

ARTICLE

Leadership, Mental Health Ethics, and Biopolitics: The Case of Autism

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INTRODUCTION

One in every one hundred fifty children is diagnosed with autism (Offit, 2008, 3). This statistic is one that is likely familiar to most, and it is one that sets the tone for the autism movement. Autism has, in recent years, become as much a social movement as a diagnosis. Perhaps this should not come as a surprise. The intersection of politics and biology is often at the center of political debates and it is not uncommon for discussions of value to hinge on scientific controversy. Jonathan Moreno (2011) argues that biopolitics will have wide-reaching implications for our culture's value system. Autism, hallmarked by various social movements, celebrity protagonists, and scientific and political controversies, is a prime example of Moreno's notion of biopolitics.

The questions raised by the biopolitical discussions of autism are certainly worthy of address by ethicists. How should autism be defined? Is it a disability or a difference? What kind of leadership would be appropriate for a movement based on mental health politics?

There are two pervasive movements in autism, the recovery movement (RM), which is a movement developed specifically around autism and views it as a disability, and the neurodiversity movement (NM), which is a growing movement that views itself as the newest frontier of civil rights. In this paper, I will outline the ways in which the aims of these two movements are often at odds with each other. Next, I offer three reasons why RM has, despite its best efforts and good intentions, done a disservice to the autistic community. Specifically, I will claim that it has further stigmatized adulthood autism, that it precludes families of children on the spectrum from adequately preparing for their children's future, and that it has stalled research on and the development of resources for adulthood autism. Finally, I will argue that the aims of NM are a much better fit for autistic adults, if autism is to continue to be at the center of social and political disability rights movements.

AUTISM AS POLITICAL: EXPLORING THE MOVEMENTS

At first glance, the very public debates surrounding autism may look like a step in the right direction. The disorder has sparked not just one, but several successful social and political movements, become a topic familiar to the media and the general public, and is specifically mentioned in federal budget as an area where research ought to be funded (Office of Management and Budget, nd.). Still, it is not clear that the politicizing of autism has been a straightforwardly positive thing for those with the disorder and their caretakers, in part because there are two clearly distinct political and scientific paradigms with regard to autism.

Tension of the sort that exists between the neurodiversity and recovery movements is commonplace in disability studies. Often, the polar ends of the range of theories within disability studies are referred to as the medical and social models, or the biomedical and behavioral models (Johnston, 1996). NM applies a social/behavioral model of disability to autism while RM applies a medical or biomedical model. A look at each model and the respective ethical implications reveals how high the stakes of this conceptual debate are for those on the spectrum.

NM seeks to change the conception that autism is a disorder that needs to be cured, and replace it with the understanding that autism is simply a normal human difference or minority experience, and that treatments and research are choices that an individual may make in order to better flourish. Proponents of it claim that the trouble lies in the lack of neurological pluralism within society, and argue that autism is simply neurologically divergent, though not better or worse than the neurological majority (Blume, 1997). Proponents of the movement claim that it safeguards the autonomy of those with autism and respects them as individuals by supporting freedom of choice and reducing stigma. Critics, however, claim that the movement considers the interests only of highly-functioning individuals, and overlooks both the needs of those who are not as highly-functioning and their caregivers.

RM accepts the biomedical model and frames autism as a disorder or a disability, and its goal is to identify the causes of autism in

order to develop effective cures and treatments. Proponents of it claim that it embraces progress, offers hope to caregivers, and takes into account medical evidence that autism is a disorder. Critics claim that it relies on bad science and stigmatizes those with autism rather than empowering them.

In this paper I will argue that RM also overlooks the chronic nature of autism and excludes adults on the spectrum from its cause. The power behind both movements is connected to the way in which they frame autism using either the social or biomedical models. The problem with RM is that it frames autism as something that affects children, and there is little to no focus on the effects of autism in adulthood. In part this is because pediatric campaigns are so effective. They tug at the heartstrings and engage newly-concerned parents before they are able to weigh their options.

In this paper, I will argue that RM's framing has been directly unjust to adults on the autism spectrum and indirectly to all individuals on the spectrum insofar as children on the spectrum are to be considered with respect to their identity as future adults with autism. The politics surrounding autism are indicative of larger issues and controversies surrounding psychiatric diagnosis and mental health more generally.

THE SEARCH FOR CAUSES AND CURES

Any look at autism ought to begin with a critical look at the various sources that inform discussions on autism. Hacking (2009) points out that there is a role for stories in clarifying the public image of autism. Though Hacking aims to focus his discussion on the role of fiction, he also acknowledges a role for biography and autobiography about autism in increasing understanding of the autistic experience. More commonly, however, the popular media serves as the public's main source of information about autism. The case of Andrew Wakefield points to one of the most significant challenges posed to ethicists in clarifying public awareness of autism.

Wakefield, a former physician and surgeon at Britain's well-known Royal Free Medical School, published a paper in 1998 connecting autism to a vaccine for measles, mumps, and rubella (MMR) that is commonly given to toddlers (Wakefield et al., 1998). Wakefield was certainly not the first researcher to propose a cause or cure for autism, but he is the most commonly known. Wakefield's research, however, was problematic. He conducted trials on autistic children, going so far as to send autistic children to the United States where he could more easily order investigative spinal taps, and made proclamations about the ills of vaccines. It was later shown that Wakefield had neglected to acknowledge competing interests in the project, including the fact that he had been paid a large sum of money to conduct the study by parents of autistic children. Further scrutiny showed many more ethical conflicts with Wakefield's study, including the fact that he had paid for blood samples from children who attended his son's birthday party, that he had run invasive tests on children without approval from the proper ethics board, that he had marketed products to parents of autistic children based on his purported findings, and, perhaps most damning, reports from research assistants claimed that he had falsified data (Offit, 2008).

In March 2004, ten of the thirteen co-authors of Wakefield's article published a retraction of the study in *The Lancet* (Murch et al.) and in February 2010 that *The Lancet* published a notice retracting Wakefield's research (Editors of *The Lancet*). This retraction came on the heels of a report of over 100 pages released by Britain's General Medical Council (GMC) on January 28, 2010, which declared that Wakefield's work on autism and the MMR vaccine was unethical (Harroll, 2010). In May 2010 the GMC barred him from practicing medicine in Britain (Burns, 2010).

The public had been quick to take research such as Wakefield's at face value. The research had passed rigorous peer review, was published in one of Britain's oldest and most well respected medical journals, and the public had little reason to doubt it. The disease paradigm of disability research had defined autism research for so long that the public heard only about the search for causes and cures. Descriptions of the lived experience of those on the spectrum are only now becoming common, and so the public's understanding of autism is undeniably skewed.

This search for causes and cures has served to frame autism as a pediatric disorder. The public is most familiar with autism through the controversy over vaccines, the ad campaigns of advocacy organizations that tote puzzle symbols, indicating that research is needed to "unlock" or "solve" the mystery of autism, curing children of it and returning them to real, healthy versions of themselves (Autism Speaks). Cures for autism have included attempts to rid children's bodies of toxins, heavy metals, and other environmental and vaccine-based hazards. There have been anti-vaccine protests, new diets and educational initiatives, all aimed at finding a cure for autism (Offit, 2008). These biopolitical controversies are all characteristic of the recovery movement.

RM has been led by advocacy groups, concerned parents, and scientists like Andrew Wakefield. Its goal is to normalize those with autism, to find a cure, to "unlock" autism's mysteries. This movement has been driven by good intentions and unwavering devotion to solving the problems of autistic children. By many measures, the movement has been very successful. Funding for autism research and treatment is at an all time high. Public knowledge of autism has increased ten-fold. The number of educational resources available for autistic children is increasing on a daily basis. Still, the fundamental assumptions of this movement, that autism can be cured, that those with the disorder can be normalized, that the goal for children on the spectrum is to move off the spectrum before adulthood and become independent, fully-functioning adults, are highly problematic.

WHY THE RECOVERY MOVEMENT NEEDS RETHINKING

One of the most often-cited hurdles facing researchers and clinicians as they try to understand the nature of autism, decide whether intervention is necessary, and develop such interventions as they determine that they are necessary, is that there is very little information about the nature of autistic experience outside of clinical reports and educational literature (Hacking, 2009). It is difficult for neurotypical clinicians and researchers to understand autistic experience and, in turn, it is difficult for autistic individuals

to understand neurotypical experience in a way that is useful for them in conveying their experiences. This is especially true of information regarding autistic experience insofar as it relates to the quality of the lives of those on the spectrum. As Hacking argues:

Many people with autism have a great deal of difficulty in understanding what other people are doing, feeling, or thinking. The intentions of others are opaque. The situation is symmetric. Neurotypicals like me have a lot of problems understanding autistic individuals, even if they become quite articulate. The more severely affected among them, the ones who talk in strange ways or not at all, sometimes seem simply 'other' (504).

The nature of autism is widely debated. Organizations like "Defeat Autism Now," "Cure Autism," and "Autism Speaks" view autism as a disability or disorder and lobby for research into a cure for autism. They view the sensory disturbances and social difficulties faced by those on the spectrum as symptomatic of the disorder's seizing of individuals' true identities. In contrast, organizations like "Autism Self-Advocacy Network" (ASAN), which is led by Ari Ne'eman, an elect to President Obama's National Council on Disability, view autism as a neurological difference, and the sensory disturbances and social difficulties experienced by those on the spectrum as a different way of experiencing the world, a part of the autistic individual's identity, and not symptoms that a disorder is masking this identity (Harmon, 2010).

The political discord that results from this difference of opinion detracts from any meaningful attempt to understand and improve the lived experience of individuals on the autism spectrum. While this contrast in views over the essence of the phenomenological experiences of those on the spectrum certainly does have important ethical and political implications, both sides of this debate agree that the sensory disturbances are, in fact, disturbances, and the social difficulties are, in fact, difficulties. Both sides also concede that the lived experience of many on the spectrum has room for improvement; there simply is disagreement over whether this improvement ought to come in the form of a cure or accommodation.

This political debate, however, has made it very difficult to make much progress toward improvement. Because classical autism is typically characterized by impediments in communication, at the outset, clinicians and researchers are faced with difficulty in fully understanding autistic experience. In order to understand the experiences of individuals on the spectrum, they are limited to the narratives only of those with high communicative abilities and to observational data in every other case.

Narratives of those on the spectrum are becoming more widely available, but the highly political nature of autism drowns out these narratives because they are often offered in the spirit of contributing to this debate, and, as such, viewed as being biased and less than objective. In short, trustworthy information about the nature of autistic experience is difficult to come by. This is particularly true with regard to information about the effects and experience of phenomenological differences that may affect the practical accommodations made for autistic individuals. While RM has been successful in securing funding for autism research and treatment and increasing public awareness of autism, it has been powerful because it has promoted the idea that autism

is a pediatric disorder and that it can be cured. The desire to normalize children with autism has turned the focus of autism research away from understanding adulthood autism and from the development of services and resources for adults for whom the RM is not successful, those who still exhibit atypical social behavior into adulthood. As Donovan and Zucker (2010) argue:

The discussion of autism to date has skewed, understandably, toward its impact on childhood. But the stark fact is that an epidemic among children today means an epidemic among adults tomorrow. The statistics are dramatic: within a decade or so, more than 500,000 children diagnosed with autism will enter adulthood. Some of them will have the less severe variants... and may be able to live more independent and fulfilling lives. But even that subgroup will require some support, and the needs of those with lower-functioning varieties of autism will be profound and constant (7).

There are two factors that make RM particularly problematic. First, despite all of the research into the causes of and cures for autism, there has been very little scientific evidence to support any environmental cause or potential cure. While RM is founded on the belief that there will be a cure for autistic children, scientific research points toward evidence that autism is more likely a way of being or a life-long difference (Offit, 2008). Second, the RM is problematic in light of research by Clarke and van Amerom (2007, 2008), which shows that understandings of autism and conceptions about its treatment vary greatly between parents of autistic children and adults with autism. While their research shows that parents are likely to view autism as a disorder, it also shows that adults on the spectrum are far more likely to view autism as a difference or a way of being. These factors raise questions about whether RM aims to cure a group of people who would prefer not to be cured, and further, whether RM rests on an assumption that autism can be cured in the first place.

RM has had profound implications for adulthood autism. Perhaps most superficially, RM has served to further stigmatize the experience of the autistic adult. While adults with autism have long carried a stigma of being "socially awkward, isolated, or uncommunicative beings, with idiosyncratic needs and interests, and a very poor- often debilitating- understanding of what other people are up to, or the kind of mutual expectations that govern our myriad forms of interpersonal life," RM has added the stigma of failure to adulthood autism (McGeer, 2009, 518). A core idea of RM has been that children with autism ought to try hard to overcome their diagnosis and that parents ought to fight for services that will enable autistic children to test off the spectrum eventually. If these are beliefs that we hold about autism, then logically those who still exhibit autistic traits in adulthood have "failed" to overcome the spectrum. This sort of thinking is dangerous and stigmatizing to those on the spectrum, the very people who RM aims to help.

Beyond stigma, RM has created some practical problems for those on the spectrum and their caregivers. By promoting unscientifically-founded ideas that autism can be cured though the right interventions, educational initiatives, and therapies, families of autistic children, particularly those with low-functioning autism (LFA) and high-functioning autism (HFA) are given false hope. They often pour their resources into the search for a cure and

inadequately prepare for their children's future. Public policy reflects this and adults on the spectrum receive few government benefits, which are often reserved for adults whose developmental disabilities include a lower than average IQ. Adults with autism, in contrast, often have average to high intelligence. Public policy is slow to address this problem, and has not yet put in to place safety nets for adults who need high levels of care but do not have mental impairments.

In the case of *T.H. vs. the Division of Developmental Disabilities* (2007), an adult with Asperger's syndrome was denied services through the New Jersey Division of Developmental Disabilities after his parents, who had formerly served as his caretakers, passed away. T.H. had no social connections, was not able to secure or keep employment, cook, or care for his own personal hygiene, and was not responsible for his own health, yet did not qualify for services because he was of average to above average intelligence. Parents, wary of this future for their children and themselves, are quick to become hopeful of RM's promise of a cure for autism, and are likely to prepare inadequately for their children's care in to adulthood.

Another practical implication of RM's success is that very little research has been done on autism and adulthood, and resources about the disorder's effects on adults are scarce. The autistic community has begun to piece together anecdotal resources about employment, social relationships, sexuality, and well-being for autistic adults, but adults on the spectrum are likely to have trouble finding information about what the typical autistic experience is like, what strategies are known to be effective, and what resources exist.

This lack of information also has serious clinical implications, as there are far fewer physicians and psychiatrists familiar with adulthood autism than pediatric autism. As a result, adults who seek treatment for autism in adulthood are likely to be met with substandard options. For example, the presence of certain comorbid diagnoses such as bipolarity, speech disorders, and attention deficit hyperactivity disorder (ADHD) might be treated without any real understanding of the relationship of autism to these disorders. Bipolar disorder, for example, is often diagnosed co-morbidly with autism and treated with the use of psychotropic drugs, which data shows is effective in treating individuals with autism (Lubetsky & Handen, 2008). This interpretation of the data is misleading, however, as the term "autism" could be taken to refer to all of the individuals on the autism spectrum. In reality, such medications are not recommended for individuals with Asperger's syndrome because "antidepressants, including selective serotonin reuptake inhibitor (SSRIs), have been shown to induce hypomania" in this population (Duggal, 2003, 184). RM's framing of autism as a pediatric disorder might result in misinformation about autism among clinicians, as pediatric patients are far less likely to be treated for such co-morbid conditions.

NEURODIVERSITY AND JUSTICE: THE CHALLENGE OF LEADERSHIP

RM should be hesitant to continue its efforts given the fact that there is such controversy over and so little scientific evidence to

support its claims. One such controversy is over the classification of Asperger's Syndrome, perhaps the most highly functioning autism diagnosis, in the DSM. In the most recent DSM revision, which was published in 2013, Asperger's and autism will be merged into one diagnosis. Some are pleased with this movement, arguing that using a spectrum approach serves to remove the stigma from the autism diagnosis wherein low-functioning autistics receive the same diagnosis as their high-functioning or Aspergerian counterparts (Grinker, 2010). Many in the Asperger's community, however, reject this re-categorization, citing that it is likely to undermine efforts toward neurodiversity, that is, to construct public opinion of Asperger's as a difference, rather than a disability.¹ Many scientists and psychiatrists also agree, arguing that:

[W]hat is needed is a revision of its criteria taking into account its quality of social impairment (active but odd rather than aloof and passive); idiosyncratic interests (often sophisticated and intellectual); communication style (often pedantic and verbose); and age of onset/emergence of symptoms (often around 7–8 years). In addition, efforts should continue to establish its validity not only from autism but also from other conditions. (Ghaziuddin, 2010, 1147).

The confusion regarding the diagnosis and categorization of autism illustrates some features that are central to NM, a movement very different from RM. This struggle raises many questions about autonomy, agency, and the rights of autistic individuals. NM has started to bring some of these questions to ethics scholarship, but still neurodiversity faces many of the challenges historically faced by groups who were marginalized because of their race, gender, class, or sexual orientation. Social institutions, for the most part, have yet to recognize this as a civil rights struggle despite the fact that proponents of the movement argue that the discrimination and pseudoscientific search for a cause and cure is analogous to the features of other, widely recognized, struggles for civil rights.

In contrast to RM which views autism as a disorder that ought to be cured without question, neurodiversity allows for research in this direction if autistic individuals feel that it would bring more value to their lives. However, because it allows for the possibility that autism will not (or should not) be cured, it also grants that resources ought to be made accessible for adults on the spectrum, and that society ought to find ways to understand and promote the needs of adults on the spectrum whether or not they need accommodations and regardless of the degree to which they rely on these resources.

In many ways, NM resembles earlier anti-psychiatry movements. A group of people rebels against the idea that they are in need of a cure and the idea that they are disordered in the first place. Their way of being, they claim, is as natural as any other; it is simply not as common. And, like other anti-psychiatry movements, NM faces criticism from within and from without. Many people with Asperger's syndrome, for example, wish for a cure. They don't value their place on the autism spectrum, and they don't identify with the movement or its aims. Similarly, while many parents of children with mental health or developmental disorders value their children's differences, many others feel despair, not pride, at the thought of their children living such different lives.

The criticisms from the outside, which often come from mental health professionals, educators, and clinicians, point to some of

the difficulties posed by mental health and claim that it cannot rightly be called a simple difference. Neurological difference, they claim, often times results in disordered behaviors. Often they argue that the neurodiversity movement's roots in Asperger's syndrome make it difficult to see the larger picture. While repetitive movements, an increased interest in particular topics, or a diminished ability to understand social cues—all characteristic of autism and Asperger's—may not be pathological; periods of psychosis or mania—common features of many other neurological differences—may well be.

Many of these trials and criticisms illustrate the leadership challenges facing NM. The movement has long held that self-advocacy was the appropriate kind of leadership for the group. The tagline of the Autistic Self-Advocacy Network (ASAN) is “Nothing about us without us” is common among minority interest groups, and communicates the idea that the self-representation of minority groups is critical to policy discussions. Though this strategy is effective, it has made it difficult for NM to gain the momentum that RM has through its large-scale ad campaigns and celebrity spokespeople.

NM has constituents who are often wholly committed to the cause as activists or “diehards.”²² The movement values this level of commitment over what critics might call a more sustainable strategy that focuses on winning over the mainstream or managing public relations wherein the group might be a bit flexible in order to move more easily toward their ultimate goal, as based on Kellerman's taxonomy of followers (2008). Though this is a commendable goal, it does highlight some of the challenges facing the movement.

Proponents of NM have long supported the idea that autism falls within a struggle for civil rights, and that autistic agents are often restricted with respect to their ability to flourish as autonomous agents. Autism, they say, should be understood and recognized as a valuable difference (Fenton & Krahn, 2007). This movement is a step in the right direction in the struggle over autism and justice, and it need not preclude the strides made by RM. Because neurodiversity places the agency of autistic individuals above other values, this movement is better situated to address the needs of all affected by autism whether child or adult, caretaker or clinician.

Footnotes

1. Members of this community often refer to themselves as “Aspies” according to Robison (2007).
2. Hersey and Blanchard (1977) have a theory of situational leadership in which groups that have high levels of commitment but low levels of experience (i.e., in advocacy work, politics and so on) call for a leader who will be directive and engage the group in effective strategy.

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