

Autism, Neurodiversity and Equality Beyond the 'Normal'

A Special Theme Issue Article

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ABSTRACT

"Neurodiversity" is associated with the struggle for the civil rights of all those diagnosed with neurological or neurodevelopmental disorders. Two basic approaches in the struggle for what might be described as "neuro-equality" are taken up in the literature: (i) There is a challenge to current nosology that pathologizes all of the phenotypes associated with neurological or neurodevelopmental disorders (e.g. Autism Spectrum Disorder (ASD)); (ii) there is a challenge to those extant social institutions that either expressly or inadvertently model a social hierarchy where the interests or needs of individuals are ranked relative to what is regarded as properly functioning cognitive capacities. In this paper, we explore some of the reasons justifying (i) which make it an important tool for achieving greater neuro-equality, while still recognizing its limitations for achieving this goal. Particularly, we explore how an appeal to functionality and neurological diversity can support a re-seeing of at least certain forms of ASD.

dyspraxia, dyslexia, epilepsy, and Tourette's syndrome. The neurodiverse, as they call themselves, contest the default pathologizing of differences in brain circuitry that are revealed in behavioral deviances from the standard norm (Harmon, 2004b). Autistic individuals, or the neurodiverse more generally, seek, among other things, better social support mechanisms, greater understanding from those around them or those who treat them, and a recognition that, though they are neurologically, cognitively and behaviorally different, they do not necessarily suffer from being neurodiverse nor do they need to be cured (Sinclair, 1993; Trivedi, 2005).

Two basic approaches in the struggle for "neuro-equality" (understood to require equal opportunities, treatment and regard for those who are neurologically different) are taken up in the literature: (i) there is a challenge to current nosology that pathologizes all of the phenotypes associated with neurological disorders (e.g. ASD) (Edelson, 1995; American Psychiatric Association, 1994); (ii) there is a challenge to those extant social institutions that either expressly or inadvertently model a social hierarchy where the interests or needs of individuals are ranked relative to what is regarded as properly functioning cognitive capacities. Though these approaches are sometimes used in tandem and thought to be compatible, they are not necessarily so. (i) challenges widely held but inaccurate views of what constitutes functional human cognition—inaccurate views that pathologize certain phenotypes that are properly regarded as non-maladaptive cognitive variations in *Homo sapiens* (*sapiens*). (ii), on the other hand, is firmly grounded in motivations of an egalitarian nature that seek to re-weight the interests of minorities so that they receive just consideration with the analogous interests of those currently privileged by extant social institutions. An appeal to expected variation associated with (i) still implies that certain human phenotypes – some of which are expressed by those who qualify as neurodiverse – are maladaptive and so properly pathologized. This feature of (i) places limitation on its usefulness to the neurodiversity movement. In this paper we explore some of the reasons justifying (i) which make it an important tool for achieving greater neuro-equality, while still

Introduction:

Though it was first associated with those diagnosed as autistic – particularly those diagnosed with high functioning autism (HFA) – "neurodiversity" is now associated with the struggle for the civil rights of all those diagnosed with neurological or neurodevelopmental disorders (Ward & Meyer, 1999; Nadesan, 2005:203-210). The current scope of the term includes not only lower functioning autistics (LFAs) but also those diagnosed with such neurological or neurodevelopmental disorders as attention deficit-hyperactivity disorder, bipolar disorder, developmental

recognizing its limitations for achieving this goal. We hereby also suggest that these limitations point to a need to ground neuro-equality more adequately and in fact more forcefully by way of (ii), though admittedly we must leave any detailed discussion of this to another time. We will further narrow our scope by limiting discussion to those neurodiverse diagnosed with ASD. To that end, we will begin our discussion with a summary profile of autism.

On Autism

Autism is a spectrum neurodevelopmental disorder (or set of disorders) characterized by impairments in verbal ability and social reciprocity as well as obsessive or repetitious behaviors (Lord et al., 2000). In particular and among other symptoms, autistic children find it difficult to initiate interactions with others, engage in or maintain eye contact, employ imaginative play, distinguish linguistic play (e.g. sarcasm) from literal speech, and ascribe to others emotional states different from those they are currently experiencing (Frith & Happe, 2005:788). Many of those diagnosed with LFA are virtually indistinguishable from individuals with mental retardation (Burack & Volkmar, 1992:608; Lord et al., 2000:357). This contrasts with many of those diagnosed with HFA, particularly Asperger's Disorder, who can successfully attend pre- or post-secondary institutions and acquire employment including, sometimes, professional vocations (Harmon, 2004a; Grandin, 1996).

As a category, then, ASD covers a relatively wide range of phenotypes, typically described as behavioral or cognitive impairments or deficits, from the very mild to the quite severe. With the inclusion of Childhood Disintegrative Disorder or Pervasive Developmental Disorder–Not Otherwise Specified, it is doubtful that there is one simple cause of autism or that autism is even one underlying condition (Frith & Happe, 2005). Though this fact alone problematizes questions of treatment – including whether treatment is necessary at all – it is further complicated by voiced opposition from a number of disability advocates with autism (or their compatriots, friends and family). Rather than a disorder to be cured or eliminated from the human population, advocates contend that autism is, or perhaps certain forms of autism are, best regarded as different “ways of being” from what is commonly represented or understood as normal or neuro-typical. For these individuals autism is not something from which they suffer, but is rather who they are—an integral part of their personal identity (Harmon, 2004a; Sinclair, 1993; Trivedi, 2005) that is similar to the way that being deaf is integral to those persons identifying as members of Deaf culture (Lane, 1993:17-19,96).

On Resituating Autism

In discussions that seek to problematize the pathologization of autism, whether HFA or non-HFA, it is not unusual to find certain exceptional individuals show-cased as examples of the neurodiverse who contribute to society or who otherwise succeed as active, autonomous citizens in ‘the world of the normal’ (e.g., Temple Grandin, Lucy Blackman, Alan Turing) (Sacks, 1993; Rudy, 2006; Blackman, 2001). Though important for disabusing some

of the misconceptions surrounding ASD, showcasing the successful among the neurodiverse risks two untoward implications: (i) that the cognitive capacities of the neurodiverse (minus the exceptional cases) are still seen as typically lying outside of what is properly regarded as normal or functional for humans; (ii) that the cognitive capacities which are to properly qualify as functional, or at least non-pathological, must enable successful living in the world of those described as normal. (i) is problematic because of its inherently conservative view of what counts as functional or non-pathological. As we will argue shortly, cognitive diversity across taxa and within species supports a liberal understanding of those capacities that exemplify non-maladaptive variation (Scotch & Schriener, 1997:154-155). (ii) is problematic because it serves to obscure and conceal those features of common social institutions specially fitted to a narrowly construed view of normal human capacities (Nadesan, 2005:29-52). These features set up an environment that is not conducive to the full expression of capacities possessed by those described as neurologically impaired. It is unfair to use successful living in such an environment as a litmus test of who properly qualifies as functional.

There are also theoretical reasons for motivating a re-conceptualization of autism. One example consists of critically examining what properly counts as functional. In contrast to impairment, functionality (or being functional) implies a to-be-specified ability to succeed in the relevant behavioral domain. Success in independent living, for instance, is one way of understanding functionality as applied to the neurodiverse. Such an understanding of functionality is attractive in part because it coheres with a common view of autonomy (i.e. self-sufficiency), and autonomy is regarded as a necessary condition of human agency (Beauchamp & Childress, 2001:58). This sense of functionality suffers from at least two drawbacks, however. First, though individuals with HFA would qualify as functional so understood, this will not be the case (or only partially the case) for individuals diagnosed with LFA or those who fall somewhere along the spectrum between LFA and HFA. Second, those who do qualify as functional in this sense do so because of their capacity to integrate into the world of those described as normal (Willey, 1999), but, as we have already stated, this carries undesirable implications about ASD and also leaves unanswered the question of how those currently outside the norm should be granted equal status or inclusion.

Another, less biased, sense of functionality arises out of the notion of human flourishing—where “flourishing” is understood in the loosely biological sense of an animal faring well (broadly construed to include an animal's psychological state over time). This nicely connects flourishing with biological (qua psychological) functionality, though in a way that does not require fitness conferring capacities. This is an important feature of such a sense of functionality as it allows many of us currently described as normal to qualify as functional even though we possess traits that are not strictly-speaking fitness conferring (e.g., poor eyesight, poor sense of smell, slightly overweight, possessing a slight physical build and so on). Though the meaning of “human flourishing” needs

¹ We will understand “impairment” as “[a]ny loss or abnormality of psychological, physiological, or anatomical structure or function.” (Cohon, 2004:qtd on 656).

clarification, it can be indexed to such factors as contentment, self-worth, confidence and personal achievement (Fredrickson & Losada, 2005; Keyes, 2002). Under such a sense of functionality, an individual with ASD need not have HFA to qualify as functional. An argument in favor of adopting this sense of functionality can appeal to current moves to de-pathologize various physical or psychological impairments – which seem to appeal to the sense of functionality just outlined – and a principle of equal treatment (i.e., that like cases be treated alike) (Snyder & Mitchell, 2006).

A common defense of re-conceptualizing autism found in the literature contends that cognitive diversity, and the correlated neurological diversity, is the naturally occurring state of affairs for animals such as humans (i.e. cognitive diversity is normal) (Natural Variation - Autism Blog, 2007). Neuro-typicals, it is argued, hold too conservative a view of the extent of this diversity (Armstrong, 2005). The contention that cognitive and neurological diversity are the norm in the natural world gains partial support from the observed diversity of cognitive capacities as we move across taxa (consider the diversity associated with the class Mammalia). This is not enough, however. If this diversity is to problematize an overly homogenous treatment of human cognition or neurology, it must be observed within human and nonhuman species. Among chimpanzees (*Pan troglodytes*) and bonobos (*Pan paniscus*), who are neuroanatomically similar to humans, this diversity can be observed. Free-living and captive chimpanzees exhibit a variety of skills in using tools to forage for food, engage with conspecifics, groom themselves, and so on (McGrew, 2004). Bonobos in captivity can be observed using tools, something rarely seen in members of free-living populations (Fruth et al., 1999:67-68). Both captive chimpanzees and bonobos have been able to communicate with humans using lexigrams or sign language, skills absent among free-living populations (Fouts & Fouts, 1999; Savage-Rumbaugh et al., 1998). The variety of skilled behavior expressed by these great apes suggests differences in the neurological structures subverting the relevant cognitive processes. This, then, further supports the contention that neurological diversity is the norm in the natural world.

This defense of the normalcy of cognitive, and so neurological, diversity must respond to worries about over-inclusiveness—i.e., by regarding as normal the neurological structures that underlie the behavior of autistic individuals we run the risk of including maladaptive cognitive and neurological traits. A partial response can note that what qualifies as maladaptive, or adaptive, is context sensitive. What is fitness conferring in one environment may not be in another (e.g., peppered moths in industrial England). Consider cross-fostered chimpanzees—those raised by humans rather than conspecifics. Chimpanzees raised in captivity, but particularly those cross-fostered, have a limited skill set for dealing with the natural world. For example, releasing cross-fostered chimpanzees into the wild is not a responsible choice, their chance of survival and successful reproduction is low (Yeager & Silver, 1999:167-168). Despite this lack of certain fitness-conferring behavioral traits, however, cross-fostered chimpanzees enjoy a fit within their captive setting (i.e., they appear to flourish) (Fouts & Mills, 1997). Importantly for our discussion, it is not obvious that because captive chimpanzees lack certain fitness conferring traits they are properly described as cognitively or neurologically abnormal or dysfunctional.

In moving to the human population, we should acknowledge that we already tolerate, if not accept a variety of cognitive differences—again, attendant differences in the underlying neural structures. It is common knowledge that certain people excel in social skills, while others excel in analytic or physical skills. Even individuals who have noticeable problems socializing or who engage in obsessive behaviors – think here of social introverts or “computer geeks” – are typically described as “normal” (or normal enough to qualify as “normal”). Perhaps some of these individuals are properly regarded as autistic (i.e., as having Asperger’s Disorder) (Jackson, 2003), at least under the current diagnostic criteria (American Psychiatric Association, 1994), but this is not essential for our point.

From these observations we can conclude that, unless the relevant deficits qualify as dysfunctions (i.e., are maladaptive), the given cognitive and accompanying neurological differences—even when these are associated with deficits in skilled behavior—are not ordinarily grounds for pathologizing a certain way of engaging with the world. Accordingly, there is good reason to re-conceptualize HFA. Unfortunately, LFA, or forms of autism that fall along the spectrum between LFA and HFA, are not so ‘easily’ re-conceptualized. Here we are forced to own that the mere existence of neurological diversity within our species in and of itself does not require moral recognition. Though this feature of the argument from diversity indicates its limitations as a tool for the neurodiversity movement, two possibilities that might justify extending the conclusion beyond HFAs present themselves here: (i) even in what is described as LFA, there are individuals who excel in certain kinds of localized information processing; (ii) the epistemic standpoint of those generally diagnosed with ASD yields knowledge often missed by those who meet the current standards of normality (Happé, 1999).

(i) calls for a resituating of the received perspective on cognitive skill and deficit, seeing the generalized skills in information processing – which characterize those typically regarded as normal – as coming with their own deficits and seeing the localized skills in information processing – which can characterize those typically regarded as autistic – as skills (Motton et al., 2006). This is not panglossian. We are not suggesting that those with LFA have an easy life nor are we denying that their carers sometimes shoulder a heavy burden of care. What is being problematized is a panglossian view of ‘the ordinary’ and an overly narrow perspective on expected neurological variety within the human species.

(ii) faces similar pitfalls to showcasing HFAs mentioned above. Defending the inclusion of the neurodiverse in the community of those currently described as normal by appealing to an epistemic success judged according to the standards of the neuro-typical risks othering the neurodiverse as abnormal (or sub-normal). If, however, we recognize accurate information states, arising from a to-be-specified sensitivity and responsiveness to changing environmental cues, as valuable to any cognizer, then the insights arising out of autistic experience can enjoy a high epistemic status not predicated on the epistemic standards of the neuro-typical. Temple Grandin’s ability to understand some nonhuman behavior and make breakthroughs in the treatment of slaughter animals (Grandin & Johnson, 2005) is just one example of many within the autistic community (Dekker, 1999) that point to autistic experience as an important epistemic standpoint. The general human

community of believers loses by failing to recognize the value of insights arising from autistic experience, but the value of an autistic standpoint need not depend on the general community recognizing it as such.

In sum, to pathologize the entire spectrum of autistic “disorders” sits uneasily with the observed variety of cognition (and the sub-vening neurological structures) seen across Hominini, including humanity. Even if many examples of LFA are properly pathologized, perhaps with reference to functionality as understood above, the current practice and accompanying general negative outlook on autism is unwarranted (Avdi, 2005).

Autism Resituated

Resituating, or re-conceptualizing, ASD has several implications for treatment. In addition to a required reassessment of how the neurodiverse are regarded in the health care system, we should re-conceptualize healthy living and independence (or independent living).

First, we should recognize that the neurodiverse are not necessarily in need of a cure, nor do they necessarily suffer from any condition, disease, disorder or illness (Dallos et al., 1997; Dallos & Hamilton-Brown, 2000). What’s more, to qualify as functional, the neurodiverse need not meet the standards of living accepted or assumed by those currently described as normal (Ward & Meyer, 1999). Consequently, the nomenclature used in descriptions of the neurodiverse – terms like “Autistic Disorder”, “Asperger’s Disorder” or “Autistic Spectrum Disorder” – should be revised.

Second, we should broaden our understanding of healthy or independent living. As stated earlier, individuals with HFA can enjoy healthy living (i.e., they can be functional). More importantly, much the same can be said for those who, though diagnosed with ASD, are not HFAs. What is crucial is whether they are content, have self-worth, confidence or enjoy personal achievements. This cannot be decided in the arm chair, or without re-seeing the putative patient and listening to her caregiver (Lynch, 1998).

What qualifies as independent living or autonomy should also be reassessed. Though many among the neurodiverse require special care and social support, this need not undermine the claim that they live independently or enjoy a degree of autonomy. Rather we need to understand independent living as inter-dependent living (Fisher, 2007) and autonomy as relational (Sherwin, 1998). This change in our understanding of independent living, or autonomy for that matter, is long overdue. As has been noted by others, our ability to successfully live together either in urban or rural environments requires us to inter-exist (Reindal, 1999; Stewart & Bhagwanjee, 1999). Arguably in societies like Canada, recognition of interdependence motivates the construction and maintenance of social institutions that protect the vulnerable and enhance the opportunities of the dispossessed. This sense of interdependence, and regard for others in one’s greater community, is not unrelated to the kind of support required to help the neurodiverse realize their full potentials.

Third, those diagnosed with ASD should be given more control over the types of treatment that they receive and when they receive it (Moloney & Paul, 1989). For example, it is not acceptable to expect that an autistic individual undergo behavioral therapy that teaches them to suppress various physical or verbal ticks. An important criterion for whether they undergo treatment is whether it is in their interests, understood as a recognizable interest from their perspective—i.e., what qualifies as being-in-their-interest enables their faring well.

Conclusion

In conclusion, naturally occurring cognitive diversity, and the accompanying neurological diversity, coupled with a robust understanding of functionality, make it impossible to maintain the current view that HFA is pathological. However, it is important not to fail to appreciate the limitations of appeals to cognitive or neurological diversity when seeking neuro-equality. Under such appeals LFA continues to qualify as pathological. This said, there is little doubt that both higher and lower functioning autistics can be functional in the sense we defended earlier, and this should impact how neuro-typicals perceive ASD. Such a re-seeing of ASD will advance the struggle to one day see equality beyond what is now regarded as normal.

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