

The Social Constructions and Experiences of Madness

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Has Autism Changed?

Simon Cushing

Abstract

The fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM) has just been published and it contains the following changes from the previous edition: gone are the subcategories ‘Autistic Disorder,’ ‘Asperger Syndrome’ and ‘PDD-NOS,’ replaced by the single diagnosis ‘Autism Spectrum Disorder,’ and there is a new category ‘Social Communication Disorder.’ In this paper I consider what kind of reasons would justify these changes if one were (a) a realist about autism, or (b) one were a constructivist. I explore various analyses of autism in the research literature that portray it as essentially either a psychological, neurological or genetic phenomenon, and discuss these by reference to the diagnostic criteria and by analogy with the way we understand race and sex categories. I conclude that no realist reasons are available to justify the changes in the diagnostic criteria, and further, that the only way the changes could be justified is if one takes the position that the DSM categories are social constructs. I conclude by exploring what implications follow from this.

Key Words: Autism, Autistic Disorder, Asperger Syndrome, PDD-NOS, DSM-5, realism, constructivism, mindblindness, weak central coherence, executive dysfunction, Simon Baron-Cohen, Uta Frith.

1. Introduction

The most notorious change associated with autism in recent decades has been the sharp increase in the number of diagnoses. However, it is a second, more recent change, one that is often claimed to be motivated by the former, which shall concern me here: the alteration in diagnostic criteria in the Diagnostic and Statistical Manual of Mental Disorders (DSM), the standardized reference guide published by the American Psychiatric Association and used by clinicians in the US as a basis for their diagnoses.

On 18 May 2013 the fifth edition of the DSM was published. It had been at least 13 years since the last update (the DSM-IV-TR) and this time there was considerable controversy surrounding the new definitions contained therein. There were two major changes that directly concerned autism:

1. Three separate diagnoses, “Autistic Disorder” (AKA “classic autism”), Asperger syndrome and PDD-NOS (Pervasive Developmental Disorder Not Otherwise Specified) were

unified into the single diagnosis, “Autism Spectrum Disorder [ASD].”

2. A new diagnostic category, “social communication disorder” (SCD) was created that will cover some people who would formerly have been diagnosed as one of the three sub-categories above (probably PDD-NOS).¹

It is worth noting that this is not the first time the criteria for identifying autism have been tinkered with. To see that, we need to look at the ur-text of our contemporary notion of autism (at least in the English-speaking world): Leo Kanner’s paper, ‘Autistic Disturbances of Affective Contact.’ In that report, Kanner describes ‘a unique ‘syndrome,’ not heretofore reported’ marked by a set of common characteristics.² Those characteristics include: late speaking; a use of language that is rote and focused mainly on the use of nouns to identify objects, colours or numbers; excellent rote memory; ‘delayed echolalia’; personal pronouns ‘repeated just as heard, with no change to suit the altered situation’; common failure to attend to people calling on the subject; fussiness about food; adverse reaction to loud noises and moving objects; lack of spontaneity; treatment of people like objects; possession of ‘good cognitive potentialities’ and ‘strikingly intelligent physiognomies’; and clumsiness in gait allied with skill in finer muscle coordination.³ All or most of these features will seem familiar to anybody with a friend or family member who has been diagnosed as on the autism spectrum and indeed later commentators remarked that Kanner’s list stood up remarkably well.⁴ However, there have been significant changes both between Kanner’s original list and diagnostic criteria in the DSM-IV, and between those criteria and those of the DSM-5.

Since word of these changes leaked before the publication of DSM-5 there has been a flood of articles discussing them, prognosticating about their impending effects both on new diagnoses and on the status of those diagnosed under the former criteria, and wondering about the motivation and/or justification for the changes. For example:

When the APA publishes the *DSM-5*, people who have already met the criteria for autism in the current *DSM-IV* will not suddenly lose their current diagnosis as some parents have feared, nor will they lose state services. But several studies recently published in child psychiatry journals suggest that it will be more difficult for new generations of high-functioning autistic people to receive a diagnosis because the *DSM-5* criteria are too strict. Together, the studies conclude that the major changes to the definition of autism in the *DSM-5* are well grounded in research and that the new criteria are more accurate than the

current *DSM-IV* criteria. But in its efforts to make diagnosis more accurate, the APA may have raised the bar for autism a little too high, neglecting autistic people whose symptoms are not as severe as others. The studies also point out, however, that minor tweaks to the *DSM-5* criteria would make a big difference, bringing autistic people with milder symptoms or sets of symptoms that differ from classic autism back into the spectrum.⁵

There is a lot going on in this passage that is of interest. First, why the difference in status between those old enough to be diagnosed under earlier editions of the DSM and those now under the aegis of the DSM-5? Surely either the new standards are right and the old wrong (which is implied by the fact that only the new criteria will be applied to new diagnoses) or both are equally valid, which would seem to obviate the need for the new criteria. There is a similar tension between ‘making diagnosis more accurate’ and ‘raising the bar too high.’ If the changes are ‘well grounded in research,’ in what sense could they ‘raise the bar too high?’ Are we operating on two sets of standards here, only one of which is supposed to be objective and value-free? Which of the sets of standards would motivate the ‘minor tweaks?’

The central question of this paper then, is what are the reasons for the various changes to the diagnostic criteria that I have delineated above?

2. Realism vs. Constructivism

Before we get to the main discussion, I would like to consider and reject one possible way of denying the premise of my question. This is to assert that there *haven't* been any changes of criteria. Notice that each of the three sets of diagnostic criteria, Kanner's and the DSMs IV and 5, are associated with conditions of different names. It may be true that there is significant overlap in the conditions, but they are none-the-less distinct, and it is not the case that any has *superseded* any other, they just all exist in parallel: Kanner's syndrome, PDD-NOS and ASD all exist alongside one another as conditions it is possible to have right now. The advantage of this view is that it allows us to say that Kanner was *right*: he accurately identified a genuine condition and modern advances have not contradicted him.

While this view is certainly coherent, it is not worth much discussion. Why, one would ask, if Kanner's syndrome is a live possibility, is it nowhere to be found in either edition of the DSM discussed here, and why has Asperger syndrome vanished from DSM-5? I shall proceed on the assumption that contemporary researchers and clinicians believe that they are refining what Kanner started: that he noticed *something* and it is that same something that contemporary diagnostic criteria are meant to capture, and capture more accurately. His list itself is not

sacrosanct, it was just a set of characteristics (most of which) were the effects of a condition that is distinct from any subset or individual instantiation of those characteristics.

So, given that we are assuming that there has been real change in the diagnostic criteria, and that Kanner and the DSMs *disagree*, what grounds can the compilers of the criteria of the DSM-5 give to defend *their* criteria as an improvement over what came before?

The answer to that question can both depend on and influence our metaphysical stance on what autism is (where I am using ‘autism’ here to stand in for any and all of the related syndromes described in various diagnostic manuals). Let’s crudely divide our metaphysical possibilities into *realism* and *constructivism*. Realism, we shall say, assumes that our conceptual categories ‘carve nature at the joints,’ or map on to real differences in the mind-independent world, whose existence, while influenced by the way people act towards it, is distinct from the way we think about it. Constructivism, by contrast, assumes that the nature of autism is somehow determined by human intellectual activity, in that the *concept* of, in this case, autism is intimately tied to autism itself.

The controversies and competing positions regarding *race* and racial categories offer instructive parallels. For one thing, the racial categories used on US census forms change with every new census, and millions of US census respondents change their self-identification from one census to the next.⁶

What response should the fact of these changes provoke in us? Clearly it could make us suspicious of *any* racial categories. One would think that race categories should not be like rankings of popular baby names, which can be expected to change from year to year with no public outcry. Nor should one’s racial identity vary like the width of one’s lapels from season to season. If we find race categories behaving in this way we might suspect that there is no more to them than public perception. Of course, for constructivists, this is neither surprising nor to be regretted. Race categories are *social constructs*, projections of the collective *zeitgeist* on to the world.

On the other hand, it is hard to reconcile such changeability with a robust *realism* about racial categories. Realism about racial categories demands a justification for any alteration in our list of recognized races, ideally one based on improved knowledge of the world, so that our new categories are in some way a *more accurate* reflection of the reality they purport to map. But what kind of reality is it that our concepts are supposed to represent? What is it that divides into groups that our conceptual categories track with increasing accuracy?

For race, the reality would be biological, as racial traits are themselves biological. Indeed, this is why the very concept of ‘race’ has come to be challenged, because it does not seem that there *is* any biological essence that any of our racial categories map on to. Of course, this does not mean that there is no such thing as *racism*, sadly, as humans persist in acting as if race were a real thing. And

this very fact, say the social constructivists, is what *makes* race real, a reality of human making, by which humans who move around in it cannot help to be affected. This means that social constructivists, too, will demand justification for change in categories, particularly given the impact of such categories on people's lives and status. Depending on one's overarching ideology, one might look for the influence of powerful interested manipulators or one might point to certain impersonal engines of cultural change, but certainly the question of whose interests are served by the changes in categories will be raised.

I draw two morals from the foregoing. First, whether or not one is a realist or social constructivist about racial categories can and should be influenced by what one observes about shifts in the categories themselves. Second, whether or not one is a realist or social constructivist will affect what kinds of justifications one will demand for such shifts. I will apply these morals to the changes in the diagnostic criteria for autism and closely associated conditions.

3. Justifying the Changes

Suppose we are realists about autism, and we believe that there really is something out there in the world that we have discovered and can perhaps learn more about, what kinds of reasons would motivate the kinds of changes in diagnostic criteria we have seen?

The most obvious reason would be that we now *know more* about autism, we have discovered *more facts* that necessitate *more accurate* diagnostic criteria. But what is the 'more' that we could know? A radical kind of advance would be if we now know that autism is a different *kind* of phenomenon from what we previously thought, like the shift from thinking about light as a wave to thinking of it as a particle. So, for autism, it might be that we previously thought of it simply as a cluster of behaviours but now we identify autism with, say, a psychological 'module,' or a biological feature of the brain, or a genetic condition.

Alternatively, it might be that we have not changed what *type* of phenomenon we think it is, we just know *more* about the phenomenon, presumably because of improved scientific studies or technological advances.

Finally, it might be that the change is in that the original diagnosticians, beginning with Kanner, were agnostic – neither realists nor constructivists – and the change is that since that time we have *become* realists. That is, Kanner just noticed that he had several patients who could be grouped together, but reserved judgment on what kind of thing explained the similarity.

The kind of reasons that a realist would *not* endorse as reasons to change diagnostic criteria would be reasons that were unrelated to changes in knowledge of the nature of the phenomenon itself. So, for example, a change in attitudes (moral or otherwise) towards autism, like the changes in attitude towards homosexuality or transgenderism that we have seen in the US over the past few decades, would not affect the criteria of diagnosis. Whether or not society regards

it as a disorder or a feature should have no bearing on whether or not you *are* autistic, according to the realist. Neither should pragmatic monetary concerns have any bearing. It is certainly true that, should the numbers of people diagnosed as autistic continue to rise exponentially, and insurance companies be required to pay for treatments, then there might be pressure on diagnosticians to narrow the diagnostic criteria or to come up with a greater spectrum of diagnoses and only label some of them as requiring treatment. But this would not be driven simply by knowledge of the phenomenon, as realism requires.

But perhaps it's not that simple. Consider how the criterion of death has changed. Here is the opening paragraph of the Report of the Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Death, which met in 1968:

Our primary purpose is to define irreversible coma as a new criterion for death. There are two reasons why there is a need for a definition: (1) Improvements in resuscitative and supportive measures have led to increased efforts to save those who are desperately injured. Sometimes those efforts have only a partial success so that the result is an individual whose heart continues to beat but whose brain is irreversibly damaged. The burden is great on patients who suffer permanent loss of intellect, on their families, on the hospitals, and on those in need of hospital beds already occupied by these comatose patients. (2) Obsolete criteria for the definition of death can lead to controversy in obtaining organs for transplantation.⁷

That is, with the old criterion of death, people who were 'brain dead' still counted as alive. This hadn't been a problem before the development of artificial respiration, as the majority would have died anyway, but since that advance, wards were 'filling up' with brain dead patients who could live for months or years longer. At the same time, the technique of heart transplantation had been pioneered by Christiaan Barnard, which was (and remains) only possible with a heart that was beating very recently before the surgery. Before the advent of respirators, such hearts were very hard to come by. The Harvard Committee are openly admitting here that their goal is both to allow hospitals to remove 'patients who suffer permanent loss of intellect' from life support and to provide a source of organs for donation. And so the criterion of death was changed.⁸ Notice two things: both the prior and current criteria of death are very much realist: they point to actual phenomena in the world as the signs of death. But at the same time, the change was motivated by pragmatic concerns. And there are signs that the same thing might be happening for autism, as these quotes from reports about the changes between the DSM editions show:

“We have to make sure not everybody who is a little odd gets a diagnosis of autism or Asperger disorder,” said Dr. David J. Kupfer, a professor of psychiatry at the University of Pittsburgh and chairman of the task force making the revisions, which are still subject to change. “It involves a use of treatment resources. It becomes a cost issue.”⁹

The changes would narrow the diagnosis so much that it could effectively end the autism surge, said Dr. Fred R. Volkmar, director of the Child Study Center at the Yale School of Medicine and the author of the new analysis of the proposal. ‘We would nip it in the bud.’¹⁰

The effects, in particular, of moving some patients who would have fallen under the DSM-IV definition of ‘Autistic Disorder’ to the new ‘Social Communication Disorder’ may indeed have cost-saving effects (although not for the patients or their caregivers, of course):

For students re-classified into the new proposed diagnosis of Social Communication Disorder or who are otherwise ineligible for an ASD diagnosis under the DSM-5, the IDEA (Individuals with Disabilities Education Act) eligibility process may prove more challenging.¹¹

Interestingly, a recent study casts doubt on whether or not the changes between the DSMs have had any effect on rates of diagnosis.¹² What lessons should we draw from the example of the criterion of death and the quotes of Drs. Kupfer and Volkmar above? Can we be realists but have changes in diagnostic criteria still be driven by pragmatic or value-driven concerns? I don’t think so. First of all, remember that the criterion of death is not the same as a *definition* of death. Presumably, if we are realists, the definition of death doesn’t change, it’s just that we don’t necessarily know what it is. Assuming that water really is H₂O, it always *was* H₂O, even when we didn’t have a conception of atomic structure and even if our criterion for recognizing it was ‘potable clear-ish liquid.’ Secondly, the fact that our criteria of death both before and after the Committee’s recommendations include real-world phenomena doesn’t mean that the metaphysical view of *death itself* is realist. It could still be ‘whatever we decide death is.’ Compare beauty: we can say with perfect consistency that beauty is a socially-constructed phenomenon and changes from culture to culture and epoch to epoch, without denying that the features that make it up (body mass, facial structure, skin texture, et. al.) are *not* socially constructed.

So, I argue that if the reasons motivating the changes in diagnostic criteria *were* really driven by financial worries, then that strongly indicates that the diagnostic categories of the DSM-5 should not be given a realist interpretation. However,

consider this claim, published in an article in ‘the official newsmagazine of the American Academy of Pediatrics’:

The diagnostic criteria for autism spectrum disorder has been modified based on the research literature and clinical experience in the 19 years since the DSM-IV was published in 1994.¹³

That is, the diagnostic criteria *have* been modified, and in response to knowledge acquired in the interim. This would ring true if there was some emerging consensus about autism, like the consensus that AIDS was caused by the HIV virus, where previously it was just known by its symptomatic effects. But no such consensus can be found when it comes to autism, and certainly not a consensus that would justify the specific rejection of Asperger Syndrome and the introduction of SCD. In fact, according to Harker and Stone, the collapsing of Autistic Disorder, Asperger’s Disorder and PDD-NOS into the single category of ASD was ‘reflecting research indicating a lack of reliability across clinicians in assigning subcategories,’¹⁴ which suggests that if there was some consensus before DSM-IV that motivated the three separate subcategories, it has vanished. What seems to have been learned by the clinical experience of those trying to apply the DSM-IV criteria is that they were hopelessly vague and open to diverse subjective applications.

But again, if the DSM-IV’s criteria were merely intended to give the visible signs of a reality only visible at the brain or genetic level, then the only lesson we could learn from looking at lack of clinical consensus is that the diagnostic criteria needed to be tied closer to the invisible reality. It shouldn’t be that *the subcategories themselves* do not apply.

Let me give another analogy to illustrate. It used to be the case that there were clinical ‘experts’ on the ‘disorder’ of homosexuality. They believed, not just that homosexuality was a sign of ill mental health, but that it could be recognized from the results of (then) respectable psychological tests – the Rorschach, Thematic Apperception and Make-A-Picture-Story tests, none of which was directly correlated to sexual preference. In other words, it was believed that there was an *essence* to homosexuality which had pervasive effects across all areas of personality, not just on one’s preferred love interest or sex object. Indeed, this was part of what made homosexuality a disorder: it disrupted all areas of one’s life. Of course this belief was famously debunked by Evelyn Hooker, as she demonstrated that the so-called experts fared no better than blind chance at distinguishing homosexuals from heterosexuals from the results of the tests.¹⁵ Notice, though, that this did not cause us to abandon the notion of homosexuality itself, just the idea that it was a mental disorder. If we think of the results of the three tests above as analogous to the diagnostic criteria for autism, then the lesson of the clinicians’ inability to reach consensus on who fits in what subcategory should only be a sign that the criteria themselves are not good indicators (as the results of the Rorschach

et. al. were not good indicators of homosexuality), but not that the categories themselves are wrong... unless we never had good reason for the categories in the first place. But then, why should we think that current confusion *lends support* for the new categories of the DSM-5. Furthermore, consider the following advice from the same article in AAP News referenced above:

Because almost all children with DSM-IV confirmed autistic disorder or Asperger syndrome also meet diagnostic criteria under DSM-5, re-diagnosis is not necessary. Referral for reassessment should be based on clinical concern. Children given a PDD-NOS diagnosis who had few DSM-IV symptoms of autism or who were given the diagnosis as a “placeholder” might be considered for more specific diagnostic evaluation.

Patients may wish to continue to self identify having Asperger syndrome, although the DSM-5 diagnostic category will be ASD.¹⁶

On the one hand this advice is consistent with a realist interpretation of the changes (PDD-NOS as a ‘placeholder’ for the newer, better diagnoses), but it also allows that one can keep a ‘self-identity’ of Asperger condition. Why, if it is inaccurate? The answer indicates the minefield the writers of DSM-5 had to traverse: they were not just altering medical diagnoses, but labels that individuals looked to as a source of identity. It is certainly telling to see identity politics seeping into a supposedly value-free clinical enterprise.

4. Psychology, Neurology and Genetics

So much for clinical experience justifying the changes in diagnostic criteria: what about the ‘research literature?’ Here, if anything, there is even less consensus. There is not even consensus over what level of phenomenon autism might be. The options are as follows.¹⁷ First, autism could be located at the level of behavioural characteristics. That is, on this view, if one exhibits the characteristics described in the DSM, then one is autistic. If not, one is not. On this view, autism would be both treatable and, in theory, curable, if one ceased to exhibit the symptoms. Some do indeed claim that it is possible to ‘recover’ from autism.¹⁸

Second, autism could be a psychological phenomenon. This differs from the first option in that one could have the condition but not exhibit it. Compare with homosexuality: if it were at the first level, then anyone having same sex sex, would at least meet a most basic condition for being gay. The idea of a lifelong gay virgin would lack content. However, if homosexuality were a psychological phenomenon—say, ‘same-sex sexual attraction’—then one could be gay even while living the

same life as someone heterosexual. It allows for one to be closeted to everyone, even possibly oneself.

Third, autism could be a feature of the brain, such that all and only those with the requisite kinds of neural arrangements would be *really* autistic, allowing for the possibility of exhibiting either psychological or behavioural features associated with autism while not being autistic, or conversely, lacking either but being autistic.

Finally, autism could be located at the level of the genes, so that one would need a genetic screening to tell if one were *really* autistic. Some people believe that biological sex is like this, so that one can *appear* female (say) but if one has XY chromosomes, then one is *really* male. It was this view of what sex amounts to that led to the dismissal of a malpractice suit brought by Christie Lee Littleton against the doctors responsible for her husband's death: the Fourth Court of Appeals of Texas ruled that the man who died could not have been her husband because she was actually biologically male because she was XY (Littleton was transsexual, a transwoman) and Texas did not (and does not) recognize same-sex marriage.¹⁹ It also led to the end of Spanish hurdler Maria Patino's athletic career because she failed a 'sex test' at the 1985 World University Games in Kobe, Japan. Unbeknownst to her, Patino had Androgen Insensitivity Syndrome (AIS), so named because typically an XY fetus develops male genitalia as a result of exposure to androgen *in utero*, but AIS individuals do not respond to that androgen. As a result, they are usually designated female at birth, and grow up thinking of themselves in that way.²⁰

It is a fairly striking disagreement that researchers have not even settled where autism is to be located. I think the assumption most people have is that these levels will line up, so we don't necessarily have to settle this issue. But the example of sex shows the problems with this: Christie Lee Littleton's and Maria Patino's self-identities as female matched their outward appearances and secondary sexual characteristics, but did not match up with the 'right' kind of chromosomes. What are we to say in these kinds of instances?²¹ This is not something that science can help us with. Science can tell us, for example, what genes correlate with what brain types or patterns of behaviour, but it is up to us to decide which represents the 'true essence' of something. With 'water' we appear to have decided that the essence lies at the molecular level. If something is *not* H₂O, then it does not matter how clear or potable it is, or even if it boils at 100°C, it is not water.²² I think it is assumed, therefore, that science *showed* that 'water' was H₂O. This is not the case: 'water' used to refer to a much wider range of things than simply H₂O (basically anything wet) and still does refer to things that contain a lot more than just H₂O. We have *decided* to alter our usage because H₂O covers a significant chunk of what we were calling water. But we could have gone another way. And it looks like we might with sex: while many are still under the impression that XY=male and XX=female, the emerging acceptance of transgender individuals and the

changing societal view that we should honour their self-identifications will mean that decisions like that in *Littleton v. Prange* will soon be as scorned as the one in *Dred Scott v. Sandford*. One's sex will be up to oneself in a way that one's chromosomes are not.

There is a further lack of consensus even between researchers that agree on what level is most basic. For example, assuming autism is a psychological feature most essentially, *what* psychological feature? Simon Baron-Cohen is often cited as a leading expert, but his own theory continues to mutate, from 'mindblindness,' through 'empathizing-systematizing' and the 'extreme male brain.' His various theories all have similar problems, though, in that they only even attempt to explain a subset of the features that the DSM asserts are definitive of autism disorders.²³ Uta Frith has offered 'Weak Central Coherence' as an alternative, but that too has the problem that it would at best explain a subset of the diagnostic criteria (noticeably having nothing to say about motor issues), and furthermore that those features are shared by individuals who are *not* labelled autistic.²⁴ A third major contender is that autism is 'executive dysfunction.' The features of autism that executive dysfunction is said to explain are the repetitive behaviours, reliance on routine, 'obsessive' interests and (purported) lack of creativity,²⁵ as well as the inability to plan a schedule for oneself. However, once again, it does not seem equipped to explain any sensory issues or the things the other theories purport to explain, such as social difficulties or enhanced perception of detail, so it is at best incomplete. Also, repetitive behaviours, reliance on routine, *et al.* are features of other distinct psychological conditions, like Obsessive Compulsive Disorder or Tourette's syndrome, so even if executive dysfunction explained these things it would not be a unique indicator of autism.

What we see, then, is that the contenders that offer a psychological account of the 'essence' of autism would, if correct, require a major re-working of the diagnostic criteria, or, failing that, are incomplete. Does it seem likely that any of these theories is behind the changes between DSMs IV and 5? Well, no: if anything they seem tied to the distinction between Asperger's and autism, and they do not seem amenable to underpinning the new category of SCD. Furthermore, the fact that sensory issues are stressed in DSM-5 also counts as a blow against these theories.²⁶ The prevailing view seems to be that the diagnostic criteria provide the more accurate guide to who fits the syndrome and the theories need to be adapted until they agree with the criteria – in other words, the influence is in the opposite direction from what it would be if the theories explained the changes in diagnostic criteria.

So, if psychological theories cannot explain the changes, what about studies of brains?

Perhaps it will not surprise you to hear that there is as much disunity amongst brain researchers as we have seen amongst psychologists. Jill Boucher provides a reason why this might be:

The implications of findings on brain function are easily identified because the research is always hypothesis-driven. That is to say, each study is designed to test a specific hypothesis concerning the neural activity that occurs when the person being tested is carrying out a specific task.²⁷

In other words, the brain research does not drive the psychological theorizing but rather the reverse. That is, researchers identify a feature that they associate with autism and then do studies to find out if that feature correlates with an identifiable part of the brain. Reading these studies is rather depressing, as the underlying presuppositions of the studies are often rather crude and it is clear that it is less the case that brain studies are advancing our view of autism than that our current view of autism is holding back brain studies.²⁸

As a materialist I have to believe that *some* of the phenomena that Kanner noted are associated with particular brain structures, but perhaps it would be fair to say that autism is not located at the neural level. If we speak of an ‘autistic brain’ then, maybe we can say it is the *result* of a particular genetic structure. Maybe autism, like Down syndrome, has a specific genetic origin. Certainly that would make sense of the fact that ‘there is now considerable evidence from family and twin studies that, for a subgroup of autistic individuals, the etiology is mainly genetic.’²⁹ What recent studies seem to show is that autism is *genetic* (like Down syndrome) because of the high rate of concordance in monozygotic twins, *familial* (unlike Down syndrome), but that *environmental factors* also must play a part (because in 10% of cases one monozygotic twin has autism but the other doesn’t at all, and in cases where both have it, the severity can vary widely).³⁰ But a complicating factor to the notion that autism is ‘in the genes’ is the now well-accepted notion of ‘broader autism phenotype’ (BAP). This is

a behavioral phenotype that is qualitatively similar to but more broadly defined than that which defines autism occurs more commonly in relatives of autistic individuals than in the general population.³¹

Or, as Baron-Cohen puts it, ‘mild echoes’ of autism:

This might take the form of being socially withdrawn or confused by social interaction, or mildly obsessive (in the sense of having strong narrow interests or a need for sameness) or having excellent attention to detail and remarkable memory. Although [the close relatives of autistic individuals] don’t have autism or Asperger syndrome itself, they have a milder manifestation of the same characteristics.³²

The existence of ‘BAPs’ in families of autistic individuals would appear to explain the apparent high incidence of autism in the children of academics in such disciplines as Philosophy and in such places as Silicon Valley: the kind of focus and interest that leads one to succeed in certain intellectual pursuits is itself evidence of BAP. However, I would argue that actually BAP threatens the coherence of the concept of autism because it allows that one can have *some* of the criteria but not all. While this is acknowledged by the DSM (each edition makes clear that there are several conditions, each of which is necessary, none of which is individually sufficient), it also makes each diagnostic category look very arbitrary. Why *that* number of symptoms? What if you have one very severely, but others below the level necessary for a diagnosis? Then you would not meet a diagnosis, but clearly you have some challenges such that you would benefit from assistance of some kind.

What if a genetic test did emerge? It seems very possible that, on the one hand, many people who currently have no diagnosis for ASD would test positive, and at the same time many who do have a diagnosis would lack the gene. By analogy with a genetic definition of biological sex: AIS people like Maria Patino would previously have had the category of ‘woman’ but lose it on genetic testing, while, conversely, they would *gain* a ‘diagnosis’ of ‘male.’ But just as in the case of AIS individuals, science does not make the final decision as to what we regard as definitive of a person’s sex. And when we are considering autism, where social services and insurance issues depend on a diagnosis, it would seem perverse to provide services for somebody who does need or want them because of a genetic marker while denying them from somebody who would clearly benefit from them on the basis of its absence.

But we are a long way from that, anyway: a study of over 200 papers published between 1961 and 2003 on the genetics of autism reached the following conclusion:

Although many genes and proteins have been implicated as causes of autism, too little is known about their functions or their role in brain development to generate a parsimonious hypothesis about the brain dysfunctions that underlie autism. Evidence from multiplex families with the broader autism phenotypes, together with twin studies, indicates that single-gene defects are rare even within families... Despite the profusion of investigations into the genetics of autism, few significant genetic linkages to autism have been identified.³³

Clearly, then, any changes between DSM-IV and DSM-5 cannot be justified by ‘knowledge’ of a genetic basis to autism.

5. Conclusion

Realism about the various conditions that could be grouped under the heading of autism would demand that any changes to our diagnostic criteria be motivated by an advance in our knowledge of the real, mind-independent phenomenon that we refer to with that term. I argue that there is no consensus among clinicians or researchers that could possibly justify us claiming better knowledge of such a phenomenon. We don't even know what we're looking for. That would appear to imply that I am denying that people are autistic, just as people who question the biological basis for race deny that individuals really have a race. I am hesitant to go that far. What I will say is that there are no doubt conditions that the diagnostic criteria in the DSMs identify that have a biological realization, just as one's hair texture, skin pigmentation and facial structure have a biological realization, even if race does not. This leaves the door open to the idea that 'autistic,' like, say, 'black,' is amenable to a constructivist analysis. What that would mean, however, is that the kind of questions we would ask about the changes between the editions of the DSM would be about whose interests those changes serve and not assume that scientific impartiality is what is driving them. Indeed, a constructivist would be very suspicious of the medicalization of autism as a category. Those who press for the rejection of any notion that autism is a disorder, and argue that it is simply a different way of being, and that we should talk of 'neurodiversity' instead of 'the normal' and 'the disordered' are motivated by just such a suspicion. Again, I am not going to put myself firmly in that camp, as I believe that there are plenty of people whose 'autistic' symptoms are severe and whose lives are hampered and made miserable by them, such that they would benefit from services that can only be paid for if they meet a medical diagnosis. I just do not think that clustering conditions together under particular headings, and re-ordering them between editions of the DSM is a practice that can be said to be justified by advances in science. Be wary of clinicians who treat the DSM as anything more than a rough guide for locating helpful services.

Notes

¹ For a much more thorough listing of all the differences between the DSM-5 and its immediate predecessor, see Colleen Harker and Wendy Stone, 'Comparison of the Diagnostic Criteria for Autism Spectrum Disorder Across DSM-5, DSM-IV-TR, and the Individuals with Disabilities Act (IDEA) Definition of Autism,' The Iris Center 2014, viewed on 4 November 2014, <http://iris.peabody.vanderbilt.edu/wp-content/uploads/2014/09/ASD-Comparison-092214.pdf>.

² Leo Kanner, 'Autistic Disturbances of Affective Contact,' *Classic Readings in Autism*, ed. Anne M Donnellan (New York: Teachers College Press, 1985), 41.

- ³ This list, and each quote, comes from Kanner, 'Autistic Disturbances of Affective Contact,' 42-48.
- ⁴ Michael Rutter, 'Commentary on Kanner's Autistic Disturbances of Affective Contact' *Classic Readings in Autism*, ed. Anne M Donnellan (New York: Teachers College Press, 1985), 50-52.
- ⁵ Ferris Jabr, 'Redefining Autism: Will New DSM-5 Criteria for ASD Exclude Some People?' *Scientific American* (January 30, 2012), viewed on 7 May, 2014, <https://www.scientificamerican.com/article/autism-new-criteria/>.
- ⁶ D'Vera Cohn, 'Millions of Americans Changed Their Racial or Ethnic Identity from One Census to the Next,' viewed on 22 March 2015, <http://www.pewresearch.org/fact-tank/2014/05/05/millions-of-americans-changed-their-racial-or-ethnic-identity-from-one-census-to-the-next/>.
- ⁷ JAMA, 'A Definition of Irreversible Coma,' *Journal of the American Medical Association* 205.6 (Aug. 5, 1968): 85.
- ⁸ See Peter Singer, *Rethinking Life and Death* (New York: St. Martin's Press, 1994), chapter 2.
- ⁹ Amy Harmon, 'A Specialists' Debate on Autism Has Many Worried Observers,' *New York Times*, January 20, 2012.
- ¹⁰ Benedict Carey, 'New Definition of Autism Will Exclude Many, Study Suggests,' *New York Times*, January 19, 2012.
- ¹¹ Ari Ne'eman and Steven Kapp, 'What Are the Stakes? An Analysis of the Impact of the DSM-5 Draft Autism Criteria on Law, Policy and Service Provision,' *Autistic Self Advocacy Network (ASAN) Policy Brief*, June 2012.
- ¹² Young Shin Kim, et al., 'A Comparison of DSM-IV Pervasive Developmental Disorder and DSM-5 Autism Spectrum Disorder Prevalence in an Epidemiologic Sample,' *Journal of the American Academy of Child & Adolescent Psychiatry* 53.5 (2014): 500-508.
- ¹³ Susan L. Hyman, 'New DSM-5 Includes Changes to Autism Criteria,' *AAP News*, originally published online June 4, 2013, viewed on 22 March, 2015, <http://aapnews.aapublications.org/>.
- ¹⁴ Colleen Harker and Wendy Stone, 'Comparison of the Diagnostic Criteria for Autism Spectrum Disorder across DAM-5, DSM-IV-TR, and the Individuals with Disabilities Act (IDEA) Definition of Autism.'
- ¹⁵ Evelyn Hooker, 'The Adjustment of the Male Overt Homosexual,' *Journal of Projective Techniques* 21 (1957): 18-31.
- ¹⁶ Hyman, 'New DSM-5 Includes Changes to Autism Criteria.'
- ¹⁷ I go into this in more detail in Simon Cushing, 'Autism: The Very Idea,' *The Philosophy of Autism*, eds. Anderson and Cushing (Lanham: Rowman and Littlefield, 2013), 17-45.
- ¹⁸ See Jennifer Richler, 'Is It Possible to Recover from Autism?' *Scientific American* 24.3 (2013): np, viewed on 26 May 2015,

<http://www.scientificamerican.com/article/is-it-possible-to-recover-from-autism/>.

¹⁹ *Littleton v. Prange*, 9 S.W.3d 223 (1999).

²⁰ Alison Carlson, 'When is a Woman Not a Woman?' *Women's Sports & Fitness* 13 (1991): 25. See also Ann Fausto-Sterling, *Sexing the Body* (New York: Basic, 2000): chapter 1. Patino agreed to fake an injury at the Kobe games so that the reason for her dismissal did not get out and cause embarrassment, and she was encouraged to keep training. However, 4 months later, at the first meet of the Spanish indoor season the head of the Spanish federation told her she would have to fake another injury—this time supposedly career-ending—or risk exposure in the media. She refused, won her race, and, as promised, she was exposed in the media, lost her boyfriend and many friends and all of her records were stripped from the books.

²¹ Similar issues arise concerning race, see Charles Mills, "‘But What Are You Really?’ The Metaphysics of Race," *Blackness Visible: Essays on Philosophy and Race*, ed. Charles Mills (Ithaca, NY: Cornell University Press, 1998), 41-66.

²² Hilary Putnam, 'Meaning and Reference,' *Journal of Philosophy* 70.19 (1973): 699-711.

²³ See the papers by Sample, Pentzell, Stubblefield and Maiese in Anderson and Cushing, *The Philosophy of Autism*, for more in depth critiques of Baron-Cohen's various views.

²⁴ See Jill Boucher, *The Autistic Spectrum: Characteristics, Causes and Practical Issues* (London: Sage, 2009), 211, 213. This theory presents what I think is a caricature of the autistic individual as one who cannot see the forest for the trees. But note also Baron-Cohen's most recent theory posits instead that autistic individuals are *superior* 'systemizers' (sic) where 'systemizing is the drive to analyze or construct systems'. Simon Baron-Cohen, *Autism and Asperger Syndrome: The Facts* (Oxford: Oxford University Press, 2008), 63, emphasis added.

²⁵ I say 'purported' because there seems to be ample evidence of creativity even amongst quite severely autistic individuals. Consider Derek Pavancini, the blind British pianist, who, while he has memorized 'an enormous repertoire' of jazz songs, is also able to improvise on the spot. Baron-Cohen, *Autism and Asperger Syndrome*, 104. There are more and more examples of autistic visual artists as well.

²⁶ 'Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of environment; (such as apparent indifference to pain/heat/cold, adverse response to specific sounds or textures, excessive smelling or touching of objects, fascination with lights or spinning objects).' The best candidate would be Frith's WCC theory, but even that does not seem equipped to explain the insensitivity to heat/cold. Uta Frith, *Autism: Explaining the Enigma* (Oxford: Blackwell, 1989.)

²⁷ Boucher, *The Autistic Spectrum: Characteristics, Causes and Practical Issues*, 139.

²⁸ For an illustration, see Cushing, 'Autism: The Very Idea,' 31-33.

²⁹ Joseph Piven, et al., 'Broader Autism Phenotype: Evidence From a Family History Study of Multiple-Incidence Autism Families,' *American Journal of Psychiatry* 154 (1997): 185.

³⁰ Boucher, *The Autistic Spectrum: Characteristics, Causes and Practical Issues*, 118.

³¹ Piven, et al., 'Broader Autism Phenotype: Evidence From a Family History Study of Multiple-Incidence Autism Families,' 185. As evidence, the authors offer: 'Wolff et al... interviewed the parents of autistic children and the parents of nonautistic mentally retarded comparison subjects and found that the parents of the autistic children were more often judged to lack emotional responsiveness and empathy, show impaired rapport with the examiner, and have histories of oversensitivity to experience, special interest patterns, and oddities of social communication... Gillberg, in a study of the parents of 23 children with Asperger syndrome, reported social deficits in 11 of the 23 fathers that were similar to, but milder than, those seen in Asperger syndrome.' Piven, et al. 'Broader Autism Phenotype: Evidence From a Family History Study of Multiple-Incidence Autism Families,' 186.

³² Baron-Cohen, *Autism and Asperger Syndrome*, 93.

³³ Rebecca Muhle, Stephanie V. Trentacoste and Isabelle Rapin, 'The Genetics of Autism,' *Pediatrics* 113.5 (2004): e482.

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