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Neurodiversity and the Rejection of Cures

Richard Dean

It is relatively easy to support many of the assertive demands for recognition, inclusion, and acceptance that people with disabilities have made in recent years. Ending the stigmatization and mockery of people with disabilities is only decent, and giving them a chance to participate in public life and to have a voice in shaping public policies, to whatever extent possible, are minimal requirements of respect and justice. But even someone receptive to such reforms may find it more puzzling and problematic when some people with disabilities reject attempts to cure them of their disabling conditions. My aim in this chapter is to examine the rejection of cures, in order to understand the position, and to consider whether it makes a morally compelling point.

More specifically, I will focus on the relatively recent phenomenon of the neurodiversity movement, and the rejection of cures for autism. Focusing on one type of rejection of cures is more feasible than tackling all of the conditions for which cures might be rejected, since opposition to cures for some conditions (like the Deaf community's opposition to technological cures for hearing impairment, on the grounds that widespread cures will destroy a rich Deaf culture) are much more plausible than for other conditions (like severe spina bifida). I also will distinguish, when necessary, between refusing a cure for one's own autism, refusing a cure for one's children, and opposing the search for a cure altogether. Of course, the very idea of an "autism spectrum disorder," which is currently the most common diagnostic label related to autism, implies a wide divergence in the ways that autism is manifested and in the extent to which it impairs a person's functioning. I acknowledge that points about rejecting cures may apply to some conditions on the autism spectrum and not others, but limiting the discussion to autism nevertheless seems more manageable than discussing disability in general. For similar pragmatic reasons, I will consider only autism spectrum disorder, rather than other conditions that are sometimes included in the neurodiversity movement, such as dyslexia, bipolar disorder, or schizophrenia.

Although my tentative conclusions about the rejection of cures for autism are, overall, unsurprisingly moderate—I think it is justified for an individual to reject a cure

for herself but much more questionable to demand an end to the search for cures altogether—along the way I believe that I usefully disentangle different lines of argument, and vitiate the force of some of them. The legitimacy and authority of an anti-cure position are closely tied to some of the most central issues in the disability rights movement, mainly the social versus medical model of disability and the importance of personal autonomy, but some other common arguments for more broadly dismissing or endorsing all potential cures for autism are unconvincing when conceptually separated from these basic issues.

A basic explanation of the currently prevalent concept of autism spectrum disorder will be needed as a background for some of the points in this chapter. Autism spectrum disorder is not identified through any specific biological marker, but through clusters of atypical behaviors. Non-standard social interaction and means of communication are common, ranging from striking problems such as not communicating linguistically at all, communicating only through writing but not orally, or seeking isolation from others, to milder variations such as avoiding eye contact, feeling uncomfortable with personal physical contact, taking statements literally when they are not meant literally, or failing to pick up non-verbal cues in communication. Some people on the autism spectrum (hereafter, PAS)¹ are prone to habitual, repetitive actions and gestures (“stimming”), in some cases including inflicting injuries on themselves. Many PAS develop “perseverative” or obsessive interests in a particular subject (such as dinosaurs, train schedules, or the like), and they often dislike changes in routine, sometimes to such an extent that they panic or retreat physically from new situations. PAS are at increased risk of some other conditions, including seizures, digestive problems, and intellectual disability. The popular image of autism as bestowing special gifts for mathematics or musical ability is not completely misguided—some PAS do show such gifts, but most do not. It apparently is common for PAS to possess a strong ability to focus on a particular task for long periods of time, and to tend toward a visual thinking style.

The idea of an autism spectrum is a little misleading, since different PAS do not display all the same particular traits, varying only in degree, as suggested by the word “spectrum.” Andrew Solomon has said that autism is better described as a “three dimensional universe of behaviors” (Solomon 2008). A person who strongly manifests one type of autistic trait may not display some other types at all. This suggests that there may not be one root genetic or environmental cause common to all autism.

The neurodiversity movement, founded mainly by PAS and their relatives, emphasizes the idea that autism (and some other neurologically influenced conditions, such as dyslexia, bipolar disorder, or schizophrenia) should not be seen as a medical problem or a defect, but instead as just an alternative form of neurological organization. On this view, variations in brain organization are a normal form of genetic variation. It is worthwhile to maintain neurodiversity in the human species for the same reason it

¹ I will use the abbreviation for both the singular “person on the autism spectrum” and plural “people on the autism spectrum”.

is useful to maintain genetic diversity in general, namely that divergent genotypes may be more adaptive as environments change. Some advocates of the neurodiversity movement point out that some of the traits often associated with autism, such as a tendency to focus on detail and a willingness to perform repetitive tasks, are actually advantageous for work in computer technology. Since the neurodiversity movement emphasizes that autism is not best seen as a medical problem, but as just an alternative form of neurological organization, it is natural enough that most members of the movement also in some way or other reject the idea of “curing” autism. The anti-cure position is often left vague—on the one hand, many members of the movement emphasize that each neurodivergent person should be allowed to make her own choices about how to deal with her autism and its accompanying conditions, which suggests that the search for a cure should not be abandoned, but on the other hand, the neurodiversity movement generally condemns the group *Autism Speaks* because of its emphasis on trying to cure autism. I think there is no unequivocal or unanimous position within the neurodiversity movement on the status of developing possible cures, despite a general anti-cure tone. There is still less agreement between members of the movement and some other PAS, who criticize the neurodiversity movement and support the search for a cure for their own and others’ autism.

1 Is It Unreasonable to Reject a Cure?

One fundamental element of the neurodiversity movement is the position that PAS do not need a cure, because there is nothing wrong with them. They do have atypical, or “neurodivergent,” brain organization, and this can cause them some difficulties which “neurotypical” people do not face. But, members of the neurodiversity movement add, these difficulties generally arise not because of their neurodivergent traits themselves, but because society is structured to accommodate neurotypical people at the expense of the neurodivergent. So a better use of resources, if one wishes to help PAS, is to rethink and reform the educational, professional, and social opportunities that are available to the neurodivergent, rather than trying to cure them. Although the details and extent of commitment to this position are often left vague, some significant level of resistance to cures seems to be an essential feature of the neurodiversity movement.

The general public is no doubt much more willing to take seriously the neurodiversity movement and its rejection of cures nowadays than it would have been a few decades or even years ago, partly because of the eloquent depictions of autism and related conditions that have appeared in the last few years.² But there is still no shortage of people who find puzzling, or even “crazy,” the idea that autism is not in need of a cure.³ In this section, I will examine the position that there is something fundamentally unreasonable about opposing a cure for autism, and perhaps even about refusing to

² For example, Temple Grandin’s books, or Steve Silberman (2015).

³ The word has been used (by others) in conversations I have had on the topic.

accept a cure for oneself if it is offered. I think this reaction of incredulity to the anti-cure position ultimately is unjustified, because it does not sufficiently take account of the overall oppressive situation that PAS have faced. The injustice that PAS have faced makes the rejection of cures a reasonable act of resistance, rather than an irrational overreaction.⁴

There are a number of specific claims that fall under the general heading of thinking it is unreasonable to reject potential cures for autism. One might think that an individual on the autism spectrum would have to be thinking irrationally to refuse a cure for herself. After all, if a cure were available for her, it probably would make her own life easier. She most likely still could have the same friends and family, pursue the same interests, and perform at least as well in most jobs, while a cure would make it much easier to interact with others (especially neurotypical people), with an additional benefit of escaping any negative physical conditions related to her autism (digestive problems, seizures, etc.). A thoughtful proponent of the “it’s unreasonable to refuse a cure” position might acknowledge that some of the same advantages could be achieved by reforming society to better accommodate neurodivergence, but might still point out that it is unrealistic to expect such changes to happen on a large scale any time soon. So, one might think, only some degree of being stubbornly out of touch with reality would lead a PAS to refuse a cure that probably would make her life better sooner rather than later. To refuse a cure for one’s children, or to oppose scientific research on a cure, seems even more unreasonable. To make people’s lives easier, especially one’s own children, and to make so many more options available to them, seems like such a laudable goal that opposing it may appear to be more of a matter for psychoanalysis than for serious moral consideration. And one need not search far to find “irrational” potential motives that plausibly could play a role in the opposition to cures. Exclusion and rejection, especially such extreme versions as PAS have faced, are deeply harmful practices that are quite capable of eliciting extreme reactions. The historical treatment of the neurodivergent as useless and embarrassing defectives has triggered a reaction of a demand for acceptance and inclusion, and it may be tempting to see this as partly an irrational backlash, which not only demands (reasonably) that opportunities be maximized for the neurodivergent, but also (unreasonably) demands that all talk of neurodivergence as a defect or something to be cured should be abolished. The rejection of cures, then, would be an understandable but fundamentally unreasonable overreaction to past stigmatization and exclusion.

The position that there is something unreasonable about opposing a cure for autism seems to be supported by some intuitive thought experiments. The most obvious and rudimentary thought experiment would be to ask oneself whether one would want a cure if one suddenly found oneself on the autism spectrum. For most neurotypical

⁴ I mean to use the concepts of “reasonable” and “unreasonable” in a non-technical way, but in a way compatible with, for example, John Rawls’ idea that what is reasonable encompasses more than what “rationally” maximizes utility. So, different positions may be reasonable, given not only different personal preferences, but also different attitudes and fundamental beliefs.

people, the answer to this is that they would want to be cured. Perhaps most strikingly, to suddenly find oneself on the autism spectrum would often involve being subject to a variety of new fears and anxieties. Social interactions would more likely be a source of dread than enjoyment, and new situations and deviations from familiar routines would be distressing. Communication would likely be more difficult and require more deliberate planning and energy. In worse cases, one might feel urges to perform actions that injure oneself, might be incapable of any verbal communication, and might experience a variety of physical problems. The possible benefits, such as being able to focus on a task more intently for longer periods of time, or being able to see categories and patterns in unconventional ways, may seem like small compensation.

But of course, this thought experiment is not only obvious and simple, but actually too simplistic. Part of the distress that a neurotypical person may imagine she would feel at being put in the place of someone on the autism spectrum would arise from the adjustment to a radically different way of experiencing the world. An autistic person might feel similar distress if suddenly put in the place of a neurotypical person. And at least some of the difficulties in social interaction and communication that the neurotypical person would imagine facing could be minimized by changing society's assumptions and social conventions, to be more accommodating to alternative versions of interaction.

A slightly more sophisticated thought experiment in favor of the "it's unreasonable to reject cures" position could attempt to address these shortcomings. This thought experiment would ask us to imagine how PAS, or parents of PAS, would react to the possibility of cures if society currently were more hospitable to them in other ways. So, one could imagine that schools uniformly incorporated the types of changes advocated by neurodiversity advocates, that employment opportunities for autistic adults were maximized, that whatever support and medications PAS or their families desired were widely available,⁵ that autistic styles of social interaction and behavior were not stigmatized, and that individuals were usually allowed to control their own types and level of social interaction. In such circumstances, one might imagine, many PAS would find their lives easier to manage, and they also would feel like society was taking account of their well-being and listening to their own statements about their needs. In these hypothetical, idealized circumstances, one might think that decisions about whether to support the search for a cure in general, or to seek a cure for oneself, would be more reflective of any problems intrinsic to autism, rather than being a reaction or backlash to the unjust treatment of PAS. In these hypothetical circumstances, it is not difficult to imagine that many PAS would find life quite satisfactory and would not find much incentive to seek to change or "cure" their basic state. But even in these idealized circumstances, it is quite plausible that there might be many PAS who found the intrinsic limits and problems of their condition to be very significant, and who would want a cure. So, the thought experiment may seem to show that opposition to a search for

⁵ Here I mean medications to treat some of the effects of autism, not a cure.

a cure must really be a sort of overreaction to the current limited opportunities and unjust treatment that PAS face. If society provided more respect and better opportunities for PAS, then there would not be such strong opposition to finding and providing cures for autism.⁶ And one might think this shows that the neurodiversity movement's strong opposition to cures is just a sort of unreasonable overreaction, an overreaction which mistakenly lumps a cure for autism together with genuinely unjust practices and attitudes.

This thought experiment, while more sophisticated than the first, still fails to show that opposing a cure is unreasonable. The main problem with this thought experiment is that it ignores the fact that whether it is reasonable or unreasonable to oppose a cure for autism depends on the other ways in which PAS are treated. An example unrelated to autism may help illustrate the point. Imagine two families, each consisting of a mother, a father, and an adolescent daughter who is obese. The parents in family A have provided loving attention and guidance to their daughter Anita throughout her life, and continue to communicate with her frequently, offering encouragement, affection, and advice. The parents in family B have not been as attentive. They have been more occupied with their own problems and opportunities, and while they have provided adequate material and financial support for their daughter Brenda, and have not been actively abusive or criminally neglectful, they have not provided Brenda with consistent encouragement and loving attention, but instead have offered feedback mostly in the form of occasional complaints about ways in which she needs to improve herself. Now suppose that after medical checkups, the families' respective doctors have told the parents in each family that their daughters' obesity poses a significant risk of current or future health problems. And suppose that each set of parents have similar talks with their daughters, similar both in tone and content. The parents in each family express concern (which is the approach the doctors have recommended), they emphasize that they are not dissatisfied with their daughters (particularly that their daughters' appearance is not the problem), but are worried about their daughters' health, and they offer several options for assisting their daughters in achieving a healthier weight. If Anita, the daughter in family A, is more receptive to her parents' suggestions, and agrees to accept their help in following a diet and exercise plan, while Brenda, the daughter in family B, dismisses her parents' comment in a rather chilly way, this is not evidence that Brenda is being unreasonable. Perhaps her parents are, in this one instance, treating her in a way suggestive of genuine concern. But their action is not in fact the same as the action performed by Anita's parents, because the context of an action, the pattern of which it is a part, makes a difference to the import and nature of the action. The overall pattern of interactions between Brenda and her parents makes it

⁶ For purposes of this thought experiment, I am imagining a society that provides the best possible situation for PAS. That differs from a society that is morally idealized in many ways, but weighs the needs of PAS along with other factors, such as limited resources and the needs of other citizens (disabled or not). See my footnote later, on Anita Silvers' "historical counterfactualizing" test. Thanks to Adam Cureton and John Dail for this clarification.

difficult for their action to be anything other than a complaint about how she needs to change. Of course, they might begin to set a new pattern, but one instance is not enough to do that.

Another way to think of basically the same point about an overall pattern changing the meaning of an action can be drawn from Marilyn Frye's (1983) influential discussion of oppression. One cannot determine whether a particular act is oppressive without looking at the entire system of rules, obstacles, and expectations of which it is a part. The same type of action may be wrong when it contributes to someone's oppression, but acceptable when it is not part of an oppressive overall system. This is the problem with thought experiments like a man claiming that there is nothing wrong with him complimenting his female co-workers on their appearance, because he would not mind it a bit if they complimented him. Men assessing and freely commenting on women's appearance is a significant obstacle to women being taken as seriously as men in many venues, and so it is part of a structure of systematic oppression of women. Men do not face the overall oppression that women do, and occasional comments on their appearance do not generally undermine overall respect for men. In one case, the act is oppressive, in the other case it is not, even though it is the same type of action, viewed in isolation. Along similar lines, the very same action of local police stopping someone and questioning him does not have the same meaning if it happens once in a person's lifetime as it does if it happens five times per month.

The thought experiment offered in favor of the "rejecting-cures-is-unreasonable" position assumes that developing or offering cures for autism has the same import in our current society as it would in the idealized society that provides maximal opportunities for PAS. But this is mistaken. In the society that was welcoming to PAS, a cure would genuinely be just one option, which might be desired by some PAS. But in a society that historically has regarded autism as a cause for shame and permanent isolation, and which still does not structure schools, careers, or social expectations to maximize the prospects of PAS for a satisfying life, a cure has different implications. It is not just one option among many, but also a way of reinforcing the familiar message that PAS are deficient, and hopelessly deficient unless they can be changed or cured. The thought experiment is misguided, because it does not compare real-world attitudes and hypothetical attitudes toward the same thing, namely a cure as one option among many, but instead compares attitudes toward two different things, a cure as one option versus a cure as a message that PAS are defective unless they can be cured.

The history of exclusion and stigmatization of PAS, and the significant obstacles and lack of assistance that they still face, make the rejection of cures a reasonable act of resistance to one of the elements of an unjust pattern of treatment. If one is interested in seeing what choices PAS would make if a cure were just one option for improving their lives, then one ought to work toward making the overall treatment of PAS more just and beneficent. In the meantime, the thought experiment about what PAS would choose in a more ideal society is irrelevant, or at best inconclusive, regarding the question of whether the rejection of cures is unreasonable in our current circumstances.

So, there is nothing inherently unreasonable about PAS opposing the search for a cure, or rejecting a cure for themselves if one becomes available. But this does not definitively settle the larger issue of whether the search for a cure actually ought to be stopped. Even if opposing a cure is a reasonable position, other positions also may be reasonable. One person may reasonably see the search for a cure as one more way to reinforce a message of inferiority, and someone else may focus on the possible advantages a cure would provide for PAS, and conclude that it is important to develop such a cure. Both positions are reasonable.⁷ Being a reasonable reaction is not like being true—very different reactions may all be reasonable, while incompatible claims cannot all be true.

In this section, I have only addressed one type of general reason (that “the rejection of cures is unreasonable”) for thinking that attempts to find a cure for autism should continue. That reason fails, I think. But there may be other general arguments for or against opposing the development of a cure for autism. In Section 2, I consider one of the neurodiversity movement’s main arguments against attempting to develop a cure for autism.

2 Changing a Person’s Identity

One of the reasons given by neurodiversity advocates against seeking a cure for autism, and against parents accepting such a cure for their autistic children if one is developed, is that it is objectionable to attempt to change someone’s identity so radically.

The emphasis on the centrality of autism to a PAS’s identity is a frequent theme of the neurodiversity movement, beginning with Jim Sinclair’s (1993) “Don’t Mourn for Us,” which, although it does not contain the word “neurodiversity,” is often regarded as the founding manifesto of the neurodiversity movement.⁸ Sinclair says,

Autism isn’t something a person *has*, or a “shell” that a person is trapped inside. There’s no normal child hidden behind the autism. Autism is a way of being. It is *pervasive*; it colors every experience, every sensation, perception, thought, emotion, and encounter, every aspect of existence. It is not possible to separate the autism from the person—and if it were possible, the person you’d have left would not be the same person you started with.

The relationship of autism to identity seems also to be the main point in a dispute over the best way to refer to PAS. Some autism advocates prefer the term “person with autism,” placing the word “person” first to emphasize that PAS should be regarded as having the same importance and dignity as other people. But some neurodiversity advocates think this de-emphasizes the fact that autism is central to the identity of

⁷ It may turn out that it’s wrong to search for a cure, or wrong to oppose finding a cure, and a fortiori unreasonable for whatever moral reasons are discovered in this later argument. But so far, no reason has been given for thinking it is unreasonable. See note 4.

⁸ Sinclair’s article is an outline of the presentation he gave at the 1993 International Conference on Autism in Toronto, and is addressed primarily to parents of autistic children.

PAS—they are not just people who happen to “have” autism, any more than someone might be a “person with femaleness”—so they favor the phrase “autistic person,” to emphasize the inseparability of the person and her autism.⁹ The point about the inseparability of autism from the person is at least sometimes used as an argument against curing autism—Sinclair certainly uses it that way. But a charitable understanding of the argument requires some work.

The argument against initiating fundamental changes in a person’s identity is not best taken to involve any deep, metaphysical issues of identity. At least, I do not think neurodiversity advocates mean it that way, and for purposes of this chapter I also will put aside the possibility that the argument relies on implicit metaphysical assumptions about identity. So I will try to consider the point without delving into thought experiments about brain transplants or teleportation.

Sometimes, the claim about autism being interwoven with a person’s basic identity is contrasted with the situation of people who have various diseases or medical problems. For instance, neurodiversity advocates explain that someone can be just a person who has cancer, and one can cure the cancer and be left with the same person, cancer-free. This needs some exploration. Having cancer, especially long-term cancer, can have profound effects on a person’s outlook, mood, and patterns of thought, as well as her physical state, habits, diet, and energy levels. So changes in all of those are presumably not enough to fundamentally alter a person’s identity in the ways that neurodiversity advocates find objectionable. So what sort of change is so deep as to be problematic?

Using Sinclair’s position as a guide, it seems that what is thought to be different about autism is that it does not just affect the content of particular thoughts or moods, but the whole modes of thinking, feeling, and expressing oneself. So, it does not just make one sad or happy, and does not just make one’s thoughts optimistic or pessimistic, or focused intently on a topic like new chemotherapy developments, nor does it just change some of one’s interests and goals. It affects how one organizes one’s thoughts, and how one develops and pursues interests, and what feelings one can experience or recognize in oneself. It also affects how one perceives the world, for example by making it impossible to notice some social details, or making some sounds and lights painfully intense, or by allowing one to conceptualize things visually in a way few neurotypical people can. Of course, autism also often has physical effects, and presumably can affect the content of thoughts and moods. But what differentiates it from other conditions that (presumably) are separable from a person’s identity must be that it affects not just the content, but the manner of thought and experience.

If this is the way in which autism is thought to be intertwined with identity, then is it obvious why it is wrong to change a person in identity-altering aspects like this? There are at least two objections to thinking that it is wrong.

⁹ See, for example, Brown (2011).

The first objection is drawn from recent empirical studies of children on the autism spectrum. Although few clinical claims about autism are uncontroversial, there is evidence that a significant percentage of very young children who are diagnosed as being on the autism spectrum (perhaps about 10 percent) later “recover,” meaning they no longer meet the diagnostic criteria for being autistic (Padawer 2014).¹⁰ Supposing that this is true, it seems that someone who views autism as intertwined with identity ought to feel some sadness for these children. The children they were are lost, replaced by radically different children. I suppose that some neurodiversity advocates might bite the bullet and in fact say that we ought to mourn the autistic children who were replaced with neurotypical children.¹¹ But at least in the cases in which this loss of autism happens with minimal intervention, it is hard to feel great sadness.¹² Of course, this is just my intuition, and maybe my intuition draws on some deep bias in favor of the neurotypical. But if neurodiversity is what is important, I do not see a reason to mourn the neurotype that begins on the autism spectrum and then, with minimal intervention, moves off it. There is a resolution to possible disagreement about this, which gives weight both to the claim that it is wrong to fundamentally change someone’s identity by curing him of autism, and the intuition that I think would be shared by many people both on and off the autism spectrum, that cases of (more or less) spontaneous “recovery” from autism are nothing to feel sad about. This resolution is that what is wrong about changing the identity of a PAS by curing her is not that the change of identity itself is lamentable, but that the wrongness lies in the active attempt to change someone’s identity. This leads to the second objection.

If taken in its most straightforward, literal sense, the claim that it is wrong to take steps to change someone’s identity leads to a quite counterintuitive result. It implies that it would be wrong for someone to seek to change her own identity, or for others to help her in this project if she requests help. To find cases in which this seems implausible, one need look no further than neurodivergent people. Certainly not all PAS embrace the neurodiversity movement or the accompanying rejection of cures, and some avow that they would very much want a cure if one were available.¹³ If it is wrong to play a role in changing someone’s identity, then (supposing a cure were available) providing a cure to these PAS would be wrong. Anyone without a prior commitment to the “no-cure” position would find this hard to endorse.

¹⁰ The article mentions two scientific studies, as well as anecdotal reports.

¹¹ Some neurodiversity advocates also have denied that the children’s change is more than apparent, but this does not appear to fit with the descriptions of the children. In addition, neurodiversity advocates object to trying to “cure” autism by using advanced behavior analysis (ABA), a therapy that aims at focusing the attention of a PAS on developing “normal” communications skills. The objection is that ABA only allows a PAS to “pass” as neurotypical, at the cost of draining energy and attention that the PAS might focus on more important cognitive tasks. But according to one of the studies cited in Padawer (2014), a significant percentage of children (about a quarter of those who have become non-autistic) have lost the diagnosis of autism without receiving ABA.

¹² By “with minimal intervention,” I mean without ABA.

¹³ Jonathan Mitchell, a PAS who opposes the neurodiversity movement, says, “I long for a cure for autism” (Mitchell 2007).

Both of the objections above can be avoided, by modifying the claim that it is wrong to be involved in changing a person's identity. Perhaps it is not that a change in identity is necessarily a harm or something to be mourned, nor that it is wrong to assist competent adults who wish to make fundamental changes to their identity. Instead what is wrong is forcibly attempting to change someone else's identity. One's own identity, or at least one's sense of identity, is something that is generally valued quite highly. So even if a person may decide for herself that it is worth changing characteristics essential to her identity, it is wrong for others to presume to initiate such changes except at the person's own request. This at least resembles the claim about identity made by neurodiversity advocates, but seems more intuitively plausible, and in fact is roughly in line with common views about requirements of obtaining informed consent before performing medical procedures.

If it is wrong to change another person's identity without her request or consent, then this would seem to accomplish most of what is wanted by neurodiversity advocates who oppose a cure. If a cure or set of cures for autism are developed, then it is likely the main targets of those cures will be young children, or even fetuses, who are incapable of requesting or consenting to attempts to cure them. So if it is wrong to cure people without their explicit consent, then it may be *de facto* wrong to attempt cures at all. But on closer examination, the concerns about changing identity seem to be inert in decisions about whether it would be acceptable to attempt cures for autism *in utero* or at a very young age. Very young children's sense of their relation to the world and of their own identities are, by their very nature, rapidly changing and prone to huge revisions. So, if a toddler is diagnosed as being on the autism spectrum at 2 years of age, cures that change her basic conception of herself would not be of a radically different magnitude than the developmental changes for neurotypical children. If a cure for autism would be applied *in utero*, then it is all the more clear that attempting to steer fetuses from a path of neurodivergence toward being more neurotypical would not affect their own sense of identity, which is not yet formed. So, in the cases that seem most likely to be the setting for curing autism, the individuals being cured would not yet have a firm sense of identity that would be forcibly changed, and the principle that it would be wrong to change a person's own sense of identity would not be applicable. Considerations about changing identity do not provide a reason to avoid autism cures for fetuses or very young children.

On the other extreme, there are many high-functioning PAS who have a sense of their own identity, and do not want to be "cured" of their autism. These are, in fact, the very people at the core of the neurodiversity movement. History provides many examples of the moral perils of attempting to impose changes against the will of people who can express their desire not to be changed, and I see no reason to resist the lessons of history here. If we accept the claims of competent PAS who desire not to be changed into non-autistic persons, but also accept the claims of other high-functioning PAS who do wish they could be cured, then the *prima facie* result is that it would be ideal if a cure were available, but that the choice of accepting a cure were up to each individual PAS.

If the claims I have argued for are all correct, then concerns about changing identity fail to show that it is wrong for parents to decide to cure their children of autism in utero or in very early childhood, and fail to show that it is wrong to support research for a cure, but do suggest that it is wrong to impose a cure on adult PAS who do not want to be “cured.”¹⁴

But it may be that the anti-cure argument based on “changing identity” is best understood differently, as really being about a message of respect and acceptance versus a message of rejection. I turn to that reading of the argument in Section 3.

3 Respect, Rejection, and Cures

The emphasis on identity may be misleading, inasmuch as identity may serve mainly in a supporting role for a different argument, an argument that to seek to cure autism sends a message of disrespect and rejection. The main claim of this argument, that to seek to cure autism sends a negative message to PAS, may be met with an initial skepticism, since after all (the advocate of cures may say) we seek cures for all sorts of medical problems, and no one takes attempts to cure cancer, AIDS, or multiple sclerosis to be disrespectful rejections of people with those conditions. Neurodiversity advocates respond by pointing out that autism, unlike those conditions, is an inseparable part of a person’s identity, so trying to cure autism is necessarily a deeply insulting message of devaluing a PAS as a person. This is a reasonable interpretation of Jim Sinclair’s passages on identity in “Don’t Mourn for Us.” Immediately after emphasizing that autism cannot be separated from a person with autism, he adds that when parents wish that their children did not have autism, then “what they’re really saying is, I wish the autistic child I have did not exist, and I had a different (non-autistic) child instead.” The real problem in seeking to change someone’s identity by curing them of autism, then, is not that it changes identity, but that it is a deeply disrespectful message of rejection, that PAS cannot be accepted or loved as they are. Society sends this message by devoting resources to a cure for autism, and parents who accepted a cure for their autistic children would be sending this message to their children, if the children were old enough to comprehend the situation, and at least to other PAS, even if the children who are cured are too young to get the message.

It is worth replying separately to concerns about the message sent by overall research for a cure, and the message sent by parents or other decision makers who would choose a cure for individuals with autism. I think that the message sent by trying to discover a

¹⁴ This leaves unanswered how borderline cases should be decided, when a PAS expresses some view but it is not clear whether the view reflects a genuine understanding of her condition and the options that are (hypothetically) available to her. This range of cases may prove to be hypothetical—it may turn out that if there is any “cure” for autism, it must be a gene therapy administered in utero—but might need to be part of a fuller account. It also leaves open that some argument could show that it is wrong after all to participate in trying to cure autism, if the only reason a PAS would want a cure is that she is suffering a kind of false consciousness, embracing dominant biases in favor of the neurotypical. See Section 4.

cure for autism would vary, depending on the total package of actions and attitudes of which it was a part. As suggested above, in Section 1, if PAS received good opportunities for satisfying lives, then a cure really might be just one option among many. It need not send a message that the only way to be a worthwhile person is to become neurotypical. So, research on a cure for autism does not *necessarily* send a message of disrespect and rejection. But, necessity aside, it seems at least contingent to send this message, given the historical injustice neurodivergent people have faced, and given the inadequacy of the current support and respect they receive. Since the search for a cure plays a role in an overall unjust set of practices and attitudes, it is reasonable for autism advocates to resist research on a cure, and the message of rejection is at least a *prima facie* reason for thinking it is wrong to pursue a cure now. But this *prima facie* reason may be outweighed by some other consideration, especially the fact that basic research on autism, even if it is aimed at understanding autism, or providing better assistance and therapies, may be indistinguishable at this early stage from research that could lead to a cure.¹⁵ The most certain conclusion to draw from the claim that searching for a cure sends a negative message, given the current situation that PAS face, is that the current situation ought to be changed. We ought to seek to improve opportunities and decrease obstacles for PAS, and to make society more inclusive of them. If we take these steps, which we ought to anyway, then this may also make research on a cure one legitimate option among many.

If it is true that developing a cure for autism would not necessarily be disrespectful, in the absence of a general framework of oppression, obstacles, and negative attitudes, this still leaves open the question of whether particular parents who choose a cure for their children would be displaying a problematic attitude. The same question would arise regarding choosing a cure for adult PAS who are not competent, if a cure were developed that could affect them. Would people who choose to accept a cure for others be demonstrating a lack of respect, or lack of love and caring, for those being cured? Some neurodiversity advocates equate parents' desire for a cure for their children's autism with wanting to exchange their unsatisfactory autistic children for better, neurotypical children—a profound rejection of the children as they are.

But I do not think attempting to change a person necessarily shows a lack of respect, concern, or even of love. Motivations can vary hugely. Staging an “intervention,” to persuade someone to seek treatment for an addiction, is generally taken to be a demonstration of love and concern, undertaken at the cost of significant inconvenience and psychological distress to the people staging the intervention. It seems that substance addiction does deeply affect someone's identity in some of the same ways that neurodivergence does—it affects how one perceives the world, how one views and interacts with others, and how one forms goals and preferences. So at least in some cases, attempting to make basic changes to someone's identity is consistent with attitudes of love and respect for that person. Other examples in which it seems consistent

¹⁵ I explain this point more fully in Section 4.

to love someone and to want to play a role in profoundly changing that person include cases that appear to depend significantly on neurological factors, such as wanting a close relative to stop hoarding, or to stop experiencing chronic anxiety. These conditions can certainly color a person's experiences, deeply affecting how she perceives the world, and how she thinks and feels. The mere fact that losing an addiction, a hoarding disorder, or chronic anxiety would deeply change a person's way of being in the world does not, by itself, seem to tell one way or the other regarding whether it is morally acceptable to play a role in initiating these changes. It depends a lot on the details, and going down into the muck of complicated personal relationships, respect, and love is an unavoidable consideration in examinations of the morality of attempts to change someone. The wrongness of some attempts to change a person, based on the message sent by the attempts at change, seems again to depend not on the mere fact that important features of identity may be changed, but on whether those attempts are forcibly imposed, against a person's will.

But even this may be too strong a statement. Even if a person is competent and resists changing herself, it seems that close friends and family may be justified in applying some kind of pressure to change. This kind of pressure is different from the paradigm case of forcing unwanted treatments on someone with a purported physical or psychological problem, namely the case of physically forced procedures, often accompanied by involuntary institutionalization. If we distinguish these two types of pressure on someone to receive treatment, there is not an obvious reason to abandon the widespread sentiment that strongly influencing someone to change her personality-shaping traits or even her basic identity can sometimes be a sign of deep devotion and love, not of rejection and disrespect. Parents especially may be motivated by love to change their deeply depressed child into a happier one, their nihilistic teenager into an engaged citizen, or their extremely shy child into someone who enjoys social interactions.

So far, it appears that concerns about sending a message of rejection provide, at most, a contingent and *prima facie* reason to oppose a search for cures. And if a cure is developed, there is little reason to suppose that choosing to try to cure a family member would express rejection or lack of love. But . . . all of this seems to miss some element of the neurodiversity position. This missing element can best be captured by noting comparisons that neurodiversity advocates often make between trying to cure autism and trying to "cure" someone of being gay. Many of us would think there is something morally misguided about attempting to cure a person of his or her sexual orientation, even if such a "cure" were possible. In the same way, even if an African American in the 1950s (or, pick more or less any decade in American history) would have faced many fewer obstacles, and would have had an easier life, if she were white, it still seems that both a search for a "cure" for blackness and the administering of it in specific cases would have been a kind of rejection, sending a message that there was something wrong with an important aspect of a person's identity.

If I want to maintain, then, that some cases of being involved in changing a person's identity are acceptable, while others really are cases of sending a message of rejection, I owe an explanation of how the cases are different. And I think the difference is that in cases in which the "problem" being fixed could actually be addressed by making society more just and accommodating to people with the "problem," then it is an act of rejection and disrespect to attempt to change the people instead of changing society. It is treating them as if they have some defect when they do not, and it is a refusal to acknowledge that it is worth making large-scale changes in society to make their lives better. To attempt to change a person in these circumstances is both unjust in itself and is a refusal to acknowledge the injustice the person faces. But, if someone has a problem or deficit that cannot be addressed by changes to society, then it is not necessarily an act of rejection to seek to improve their condition by "fixing" or curing them.

Applying this general claim to PAS, it is not surprising to find that the moral status of seeking or rejecting cures depends centrally on whether the medical model or the social model of disability is more applicable to autism.

4 The Medical versus Social Model of Disability

It is no shock that the contrast between the medical and social models of disability is of central importance to the issue of rejecting a cure for autism. But it is more notable that, if my analysis is correct, then the arguments described above, based on identity and disrespect, actually reduce to the issue of whether autism best fits the medical or the social model.

Neurodiversity advocates themselves, in explaining their position, often rely on the contrast between the social model of disability with the medical model of disability. The medical model of disability is the view that a given disability is a defect or problem that an individual faces, which is best addressed through medical treatment or cure. The social model of disability maintains that the reason a disability places people at a disadvantage is not because of the physical or psychological condition itself, but because society is structured to accommodate people without that disability, and that the disadvantage could be removed by making changes to society. One need not take an "all or nothing" view, claiming that all disabilities are medical problems, or that all disabilities could be remedied by making society more accommodating. For example, one might say that quadriplegia due to spinal cord injury is best seen as a medical problem, while deafness is best seen as a disadvantage that could be eliminated by changing society's assumptions about how information should be transmitted. Neurodiversity advocates maintain that autism is just an atypical neurological system, a kind of "alternative wiring," and that it is not in itself necessarily a disadvantage, but that society's treatment of PAS is what makes autism a disadvantage. Schools are not designed to maximize educational opportunities for PAS, work environments are not welcoming, alternative forms of communication (favoring less face-to-face interaction

and fewer assumptions about body language, eye contact, etc.) are not widely accepted, and atypical social behavior is stigmatized. Changing these practices would, according to the neurodiversity movement, make autism just a difference, no longer a disadvantage. The medical model, applied to autism, views autism as a neurological disorder and views the best long-term solution as being to change PAS by curing them.

In effect, I have argued above that concerns about changing a person's identity or sending a message of rejection really reduce to a more basic issue of whether autism is best seen as a medical problem, or as just a difference that can and should be accommodated by society and made into a non-problem. Just the fact that one is changing a person's identity is not enough, by itself, to show that seeking a cure for autism is wrong, I argued in Section 2. But it might be wrong, if the only reason for seeking to change part of a person's basic identity is that society disvalues the otherwise neutral identity-making feature of autism, and so is participating in the perpetuation of an ungrounded prejudice against PAS. On the other hand, if autism is a medical problem which places PAS at a disadvantage regardless of society's stance, then there is a good reason to attempt to develop a cure for it, to be offered to, but not forced on, PAS. And regarding the claim that attempting to cure autism sends a message of rejection and disrespect to PAS, it seems to depend on whether autism is in itself a neutral condition, and attempts to change PAS are undertaken in order to make PAS conform more to a neurotypical state that society arbitrarily values, or whether attempting to cure autism would be more like offering to free PAS of a medical problem that is often an objective obstacle to their well-being. So the issue of whether the medical model or social model of disability best captures the situation of PAS is crucial to deciding the moral force of anti-cure arguments.

So, is autism best seen as a problem in itself and a condition to be cured, or is it in itself just an alternative form of mental wiring, which only becomes a deficit or problem because of society's bias toward the neurotypical? Anita Silvers offers a thought experiment that is helpful in deciding this question.¹⁶ Silvers proposes a "historical counterfactualizing" test for whether some practice is unjust toward people with a disability. The test asks whether the given practice, which is problematic because it appears to place people with a disability at a disadvantage, would be the same if people with the disability were the majority in society, instead of "a powerless minority" (Silvers 2005, 312). If the practice would be the same in the imagined society, then it is not unjust, but if it would be replaced by a practice that did not disadvantage people with the disability, then the current policy or practice is unjust because it "grows out of the dominance of non-disabled people's convenience and tastes." For example, if a majority of people in society used wheelchairs, then buildings would be made accessible, which shows, according to Silvers' historical counterfactualizing test, that it would be unjust for some society to refuse to take steps toward making buildings wheelchair accessible. This test can be applied to the issue of developing a cure for autism. It can be

¹⁶ Several writings, including Silvers (2005).

applied directly, to the issue of whether seeking a cure for autism is unjust. But I think the case of testing whether it would be unjust to seek a cure for autism also is equivalent to asking whether the social model or medical model of disability applies to autism. The historical counterfactualizing test would ask whether a society composed mainly of PAS would be viable and would provide satisfactory lives for PAS, without attempts to cure autism, or whether even in a majority-PAS society, PAS would face such significant problems that they would seek to develop cures for autism.¹⁷ If the former, then current attempts to cure autism stem from the mere convenience and bias of our society's dominant neurotypical majority, so seeking a cure for autism is unjust, and autism best fits the social model of disability. If the latter, then autism best fits the medical model of disability, and there are good, unbiased reasons to seek a cure for autism.

So, in a PAS-majority society, would a cure for autism be sought? The answer is ambiguous, but nonetheless illuminating. I think the first step in the thought experiment, namely trying to imagine a society of PAS, is the most difficult and revealing step. Trying to imagine this society emphasizes how heterogeneous autism is. If we imagine a society of very high-functioning PAS, then it seems plausible that the society would do just fine without attempting to “cure” its members. The society would presumably be different from ours in many ways—there would be less importance placed on face-to-face communication, schools and workplaces would be organized differently, there would probably be easy access to quiet rooms in which to seek refuge from sensory overload, and so on. But there is no obvious reason to doubt that high-functioning PAS could maintain a society that served their needs fairly well, so there is no obvious reason to think that such a society would be highly concerned with “curing” or changing the basic nature of most of its members. If, instead, we imagine a society of PAS who occupy a very different space on the autism spectrum, then that society might face disaster—a failure of its citizens to be able to coordinate their activities or communicate effectively with one another, intellectual limitations, a slew of physical problems comorbid with autism—and such a society might desperately welcome a cure for the majority of its population. If we imagine a society that is composed of a mixture of different types of PAS, proportional to the current makeup of the autism spectrum, then I think the answer is that we do not know what such a society would be like. We understand autism too little, and have too few resources for predicting how well a variety of PAS would respond to living in a society that treats them as normal. Our ignorance here is not a dead end, but an important point that can lead to significant conclusions.

¹⁷ Silvers' counterfactualizing test deserves closer scrutiny in several ways. In particular, by focusing on one disability and what the effects would be if people with the disability were the majority, it leaves aside any considerations of a possible strain on resources in the real world if society were to try to accommodate all disabilities simultaneously. Due to space considerations, I leave aside these complications here. (Thanks to the editors and to students in my graduate course on respect, for bringing up various issues regarding the counterfactualizing test.)

As far as the historical counterfactualizing test for curing autism is concerned, although it is not obvious what the imagined society would decide about a cure for autism, trying to imagine the society itself is instructive. It emphasizes how different PAS are from each other. People are categorized as being on the autism spectrum because they display certain sets of traits, but the traits a PAS displays vary hugely. This is not just a matter of degree, but of whether an individual displays any degree of the trait at all. It may well be that not only the current diagnostic category of “autism spectrum disorder,” but the whole category of “autistic” in general is an artifact of our current state of ignorance about the causes, the biology, and the psychology of autism, and that history will see it as a misguided conflation to place many disparate conditions together in the same category of “autistic.” So our attempt to imagine a society of PAS may be as eccentric as trying to imagine a society of people who fall into an idiosyncratic historical category like “non-aristocratic” or “ruled by phlegmatic humours.” The main point to draw, I think, is that more basic research and understanding is needed, before we can draw significant conclusions about autism, whether these are medical, neurological, or moral conclusions.

But it is also worth offering a plausible speculation about what the society of PAS would think, about developing a cure for autism. It might go like this. In that imagined society, many well-functioning and happy citizens (who do quite well within their society’s “autism-friendly” practices) would wonder what they can do to help their less functional fellows, who seem to have various behavioral and/or medical problems that are rooted in their neurological makeup. They would engage in basic research to understand the causes of the medical problems of their fellow citizens, and would discover various similarities and differences between “normal” (high-functioning) people and the less flourishing, poorly integrated members of their society. This might lead to medical treatments for the worse off, which would allow them to interact in ways that were more typical and normal for that society. It is hard to say for sure, but it might well go like that. If so, this would further reinforce my claim that what is needed at this point, in order to even begin to reach conclusions about the best ways to treat PAS, is more basic research to understand the nature of autism, whether there really is one condition that the word refers to, or a variety of heterogeneous conditions, and what sorts of treatments or interventions are possible.

Because so little is known currently about the causes of autism, the role genes play in the development of different neurotypes, and the interventions that could lessen some of the more devastating aspects of autism that some PAS face, it is premature to speculate on what form a “cure” could take. And it is *a fortiori* too soon to insist that all cures must be resisted. Virtually all neurodiversity advocates emphasize that it is desirable to make “treatments” (as opposed to a cure) available to mitigate the severe problems that some PAS face, for example, to decrease the incidence of sensory overload. It is too soon to know whether the most effective “treatment” for some cases of autism might not turn out to be to “cure” whatever root causes there may be. There is a current consensus that autism probably has a strong genetic component, and research on

understanding the genetic components of autism may lead to an understanding of how to alter early brain development to avoid some of the most harmful aspects of autism. But, that type of intervention might be indistinguishable from a cure. It seems worthwhile to engage in basic research on the nature and causes of autism, and to try to develop treatments to mitigate the most harmful effects of autism. At this early stage of understanding autism, however, this kind of research is not clearly distinguishable from lines of research directed at “curing” autism. In fact, the distinction seems largely verbal, and easily subject to manipulation by opponents or supporters of the search for a cure. To block all searches for a cure would require blocking too much useful research that should continue.

I think that it is reasonable for neurodiversity advocates to resist the search for a cure, and there are morally compelling reasons to devote more resources to increasing the chances for PAS to have satisfying lives, even without a cure. But concerns about changing identity and sending a message of rejection are not compelling reasons to reject all search for a cure, unless autism is best seen on the social model of disability instead of the medical model. We do not yet know which model fits autism best, but we do seem to know enough to conclude that more research is needed if we are to understand what autism is, whether autism is really one thing or many, and what the best treatments are to minimize the negative effects of autism. If we engage in that kind of research, we may well stumble across possible cures along the way. But that possibility is not enough reason to reject all research on autism, and *a fortiori* is not enough reason to reject all research that may lead to a cure.

Works Cited

- Brown, Lydia. 2011. “The Significance of Semantics: Person-First Language: Why It Matters.” *Autistic Hoya*, August 11. <http://www.autistichoya.com/2011/08/significance-of-semantics-person-first.html>.
- Frye, Marilyn. 1983. “Oppression.” In *The Politics of Reality: Essays in Feminist Theory*, 1–16. Trumansburg, NY: Crossing Press.
- Mitchell, Jonathan. 2007. “Neurodiversity: Just Say No.” *Jonathon’s Stories*. <http://www.jonathans-stories.com/non-fiction/neurodiv.html>.
- Padawer, Ruth. 2014. “The Kids Who Beat Autism.” *New York Times Magazine*, August 3, MM20. <https://www.nytimes.com/2014/08/03/magazine/the-kids-who-beat-autism.html>.
- Silberman, Steve. 2015. *Neurotribes: The Legacy of Autism and the Future of Neurodiversity*. New York: Penguin Random House.
- Silvers, Anita. 2005. “People with Disabilities.” In *The Oxford Handbook of Practical Ethics*, edited by Hugh LaFollette, 301–27. Oxford: Oxford University Press.
- Sinclair, Jim. 1993. “Don’t Mourn for Us.” *Our Voice: Autism Network International Newsletter* 1 (3).
- Solomon, Andrew. 2008. “The Autism Rights Movement.” *New York*, May 25.