

Neuropluralism

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ABSTRACT

Autism is currently one of the most pressing issues in healthcare. Scholarship on the topic is commonly found among psychologists, educators, and, to some extent, philosophers. Surprisingly little scholarship, however, has focused on the ethical issues relevant to autism. Bioethicists ought to give autism consideration, though this may prove to be more difficult than it seems at first glance. The neurodiversity movement is likely to be credited with starting discussions on autism and related issues of justice and ethics, but perhaps this movement has set its sights short. Rather than looking for recognition of neurological divergence, a society that is grounded in neurological pluralism may be better suited to reach this movement's aims.

Key words: Autism; Bioethics; Neurodiversity; Pluralism

Introduction:

One in every one hundred fifty children is diagnosed with Autism (Offit, 2008, pp. 3). The statistics surrounding autism are incredible, and yet still do not take in to account the adults and children who go undiagnosed. Even more incredible is the lack of information about autism that is available to the public. The usual sources of information- scientists, physicians, medical journals and the like engage in heated debates about autism's causes and cures, diagnostic procedures, and categorization. A common perception of autistic individuals, no doubt influenced by this lack of understanding, is that they are:

[S]ocially awkward, isolated, or uncommunicative being, 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 (McGeer, 2009, pp. 518).

The lack of understanding is not simply unfortunate, but, in some cases, leads to questionable moral judgments. It is expected in the U.S, for example, that people will make eye contact as they have conversation. A lack of eye contact might be taken to indicate some degree of guilt, and it's common to use such expressions as "He couldn't even look me in the eye!" to imply this. Often, one of

the indications that a person may fall within the autism spectrum is the unwillingness or inability to make eye contact. Parents of autistic children are more often than not familiar with the results of developmental evaluations noting a lack of eye contact, and many autistic children are sent squirming with the words "look me in the eye..." Autistic adults, too, often note that they tire of being reminded to make eye contact.¹

John Elder Robison (2007) wrote a well-known memoir on the experience of growing up autistic. Robison remembers people noting his lack of eye contact with such comments as "You look like a criminal," or "nobody trusts a man who won't look them in the eye." (pp. 2) Robison also notes that:

'[S]ociopath' and 'psycho' were two of the most common field diagnoses for my look and expression. I heard it all the time. 'I've read about people like you. They have no expression because they have no feeling. Some of the worst murderers in history were sociopaths.' (Robison, 2007, pp. 2).

Such sentiments become ingrained in the autistic experience, and, Robison claims, it is easy to begin to believe them. He remembers spending much of his childhood "waiting to go bad." (pp. 2). Though he never started to make eye contact, Robison no longer believes that not doing so makes him "shifty" or "evasive." He writes:

To this day, when I speak, I find visual input to be distracting. When I was younger, if I saw something interesting I might begin to watch it and stop speaking entirely. As a grown-up, I don't usually come to a complete stop, but I may still pause if something catches my eye. That's why I usually look somewhere neutral...and now I know it is perfectly natural for me not to look at someone when I talk. Those of us with Asperger's are just not comfortable doing it (Robison, 2007, pp. 3).

Are such experiences common across the autistic community? It's likely, though this interpersonal side of the spectrum is rarely the focus of debates in scholarship. Such a disparity between fact and reality illustrates that autism is quickly becoming an issue that ought to be taken seriously by ethicists.

Ethicists have written surprisingly few articles and books about autism. Scholarship on the topic continues to be predominately the subject of psychology, medicine, and special education. Philosophers, when they make note of autism, commonly do so in discussions of the philosophy of mind or the philosophy of

language, discussing autism in relation to the problem of other minds; philosophical work on consciousness, attention, memory, and focus; or use selective mutism, a common symptom of autism, to inform discussions on language and thought. Ethicists, on the other hand, are slow to recognize autism as a problem worth exploring in, for example, bioethics. A small amount of articles have been published on the autistic experience and the neurodiversity movement.² Barnbaum (2008) wrote one of the only books in bioethics devoted to autism. Barnbaum presents autism as a challenge to traditional moral theories, and discusses the value of an autistic life, whether autistic agents are autonomous, and the ethics of research involving autistic individuals. Still, very little scholarship has focused on applied ethical issues relevant to autism.

In this paper, I will argue that the public is not being informed nearly enough by science or the autistic community, and that ethicists have many reasons to talk about autism, and perhaps more challenges facing them as they try. I will also focus on the growing neurodiversity movement and argue that, in order to best achieve three aims of this movement, namely: public access to knowledge about autism; autonomy for autistic agents; and accommodation among social institution (Fenton & Krahn, 2007), a framework that calls for neuroplurality, rather than neurodiversity is necessary. I will begin by discussing the challenges that ethicists face in discussions of autism. In particular, I will discuss the problem of public information regarding autism, and the categorization of autism as a spectrum disorder. In addition, I will propose neuroplurality as a modification to neurodiversity, and will offer reasons why it is well suited to face the challenges posed by considering autism as relevant to ethics.

Why Autism is Challenging for Ethicists:

The Problem of Information

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 (1998), a former physician and surgeon at Britain's well-known Royal Free Medical School, published a paper connecting autism to a vaccine for measles, mumps, and rubella (MMR) that is commonly given to toddlers. Wakefield was certainly not the first researcher to propose a cause or cure for autism, but he is the more commonly known. Wakefield's research was problematic, however. 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'd 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'd 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'd 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*, and in February 2010 that *The Lancet* published a notice retracting Wakefield's research. This retraction came on the heels of a report of over 100 pages released by Britain's General Medical Council (GMC), on January 28th 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, and was published in one of Britain's oldest and most well respected medical journals, and the public had little reason to doubt it. Rather than focusing on clarifying the public's image of autism, researchers had been caught up in a search for the causes of, and cures for it. Research has shown that individuals who are diagnosed with autism in adulthood have radically different perceptions of the disorder-diversity debate than parents who have children who are diagnosed (Clarke, 2008) This seems to indicate that information is so scarce, that opinions on the debate are likely personal and not traditionally informed.

On the Spectrum

The information available to the public about autism and the confusion regarding this information and the various sources of it certainly presents a challenge to talking about autism in ethics scholarship, however, it is not alone. Another challenge to discussions of autism and ethics is the way that Autism is diagnosed and categorized. Autism is not defined by the DSM as one particular disorder, but, rather, a spectrum of neurological differences characterized by the presence of common behaviors and traits, not a common cause or cure. Autism diagnosis relies primarily on phenotypic categorizations (Micali, 2004), that is, the identification and grouping of various behaviors, traits, and abilities that are held in common by the people being diagnosed. A similar mapping of "constellations of symptoms" (Carroll, 2009) is done in order to diagnose a range of mood disorders and other neurological differences (Towbin 2005).

To complicate matters even further, though autism is diagnosed through the use of phenotypic categorization, research is beginning to show that there may be a genetic underpinning to the autism spectrum, however, genetic research is showing that the biological differences that are common to the autism spectrum are also common to other neurological differences, such as bipolar disorder and schizophrenia (Carroll, 2009). Define autism by its phenotype, and the spectrum is so broad that it becomes, in essence, useless, with extreme variance between ends. Yet, if autism is defined

by its genetic connection, and the boundaries between autism and other neurological differences become so blurred that the diagnosis might be meaningless. The Autism Spectrum is widely misunderstood and misinterpreted, and, as a result, much of the research into and data involving Autism is skewed because the spectrum is so wide-ranging that it is, in essence, ineffective for categorization.

In fact, there is much controversy over the classification of Asperger's Syndrome, perhaps the most highly functioning autism diagnosis, in the DSM. In the next DSM revision, due out in 2014, it is likely that Asperger's and Autism will be merged in to one diagnosis, further blurring boundaries. Some are pleased with this movement, arguing that using a spectrum approach serves to remove the stigma from the autism diagnosis, low-functioning autistics receiving the same diagnosis as their high-functioning or Aspergerian counterparts (Grinker, 2010). Many in the Asperger's community, however, reject this recategorization, 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.³ Many scientists and psychiatrists also agree, arguing that:

...what 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, p. 1147).

The confusion regarding the diagnosis and categorization of autism illustrates some features that are central to the struggle for the recognition of neurodivergence. This struggle raises many questions about autonomy, agency, and the rights of autistic individuals. The neurodiversity movement 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.

Neuropluralism:

The struggle for the recognition of neurodiversity, a movement that began in the Aspergerian Community, has expanded to include not only AS and HFA, but also the entirety of the autism spectrum as well as other neurologically diverse individuals, such as those with epilepsy, bipolar disorder, and schizophrenia. 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. Proponents of this movement such as Ari Ne'eman, President Obama's appointee to the National Council on Disability and a 24-year-old man with AS, argue that "stereotypes of autism are self-fulfilling." Others argue that Autism is so central to their personhood that the idea of "curing" it seems to imply a desire for the inexistence of the Autistic person (Solomon, 2008).

Defining autism certainly poses a problem worthy of address by ethicists. How should autism be defined? Is it a disability, or a difference? The neurodiversity movement seeks to rid the media of the idea that autism needs to be "cured," and, rather, aims to view treatments and research as 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 argues that autism is simply neurologically divergent, though not better or worse than the neurological majority (Blume, 1997).

Proponents of the neurodiversity movement 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, however, ought to set its sights higher. It's not enough to simply recognize neurodivergence, but, rather, it ought to be put to work and legitimized through a neuropluralist framework.

Rescher (1993) describes four aims for pluralism: "(1) Legitimate diversity; (2) restrained dissonance; (3) acquiescence in difference, and (4) respect for the autonomy of others." The first of his aims is crucial for the neurodiversity movement. To maximize agency, the recognition of neurodivergence must be made legitimate, recognizing that "the varying experiential situation of different people makes it normal, natural, and rational that they should proceed differently in cognitive, evaluative, and practical matters." (Rescher, 1993, p. 3) It's not enough to simply acknowledge that differences exist, if the aim is maximized agency for all individuals within a neurodiverse society. Legitimizing divergence allows for discussions on how best to mediate diversity.

Rescher's "restrained dissonance" is also central to this movement. If diversity is legitimized, the social system must work to make society safe for difference. Society can't simply consider neurodivergence, it has to restructure itself in a way that this consideration is embedded. Rescher argues that:

A sensibly managed social system should be so designed that a general harmony of constructive interaction can prevail despite diversity, dissensus, and dissonance among individuals and groups- that differences can be accommodated short of conflict. (Rescher, 1993, pp. 3)

But, he claims, this requires that "people can and should, to everyone's benefit, accept and come to terms with the idea-and the fact- that others will differ from themselves in opinion, in evaluation, and in customs and modes of action." This understanding of neuropluralism, that its acceptance is for "everyone's benefit," is fundamental to the neurodiversity movement. It's not enough for autistic individuals to be "tolerated" or "accepted," rather, they need to be considered as essential to the community as neurotypical agents. To this point, Rescher writes:

The rational and productive reaction to dissensus is not so much that we 'tolerate' others as that we respect their autonomy- that we concede their right to go their own variant way within the framework of such limits as must be imposed in the interests of maintaining that peaceful and productive communal order that is conducive to the best interests of everyone alike. (Rescher, 1993, pp. 3-4).

Neuropluralism, then, would place the autonomy of agents, both neurotypical and neurodivergent, at the forefront of ethical appraisal. Neurodivergence would be considered a right, and limitations on variance would only be imposed if they posed a threat to the framework's being for to the benefit of everyone, not only those in the neurological majority. More than simply recognition of divergence, neuropluralism reacts to dissensus among agents by putting variance to work and assuring the protection of their autonomy.

Conclusion:

Replacing the neurodiversity movement with a call for neuropluralism grants and guarantees the consideration of agency and autonomy to autistic individuals. Levels of autonomy and consideration would be a function of each agent's ability to flourish independently, and would be the same for neurotypical and neurodivergent agents. Such a framework would give a legitimate stance from which to critique pseudoscientific efforts.

Neuropluralism also provides science with parameters within which to do its job. Considering agency as central to research and treatment might shed light on what sorts of treatment and research are worthwhile. Wakefield, for example, would have been challenged to defend his research in terms of the agency of his patients. Can consent really be said to have been informed? Did he respect the autonomy of the autistic patients that he used in his research? The research ought to cash out in the ability to increase flourishing or decrease threats to autonomy and agency. Further still, and perhaps most essentially, neuropluralism serves to insure that ethics lands on more sure footing as it leaps in to discussions of autism. While the various debates surrounding autism complicate the broad picture, the concept of agency ought to be enough to start discussions of autism in ethics.

Endnotes:

1. John Elder Robison (2007), a celebrated author who has Aspergers, took this feature to be so central to the autistic experience that he titled his memoir *Look me in the Eye: My Life with Aspergers*. New York, NY: Crown Publishers.
2. The *Journal of Ethics and Mental Health* featured a special issue on Neurodiversity in November 2007.
3. Members of this community often refer to themselves as "Aspies" according to Robison, 2007.

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Acknowledgments: Many thanks to Chris Herrera for comments on earlier drafts of this paper.

Funding and Support: none.

Competing Interests: none.

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Published: November 30, 2011