies that achieve 'maximum life potential, self-reliance, independence, productivity, and equitable mainstream social participation in the most productive and least restrictive environment'" (as cited in Vaughn Switzer, 2003)." Such a significant shift is apparent in the rise of civil rights movements such as the Americans with Disabilities Act and in the increasing prominence of self-advocacy groups and neurodiversity proponents.

With the President's recent council appointment of Ari Ne'eman, the board's first appointee with a spectrum disorder and a strong advocate of neurodiversity, disability policy stands at an important crossroads. Ne'eman is known for having already done extensive work in support of neurodiversity. He currently serves as president of the Autistic Self-Advocacy Network (ASAN), a non-profit organization that fights to ensure that people with autism have the same "access, rights, and opportunities as all other citizens" (Sinclair, 2012). ASAN proclaims a commitment to "self-advocacy, self-determination, self-awareness, and independent living" in its mission goal, further marking proof of a shifting paradigm ("ASAN"). The success of such organizations reflects a growing movement that recognizes the need to encourage autonomy for disabled individuals. Due to the important role the council plays in advising the president on disability policy, Ne'eman's appointment has the potential to drive the neurodiversity movement forward, fostering its growth and influence through increased promotion and policy implementation.

Ari Ne'eman's nomination to the National Council on Disability has already elicited mixed reactions and heated controversy. One could interpret the President's appointment as a gesture more significant than simply an endorsement of a qualified candidate; Ne'eman's delegation could be seen as Obama's effort to respond to the interests of the disabled and neurodiversity and self-advocacy proponents in particular. However, opposition stems from members of the community who believe that being only twenty-two years old when nominated, Ari Ne'eman has not yet acquired the experience required to responsibly manage such an influential position. Additionally, opposition remains wary of Ne'eman's strong neurodiversity stance on autism, fearing that with his appointment, resources will be directed away from research for a cure. One group of individuals voiced its outrage in a statement that attempts to identify Ne'eman's stance as illogical: "without making the goals of prevention and cure a top priority, there will not be

sufficient funding to adequately provide for the growing population of people with autism” (“Age of Autism,” 2010).

Another petition by members of the Age of Autism group exemplifies intense disapproval of Ne’eman in its statement that he “rather than unifying the autism community, divides it” (2010). Knowing the strong opposition to Ne’eman, one can understand the controversial and arduous nature of his appointment to leadership. However, in spite of the dispute and temporary hold placed on the President’s nomination, the Senate approved Ne’eman’s appointment on June 22, 2010 (“NCD”). Ne’eman’s atypical approach to disability policy is sure to perpetuate the paradigm shift toward an altered political consciousness under which autism is viewed with renewed and broadened perspective.

Future Possibilities for Model Integration

While controversy remains heated and the boundaries that separate the ideals of neurodiversity from those of other models remain clear, the future of autism does not likely remain in the hands of one ideology. Recent discussion promotes the idea of an emerging autism community as a marker of social constructions continuously being reinvented. Many believe this growing reconceptualization of autism will force health care professionals to reevaluate their notions of disability and how practice should be shaped to fit those beliefs. In her article, Nancy Bagatell (2010) asserts an interesting and valid point that a growing trend toward client-centered health care practice creates room for model integration. In other words, clients who express their needs based on their beliefs of autism assert the power to control their course of treatment regardless of the disposition of the medical model for cure or behavior modification. In her argument, Bagatell (2010) makes the concession that “although the autism community has, by and large, rejected research from a biomedical perspective, partnering with social scientists in

participatory action research projects offers the opportunity to transform societal notions of autism and appropriate services.”

Considering that the drifts between neurotypicals and people with autism and between neurodiversity and the medical model appear to go hand in hand, a similar model integration approach can be taken to begin resolving both. As Bagatell suggests, it is possible that treatment as supported by the medical model does not have to be eliminated. Rather, implementation of choice and varying degrees of intervention could serve as an effective way of respecting people with autism as independent individuals and ensuring treatment is not coercive. Shaping of treatment around the self-assessed needs of people with autism appears to be a reasonable method of compromise. Combination of theory in this manner creates a greater air of acceptance, eliminating the notion that autism needs to be “fixed” while still making therapy available to improve quality of life in the case of self-injury or hindered ability to carry out daily activities. For many individuals who believe autism has come to shape their identities and talents, choice is a simple yet critical factor currently missing from the medical model of treatment.

Conclusion

While the general consensus would agree the last forty years have achieved much progress in that social norms have grown to foster a greater acceptability and understanding of autism, it is still important to continue the effort to reframe autism in more positive terms. In the midst of an economic crisis and the appointment of Ari Ne’eman to the National Council on Disability, it is likely the government’s political stance on disability will face many changes in the near future. As budget cuts and redistribution of funds at both the national and state levels hang in the balance, it will be interesting to see how Ne’eman’s neurodiversity stance influences decisions made by the council and the course of change in disability policy.

With support and feedback from the autism community, Ne'eman has the opportunity to use his influential position on the council to encourage a greater awareness of neurodiversity and direct resources into self-advocacy and support groups. As with any theory, however, one must question the practicality and realistic implications of applying neurodiversity to policy and society in general. While it is unlikely and unrealistic to believe all supporters of autism research are going to abandon the search for a cure, it is reasonable to believe in the possibility of “equality without sameness”: that society has the potential to eliminate discrimination and attain a greater range of acceptability for unique individual qualities. The capability of interventions to achieve results is undeniable and valuable for those who choose to participate, but that does not necessarily mean treatment should be mandatory. Expansion of the neurodiversity movement is sure to face resistance by proponents of the medical model, but successful integration of theory into a more self-directed system of treatment would be taking a step toward easing the inherent conflict of interests barring these two groups.

While it may not be a simple process, if social construction of normalcy is possible, so is social deconstruction of stigma. Evidence of this process is embodied in the continually shifting political atmosphere and paradigm of disability. Spread of neurodiversity would encourage a greater understanding of the individual and promote inclusion to break barriers which people with autism currently face. A philosopher named Arthur Schopenhauer once said, “All truth passes through three stages. First, it is ridiculed. Second, it is violently opposed. Third, it is accepted as being self-evident.” And so we can take a step from cure to community (Bagatell, 2010) by accepting autism as it currently exists as an inevitable condition regardless of cultural attitudes stemming from opposing belief systems. In his work through ASAN, Ari Ne'eman recognizes challenges but continues to strive to protect the civil rights of people with spectrum

disorders with a goal of “creating a world in which all people can benefit from whatever [...] may be necessary to empower them to participate fully in society, with respect and self-determination as the guiding principles” (“ASAN,” 2011). With such vision, Ne’eman has the potential to use neurodiversity as a medium to revolutionize autism and mobilize disability policy as it exists today.

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