

Gray Matters: Autism, Impairment, and the End of Binaries

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TABLE OF CONTENTS

I.	INTRODUCTION	162
II.	AUTISM 101	168
III.	AUTISM AND ITS DISCONTENTS	171
	A. <i>Defeating Autism</i>	172
	1. <i>“Autism as Puzzle”: Mainstream Medicine and Autism Research</i>	173
	a. <i>Prenatal Testing and Embryo Selection</i>	174
	b. <i>“You Are Scared, and You Should Be”: Fundraising for Autism Research</i>	177
	2. <i>“Autism as Toxic”: Alternative Medicine and Chelation</i>	182
	B. <i>“Autism as Way of Being”: Neurodiversity and Applied Behavioral Analysis</i>	186
IV.	CONSTRUCTING DISABILITY: THE MEDICAL VS. SOCIAL MODELS	193
	A. <i>Social Construction Generally</i>	193
	B. <i>The Social and Medical Models of Disability</i>	194
	1. <i>Medical Model</i>	194
	2. <i>Social Model</i>	196
	C. <i>Similarities</i>	199
	D. <i>Autism and Disability</i>	202

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V.	CONSTRUCTING IMPAIRMENT: PATHOLOGY VS. EXPERIENCE	203
	A. <i>Beyond Diagnosis</i>	204
	B. <i>Ideas and Objects</i>	206
	1. <i>Ideas</i>	206
	2. <i>Objects</i>	209
	a. “Interactive” Kinds: Classifications of People.....	210
	b. “Indifferent” Kinds: Classifications of Material	
	<i>Things</i>	212
	c. <i>Impairment X: Classifications of People and</i>	
	<i>Material Things</i>	213
	C. <i>Autism and Impairment</i>	215
VI.	CONCLUSION	218

I. INTRODUCTION

There is a war raging over autism.¹ On one side are the parents of autistic children who desperately want a cure for their children’s condition. On the other is the “neurodiversity movement”—autistic adults who proclaim that they do not want to be cured because there is nothing wrong with them.² Although this war has been going on for some time, proposed changes to the fourth edition of the American Psychiatric Association’s (APA) *Diagnostic and Statistical Manual of Mental Disorders (DSM-IV)* have reinvigorated the debate. Under the proposed fifth edition (*DSM-V*), there are no longer subtypes of autism—no “Asperger’s syndrome,” no “pervasive developmental disorder not otherwise specified (PDD NOS).”³ You are autistic, or you are not.

The autism debate is ground zero in a much larger and older debate over the meaning of disability. The word *disability* inhabits a world of binaries. It calls to mind a seemingly endless array of opposites that touch on

1. MICHAEL FITZPATRICK, *DEFEATING AUTISM: A DAMAGING DELUSION* 8 (2009).

2. For simplicity’s sake, this Article speaks of two sides in the autism debate. One might reasonably argue that there are more. See Ian Hacking, *Humans, Aliens & Autism*, 138 *DAEDALUS* 44, 44–45 (2009) (“Autism is a highly contested field, and there are many collectives with quite distinct agendas.”); see also Andrew Solomon, *The Autism Rights Movement*, *N.Y. MAG.*, June 2, 2008, <http://nymag.com/news/features/47225/> (“There are in reality three sides in this debate: those who believe autism is caused by environmental toxins (especially vaccines) and should be cured by addressing those pollutants; those who believe it is genetic and should be addressed through the genome; and the neurodiverse, who believe that it is genetic and should be left alone. These camps are blatantly hostile to one another.”).

3. See *Autism Spectrum Disorder: Proposed Revision*, AM. PSYCHIATRIC ASS’N DSM-5 DEV., <http://www.dsm5.org/ProposedRevision/Pages/proposedrevision.aspx?rid=94> (last revised Jan. 26, 2011) [hereinafter *DSM-V Proposed Revision*]; AM. PSYCHIATRIC ASS’N, *DIAGNOSTIC AND STATISTICAL MANUAL OF MENTAL DISORDERS: DSM-IV 75–78* (4th ed. 1994) [hereinafter *DSM-IV*].

nearly every aspect of our lives—one side good or desirable, and the other side bad or undesirable. How capable we are: “ability vs. inability.” How limited we are: “mild vs. severe.” How we fit into the world: “normal vs. abnormal.” How much we contribute: “asset vs. burden.” How free we are: “independence vs. dependence.” How fit we are: “strong vs. weak.” How attractive we are: “beautiful vs. ugly.” How happy we are: “joy vs. suffering.” How fortunate we are: “blessing vs. curse.” And, of course, how healthy we are: “health vs. sickness.” What all of these binaries have in common is that they are predicated on a view of disability as a personal deficit in bodily functioning, and personal deficits are always “bad.”

Beginning in the 1970s, British scholars pioneered the “social model” of disability, which presented a new way of looking at disability.⁴ Specifically, they challenged the status quo, what they called the “medical model” of disability, which viewed disability as a personal deficit in bodily functioning.⁵ They advanced the idea of disability as a social construction, one that is synonymous with oppression or disadvantage imposed by society.⁶ Although the social model of disability did wonders to illuminate disability’s troubling binaries, it did little to resolve them. In fact, it created new ones. “Love vs. hate.” “Acceptance vs. fear.” “Difference vs. defect.” “Gift vs. flaw.” “Equality vs. oppression.” “Culture vs. cure.” “Identity vs. impairment.” “Pride vs. shame.” And above all: “social model vs. medical model.” Binaries remain.⁷

Rarely are things black or white; there is often much gray. When it comes to disability, this is especially so. A model for understanding disability ought to help us understand that gray, but in many ways, the

4. See, e.g., SAMUEL R. BAGENSTOS, LAW AND THE CONTRADICTIONS OF THE DISABILITY RIGHTS MOVEMENT 18 (2009); Rosemary Kayess & Phillip French, *Out of Darkness into Light? Introducing the Convention on the Rights of Persons with Disabilities*, 8 HUM. RTS. L. REV. 1, 6–7 (2008).

5. BAGENSTOS, *supra* note 4, at 18.

6. *Id.*

7. See, e.g., MICHAEL OLIVER, UNDERSTANDING DISABILITY: FROM THEORY TO PRACTICE 45 tbl.3.1 (2d ed. 2009) (distinguishing “individual,” or medical, from “social” model of disability); Tom Shakespeare, *The Social Model of Disability*, in THE DISABILITY STUDIES READER 266, 270 (Lennard J. Davis ed., 3d ed. 2010) (“Rather than simply opposing medicalization, [the social model] can be interpreted as rejecting medical prevention, rehabilitation or cure of impairment”); Tom Shakespeare & Nicholas Watson, *The Social Model of Disability: An Outdated Ideology?*, in 2 RESEARCH IN SOCIAL SCIENCE AND DISABILITY 9, 11 (Sharon N. Barnartt & Barbara M. Altman eds., 2001) (“The social model could be used to view the world in black and white”).

tension between the social and medical models obscures. And the autism debate demonstrates why.

At a superficial level, the competing aims of parents and autistic adults—the “autism rights” or neurodiversity movement—fit neatly into the medical-versus-social model binary. The former see autism as a disorder to be treated and possibly cured (medical model), and the neurodiverse see it as an experience worthy of celebration or at least respect (social model).

But delving deeper, there is a good deal of overlap between autism’s factions and, importantly, between the medical and social models themselves. Both models regard disability as something that ought to be gotten rid of, whether that disability is a negative medical state within the person or negative treatment imposed by society; neither model demands a particular policy response; and both models acknowledge the inevitability of impairment.⁸ Given their similarities, the stark dividing line between the social and medical models is not as clear as it seems. At bottom, the two models describe dueling theories about what causes disability, and little else.⁹

The medical-versus-social model binary is therefore a poor way of distinguishing between autism’s factions. Far from distinguishing the two sides in the autism debate, the medical-versus-social model binary suggests that both parents and the neurodiverse seek the same thing: an end to disability, albeit through very different means. Furthermore, although the two sides clash over the pursuit of cures and certain treatments for autism, those policy choices are dependent on moral frameworks—not disability’s dueling models of causation. And lastly, although both models of disability agree that impairment is inevitable, this turns out to be precisely what parents and the neurodiverse do *not* agree about.

The real fight within the autism community has to do with autism’s essence, but the hard-and-fast distinction between impairment’s¹⁰ biological

8. See *infra* Part IV.C.

9. See *infra* Part IV.B.

10. The word *impairment* is not without ambiguity, and I will explore some of that ambiguity in Part V of this Article. Here I use the word consistent with disability theory and disability rights law to describe that subset of physical and mental traits, characteristics, differences, and variations that concern the medical profession—those that are named and diagnosed, such as cancer or depression. The medical profession tends to use the word *disorder*—or *dysfunction*, *deficit*, *defect*, *condition*—to describe this subset of traits and uses the word *impairment* as a synonym for “limitation” of life functioning. Compare MICHAEL OLIVER, *THE POLITICS OF DISABLEMENT: A SOCIOLOGICAL APPROACH* 11 (1990) (using the Union of the Physically Impaired Against Segregation’s definition of *impairment* as “lacking part of or all of a limb, or having a defective limb, organism or mechanism of the body”), and Regulations To Implement the Equal Employment Provisions of the Americans with Disabilities Act, 29 C.F.R. § 1630.2(h)

core and people's experience of impairment is illusory.¹¹ Given the recent amendments to the definition of *disability* under the ADA, which defines *disability* as an "impairment that substantially limits one or more major life activities," the meaning of *impairment* is now more salient than ever.¹²

A recent second wave of disabilities studies suggests that impairment, like disability, is constructed by the social practices and institutions that name and diagnose it.¹³ This is true so far as it goes, but the autism debate suggests another way that impairment is constructed: it is constructed not only by those who name it but also by those who are

(2011) ("Physical or mental impairment means—(1) Any physiological disorder or condition, cosmetic disfigurement, or anatomical loss affecting one or more body systems . . . or (2) Any mental or psychological disorder, such as an intellectual disability (formerly termed "mental retardation"), organic brain syndrome, emotional or mental illness, and specific learning disabilities."), with THE MERCK MANUAL OF DIAGNOSIS AND THERAPY (19th ed. 2011) (describing etiology, diagnosis, and treatment of various physical and mental "disorders"), and DSM-IV, *supra* note 3, at xxi–ii (defining *mental disorder* as a "clinically significant behavioral or psychological syndrome or pattern that occurs in an individual," which may be associated with, among other things, "impairment in one or more important areas of functioning" and that "must currently be considered a manifestation of a behavioral, psychological, or biological dysfunction in the individual"). By *impairment*, I do not mean physical or mental traits that are not diagnosed, such as eye or hair color or personality type. See *Asperger's Disorder: Rationale*, AM. PSYCHIATRIC ASS'N DSM-5 DEV., <http://www.dsm5.org/ProposedRevisions/Pages/proposedrevision.aspx?rid=97#> (last visited Jan. 13, 2012) (distinguishing *personality type* from *disorder*); 29 C.F.R. app. § 1630 (2011) (excluding from definition of *impairment*: "physical characteristics such as eye color, hair color, left-handedness, or height, weight, or muscle tone that are within 'normal' range and are not the result of a physiological disorder"; "common personality traits such as poor judgment or a quick temper where these are not symptoms of a mental or psychological disorder"; "[e]nvironmental, cultural, or economic disadvantages such as poverty, lack of education, or a prison record are not impairments"; and "[a]dvanced age, in and of itself"). Nor do I mean *only* that subset of physical and mental traits that limit life functioning. A mole, for instance, is a cluster of skin cells that do not grow normally. It may be benign and not limit functioning in any way. It may also develop into cancer that can kill. Either way, it is a physical impairment. Similarly, although many mental impairments limit life functioning, not all do. Some impairments put one at risk of death or pain, for instance, but fall short of limiting life functioning. See DSM-IV, *supra* note 3, at xxi.

11. See *infra* Part V.C.

12. See generally Kevin Barry, *Toward Universalism: What the ADA Amendments Act of 2008 Can and Can't Do for Disability Rights*, 31 BERKELEY J. EMP. & LAB. L. 203, 208 (2010) (discussing the ADA Amendments Act's protection of "nearly everyone from discrimination based on impairments" under the third prong and the relaxation of the "substantial limitation" requirement under the first and second prongs). Although the social constructions of disability and impairment have implications for disability rights law, generally, and the ADA, in particular, they are beyond the scope of this Article.

13. See *infra* notes 247–57 and accompanying text.

named—autistic people, themselves.¹⁴ The neurodiversity movement, which claims autism as a way of being, is neither quaint nor quackery. It underscores that part of autism is the experience of those who are classified as having autism and who are changed by being so classified.¹⁵ For them, autism is a part of their being, not—or not only—some as of yet unknown biological pathology.¹⁶ Moreover, by adapting to, resisting, and transforming the social practices and institutions that classify them, autistic people change autism.¹⁷ Autism, like other impairments, is therefore not fixed; its meaning is evolving as the group denoted by the diagnosis changes.

Although many legal scholars have articulated the distinction between the social and medical models of disability and between impairment and disability, few have scrutinized the assumptions upon which these binaries are based.¹⁸ That is the purpose of this Article. Using autism as a case study, this Article attempts to show that the oft-claimed binary between the social model of disability (which holds that disability is socially constructed) and the medical model of disability (which holds that it is not) is not as stark as it is often made out to be, and that impairment is not solely biological but instead socially constructed, in part, by those who are diagnosed. Although these conclusions do not

14. See *infra* Part V.C.

15. See *infra* Part V.C.

16. See *infra* Part V.C. By *biological pathology*, I mean those “‘objectively’ ascertainable abnormalities of anatomy, physiology, or biochemistry” underlying various impairments. See Carol A. Bernstein, *Meta-Structure in DSM-5 Process*, PSYCHIATRIC NEWS, Mar. 4, 2011, at 7, available at <http://psychnews.psychiatryonline.org/newsarticle.aspx?article%id=108259>. *Biological* pathologies contrast with the *DSM’s psychopathologies*, the diagnosis of which is based “entirely on clinical description.” See *id.* (“[E]ven today objective tests and biomarkers for mental disorders remain research goals rather than clinical tools.”); see also HERB KUTCHINS & STUART A. KIRK, MAKING US CRAZY: DSM: THE PSYCHIATRIC BIBLE AND THE CREATION OF MENTAL DISORDERS 27 (1997) (“Defining a mental disorder involves specifying the features of human experiences that demarcate where normality shades into abnormality. . . . Determining when relatively common experiences such as anxiety or sadness or memory lapses should be considered evidence of some disorder requires the setting of boundaries that are largely arbitrary, not scientific, unlike setting the boundaries for what constitutes cancer or pneumonia.”). The boundary between biological and psychopathologies is, of course, blurred: many clinicians believe that psychopathologies are biologically rooted. See *id.* at 30 (“[M]ental disorders are a subset of medical disorders.” (quoting Robert L. Spitzer & Jean Endicott, *Medical and Mental Disorder: Proposed Definition and Criteria*, in CRITICAL ISSUES IN PSYCHIATRIC DIAGNOSIS 15, 35 (Robert L. Spitzer & Jean Endicott eds., 1978)) (internal quotation marks omitted)).

17. See *infra* Part V.C.

18. See Bradley A. Areheart, *Disability Trouble*, 29 YALE L. & POL’Y REV. 347, 353–54 (2011) (stating that “[l]egal scholars have certainly written about the social model . . . but few have been critical of the social model” (footnote omitted)). For two thoughtful articles scrutinizing these assumptions, see *id.* and Adam Samaha, *What Good Is the Social Model of Disability?*, 74 U. CHI. L. REV. 1251, 1255–56 (2007).

make peace between autism's dueling sides, they help to explain *how* the sides disagree "and why, perhaps, the twain shall never meet."¹⁹

In Part II of this Article, I provide a brief overview of autism. In Part III, I describe in some detail the dueling conceptions of autism advanced by the parents of autistic children and autism's neurodiversity movement, including their disagreement over cures and treatment for autism. In Part IV, using philosopher Ian Hacking's account of social construction as a guide, I cover some familiar territory: disability's medical and social models. According to the medical model, disability is the inevitable result of functionally limiting impairments, while under the social model, disability is socially constructed by practices and institutions that disadvantage people on the basis of impairment. After examining similarities and differences between the two models, I explain why the social-versus-medical model binary does not explain the autism debate.

Part V suggests that the real battle between the neurodiverse and parents is not about *disability* at all—it is about impairment, about the meaning of autism. Returning to Ian Hacking's version of social construction, I argue that impairment is both an "idea" (which is socially constructed) and an "object" (which may or may not be). Impairments are socially constructed ideas because they are contingent upon the social practices and institutions that name and diagnose them, and that legislate, educate, entertain, and employ people with them. The idea of autism never had to be: autism could have remained childhood schizophrenia or mental retardation (MR), or could never have been named at all; and schools, summer camps, laws, and other practices impacting autistic children need never have been put in place.

Beyond the idea of impairment, I argue that impairment refers to two very different kinds of objects: pathologies and people. Although pathologies are indifferent to social practices and institutions, people are not. Autistic people change in response to those practices and institutions—adapting to, resisting, and transforming them. In this way, the neurodiverse change, or construct, autism. Autism may be both an undiscovered pathology that is inevitable and, importantly, a different way of being that is constructed. In Part VI, I offer some concluding remarks.

19. IAN HACKING, THE SOCIAL CONSTRUCTION OF WHAT? 31 (1999).

II. AUTISM 101

There is much debate over what autism is, and this Article will touch on that debate.²⁰ As a starting point, most agree that autism is a neurodevelopmental condition, that is, a condition that impacts brain development and functioning.²¹ There is no blood test or other definitive biological marker for autism.²² “You cannot see autism under a microscope or discover it through a lab test.”²³ Instead, diagnoses of autism are based on the recognition of certain core behavioral features, namely, social communication or interaction differences and fixated interests and repetitive behaviors.²⁴ For example, an autistic person may have difficulty interpreting social cues and facial expressions, expressing emotions in conventionally recognizable ways, and developing and maintaining age-appropriate peer relationships.²⁵ The autistic person may also demonstrate

20. See *infra* text accompanying notes 243–46. The word *autism* comes from the Greek *autos*, meaning “self,” and was first used by Swiss psychiatrist Eugen Bleuler in 1912 “to describe the behavior of some people, then diagnosed with schizophrenia, who were disengaged from everything except their internal world.” ROY RICHARD GRINKER, UNSTRANGE MINDS: REMAPPING THE WORLD OF AUTISM 44 (2007). In his now-famous 1943 article titled *Autistic Disturbances of Affective Contact*, American psychiatrist Leo Kanner described eleven children who had difficulty relating to other people, speech delays or unusual language, fantastic rote memories, and an obsession with sameness and repetition. *Id.* at 44, 46. Kanner named these shared characteristics “infantile autism.” *Id.* at 44. At the same time, and unbeknownst to Kanner, Austrian psychiatrist Hans Asperger “was examining autistic children and used the word ‘autism’ to describe them.” *Id.* at 56. In his 1944 article titled “*Autistic Psychopathy*” in *Childhood*, Asperger—writing in German—described four children who, “despite being highly intelligent and highly verbal, . . . rarely made eye contact” and “exhibited unusual repetitive behaviors.” *Id.* at 58–59. “Kanner’s name is associated with the classic, severe form of autism. Asperger’s is associated with more mildly autistic, or at least highly intelligent and highly verbal, children.” *Id.* at 58. Perhaps because he wrote in English, Kanner’s work became better known more quickly than Asperger’s. *Id.* at 60. In 1968, the second edition of the APA’s *Diagnostic and Statistical Manual* listed “autistic, atypical and withdrawn behavior” in its description of “Schizophrenia, childhood type.” See Roy Richard Grinker, *Diagnostic Criteria for Autism Through the Years*, UNSTRANGE MINDS (2007), <http://www.unstrange.com/dsm1.html>. In 1980, with the publication of the *DSM-III*, autism came into its own as a distinct diagnosis called “infantile autism,” which was renamed “autistic disorder” in successive editions of the *DSM*. See *id.* Asperger’s disorder did not enter the lexicon of most mental health clinicians until the publication of the *DSM-IV* in 1994, when the APA formally recognized the impairment. GRINKER, *supra*, at 60–61.

21. SIMON BARON-COHEN, THE ESSENTIAL DIFFERENCE: THE TRUTH ABOUT THE MALE AND FEMALE BRAIN 137 (2003).

22. Daniela Caruso, *Autism in the U.S.: Social Movement and Legal Change*, 36 AM. J.L. & MED. 483, 490 (2010).

23. GRINKER, *supra* note 20, at 2.

24. *DSM-V Proposed Revision*, *supra* note 3.

25. *Id.*; see also Hacking, *supra* note 2, at 52 (“[Autistic people have] notorious difficulty with eye contact. For whatever reason, autistic people, when they look at someone’s face at all, tend to focus on the lower part of the face (the mouth and chin) and not the eyes.”).

unusual sensory behaviors such as hand- or finger-flapping, excessive adherence to routines, and inflexibility and discomfort with change.²⁶

Most also agree that autism is highly variable: the intensity of autism's core features varies significantly from person to person, and these features may change throughout an individual's lifetime.²⁷ As Dr. Ami Klin, Professor of Child Psychology and Psychiatry at the Yale Child Study Center, has thoughtfully remarked:

The variability is immense. From individuals who are burdened by severe to profound intellectual disabilities to persons who are gifted and more competent than most in the community. From those who cannot speak to those who are loquacious. From those whose isolation is manifest by complete social withdrawal to those who cannot stop approaching others albeit at times awkwardly. From persons who are enchained by self-stimulating movements, rituals and self-injurious behaviors to those whose knowledge about circumscribed areas of knowledge or special skills are prodigious. These, at times, extreme characteristics notwithstanding, all are people with emotions who can love and can be hurt, who need to meet the demands of everyday life, and who are desirous of independence and meaningful relationships. Some are in need of intensive supports whereas others require little more than an equal opportunity community. All deserve a stab at happiness and a fulfilling life. Most can make contributions to society whereas some can in fact build on their specific strengths and reach unique achievements in science, art and technology.²⁸

Given the breadth of autism's variability, autism is generally thought of as a continuum or "spectrum."²⁹ There is a saying in the world of autism:

26. *DSM-V Proposed Revision*, *supra* note 3. There are many aspects of autism beyond social communication/interaction differences and fixated interests. As Professor Hacking notes, "Many autistic children are subject to seizures. Many are hypersensitive to loud sounds, bright colors, and itchy surfaces." Hacking, *supra* note 2, at 48. Limited motor skills, such as "bad balance, a tendency to bump into things, poor hand-eye coordination, difficulties in initiating or stopping movements, and even a poor hand-grasp," are also typical among autistic children. *Id.* For a helpful discussion of autistic features beyond those listed in the *DSM*, see generally SCOTT STANDIFER, ADULT AUTISM AND EMPLOYMENT: A GUIDE FOR VOCATIONAL REHABILITATION PROFESSIONALS 1-12 (2009), available at <http://dps.missouri.edu/Autism/Adult%20Autism%20&%20Employment.pdf>, which discusses experiential and functional features of autism.

27. GRINKER, *supra* note 20, at 10.

28. Ami Klin, *Articles of Understanding: Introduction*, GLOBAL & REGIONAL ASPERGER SYNDROME PARTNERSHIP (2006), http://www.grasp.org/new_art.htm.

29. See *DSM-V Proposed Revision*, *supra* note 3 (proposing to rename "autistic disorder" to "autism spectrum disorder"); see also GRINKER, *supra* note 20, at 10 ("'Autism' today is really an autism spectrum."). While *spectrum* rightly connotes autism's diversity, it also oversimplifies. As Professor Hacking notes,

[S]pectra are linear and autism isn't. The metaphor suggests that you can arrange autistic people on a line, from more to less. It does make sense to speak of high-functioning people with autism, but that covers an extraordinary range of people. It also makes sense to speak of being severely autistic—

“When you know a person on the [autism] spectrum, you know one person on the spectrum.”³⁰ Because the autism spectrum “is broad enough to encompass both a severely mentally retarded autistic person without speech and a super-intelligent but socially awkward mathematician or physicist,”³¹ one might say that the world of autism *is* the world. Or nearly so. As a result, autism resists easy definition.

Although the *DSM-IV* tries to distinguish various points along the autism spectrum by providing diagnostic categories for various subtypes of autism, such as Asperger’s³² and PDD-NOS,³³ the *DSM-V* is poised to dispatch with that effort. According to the *DSM-V*’s Neurodevelopmental Disorders Working Group, “A single spectrum disorder is a better reflection of the state of knowledge about pathology and clinical presentation.”³⁴ Multiple diagnostic categories, the Group concedes, “were equivalent to trying to ‘cleave meatloaf at the joints’” and were found to be “inconsistent over time, variable across sites and often associated with severity, language level or intelligence rather than features of the disorder.”³⁵

Lastly, most agree that there are lots of people who have, and have had, autism. According to the U.S. Department of Health and Human Services Centers for Disease Control and Prevention (CDC), an average of 1 in 110 U.S. children have autism, or about 1% of all U.S. children.³⁶

which, if anything, covers an even wider range of individuals. . . . I would prefer to speak of an autistic manifold.

See Hacking, *supra* note 2, at 47.

30. Solomon, *supra* note 2.

31. GRINKER, *supra* note 20, at 10.

32. *DSM-IV*, *supra* note 3, at 75–77. According to the *DSM-IV*, people with Asperger’s and people with “classic” autism share limitations in social interaction and restricted interests and behaviors. *Id.* at 66, 75–77. The difference between the two is that people with Asperger’s have no clinically significant delay in speech or cognitive development—good IQ—whereas some people with autism do. *Id.*

33. *Id.* at 77–78. According to the *DSM-IV*, PDD-NOS is a catch-all condition encompassing those with *either* limitations in social interaction/communication *or* restricted interests, behaviors, and activities. *Id.* It includes “atypical autism,” presentations that do not meet the criteria for Asperger’s or classic autism, *id.* at 78, and is the most common diagnosis of those with autism. See GRINKER, *supra* note 20, at 140. According to Professor Grinker, PDD-NOS and Asperger’s disorder make up as much as 75% of all new cases of autism, and “Asperger cases account for between 14 and 19 percent of the total autism spectrum population.” *Id.* at 159, 163.

34. *Autism Spectrum Disorder: Rationale*, AM. PSYCHIATRIC ASS’N DSM-5 DEV., <http://www.dsm5.org/ProposedRevision/Pages/proposedrevision.aspx?rid=94> (last revised Jan. 26, 2011).

35. *Id.*

36. *What We’ve Learned About Autism Spectrum Disorder*, CTR. FOR DISEASE CONTROL & PREVENTION, <http://www.cdc.gov/Features/CountingAutism/> (last updated Apr. 4, 2011). Many people, including those in print, radio, and television media, have gone so far as to call autism an “epidemic.” See, e.g., GRINKER, *supra* note 20, at 143. Although extended discussion of autism’s prevalence is beyond the scope of this Article, “the increase in the rate of autism is more likely due to the result of new and improved

Beyond this, there is little agreement about the meaning of autism. As epitomized by the words of Jim Sinclair, an autistic adult, many autistic people regard autism as an experience, as a different way of being worthy of respect.³⁷ Others, such as Kit Weintraub, the mother of two autistic children, believe that autism is a disorder to be cured or treated.³⁸ Although disability's dueling medical and social models would appear to explain the autism debate, they fall short. The autism debate is not about the social construction of disability; it is about the social construction of *impairment*. Given autism's newness to the legal literature, I describe this debate in some detail in the Part that follows.³⁹

III. AUTISM AND ITS DISCONTENTS

Autism is a way of being. It is not possible to separate the person from the autism.

Therefore, when parents say, "I wish my child did not have autism," 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."

Read that again. This is what we hear when you mourn over our existence. This is what we hear when you pray for a cure. This is what we know, when you tell us of your fondest hopes and dreams for us: that your greatest wish is that one day we will cease to be, and strangers you can love will move in behind our faces.

....

You didn't lose a child to autism. You lost a child because the child you waited for never came into existence. That isn't the fault of the autistic child who does exist, and it shouldn't be our burden. We need and deserve families who can see us and value

science—more reliable [and broader] definitions of autism and more awareness among health-care professionals and educators." *Id.* at 145–46. "The bottom line is that reported autism prevalence has increased, but the real prevalence has probably remained stable." *Id.* at 169; *see also* FITZPATRICK, *supra* note 1, at 28 (noting that Grinker's conclusions "echo[] the consensus of authorities in the field of autism").

37. *See infra* note 40 and accompanying text.

38. *See infra* note 41 and accompanying text.

39. For an excellent discussion of autism's intersections with law and policy, *see generally* Caruso, *supra* note 22.

us for ourselves, not families whose vision of us is obscured by the ghosts of children who never lived. Grieve if you must, for your own lost dreams. But don't mourn for us. We are alive. We are real. And we're here waiting for you.

—Jim Sinclair, *Don't Mourn for Us*⁴⁰

I love my children, but I do not love autism. My children are not part of a select group of superior beings named "autistics." They have autism, a neurological impairment devastating in its implications for their lives, if left untreated. I do not know the cause of autism, but research tells me the most likely possibility is that there is some kind of genetic anomaly, perhaps influenced by environmental factors. In other words, it is no more normal to be autistic than it is to have spina bifida. As with any other condition that would threaten their future and their happiness, I do as much as I can to help them be as functional and as normal as possible. And no, "normal" to me does not mean "a cookie-cutter robot-child, trained to do my will." It means: "able, like most people without autism, to lead an independent, purpose-filled life." Able to speak, able to communicate, able to form and keep relationships. I have spent most of the last eight years poring over research on the treatment of autism. I have attended lectures and spent hours preparing materials for my children's ABA therapy programs. I do all of this because I love my children and because this treatment has helped them develop language, cognitive, self-help and social skills, all things that they would not have acquired without this treatment.

—Kit Weintraub, *A Mother's Perspective*⁴¹

A. Defeating Autism

For many families, particularly those whose autistic children have profound functional limitations, the challenges of autism can be overwhelming. For them, "the search for cures, or at least, for more effective treatments, is a clear consensus."⁴² Many choose the path of conventional medicine, while others pursue an alternative course.⁴³

40. Jim Sinclair, *Don't Mourn for Us*, AUTISM NETWORK INT'L, http://www.autreat.com/dont_mourn.html (last modified June 26, 2002).

41. Kit Weintraub, *A Mother's Perspective*, ASS'N FOR SCI. AUTISM TREATMENT, <http://www.asatonline.org/forum/archives/mother.htm> (last visited Feb. 4, 2012).

42. Klin, *supra* note 28.

43. See MAJIA HOLMER NADESAN, CONSTRUCTING AUTISM: UNRAVELLING THE "TRUTH" AND UNDERSTANDING THE SOCIAL 188–95 (2005).

1. “Autism as Puzzle”: Mainstream Medicine and Autism Research

For parents who subscribe to conventional medicine, autism is a puzzle, its causes and cure unknown. As a result, research is a top priority.⁴⁴ Although autism research still has a very long way to go, it has made some headway in recent years. For example, research in genetics, namely, family and twin studies and the recognition of the coexistence of autism with a number of genetic disorders, points to a substantial genetic contribution to autism “and has strengthened the case for viewing it as an essentially biological disorder.”⁴⁵ Research in neuroscience, including postmortem studies and brain imaging, has “attempted to identify distinctive anatomical, physiological and biochemical features of the ‘autistic brain,’”⁴⁶ while psychological research has “clarified some of the distinctive characteristics of autistic thought and behaviour.”⁴⁷

According to the APA, “[E]vidence for the biological basis of autism is growing with studies demonstrating variable support and variable explanatory power for biological variables,” including associations between autism and “biological markers (e.g., neurotransmitter levels), neuroimaging results (e.g., brain volume), head circumference (e.g., macrocephaly), electrophysiological testing (e.g., ERP, EEG) and neuropsychological assessments (e.g., face processing).”⁴⁸ Many in the medical mainstream believe that “the distinctive clinical presentations of autism can be linked to some, as yet unidentified, deficit in neurological function, which in turn can be traced back to some, also unidentified, genetic defect, perhaps conferring susceptibility to some, still unknown, environmental agent.”⁴⁹ For them, “[I]t is only a matter of time before

44. See Caruso, *supra* note 22, at 493.

45. See FITZPATRICK, *supra* note 1, at 78 (stating that 10% of autism cases coexist with other known genetic conditions, such as Down’s syndrome, and that in 70% of cases involving identical twins, both have autism, as opposed to only 5% of cases involving nonidentical twins).

46. *Id.* at 8; see also BARON-COHEN, *supra* note 21, at 137 (“There is evidence of brain dysfunction (such as epilepsy) in a proportion of cases. There is also evidence of structural and functional differences in regions of the brain (such as the amygdala being abnormal in size, and less responsive to emotional cues).”).

47. FITZPATRICK, *supra* note 1, at 9.

48. Michael B. First, *Autism and Other Pervasive Developmental Disorders Conference (February 3–5, 2008)*, AM. PSYCHIATRIC ASS’N DSM-V DEV., <http://www.dsm5.org/Research/Pages/AutismandOtherPervasiveDevelopmentalDisordersConference%28February3-5,2008%29.aspx> (last visited Feb. 4, 2012).

49. FITZPATRICK, *supra* note 1, at 9.

the key links in the causal chain extending from genes through brain to autistic mind are identified—and therapeutic interventions discovered.”⁵⁰

Medical research into autism raises a multitude of ethical concerns.⁵¹ This sub-Part will discuss the ethical concerns that arise with respect to one of the uses to which medical research is put—prenatal testing and embryo selection—and some of the methods used to fund it—Autism Speaks’s fundraising tactics.

a. Prenatal Testing and Embryo Selection

Mainstream science points to “a strong and unambiguous genetic component [to autism] that may explain as much as 80–90% of the risk for autism.”⁵² It also suggests that a number of different genes may be at work, with estimates ranging from 10 to over 100.⁵³ According to one author:

Notwithstanding the slow and, at times, frustrating progress in characterizing the genetic factors contributing to autism, many scientific experts in the field are optimistic that clinically useful genetic markers of autism have been, or will soon be, identified as a result of new genetic technologies and increased funding of research.⁵⁴

Most would agree that autism presents a host of challenges for autistic people and their families.⁵⁵ Genetic research may help meet some of these challenges. Because autism is currently diagnosed based on behavioral criteria, parents are often unaware that their child is autistic until the child is two or three years old.⁵⁶ Genetic testing may give parents a few months’ or even a few years’ head start—watching for autism’s features in a child with a genetic predisposition toward autism, and getting themselves educated and their child services sooner rather than later.⁵⁷ It may also lead to better pharmacological treatments.⁵⁸

50. *Id.*

51. Gary E. Marchant & Jason S. Robert, *Genetic Testing for Autism Predisposition: Ethical, Legal, and Social Challenges*, 9 HOUS. J. HEALTH L. & POL’Y 203, 219 (2009).

52. *Id.* at 204–05.

53. *Id.* at 213.

54. *Id.* at 215.

55. See Letter from Ari Ne’eman, President of the Autistic Self Advocacy Network, to Sponsors, Donors, and Supporters of Autism Speaks (Oct. 7, 2009), <http://www.autisticadvocacy.org/modules/smartsection/item.php?itemid=61> (stating that autism “comes with significant challenges in a wide variety of realms”).

56. *Screening and Diagnosis, Autism Spectrum Disorders*, CTR. FOR DISEASE CONTROL & PREVENTION (May 13, 2010), <http://www.cdc.gov/ncbddd/autism/screening.html> (“By age 2, a diagnosis [of autism] by an experienced professional can be considered very reliable. However, many children do not receive a final diagnosis until much older.” (footnote omitted)).

57. See Marchant & Robert, *supra* note 51, at 227–28.

With more tailored and effective drugs, an autistic child might be better able to cope with the stresses of a nonautistic world.

Although a cure and treatment for autism are among the goals of genetic research, another goal will inevitably be prevention, that is, “prenatal tests and embryo selection techniques that inform prospective parents about future children.”⁵⁹ Although some prospective parents “will seek out information yielded by the tests even if they intend to continue a pregnancy regardless of the finding,” many more will use this information “to decide whether to carry a particular fetus to term.”⁶⁰ Down’s syndrome is a case in point: about 90% of pregnancies testing positive for the condition are terminated.⁶¹

This raises several ethical concerns, some common to conditions with a genetic component, others unique to autism. First, having the gene or genes at issue does not necessarily mean having autism—susceptibility is not the same as certainty.⁶² “Like many complex diseases, autism appears to result from an interaction of environmental and genetic factors. . . . Not every child carrying an autism predisposing gene will develop autism”⁶³ But “[p]eople often misunderstand the implications of their genetic data, believing that a genetic predisposition necessarily results in the development of their illness.”⁶⁴ Given these difficulties in comprehension, how informed should parental consent be? Should doctors and other medical professionals be required to counsel parents in the myriad ways that the life of an autistic child may resemble those of his or her peers, “focusing on capacities for education, stimulation, play, and relationships,” or in the ways that autistic life may be different but nevertheless fulfilling?⁶⁵ Furthermore, “[a]s with any genetic test, some

58. See *id.* at 225–26; cf. Robert L. Burgdorf, Jr., *Restoring the ADA and Beyond: Disability in the 21st Century*, 13 TEX. J. C.L. & C.R. 241, 322 (2008) (noting benefits of the first genetically engineered medicine, synthetic insulin).

59. Adrienne Asch, *Disability Equality and Prenatal Testing: Contradictory or Compatible?*, 30 FLA. ST. U. L. REV. 315, 336 (2003); see also Majia Holmer Nadesan, *Constructing Autism: A Brief Genealogy*, in *AUTISM AND REPRESENTATION* 78, 90 (Mark Osteen ed., 2008) (“[T]he identification of susceptibility genes will inevitably lead to development of techniques for prenatal screening.”).

60. Asch, *supra* note 59, at 336.

61. See Amy Harmon, *Prenatal Test Puts Down Syndrome in Hard Focus*, N.Y. TIMES, May 9, 2007, at A1.

62. See Marchant & Robert, *supra* note 51, at 220.

63. *Id.* at 229.

64. *Id.* at 220 (citing Ellen Wright Clayton, *Ethical, Legal, and Social Implications of Genomic Medicine*, 349 N. ENG. J. MED. 562, 563 (2003)).

65. Asch, *supra* note 59, at 334.

level of false positives [is] to be expected.”⁶⁶ Does the risk of having a child with autism outweigh the risk of terminating a nonautistic pregnancy or not proceeding with the implantation of a nonautistic embryo?

Second, when it comes to autism, parents’ uncertainty is compounded because autism is not a single, uniform condition—it is extremely variable.⁶⁷ Even if parents know that their unborn child will have a substantial likelihood of developing autism because of this or that gene, doctors may not be able to tell them what form that autism may take.⁶⁸ Is it the nonverbal child they do not wish to bear or the verbal but socially awkward one? And if research progresses to a point where doctors *do* know, are they obligated to tell parents everything they know, or will mainstream medicine draw a line, informing parents of only certain kinds of autism?⁶⁹

Lastly, even assuming that consent is informed and the form of autism susceptibility is reasonably certain, what impact will prenatal testing and embryo selection have on autistic people’s and others’ views of their inherent worth as human beings?⁷⁰ Can these genetic procedures “comfortably coexist with society’s professed goals of promoting inclusion and equality for people with disabilities”?⁷¹ Or do such procedures send a message that autistic lives may not be worth living or may be too great an imposition for families and the rest of society to bear?⁷² As Professor Adrienne Asch explains, singling out particular impairments, or certain variants of those impairments, for testing is tricky business because it inevitably stigmatizes those on the “list”:

[C]reating an official list of conditions that parents should worry about will have an undesirable effect on the societal acceptance and self-esteem of those with the listed conditions. Why should it be acceptable to avoid some characteristics and not others? How can the society make lists of acceptable and unacceptable tests and still maintain that only disabling traits, and not people who live with those traits, are to be avoided? If it is legitimate to be a

66. Marchant & Robert, *supra* note 51, at 229.

67. See *supra* notes 27–28 and accompanying text.

68. Marchant & Robert, *supra* note 51, at 220, 233 (discussing “infeasibility of an accurate prenatal test given the genetic heterogeneity and variable expression of autistic disorders”); see also Nadesan, *supra* note 59, at 90 (“[C]ausal and mechanistic models of gene action are unlikely to explain or predict the range of autistic conditions or the severity of autistic symptoms.”).

69. See Marchant & Robert, *supra* note 51, at 220; see also Asch, *supra* note 59, at 338–39 (discussing ethical concerns with clinicians’ decision to inform prospective parents of susceptibility to some impairments but not others).

70. See Marchant & Robert, *supra* note 51, at 232.

71. Asch, *supra* note 59, at 315.

72. See *id.* Prenatal testing gives rise to some of disability law’s most vexing questions. For a good introduction to some of these questions, see BAGENSTOS, *supra* note 4, at 102–04.

person with a disability, or to parent a child with such a disabling condition, should the society make a list of “serious” and “trivial” characteristics?⁷³

Many in the autism community argue against genetic research or at least suggest that such research proceed with caution.⁷⁴ Ari Ne’eman, a member of the President’s National Council on Disability and Founding President of the Autism Self-Advocacy Network (ASAN), a “nonprofit organization run by and for Autistic people,”⁷⁵ sees “serious problems with taxpayer and well-meaning charitable funds going toward [genetic] research” and stresses that “not every dollar given toward autism causes is helpful to autistic people.”⁷⁶ Professor Simon Baron-Cohen, director of Cambridge University’s Autism Research Centre, likewise warns of genetic research’s unintended consequences: “Caution is needed before scientists embrace prenatal testing so that we do not inadvertently repeat the history of eugenics or inadvertently ‘cure’ not just autism but the associated talents that are not in need of treatment.”⁷⁷

*b. “You Are Scared, and You Should Be”: Fundraising
for Autism Research*

Autism Speaks, founded in 2005, is the nation’s “largest autism science and advocacy organization.”⁷⁸ Like many advocacy organizations, Autism Speaks raises funds by raising public awareness: from lobbying for federal moneys on Capitol Hill to soliciting major gifts from corporate and private donors; from organizing local fundraising events such as Walk Now for Autism Speaks across the country to establishing the United Nations-sanctioned World Autism Awareness Day on April 2; and from launching national media campaigns about autism to recruiting celebrity

73. Asch, *supra* note 59, at 339.

74. See, e.g., *Research and Data Collection*, AUTISTIC SELF ADVOC. NETWORK, <http://www.autisticadvocacy.org/modules/smartsection/category.php?categoryid=80> (last visited Feb. 4, 2012) (noting “potential eugenic consequences” associated with “genetic and other causation-oriented studies”); ASPIES FOR FREEDOM, <http://www.aspiesforfreedom.com/> (last visited Feb. 4, 2012) (advocating for “prevent[ion of] eugenic elimination of autistic people by opposing pre-natal testing for autism”).

75. AUTISTIC SELF ADVOC. NETWORK, <http://www.autisticadvocacy.org> (last visited Feb. 4, 2012).

76. Solomon, *supra* note 2 (internal quotation marks omitted).

77. See Simon Baron-Cohen, *Autism Test ‘Could Hit Maths Skills,’* BBC NEWS, <http://news.bbc.co.uk/2/hi/health/7736196.stm> (last updated Jan. 7, 2009).

78. *About Us*, AUTISM SPEAKS, <http://www.autismspeaks.org/about-us> (last visited Feb. 4, 2012).

spokespeople.⁷⁹ Autism Speaks has something to show for all of this. In 2005, only \$15 million in privately raised funds went to autism. Since that time, Autism Speaks has committed “over \$142.5 million to research through 2014.”⁸⁰

Autism Speaks’s advocacy efforts have also helped to expand federal funding of autism research. Following on the heels of the Children’s Health Act of 2000, which, among other things, required the National Institutes of Health to “expand, intensify, and coordinate” research on autism,⁸¹

[t]he 2006 Combating Autism Act . . . provided for approximately \$950 million in spending on autism over five years, divided among research and other programs, and was subsequently funded accordingly. . . . In President Obama’s 2011 budget proposal, overall federal research and development funding is set to decline slightly from 2010 levels, but funding for autism research is actually set to *increase*.⁸²

In raising awareness about autism, Autism Speaks emphasizes the need to find a cure for autism. This goal, of course, carries with it the implicit, but nevertheless powerful, message that autism “is unacceptable; a cure must be found,” and that anyone living with autism “should not be content with her current condition.”⁸³ But Autism Speaks’s awareness campaigns are not always so subtle. Time-tested pity and fear tactics are hallmarks of its advocacy⁸⁴ and have drawn the ire of many in the autism and broader disability community.

In 2009, Autism Speaks unveiled its “I Am Autism” video at the second annual United Nations World Focus on Autism.⁸⁵ The

79. See *Annual Report: 2009*, AUTISM SPEAKS, http://www.autismspeaks.org/docs/Autism_Speaks_Annual_Report_2009.pdf (last visited Feb. 4, 2012).

80. See Press Release, Autism Speaks, New Autism Genes Discovered: Autism Speaks and the World’s Leading Autism Experts Announce Phase 2 Results of the Autism Genome Project (June 9, 2010), http://www.autismspeaks.org/press/autism_genome_project_nature.php.

81. 42 U.S.C. § 284g (2006).

82. Caruso, *supra* note 22, at 493 (emphasis added) (footnotes omitted).

83. Bradley A. Areheart, *When Disability Isn’t “Just Right”: The Entrenchment of the Medical Model of Disability and the Goldilocks Dilemma*, 83 IND. L.J. 181, 202–04 (2008) (discussing cures and campaigns generally).

84. See OLIVER, *supra* note 10, at 93 (stating that the “prime objective” of many disability advocacy organizations “is to maximise income, regardless of the image presented,” and that many organizations “are quite shameless in the way they reinforce th[e] image” of disabled people as “burdens of charity. . . . through their fund-raising campaigns”).

85. See *Do You Want To Be in a World Autism Video?*, AUTISM SPEAKS, http://www.autismspeaks.org/inthenews/autism_video_project.php (last visited Feb. 4, 2012).

video features black-and-white footage of autistic children alone and the sinister-sounding,⁸⁶ anthropomorphized voice of autism, stating:

I am autism. I'm visible in your children, but if I can help it, I am invisible to you until it's too late. I know where you live. And guess what? I live there too. I hover around all of you. I know no color barrier, no religion, no morality, no currency. I speak your language fluently. And with every voice I take away, I acquire yet another language. I work very quickly. I work faster than pediatric AIDS, cancer, and diabetes combined. And if you're happily married, I will make sure that your marriage fails. Your money will fall into my hands, and I will bankrupt you for my own self-gain. I don't sleep, so I make sure you don't either. I will make it virtually impossible for your family to easily attend a temple, birthday party, or public park without a struggle, without embarrassment, without pain. You have no cure for me. Your scientists don't have the resources, and I relish their desperation. Your neighbors are happier to pretend that I don't exist—of course, until it's their child. I am autism. I have no interest in right or wrong. I derive great pleasure out of your loneliness. I will fight to take away your hope. I will plot to rob you of your children and your dreams. I will make sure that every day you wake up, you will cry, wondering who will take care of my child after I die? And the truth is, I am still winning, and you are scared. And you should be. I am autism. You ignored me. That was a mistake.⁸⁷

The second half of the video features color footage of the parents of autistic children speaking out against autism:

We will spend every waking hour trying to weaken you. . . . We search with technology and voodoo and prayer and herbs and genetic studies We speak the only language that matters: love for our children. . . . Autism is naive. You are alone. . . . You think because some of our children cannot speak, we cannot hear them? That is autism's weakness. You think that because my child lives behind a wall, I am afraid to knock it down with my bare hands? . . . Autism, if you are not scared, you should be. When you came for my child, you forgot: you came for me.⁸⁸

The video ends with footage of autistic children smiling with their families.

86. The video was created by Academy Award-nominated director Alfonso Cuarón, director of the third Harry Potter installment. *Id.*; *Biography for Alfonso Cuarón*, IMDB, <http://www.imdb.com/name/nm0190859/bio> (last visited Jan. 15, 2012).

87. *Horrific Autism Speaks "I Am Autism" Ad Transcript*, AUTISTIC SELF ADVOC. NETWORK (Sept. 23, 2009), <http://www.autisticadvocacy.org/modules/smartsection/item.php?itemid=58>. Although the video is no longer available on YouTube, several autism parodies are. *E.g.*, *I Am Autism*, YOUTUBE (Sept. 27, 2009), http://www.youtube.com/watch?v=a4IKK1Onx_I; *I Am Autism Speaks (Now with Added Sub-Titles)*, YOUTUBE (Sept. 24, 2009), <http://www.youtube.com/watch?v=yU2paLv1MGE>.

88. *Horrific Autism Speaks "I Am Autism" Ad Transcript*, *supra* note 87.

The “I Am Autism” video sparked an immediate outcry from many in the autism and broader disability communities. In an open letter to the sponsors, donors, and supporters of Autism Speaks, then-ASAN President Ari Ne’eman and over sixty international, national, and local disability advocacy groups called for an end to support for Autism Speaks.⁸⁹ Specifically, ASAN charged Autism Speaks with “us[ing] damaging and offensive fundraising tactics which rely on fear [and] stereotypes,” thereby “devaluing the lives” of the very people for whom they purport to speak.⁹⁰ According to ASAN:

Contrary to the “I am Autism” video, which equates autism with AIDS and Cancer, autism is not a terminal disease. It is a disability, one that comes with significant challenges in a wide variety of realms. Yet the answer to those challenges is not to create a world in which people are afraid of people on the autism spectrum. . . . It is to work to create a society that recognizes the civil rights of Autistic people and others with disabilities. It is to work to create a world in which people with disabilities can benefit from the supports, the services and the educational tools necessary to empower them to be full citizens in society.⁹¹

ASAN called the video the most recent offense in a “pattern of unethical behavior” that uses the theme of “fear, pity and prejudice” to advance a misguided agenda.⁹² A prior series of Autism Speaks public service announcements compared “having a child on the autism spectrum to having a child caught in a fatal car accident or struck by lightning,”⁹³ and in a 2006 Autism Speaks fundraising film, the then-senior vice president of Autism Speaks told of how she once contemplated placing her autistic daughter “in the car and driving off the George Washington Bridge.”⁹⁴

The ASAN letter also charged Autism Speaks with undermining the autonomy of autistic people by failing to prioritize social services and

89. Letter from Ari Ne’eman, President of the Autistic Self Advocacy Network, to Sponsors, Donors, and Supporters of Autism Speaks, *supra* note 55.

90. *Id.*

91. *Id.*

92. *Id.*

93. *Id.*

94. FITZPATRICK, *supra* note 1, at 47 (internal quotation marks omitted). Autism Speaks’s predecessor, Cure Autism Now, which merged with Autism Speaks in 2007, launched a strikingly similar ad campaign years before. See Press Release, Autism Speaks, Autism Speaks and Cure Autism Now Complete Merger (Feb. 5, 2007), <http://www.autismspeaks.org/about-us/press-releases/autism-speaks-and-cure-autism-now-complete-merger> (discussing merger). As Professor Hacking explains, “After a bit of ominous music, an intensely concerned young father intones, ‘Imagine that aliens were stealing one in every two hundred children. . . . That is what is happening in America today. It is called autism.’” Hacking, *supra* note 2, at 44.

change its governance structure.⁹⁵ The letter noted that Autism Speaks devotes only a small amount of its budget (4%) toward researching and providing social and educational supports for autistic people, while spending the bulk of its budget (65%) on genetic and biomedical research, “including the prospect of prenatal testing.”⁹⁶ Autism Speaks’s “refus[al] to include any individual with the disability they purport to serve on their board of directors or at any point in their leadership and decision-making processes,” the letter further stated, is “deeply unrepresentative and out of step with the mainstream of the disability non-profit community.”⁹⁷

Echoing the sentiments raised in ASAN’s letter, many in the autism community lamented Autism Speaks’s depiction of autism as “a devil personified”⁹⁸ and warned against conflating autistic children’s actual experience with parents’ despairing perceptions of that experience.⁹⁹ Others noted that Autism Speaks’s video was particularly objectionable given its close similarities to New York University Child Study Center’s 2006 *Ransom Notes* autism ad campaign, which was widely denounced by the autism community and was withdrawn just three weeks after it began.¹⁰⁰ That campaign featured advertisements in the form of ransom notes, one of which read, “We have your son. We will make sure he will not be able to care for himself or interact socially as long as he lives. This is only the beginning.” It was signed *Autism*.¹⁰¹ Another read, “We have your son. We are destroying his ability for social interaction and

95. Letter from Ari Ne’eman, President of the Autistic Self Advocacy Network, to Sponsors, Donors, and Supporters of Autism Speaks, *supra* note 55.

96. *Id.*

97. *Id.*

98. See, e.g., Codeman38, *Autism Speaks Hits a New Low*, DAILY KOS (Sept. 23, 2009, 12:04 PM), <http://www.dailykos.com/story/2009/9/23/785559/-Autism-Speaks-Hits-A-New-Low>; Emily Willingham, *What if Someone Did This with, Say, Down’s Syndrome?*, LIFE LESS ORDINARY (Sept. 22, 2009), <http://daisymayfattypanthers.blogspot.com/2009/09/what-if-someone-did-this-with-say-downs.html>.

99. See, e.g., KWombles, *Autism Speaks Should Learn when To Shut the Hell Up: I Am Autism. Not.*, COUNTERING . . . (Sept. 23, 2009), <http://kwomblescountering.blogspot.com/2009/09/autism-speaks-should-learn-when-to-shut.html>; Sarah, *Who Does Autism Speaks Speak for? (Or, the Diagnostic Double Standard)*, CAT DOG’S WORLD (Sept. 25, 2009, 10:01 AM), <http://autisticcats.blogspot.com/2009/09/who-does-autism-speaks-speak-for.html>; Theo, Comment to *I’m Pissed!!*, ASPIE WEB (Oct. 5, 2009, 10:15 AM), <http://www.aspiweb.net/autism-speaks-i-am/>.

100. See *When Will They Listen?*, CLUB 166 (Sept. 23, 2009, 4:06 AM), <http://club166.blogspot.com/2009/09/when-will-they-listen.html>; see also Solomon, *supra* note 2 (discussing NYU’s 2006 *Ransom Notes* campaign).

101. Solomon, *supra* note 2.

driving him into a life of complete isolation. It's up to you now." It was signed *Asperger Syndrome*.¹⁰²

2. "Autism as Toxic": Alternative Medicine and Chelation

All of the research in the world is of little comfort to overwhelmed parents who want help for their children now. With no cure in sight, many parents attempt to modify their children's undesirable behavior through a variety of therapeutic interventions.¹⁰³ Some of these interventions are conventional, like the prescription of stimulants such as Ritalin, antidepressants such as Prozac, and antianxiety agents such as Buspar,¹⁰⁴ while others fall into the alternative or "biomedical" camp.¹⁰⁵

For many parents who turn to biomedical interventions, autism is an epidemic, and time is of the essence.¹⁰⁶ Some blog about "hating autism"¹⁰⁷ and convey their level of disdain through metaphor, comparing autism to a "beast's shadow" under which they live, a stealer of souls, an alien abductor, and a condition that "relentlessly sucks life's marrow out of the family members, one by one."¹⁰⁸

Because mainstream medicine offers few answers and little hope in the short term, parents who pursue biomedical interventions are oftentimes distrustful of, and even openly hostile toward, mainstream medicine.¹⁰⁹ In particular, these parents are dismissive of mainstream medicine's focus on the role that genetics plays in autism.¹¹⁰ For them, it is our toxic environment—not some unidentified genetic defect, perhaps conferring susceptibility to some unknown environmental agent—that is to blame for autism.¹¹¹ And that means hope, for if we can identify the environmental factor or factors that cause autism, we can prevent autism, treat it, and maybe even cure it.¹¹²

102. *Id.*

103. NADESAN, *supra* note 43, at 194.

104. *Id.*

105. FITZPATRICK, *supra* note 1, at 11.

106. *Id.* at 15.

107. HATING AUTISM BLOG, <http://hatingautism.blogspot.com> (last visited Feb. 4, 2012).

108. FITZPATRICK, *supra* note 1, at 43–44 (quoting Jerry J. Kartzinel, *Introduction* to JENNY MCCARTHY, *LOUDER THAN WORDS: A MOTHER'S JOURNEY IN HEALING AUTISM*, at xvi (2007)) (internal quotation marks omitted); *see also* Hacking, *supra* note 2, at 50 ("I want my grandson back!" The metaphor of abduction feels overpowering to some families; a baby that was a lovely human being has disappeared." (quoting the CEO of NBC Universal and grandfather of autistic child)).

109. *See* NADESAN, *supra* note 43, at 194.

110. FITZPATRICK, *supra* note 1, at 11.

111. *See id.* at 9, 19–22, 84–87; *see also* Caruso, *supra* note 22, at 496 (discussing the biomedical movement).

112. *See* FITZPATRICK, *supra* note 1, at xv.

For these parents, potential environmental culprits are everywhere: in the food we eat (for example, pesticides, MSG); in the medication we take and medical procedures we undergo (for example, vaccines,¹¹³ antibiotics, reproductive and hormonal drugs, prenatal ultrasounds, and early clamping of the umbilical cord); in the technology we use for work and play (for example, television and WiFi); in the sounds we hear (for example, mechanically generated noise); and in the air we breathe, the water we drink, the ground we walk on, and the energy we produce (for example, electromagnetic and nuclear radiation, chemical waste, heavy metal residues).¹¹⁴ All have been blamed for causing autism. Given the breadth of potential causes, potential remedies run the gamut: from special diets (for example, wheat-free or dairy-free); to supplements (for example, vitamins, amino acids); to medication (for example, antibiotics, antifungals, anti-inflammatories); to medical procedures aimed at extracting toxic metals from the blood (chelation), stimulating blood-vessel formation (stem cell therapy), and improving blood circulation (hyperbaric oxygen therapy); to much-publicized antivaccine campaigns.¹¹⁵

The efficacy of biomedical interventions is debatable. Although many supporters of biomedical interventions claim that autism is not only treatable but also curable by this or that intervention, the studies upon which they rely generally have numerous “methodological defects that render their conclusions unreliable.”¹¹⁶ These defects, together with autism’s variability among individuals, autism’s evolution over the

113. “Autistic symptoms often become visible at age 18 months, exactly when children are routinely vaccinated against measles, mumps, and rubella.” Caruso, *supra* note 22, at 501–02. According to antivaccine advocates, the measles-mumps-rubella (MMR) vaccine, in combination with several vaccines containing the mercury-based preservative thimerosal, can damage a “child’s immune system, resulting in an immune deficiency that prevent[s] her from being able to ‘clear from her body the measles virus contained in the MMR.’” John Thomas, *Paranoia Strikes Deep: MMR Vaccine and Autism*, PSYCHIATRIC TIMES (Mar. 5, 2010), <http://www.psychiatrictimes.com/autistic-disorder/content/article/10168/1531916> (quoting *Cedillo v. Sec’y of Health & Human Servs.*, 89 Fed. Cl. 158, 163 (2009)). The virus, in turn, “cause[s] inflammatory bowel disease and also ‘enter[s] the child’s brain, causing inflammation and autism.’” *Id.* (quoting *Cedillo*, 89 Fed. Cl. at 163). The legal debate surrounding the causal link between vaccines and autism is beyond the scope of this Article.

114. See FITZPATRICK, *supra* note 1, at 19–22, 84–87; see also Marchant & Robert, *supra* note 51, at 216 (discussing suspected environmental causes of autism).

115. FITZPATRICK, *supra* note 1, at 115, 131.

116. *Id.* at 131 (stating that “[m]ost interventions are endorsed by small studies, carried out by sympathetic researchers in collaboration with supportive parents, using biased methods of selection, subjective measures of outcome, lacking in control groups and ‘blinding’ procedures”).

lifetime of each individual, and “the difficult[y in] isolat[ing] the effects of any particular intervention from the range of other” interventions that a child may be receiving, make it difficult to draw solid conclusions about which interventions work.¹¹⁷

The safety of biomedical interventions is also debatable. Although “biomedical diets and supplements, though not without some risks, do not raise major concerns about safety,” the same is not true for medications, which “are no safer in the hands of biomedical practitioners than they are in those of mainstream doctors,” and for certain medical procedures advocated by the biomedical movement.¹¹⁸ Chelation is a case in point.

On July 22, 2005, Marwa Nadama, the mother of a five-year-old autistic boy named Abubakar Tariq, took her son to Advance Integrative Medicine, Inc. in Pennsylvania for biomedical treatment. Dr. Roy Kerry determined that Tariq’s treatment would include the use of chelation therapy, which involves the “administration of a synthetic chemical solution which is designed to extract certain heavy metals from the body, the theory being that such heavy metals contribute to a variety of illnesses including autism.”¹¹⁹ First used during the First World War to treat victims of poison gas, chelation therapy has achieved prominence among alternative health practitioners in recent decades as a treatment for medical and psychiatric disorders attributed to environmental toxins, as well as for coronary heart disease.¹²⁰ “In more recent years, as the notion that autism is caused by vaccines containing mercury has become increasingly popular, practitioners have begun to offer chelation as a treatment for autistic children, using a wide variety of agents, in oral, injectable or even transdermal forms.”¹²¹

Dr. Kerry prescribed a series of treatments involving the intravenous administration of disodium EDTA, the chelator agent commonly used to treat heart disease and known to carry a risk of irregular heart rhythms, seizures, and even death.¹²² The first and second administrations occurred in July and early August, respectively, without incident—although Tariq had to be restrained by four adults using a “papoose board,” which is “a flat wooden board with attached fabric straps which are wrapped around the child’s body and limbs to prevent struggling during

117. *Id.* at 131–32.

118. *Id.* at 132.

119. Complaint ¶ 16, *Nadama v. Kerry* (Pa. Ct. Com. Pl. 2007), available at http://www.circare.org/lex/nadama_complaint.pdf.

120. FITZPATRICK, *supra* note 1, at 5.

121. *Id.*

122. *Id.*; Complaint, *supra* note 119, ¶ 16.

treatment.”¹²³ On August 23, 2005, shortly after the administration of the third treatment, “Tariq Nadama went into cardiac arrest. CPR and chest compression were given, but the child could not be revived . . . [and] was pronounced dead shortly after arriving at the hospital.”¹²⁴

News of Tariq Nadama’s death ignited a firestorm of debate in the world of autism. Biomedical advocates defended the safety and efficacy of chelation therapy and asserted that “the boy’s death resulted, quite simply, from a drug error”—Dr. Kerry had used the wrong drug.¹²⁵ Many adult autistics blasted back, calling Tariq’s death “tragic, needless,” and the consequence of “the whole ‘cure’ mentality. It creates a dynamic in which nearly any risk is acceptable in fighting the autism, because living with autism, as they see it, is a fate even worse than death.”¹²⁶

And the war goes on:

A 2008 study [evaluating] the quality of research on various autism treatments gave chelation the lowest possible grade, saying there are no controlled trials on the safety and effectiveness of chelation as an autism treatment. . . . That same year, the National Institutes of Health canceled plans to run a clinical trial on chelation for the treatment of autism in children, saying the risks outweighed any potential benefit.¹²⁷

And in October 2010, the Food and Drug Administration (FDA) issued letters warning several companies that it is a violation of the law to market over-the-counter chelation products.¹²⁸ In those letters, the FDA noted that chelation’s efficacy in treating autism and other conditions is “unsubstantiated,” and that there are “serious safety issues associated with chelation products, which can alter the levels of certain substances in the blood. . . . [and] cause serious harm, including dehydration, kidney failure, and death.”¹²⁹ Nevertheless, many children

123. FITZPATRICK, *supra* note 1, at 3 (internal quotation marks omitted).

124. Complaint, *supra* note 119, ¶ 18.

125. Bernard Rimland, *Chelation: The Story Behind the Headlines*, AUTISM RES. REV. INT’L, no. 3, 2005, at 3, 3.

126. FITZPATRICK, *supra* note 1, at 8 (quoting autistic blogger Joe Klein) (internal quotation marks omitted).

127. Nancy Shute, *FDA Comes Down on Chelation as Untested Autism Treatment*, U.S. NEWS & WORLD REP. (Oct. 15, 2010), <http://health.usnews.com/health-news/managing-your-healthcare/brain-and-behavior/articles/2010/10/15/fda-comes-down-on-chelation-as-untested-autism-treatment>.

128. Press Release, U.S. Food & Drug Admin., FDA Issues Warnings to Marketers of Unapproved ‘Chelation’ Products (Oct. 14, 2010), *available at* <http://www.fda.gov/NewsEvents/Newsroom/PressAnnouncements/ucm229320.htm>.

129. *Id.*

continue to receive chelation therapy each year as biomedical advocates champion its safety and efficacy.¹³⁰

B. “Autism as Way of Being”: Neurodiversity and Applied Behavioral Analysis

The neurodiversity movement originated in the 1990s in response to the dominant conception of autism as a disorder and consists primarily of generally high-functioning autistic adults and their families.¹³¹ As epitomized by Jim Sinclair’s *Don’t Mourn for Us*, the neurodiversity movement’s central claim is that autism is not a disorder but a way of being or, more specifically, a “different” way of being, of thinking, of behaving.¹³² Accordingly, the neurodiversity movement focuses on “acceptance and even admiration for autism’s most appealing traits, which range from savant-like musicality to a philosophical detachment from most mundane matters.”¹³³

With the Internet as their “sign language”¹³⁴ or “prosthetic limb,”¹³⁵ autistic people “are beginning to see themselves not as blighted individuals, but as a different ethnicity, [and] ‘[i]n a sense, autistics are constituting themselves as a new immigrant group online, sailing to strange

130. See Bernard Rimland, *The Safety and Efficacy of Chelation Therapy in Autism*, AUTISM RES. INST., http://www.autism.com/pro_chelationsafety.asp (last visited Feb. 4, 2012) (“Tens of thousands of children and hundreds of thousands of adults have been treated safely with chelation therapy for many decades.”).

131. See Solomon, *supra* note 2; see also Caruso, *supra* note 22, at 495 (discussing the neurodiversity movement). The neurodiversity movement does not represent the experience of all autistic adults, of course. See BARON-COHEN, *supra* note 21, at 145–46 (“[D]o I wish I hadn’t been born with [Asperger’s]? Yes, I hate my [Asperger’s], and if I could be rid of it I would. . . . Every day is like climbing Mount Everest in lead boots, covered in molasses. Every step in every part of my life is a struggle.” (quoting autistic adults) (internal quotation marks omitted)). Interestingly, the neurodiversity movement is not limited to those who communicate verbally. See Sanjay Gupta, *Behind the Veil of Autism*, CNN (Feb. 20, 2007, 10:57 AM), <http://www.cnn.com/HEALTH/blogs/paging.dr.gupta/2007/02/behind-veil-of-autism.html> (interviewing autism rights activist Amanda Baggs, who communicates through computer and voice synthesizer).

132. See NADESAN, *supra* note 43, at 208–09 (quoting Sinclair, *supra* note 40); see also Nancy Bagatell, *From Cure to Community: Transforming Notions of Autism*, 38 ETHOS 33, 39–40 (2010) (stating that “[a]utistic socializing [does] not necessarily require conversation,” and discussing “what Sinclair describes as ‘interactive stimming, [this] kind of spontaneous sharing of pleasure in fixations and stimming’” (quoting Jim Sinclair, *Autism Network Int’l: The Development of a Community and Its Culture*, AUTISM NETWORK INT’L (2005), http://autreat.com/History_of_ANI.html)).

133. Caruso, *supra* note 22, at 495.

134. Judy Singer, “Why Can’t You Be Normal for Once in Your Life?” *From a “Problem with No Name” to the Emergence of a New Category of Difference*, in DISABILITY DISCOURSE 59, 67 (Mairian Corker & Sally French eds., 1999) (quoting Harvey Blume, *Autistics, Freed from Face-to-Face Encounters, Are Communicating in Cyberspace*, N.Y. TIMES, June 30, 1997, at D6) (internal quotation marks omitted).

135. Solomon, *supra* note 2.

neurological shores on the Internet.”¹³⁶ Autism websites proclaim Bill Gates, Albert Einstein, and Andy Warhol as “closet ‘aspies’”—they have or had, as the case may be, undiagnosed Asperger’s syndrome—and have even coined a term for nonautistics: neurotypicals (NTs).¹³⁷ Beyond the blogosphere, Hollywood, television, radio, literature, and outspoken autistic people such as Temple Grandin have popularized autistic people’s contributions to math, science, and art.¹³⁸ Magazines such as *Wired* and *Time* have called Asperger’s the “geek syndrome” and credited autistic people with being the “dreamers and architects of our technological future.”¹³⁹ And academia has also weighed in, with anthropologists, psychologists, philosophers, sociologists, historians, and others pointing to autistic features as “a different kind of intelligence”¹⁴⁰ or “essence,”¹⁴¹ “an expression of the glory of the human brain, in itself an unimaginably complex symphony,”¹⁴² “an overexpression of the very traits that make our species unique,”¹⁴³ “human, but more so,”¹⁴⁴ a “ray of light,”¹⁴⁵ and even “a unique, masculine cognitive style.”¹⁴⁶

136. Singer, *supra* note 134, at 67 (quoting Blume, *supra* note 134); *see also* Hacking, *supra* note 2, at 56 (“In retrospect, we shall almost certainly see today’s Internet as making possible a form of life in which autistic people can thrive. It is precisely the medium for human communication that does not depend on body language or eye contact . . .”).

137. *See* NADESAN, *supra* note 43, at 199; *see also* Hacking, *supra* note 2, at 46 (“Members of [the neurodiversity movement] agree that autism is a neurological condition, but so, after all, is the state of what they call *neurotypicals*. . . . The neurodiversity movement rejects the idea that there is neuro-normality.”).

138. *See* NADESAN, *supra* note 43, at 205.

139. J. Madeleine Nash, *The Geek Syndrome*, TIME, May 6, 2002, <http://www.time.com/time/magazine/article/0,9171,1002365,00.html>; Steve Silberman, *The Geek Syndrome*, WIRED (Dec. 2001), http://www.wired.com/wired/archive/9.12/aspergers_pr.html; *see also* Andrew Watts, *Traits, Diagnosis, and Social Aspects of Asperger Syndrome*, ANDREW, <http://sr12.tripod.com/andrew/asperger.htm> (last visited Feb. 4, 2012) (“An interesting and positive trait that people with Asperger Syndrome have is that they develop unique interests and become highly intelligent especially in their main area of interest[, which] . . . may include topics in astronomy, classification of plants and animals, memorization of train schedules and other obscure but intriguing topics.”).

140. BARON-COHEN, *supra* note 21, at 149 (echoing findings of Austrian psychiatrist Hans Asperger, who called “[t]he autistic personality . . . an extreme variant of male intelligence” (quoting Hans Asperger’s 1944 paper, *Die ‘Autischen Psychopathen’ im Kindesalter*). “Autism spectrum conditions . . . appear to affect males far more often than females. In people diagnosed with high-functioning autism or [Asperger’s], the sex ratio is at least *ten males to every female*.” *Id.* at 137).

141. NADESAN, *supra* note 43, at 207.

142. GRINKER, *supra* note 20, at 280.

143. PAUL COLLINS, NOT EVEN WRONG: ADVENTURES IN AUTISM 161 (2004). According to Collins, “[A]utism . . . is as much about what is abundant as what is

While celebrating autistic differences, the neurodiversity movement does not deny autism's genetic roots, biological components, and sometimes troublesome features—for example, self-injurious behavior. Instead, the neurodiversity movement points to these biogenetic differences as “qualitatively *different*, rather than deficient, from typical minds” and characterizes autism's troubling features as “defense strategies mounted by the autistic mind” to cope with a nonautistic world.¹⁴⁷ Both ASAN and Autism Network International (ANI), for example, are dedicated to providing support services to autistic people to help them “compensate, navigate, and function in the world”¹⁴⁸ but are respectful of “characteristically autistic styles of relating to others” and eschew “changing [autistic people] into non-autistic people.”¹⁴⁹

The neurodiversity movement's distinction between difference and disorder is a somewhat vague one,¹⁵⁰ but talk of cures and therapy for autism brings the distinction into focus. Generally speaking, the neurodiversity movement opposes research that seeks to eradicate autism and therapies that “normalize” children at the expense of valued autistic

missing Other animals are social, but only humans are capable of abstract logic. The autistic outhuman the humans, and we can scarcely recognize the result.” *Id.*

144. Mark Osteen, *Autism and Representation: A Comprehensive Introduction*, in AUTISM AND REPRESENTATION, *supra* note 59, at 1, 16.

145. Hacking, *supra* note 2, at 45.

146. NADESAN, *supra* note 43, at 200.

147. *Id.* at 207.

148. *Id.* at 206.

149. *Id.* (emphasis omitted) (citing *Introducing ANI*, AUTISM NETWORK INT'L, <http://www.autreat.com/intro.html> (last visited Feb. 4, 2012)).

150. *See id.* at 208–09.

traits.¹⁵¹ Nowhere is this opposition more pronounced than in the area of intensive behavioral therapy.¹⁵²

Although behavioral therapy has been used for decades to modify undesirable behaviors, Dr. O. Ivar Lovaas is widely credited with having pioneered its use on children with autism.¹⁵³ In 1987, Dr. Lovaas published a report on the use of “applied behavioral analysis” (ABA) therapy on children with autism, showing improved outcomes in the areas of “compliance, imitation, receptive and expressive language, and peer integration.”¹⁵⁴ Generally speaking, ABA “requires children to engage in very specific responses to one-to-one demands” and uses “[p]ositive reinforcement in the form of rewards (candy, toys, etc.) . . . as the child’s primary motivator. . . . [B]ecause autistic children often resist ABA’s highly structured and disciplined demands, the program tends to be quite intensive in terms of the efforts exerted by autistic children and

151. *Id.* at 206–08; *see also* Burgdorf, *supra* note 58, at 327 (“Because of such positive aspects, many people with Asperger’s live satisfying lives and would not choose to give up the advantages for the disadvantages if they had the choice.”); Alex Plank, *Ten Myths About Autism—Debunked*, WRONG PLANET, <http://www.wrongplanet.net/article361.html> (last visited Feb. 4, 2012) (“Most autistics, in fact, do not want to be cured because they’ve already accepted autism as part of their personality, identity, and lifestyle.”). The neurodiversity movement’s objections to cures and therapy closely parallel those of the deaf community. As noted by I. King Jordan, former president of Gallaudet University, many people who are deaf “hold in common this resentment of efforts to fix us.” Burgdorf, *supra* note 58, at 324 (quoting I. King Jordan, *The Gallaudet Experience: Deafness and Disability*, 120 PMLA 625, 626 (2008)) (internal quotation marks omitted); *see also* Harlan Lane, *Constructions of Deafness*, 10 DISABILITY & SOC’Y 171, 178 (1995) (stating that most “American Deaf people . . . would refuse an operation to eliminate what sets them apart,” and citing a U.S. survey in which eight out of ten deaf adults reported that they would decline an implant operation that would enable them to hear). “[R]esearch in genetics to improve deaf people’s quality of life is certainly important . . . but must not become, in the hands of hearing people, research on ways of reducing the deaf minority.” *Id.*

152. *See* FITZPATRICK, *supra* note 1, at 141; *see also* Colleen D. Holland, Note, *Autism, Insurance, and the IDEA: Providing a Comprehensive Legal Framework*, 95 CORNELL L. REV. 1253, 1263 (2010) (discussing the neurodiversity movement’s objections to ABA).

153. Holland, *supra* note 152, at 1257.

154. NADESAN, *supra* note 43, at 192 (citing BRYNA SIEGEL, *THE WORLD OF THE AUTISTIC CHILD: UNDERSTANDING AND TREATING AUTISTIC SPECTRUM DISORDERS* (1996)); *see also* GRINKER, *supra* note 20, at 177 (discussing purported benefits of ABA).

therapists.”¹⁵⁵ Given its purported effectiveness, ABA is now one of the most favored therapies for children with autism.¹⁵⁶

Those in the neurodiversity movement object to ABA on a number of grounds. These objections were perhaps best articulated by an autistic woman named Michelle Dawson in a 2004 case before the Supreme Court of Canada, *Auton v. British Columbia*.¹⁵⁷ At issue in that case was whether Canadian law guaranteed funding for “medically necessary” services and, if so, whether British Columbia’s failure to provide funding for ABA violated Canadian law.¹⁵⁸ In her Factum of the Intervenor, Ms. Dawson challenged the premise that autistic people “require ‘medically necessary’ early intensive behaviour intervention . . . , based on the principles of Applied Behaviour Analysis.”¹⁵⁹ The court held that Canadian law guarantees funding only for services provided by physicians and therefore British Columbia’s decision not to fund ABA—which is performed by nonphysicians—was within its discretion.¹⁶⁰ Citing Ms. Dawson’s Factum, the court also noted that ABA “is not uncontroversial,” with objections “rang[ing] from its reliance in its early years on crude and arguably painful stimuli, to its goal of changing the child’s mind and personality.”¹⁶¹

Ms. Dawson’s Factum begins with the proposition that autism is “a difference” to be respected and even celebrated, not a disorder to be eradicated:

155. NADESAN, *supra* note 43, at 192 (citation omitted) (citing SIEGEL, *supra* note 154).

156. Holland, *supra* note 152, at 1257. Despite its popularity, ABA’s effectiveness is controversial. Studies show that “some children with autism benefit from ABA and some do not; some benefit more than others; and some children make progress without intensive behavioural intervention (and to a degree comparable with those who receive it).” FITZPATRICK, *supra* note 1, at 140.

157. Factum of the Intervenor Michelle Dawson, *Auton v. British Columbia*, [2004] 3 S.C.R. 657 (Can.) (No. 29508), available at http://www.sentex.net/~nexus23/naa_fac.html. Although many commentators consider Ms. Dawson a member of the neurodiversity movement, see, e.g., FITZPATRICK, *supra* note 1, at 12, Ms. Dawson, herself, does not. See Michelle Dawson, *Elizabeth Svoboda’s Autism Culture Movement: A Letter*, AUTISM CRISIS (Apr. 27, 2009), <http://autismcrisis.blogspot.com/2009/04/elizabeth-svobodas-autism-culture.html>. Nevertheless, because many of Ms. Dawson’s criticisms of ABA parallel those of the neurodiversity movement, see, e.g., *Therapies and Health Care*, AUTISTIC SELF ADVOC. NETWORK, <http://www.autisticadvocacy.org/modules/smartsection/category.php?categoryid=81> (last visited Feb. 4, 2012), her criticisms are instructive.

158. *Auton*, [2004] 3 S.C.R. at 672–74; Factum of the Intervenor Michelle Dawson, *supra* note 157, ¶¶ 4–5, 12.

159. Factum of the Intervenor Michelle Dawson, *supra* note 157, ¶¶ 4–5, 12 (rejecting facts provided by both parties).

160. *Auton*, [2004] 3 S.C.R. at 673.

161. *Id.* at 664.

It must be underlined that autism is not a disease. . . . [nor is it] a mental illness. . . .

. . . .

Autistic people, like non-autistics, sometimes develop serious physical diseases, and sometimes suffer from mental illness. . . .

. . . .

No allowance is made by either the parties[] or the Courts below that “untreated” autistic traits, which result in atypical learning and intelligence, have great benefit both to autistics and to society. The inherent strengths of autistics, based on measurable differences in cognition (perception, attention, memory; and kind, not level, of intelligence) are unavailable to non-autistics, and according to the principles of ABA as well as its practice, are unavailable to treated autistics.

. . . .

. . . In contrast to the doom painted by the parties for all untreated autistics, autistics are in the workforce, they are in academe, they are parents (often of autistic children), they are artists, architects, engineers, physicists, musicians, and writers. Many have, through the brilliance, innovation, impartiality, persistence, and courage with which they are gifted, disproportionately contributed to the progress and enlightenment of society.¹⁶²

Ms. Dawson then challenges ABA treatment on several grounds. First, she argues that it is unethical.¹⁶³ Like homosexuality and left-handedness, autism brings with it behaviors considered “odd” or “inappropriate” by many, but they are variations integral to the person.¹⁶⁴ By forcing individuals to “lose their autistic nature and traits, and become, or appear to become, indistinguishable from non-autistic [people],”¹⁶⁵ ABA seeks to extinguish these variations. Attempting to “treat” autism through ABA is therefore as wrongheaded as trying to prevent or cure homosexuality—a feat that Dr. Lovaas, himself, attempted to do years earlier through ABA—or left-handedness.¹⁶⁶ Even if it were possible to disentangle certain especially troublesome characteristics from exceptional autistic abilities for purposes of treatment, Dawson questions whether the purported benefits would outweigh the burdens to the child.¹⁶⁷ “[M]any ‘normal’ behaviours may be painful, frightening, or useless to an autistic (i.e. eye contact),” Dawson argues, while

162. Factum of the Intervenor Michelle Dawson, *supra* note 157, ¶¶ 18, 20, 27, 29.

163. *Id.* ¶¶ 33–35.

164. *See id.* (internal quotation marks omitted).

165. *Id.* ¶ 4.

166. *See id.* ¶¶ 50–51.

167. *See id.* ¶ 35.

“engag[ing] in repetitive behaviour such as arranging objects into neat rows or flapping their hands in front of their eyes”¹⁶⁸ may be comforting—a coping strategy mounted by the autistic mind.¹⁶⁹

Second, Dawson argues that ABA reinforces negative stereotypes and prejudices by depicting “untreated” autistic people as nonproductive and in need of cure.¹⁷⁰ Quoting the decision of the lower court, Dawson states that “[t]he basic premise of the parties is that without ‘effective treatment, . . . almost all autistic children are doomed to a life of physical, emotional, social, and intellectual isolation and eventual institutionalization—a tragic outcome for the children, their families, and society.’”¹⁷¹ Dawson counters that successful “untreated” autistic people are not “freakish oddities”; instead, they are everywhere—living lives filled with “learning, intelligence, achievement, innovation, and autonomy, however atypically,” and “contribut[ing] greatly to society.”¹⁷² By seeking to make autistic children indistinguishable from the normal majority, ABA is a constant reminder that “an autistic individual’s behaviour, interests and concerns are unacceptable to the majority” and that “autistic individuals can only be fulfilled (and in fact can only be ‘human’) if they are moulded to meet society’s expectation of what is ‘normal.’”¹⁷³

Third, Dawson stresses the lack of autonomy implicit in the provision of ABA.¹⁷⁴ Because children do not have the capacity to consent to ABA, the decision to receive the therapy falls to parents and their “all too human mixture of emotions and motives,”¹⁷⁵ often in consultation with advocacy organizations that consistently deny the participation of

168. See *id.* ¶¶ 28, 35 (quoting *Auton v. British Columbia*, [2000] 78 B.C.L.R. 3d 55, 231 (Can. B.C.)).

169. *Id.* ¶¶ 28, 35; see also NADESAN, *supra* note 43, at 192 (discussing ABA’s “tendency to pathologize many characteristically ‘autistic’ behaviors (such as ‘stimming’ and hand-flapping . . .)”); Ron Amundson, *Against Normal Function*, 31 *STUD. HIST. & PHIL. BIOLOGICAL & BIOMED. SCI.* 33, 50 (2000) (“[S]timming is often functionally beneficial to people with autism. It reduces the chaos they experience, chaos created by their heightened sensory sensitivity in ‘normal’ environments, and allows them to concentrate on particular features of the environment A non-stimming autistic person may be more cosmetically normal, but able to function only at a lower level.”); Hacking, *supra* note 2, at 55 (noting that although “ordinary people” may regard autistic hand-flapping as “some kind of agitation, . . . [a]rticulate autists tell us how calming it is”).

170. Factum of the Intervenor Michelle Dawson, *supra* note 157, ¶¶ 4, 5, 13.

171. *Id.* (quoting *Auton*, [2000] 78 B.C.L.R. 3d at 230).

172. *Id.* ¶¶ 30, 36.

173. *Id.* ¶¶ 40, 44; see also *Therapies and Health Care*, *supra* note 157 (opposing “the use of behavioral programs that focus on normalization rather than teaching useful skills”).

174. Factum of the Intervenor Michelle Dawson, *supra* note 157, ¶ 45.

175. *Id.* (quoting *E. v. Eve*, [1986] 2 S.C.R. 388, 429 (Can.)).

autistics in their governance structures.¹⁷⁶ Furthermore, she states, “[a]utistics have had no part in any research design or treatment decisions in ABA programs. All such roles have been taken by parents, governments and service providers.”¹⁷⁷

Lastly, Dawson argues that by envisioning autism as a disorder to be eradicated rather than a difference to be accommodated, ABA ignores society’s obligation to fine-tune its structures and assumptions to allow for the meaningful participation of autistic people.¹⁷⁸ According to Dawson, society does not require deaf people to obtain treatment—cochlear implants—to make them nondeaf; “train them to act like non-deaf persons”; or tell them that if they do not strive to become nondeaf, they cannot participate in society.¹⁷⁹ Rather, society accommodates them, for example, through sign-language interpreters.¹⁸⁰ According to Dawson, ABA does not accommodate autistic differences—it disregards them, “teach[ing] autistics to be ‘normal’ such that they can participate in society by passing as non-autistic.”¹⁸¹

IV. CONSTRUCTING DISABILITY: THE MEDICAL VS. SOCIAL MODELS

The autism debate appears to fit neatly within the broader debate between the social model of disability, which holds that disability is socially constructed, and the medical model, which holds that it is not. However, although disability’s dueling models explain parents’ and the neurodiversity movement’s disagreement over what causes disability, they do not fully explain the autism debate. To understand why, it is first necessary to look at the concept of “social construction.”

A. Social Construction Generally

As philosopher Ian Hacking notes, the phrase *social construction* is “both obscure and overused. . . . [It] has become code. If you use it favorably, you deem yourself rather radical. If you trash the phrase, you declare that you are rational, reasonable, and respectable.”¹⁸² Clearing

176. *Id.* ¶ 61.

177. *Id.* ¶ 34.

178. *Id.* ¶¶ 37–39.

179. *Id.* ¶ 58.

180. *See id.*

181. *Id.* ¶ 61.

182. HACKING, *supra* note 19, at vii.

away the underbrush, social construction accounts are, at bottom, about consciousness-raising, about unmasking assumptions, and, most of all, about hope.¹⁸³ Things are not fixed or inevitable but instead “the product of historical events, social forces, and ideology”; they can be changed.¹⁸⁴ And not only can things change, but we, as a society, can change them.

Social constructionist accounts are everywhere. Race and gender, rocks and genes—all are said to be socially constructed.¹⁸⁵ According to Hacking, socially constructed things tend to share two important features: (1) the thing that is said to be constructed is taken for granted—it “appears to be inevitable”; and (2) the thing “need not have existed, or need not be at all as it is.”¹⁸⁶ It is “not determined by the nature of things; it is not inevitable.”¹⁸⁷ Rather, it is contingent.¹⁸⁸ Importantly, there are various grades of commitment to social construction, ranging from the noncommittal (the thing is contingent, the upshot of historical events) to the rebellious and revolutionary (the contingent thing is bad and should be done away with).¹⁸⁹

B. The Social and Medical Models of Disability

Disability scholarship identifies two primary models of disability: the social model and the medical model.¹⁹⁰ Under both models, the word *disability* means some limitation on ability, some disadvantage.¹⁹¹ The primary distinction between the two models is the source of that disadvantage—the cause of disability.¹⁹²

1. Medical Model

According to the medical model, disability is inevitable and is caused by an impairment that limits bodily functioning.¹⁹³ Disability is

183. *See id.* at 6–7.

184. *Id.* at 2.

185. *Id.* at 1, 21–22.

186. *Id.* at 6, 12.

187. *Id.* at 6.

188. *Id.* at 12.

189. *Id.* at 19–20.

190. *See, e.g.,* BAGENSTOS, *supra* note 4, at 18.

191. Barry, *supra* note 12, at 210; *see also* Samaha, *supra* note 18, at 1255–56 (“Stripped down to basics, the [social] model moves causal responsibility for disadvantage from physically and mentally impaired individuals to their architectural, social, and economic environment. . . . [The ‘medical model’] focuses on the disadvantaging impact of physical or mental impairments rather than that of the environment in which they operate.”).

192. *See* Samaha, *supra* note 18, at 1255–56.

193. *See, e.g.,* BAGENSTOS, *supra* note 4, at 18; *see also* OLIVER, *supra* note 10, at 58, 69 (discussing “the view of disability as an individual, medical problem and a personal

not every impairment—just those that impose limitations that rise to a certain “disabling” level. The medical model may be expressed as follows:

Disability = impairment + profound functional limitations.

Consider a man with depression. According to the medical model, he is disabled if his depression imposes profound functional limitations. Maybe there are days when he cannot stop crying, cannot bear the thought of getting out of bed, does not want to eat, feels worthless.¹⁹⁴ If his depression is so severe that he cannot perform life functions, then he is disabled; he has a disability.

A woman with psoriasis—a skin condition—has an impairment too. She is probably not disabled, though, unless that condition imposes functional limitations, such as psoriatic arthritis, which may limit her ability to bend or perform certain tasks with her hands. Otherwise, she goes about her day—working, sleeping, eating. Does she have an impairment? Yes. Does the impairment disable her? Of course not.

As several commentators have noted, “Descriptions of the medical model often include a subordination theme as well. . . . [C]ritics of the medical model associate it with belittling norms that relieve impaired persons from social obligations yet demand they abide by professional medical judgment. Both responsibility and liberty are thereby reduced.”¹⁹⁵ By treating disability “as a medical condition or functional deficit, it is readily seen as a ‘personal tragedy—some terrible chance event which occurs at random to unfortunate individuals.’”¹⁹⁶ The medical model “encourages dependence on doctors, rehabilitation professionals, and charity”; “stigmatize[s] people with disabilities by defining them as something less than normal”; and “obscure[s] the social practices that exclude ‘the disabled’ from the opportunity to participate fully in society.”¹⁹⁷

tragedy,” which “load[s] responsibility for the restrictions that disabled people experience on to disabled people themselves, who are restricted because of the functional or psychological limitations imposed by their individual impairments rather than by the social restrictions imposed by society”).

194. See DSM-IV, *supra* note 3, at 327 (listing criteria for “Major Depressive Episode”).

195. Samaha, *supra* note 18, at 1256–57 (footnote omitted).

196. BAGENSTOS, *supra* note 4, at 18 (quoting OLIVER, *supra* note 7, at 32).

197. *Id.* at 6–7, 18; see also Mary Crossley, *The Disability Kaleidoscope*, 74 NOTRE DAME L. REV. 621, 649–51 (1999) (discussing medical model’s treatment of disability “as a personal, biological attribute that sets an individual apart from normal persons and

But the medical model need not go so far. At bottom, the medical model is simply a story of causation: impairment's functional limitations cause disability.

2. Social Model

Rather than taking disability for granted as an impairment that inevitably afflicts some people and limits their functioning, the social model holds that disability is socially constructed.¹⁹⁸ Although impairments may be inevitable, disability is contingent.¹⁹⁹ Disability is the interaction between a person's impairment and the person's environment—it is the negative treatment that a person experiences based on the person's impairment.²⁰⁰ This model may be expressed as follows:

Disability = impairment + environment (negative treatment).

There are several variations of the social model. One might say that any negative treatment based on impairment is disabling. This is the universal approach: we all have impairments,²⁰¹ and those of us who are negatively treated because of those impairments are disabled.²⁰²

A narrower approach to the social model says that the negative treatment cannot be an occasional affair—it must result in systematic

grant[s] the medical profession cognitive authority to identify and treat disabled persons"); David Pfeiffer, *The Conceptualization of Disability*, in 2 RESEARCH IN SOCIAL SCIENCE AND DISABILITY, *supra* note 7, at 29, 30 (discussing medical model's view of people as "being in the sick role, or as being sick," and requiring that they "follow the orders of the professional . . . in order to become 'well'").

198. See BAGENSTOS, *supra* note 4, at 19 (stating that social model "treats human differences as constructed by, and residing in, social relationships").

199. See *id.* at 18; see also OLIVER, *supra* note 10, at 70 (noting that while "impairment is 'real,'" disadvantage based on impairment is "neither natural nor inevitable").

200. See BAGENSTOS, *supra* note 4, at 18.

201. Shakespeare & Watson, *supra* note 7, at 24 ("No-one's body works perfectly, or consistently, or eternally. We are all in some way impaired.").

202. Barry, *supra* note 12, at 217–18. One might argue that the social model of disability is even more universal than this. One might say that the social model of disability does not require an actual or perceived impairment at all and instead applies to anyone treated negatively based on any trait or characteristic. Although this is an attractive reading of the social model, it is not a prevailing one. See Shelley Tremain, *On the Government of Disability: Foucault, Power, and the Subject of Impairment*, in THE DISABILITY STUDIES READER, *supra* note 7, at 185, 191 (Lennard J. Davis ed., 2d ed. 2006) ("[A]n unstated premise of the [social] model is . . . [that] impairment is a necessary condition for disability. For proponents of the model do not argue that people who are excluded, or discriminated against, on the basis of (say) skin color are by virtue of that fact disabled, nor do they argue that racism is a form of disability.").

disadvantage, namely, prejudice, stereotypes, and neglect.²⁰³ Because systematic disadvantage generally applies only to those impairments that are stigmatized—those considered not normal—only people with stigmatized impairments are disabled. This is the “minority group approach” to the social model.²⁰⁴

No matter what the approach, under the social model, it is society’s *negative treatment* of individuals based on their impairments—not the impairments themselves—that disables.²⁰⁵ In fact, one need not even have an actual impairment to be disabled: one may be disabled as a result of a perceived impairment—for example, a person who is perceived as having HIV and discriminated against on that basis.²⁰⁶ Under the social model, the impairment is not the problem that results in disadvantage—we are.²⁰⁷

Consider again the man with depression. He has an impairment, and the social model acknowledges that. He may also have functional limitations associated with the impairment, and the social model acknowledges that too. But under the social model, those functional limitations do not disable him. He is disabled only if society treats him negatively based on his impairment.²⁰⁸ And society often does—he may not get hired for a job if the employer finds out about his depression.²⁰⁹ His friends and family may think of his depression as a liability—something that may rub off on them—and decide to limit the time they spend with him.²¹⁰ On the other hand, he may not be disabled by

203. See Barry, *supra* note 12, at 213–14; see also Shakespeare & Watson, *supra* note 7, at 25 (“[W]hile all living beings are impaired—that is, frail, limited, vulnerable, mortals—we are not all oppressed on the basis of this impairment and illness. Only a proportion of people experience the additional disabling processes of society. Put another way, societies have evolved to minimise the problems of the majority of people with impairment, but have failed to deal effectively with the problems of a minority of people with impairment.”).

204. Barry, *supra* note 12, at 213–14 (citing Samuel R. Bagenstos, *Subordination, Stigma, and “Disability,”* 86 VA. L. REV. 397, 422, 436–37, 479 (2000)).

205. See *id.* at 212.

206. See *Equal Emp’t Opportunity Comm’n v. Gen. Elec. Co.*, 17 F. Supp. 2d 824, 827–28 (N.D. Ind. 1998) (involving harassment of employee who was erroneously perceived as having HIV).

207. Barry, *supra* note 12, at 212.

208. *Id.* at 212–13.

209. Cf. *McMullin v. Ashcroft*, 337 F. Supp. 2d 1281, 1299 (D. Wyo. 2004) (upholding employer’s termination of court security officer because of history of depression and use of antidepressant medication).

210. See Elizabeth F. Emens, *The Sympathetic Discriminator: Mental Illness, Hedonic Costs, and the ADA*, 94 GEO. L.J. 399, 430 (2006) (discussing what

his depression. Maybe he has an employer who understands that he may need to work remotely from home some days. Maybe he has friends and family who support him through those hard times. In this way, even a person whose depression imposes clinically significant functional limitations may not be disabled under the social model.²¹¹

The converse is also true. Take the person with psoriasis. She may have no functional limitations. But if she is denied a job because someone spots an odd rash along her hairline,²¹² she *is* disabled—regardless of the lack of any functional limitation.

There is one complication to the social model that is worth noting. As described above, the social model views disability as the negative treatment of impairment. Because the medical model is often understood to include not only a causation account of disability but also the negative treatment that flows from that account—stigma, dependence, and lack of regard for societal barriers²¹³—the social model might easily be conflated with the medical model. In other words, the medical model’s view of disability as a deficit in personal functioning, and the societal barriers—attitudinal and otherwise—that flow from it, might be considered disabling under the social model.²¹⁴ Taken to its logical extent, this reading of the social model reduces the medical model to a straw man—a mere descriptor of what disables under the social model. The social model need not go so far.

Although those who favor the social model might say that the medical model is, itself, disabling and therefore always wrong,²¹⁵ they can do so without undermining the theoretical legitimacy of the medical model’s central premise, which is that disability is caused by functional limitations, not societal ones.

psychologists call “emotional contagion,” by which “one person unconsciously absorbs or ‘catches’ the particular mood or emotion of another”).

211. Although this example is useful for purposes of comparison between the medical and social models, it assumes that individuals with depression do not experience negative treatment in any other aspect of their lives. This is probably not the case. Notwithstanding supportive employers, family, and friends, individuals with depression are probably still “disabled” by negative treatment elsewhere in their lives. *See id.* at 401 (discussing widespread discrimination against people with mental illness).

212. *Cf.* *Tosha Rests., LLC v. N.Y. State Div. of Human Rights*, 911 N.Y.S.2d 734, 738 (App. Div. 2010) (involving termination of dishwasher because of psoriasis and cellulitis affecting the back of his head).

213. *See supra* notes 195–97 and accompanying text.

214. The converse is not true: the social model’s view of disability as the interaction between impairment and environment does not give rise to disability under the medical model.

215. *Cf.* Samaha, *supra* note 18, at 1257 (“It is difficult to find scholars who promote [the medical] model of disability. . . . [D]isability studies scholars hold out the medical model as error.”).

C. Similarities

Beyond their causation stories, the social and medical models have much in common. First, both models regard disability as a limitation on ability—a disadvantage—and therefore something to be gotten rid of.²¹⁶ Although the medical model locates that disadvantage within the person, and the social model locates that disadvantage in the interaction between the person and the environment, both agree that the world would be a better place without disability.

Second, as a general matter, both models acknowledge the inevitability of impairment and its centrality to the disability equation.²¹⁷ Under the medical model of disability, only impairments that limit functioning give rise to disability. Under the social model, only impairments that are negatively treated give rise to disability, whether or not they limit functioning. Both models therefore leave the inevitability of impairment undisturbed, safe and sound in the annals of science, and instead clash over the contingency of *disability*.²¹⁸ The medical model holds that disability is a deficit in bodily functioning that inevitably results from impairment, while the social model holds that disability is negative

216. See, e.g., BAGENSTOS, *supra* note 4, at 7 (contrasting those who seek to eliminate disability “through the medical means of eliminating impairments” and those who seek to “eliminate the social and physical structures that create ‘disability’ by denying opportunities to people with some impairments”).

217. See, e.g., Samaha, *supra* note 18, at 1257–58 (discussing medical model’s focus on the “disadvantaging” impact of physical or mental impairments and the social model’s focus on the “disadvantage caused by the confluence of (1) personal impairment and (2) a social setting”); BAGENSTOS, *supra* note 4, at 18–19 (contrasting social model’s treatment of disability “as the interaction between societal barriers . . . and the impairment” and medical model’s treatment of disability “as an inherent personal characteristic”).

218. See Areheart, *supra* note 18, at 354 (“[T]he social model—by relying on a binary division between social disablement and physiological impairment—unwittingly underscores the notion that disability has a biological essence. . . . [A]lthough the social model was formulated to indicate disability’s constructed nature, it inadvertently reifies the idea that disability is built in part upon non-social, biological, and essential facts.”); see also Mairian Corker & Sally French, *Reclaiming Discourse in Disability Studies, in* DISABILITY DISCOURSE, *supra* note 134, at 1, 2 (“Social model theory rests on the distinction between disability, which is socially created, and impairment, which is referred to as a physical attribute of the body.”); Osteen, *supra* note 144, at 3 (“[D]isability studies [have] been unwilling or unable to theorize impairment, suffering and pain . . . perhaps because doing so would seem to yield the floor to medicine. . . . [D]isability scholars too often present impairment as a ‘fixed surface onto which disability is ‘projected’ by culture,’ abandoning impairment to the clinical fields.” (quoting Corker & French, *supra*, at 3)); Tremain, *supra* note 202, at 187 (“[T]he impairment-disability distinction . . . renders the impaired body the exclusive jurisdiction of medical interpretation.”).

treatment based on impairment and is contingent. By assuming the inevitability of impairment, both models sidestep a crucial question: are impairments themselves inevitable, or are they, too, socially constructed?²¹⁹

Part V will address this difficult question.

Third, neither model requires a particular remedy.²²⁰ As Professor Samaha notes, “Deciding how to respond to ‘disability’ depends on a normative framework that cannot be supplied by the [social] model.”²²¹ The same might also be said for the medical model. Moral frameworks—be they “libertarian, utilitarian, egalitarian, some combination thereof, or something else”—determine policy,²²² not the medical and social models themselves.

The social model, which conceives of disability as being “brought into existence or shaped by social events, forces, [and] history,”²²³ is generally understood as favoring civil rights interventions over medical ones.²²⁴ If society is causing the problem, the argument goes, then society ought to remedy it through accommodations, antidiscrimination, and so on. Removing disability, the reasoning goes, lies not in cures, charity, and social welfare interventions but rather in access.²²⁵ Although civil rights remedies are certainly consistent with the social model, they are not necessitated by it.²²⁶ The social model—at least, a more noncommittal version of it—does not demand a particular policy response or any response at all.²²⁷ One might acknowledge that society’s neglect of

219. See Areheart, *supra* note 18, at 360–62.

220. See Samaha, *supra* note 18, at 1275 (arguing that while social model explains cause of disability—combination of impairment and social setting—it does not determine appropriate policy response, which is instead “a matter of contested norms”).

221. *Id.* at 1252–53.

222. *Id.* at 1253.

223. See HACKING, *supra* note 19, at 7.

224. BAGENSTOS, *supra* note 4, at 18.

225. *Id.* at 20 (“[M]ost disability rights activists insist that society as a whole has a responsibility to eliminate the social and physical structures that deny people with ‘disabilities’ access to opportunities—the structures that, in a significant way, create ‘disability.’”).

226. Samaha, *supra* note 18, at 1308 (arguing that “[t]he social model of disability is not a justification for any policy goal,” be it social restructuring or individualized medical care).

227. *Id.* Ian Hacking traces the various grades of commitment of social construction, from those accounts that hold that something is contingent to those that “move[] beyond the world of ideas and tr[y] to change the world.” HACKING, *supra* note 19, at 19–20. The social model of disability, which was developed by the disability rights movement to challenge the dominant medical model of disability, falls into the latter camp. See Samaha, *supra* note 18, at 1280–82. In order to move beyond “the world of ideas” to concrete policy responses that “change the world,” however, the social model requires a normative framework, and that framework may yield a variety of policy responses or no response at all. See *id.* at 1253–54, 1280 (“[N]o policy response is indicated by accepting the model’s take on the causes of disadvantage.”).

people with various impairments is to blame for disability, but that the remedy—at least for now—should include continued cash benefits and charity.²²⁸ One might further acknowledge that rehabilitation and research into cures are also not antithetical to eliminating disability on grounds that, if there is no underlying impairment, there will be no negative treatment.²²⁹ Favoring policy responses outside the realm of civil rights is not abandonment of the social model because the social model has little to say about policy.

Conversely, although the medical model is generally associated with “using medical technology to cure existing disability or prevent future disability, and . . . us[ing] rehabilitative techniques to help disabled individuals approximate dominant physical standards as closely as possible,”²³⁰ medical treatment and social welfare interventions are not proprietary to the medical model. One who views disability as a personal problem of solely medical origin may favor accommodation over cure because the former is a surer bet. Schizophrenia has been around for a century and there is still no cure, one might argue, so why not support laws that take aim at stigma?²³¹

Given these similarities, the dividing line between the medical and social models is not as stark as it is often made out to be. Cures and treatments for impairments may seem a natural fit for the medical model—but the social model does not forbid the same.²³² In fact, neither model of disability has much to say about policy choices. And both models acknowledge that impairment is inevitable and that the world would be a better place without disability.²³³ What differences remain, then, lie in the models’ causation stories—the medical model’s emphasis

228. See BAGENSTOS, *supra* note 4, at 25, 149 (stating that social welfare remedies such as cash and in-kind benefits are not necessarily at odds with disability rights activists’ goal of independence, and noting that civil rights remedies such as the ADA’s reasonable accommodation mandate “might readily [be] characterize[d] . . . as a request for charity”).

229. See OLIVER, *supra* note 10, at 48 (“Some [medical] involvements are, of course, entirely appropriate, as in the diagnosis of impairment, the stabilisation of medical condition after trauma, the treatment of illness occurring independent of disability and the provision of physical rehabilitation.”); see also Samaha, *supra* note 18, at 1277 (arguing that, with respect to deafness, the social model would not prohibit policy responses ranging from do-nothing, to subsidized access to cochlear implants and genetic screening, to expansion of ASL instruction and sign language communities).

230. Crossley, *supra* note 197, at 652 (citation omitted).

231. See GRINKER, *supra* note 20, at 120–21.

232. See *supra* note 229 and accompanying text.

233. See *supra* note 216 and accompanying text.

on impairment as the cause of disability versus the social model's emphasis on the interaction between impairment and environment.²³⁴

D. Autism and Disability

The medical-versus-social model binary helps to explain part of the autism debate, but not the whole. Parents and the neurodiverse disagree about the causation of disability. The former view disability as inevitable—it is caused by the functional limitations that flow inevitably from autism. This is the medical model.²³⁵ The latter view disability as socially constructed—it is caused by societal barriers that are contingent. This is the social model.²³⁶ But beyond that, the medical-versus-social model binary fails to distinguish between autism's sides.

First, under both models, disability is a disadvantage—a negative medical state or negative societal treatment—and therefore something that ought to be gotten rid of.²³⁷ Far from distinguishing the two sides in the autism debate, the medical-versus-social model binary suggests that both parents and the neurodiverse seek the same thing: an end to disability, albeit through very different means.

Second, disability's medical-versus-social model binary has no policy implications—it does not explain parents' and the neurodiverse's disagreement over how to get rid of disability.²³⁸ Parents suggest a range of ways: from mainstream medical research that might lead to pharmacological treatments, cures, and prevention to fundraising messages that support treatment, cures, and prevention; from applied behavioral analysis that seeks to modify autistic behavior to try-anything, kitchen-sink approaches to treating autism that are dubious and even deadly. The neurodiverse are generally critical of such measures, which they regard as unethical, stigmatizing, and inconsistent with autistic autonomy. Instead, they point to, among other things, support services and other structural changes that help autistic people better navigate an NT world.²³⁹

Although disability's medical-versus-social model binary explains dueling conceptions of the causation of disability, it has little to do with how (or if) that disability is remedied.²⁴⁰ As Professor Samaha points out, moral frameworks—not models of causation—govern policy responses

234. *See supra* note 192 and accompanying text.

235. *See supra* notes 193–97 and accompanying text.

236. *See supra* notes 198–215 and accompanying text.

237. *See supra* note 216 and accompanying text.

238. *See supra* notes 220–31 and accompanying text.

239. *See supra* Part III.B.

240. *See supra* note 220 and accompanying text.

to disability.²⁴¹ As a result, the medical-versus-social model binary does not distinguish parents' choice of cures, treatment, and prevention from accommodations and other aims of the neurodiverse.

Finally, although disability's medical-versus-social model binary describes the debate over the social construction of *disability*, it takes for granted the inevitability of impairment.²⁴² It is therefore inadequate because impairment, like disability, may also be socially constructed. As discussed in the next Part, it is the social construction of *impairment*—not disability—that meaningfully distinguishes autism's sides.

V. CONSTRUCTING IMPAIRMENT: PATHOLOGY VS. EXPERIENCE

Disability's medical-versus-social model binary does not explain the autism debate between parents who say that autism ought to be defeated and the neurodiverse who say it ought to be respected. But if disability does not distinguish the two sides in the debate, then what are they fighting about? The answer is that they are not fighting about *disability* at all—they are fighting about impairment. They are fighting about autism.

According to many parents of autistic children, autism is a—as of yet undiscovered—biological pathology.²⁴³ The neurodiversity movement says, “No, that’s not what autism is, or that’s not *all* that autism is. There is something else—there is the *experience* of having autism, of being autistic.”²⁴⁴ Here, the debate shifts from the social construction of *disability* and whether disability is contingent (social model) or inevitable (medical model) to the construction of *impairment*.²⁴⁵ According to the neurodiversity movement, autism is itself socially constructed and therefore contingent, not inevitable.²⁴⁶

241. See *supra* notes 221–22 and accompanying text.

242. See *supra* notes 217–19 and accompanying text.

243. See *supra* notes 38, 41 and accompanying text.

244. See *supra* notes 37, 40 and accompanying text.

245. See *supra* notes 217–19 and accompanying text.

246. See *supra* note 40 and accompanying text (describing autism as “a way of being”).

A. Beyond Diagnosis

Recent work in disability studies has chronicled how impairment is socially constructed.²⁴⁷ As Professor Bradley Areheart has noted, impairment is principally identified and described through the practice of medical diagnosis.²⁴⁸ Medical diagnosis, he rightly argues, is a social concept in at least two ways.²⁴⁹ The first involves the creation of the diagnosis itself—the historical and political factors leading to the existence or “naming” of an impairment.²⁵⁰ For example, protests by gay activists and “the shifting fortunes of various powerful factions within the American Psychiatric Association” led to the elimination of homosexuality as a mental impairment.²⁵¹ Likewise, the naming of deafness, blindness, and mental retardation are social judgments involving line-drawing.²⁵² The creation or deletion of these impairments was not inevitable—it was the product of clinicians’, advocates’, and others’ deciding what is “normal” and what is named.²⁵³

247. See Areheart, *supra* note 18, at 349 (arguing that “impairment, though theorized as biologically asocial, is indeed a social concept”); see also Samaha, *supra* note 18, at 1266 (noting that, according to some commentators, “‘impairment’ is itself a socially ascribed characteristic, an outgrowth of practices that demand the identification of difference,” and that it is “politically naive to suggest that the term ‘impairment’ is value-neutral, . . . as if there could ever be a description that was not also a *prescription* for the formulation of the object” (internal quotation marks omitted) (citing Shelley Tremain, *On the Government of Disability*, 27 SOC. THEORY & PRAC. 617, 621 (2001))).

248. Areheart, *supra* note 18, at 362; see also KUTCHINS & KIRK, *supra* note 16, at 27 (discussing *DSM*’s role in defining mental disorders).

249. Areheart, *supra* note 18, at 363; see also KUTCHINS & KIRK, *supra* note 16, at 27–28, 52–53 (discussing arbitrariness inherent in *DSM*’s definition of mental disorders and inability of clinicians to reliably diagnose mental disorders).

250. See Areheart, *supra* note 18, at 363.

251. KUTCHINS & KIRK, *supra* note 16, at 37, 55–56 (“The dispute over the inclusion of homosexuality in *DSM* was not about research findings. It was a 20-year debate about beliefs and values. Although the professionals who formulated diagnoses couched their arguments in the language of science, the actual influence of empirical data was negligible. More often than not, the issues were settled by political compromises that promoted personal interests.”).

252. See Areheart, *supra* note 18, at 367–69; see also Lane, *supra* note 151, at 177 (“Research has shown that some children characterized as profoundly hearing impaired can understand words and sentences whereas others do not even detect sound.” (citation omitted) (citing Mary Joe Osberger & Monica Maso, *Speech Intelligibility of Children with Cochlear Implants, Tactile Aids, or Hearing Aids*, 1 J. SPEECH & HEARING RES. 186, 203 (1993))). “Likewise . . . the official definition of blindness is ‘based upon a meaningless demarcation among those with severely impaired vision.’” Osberger & Maso, *supra*, at 203 (citation omitted) (quoting ROBERT A. SCOTT, *THE MAKING OF BLIND MEN* 42 (1981)).

253. See KUTCHINS & KIRK, *supra* note 16, at 37 (“[T]he construction of *DSM* involved much more than the assembling of scientific conclusions and the making of technical decisions. It involved negotiations among contending interest groups of theoreticians, researchers, clinicians, hospitals, clinics, and drug companies—and, at times, potential patients.”).

The second way that diagnosis is a social construct involves the act of diagnosis—the process by which a person is determined to have an impairment.²⁵⁴ For example, a diagnosis of depression relies on a person’s self-assessment, “which will almost necessarily be informed by social meanings,” together with a clinician’s interpretation of these subjective phenomena to yield a diagnosis.²⁵⁵

Because the creation and acts of diagnosis are fraught with contingency, impairment may be said to be socially constructed.²⁵⁶ The social model’s anchor of “impairment,” one might say, is not a “raw, ‘unadulterated biological core.’”²⁵⁷ It is contingent.

This is true so far as it goes, but what about the closer cases where impairment is diagnosed not through a collection of subjective features pathologized by clinicians but rather through our blood, our genes, our brains, our immune system? In these types of cases, it seems more difficult to say that impairment is socially constructed—that it is contingent. Results of blood tests, genetic testing, brain imaging, and CT scans seem awfully inevitable, unaffected by social institutions and practices.²⁵⁸

I want to suggest another way in which impairment is constructed, one with implications for all impairments, including the closer cases. Drawing on the work of philosopher Ian Hacking, I argue that impairments are constructed, in part, by those classified as having the impairments.²⁵⁹ This argument takes us well beyond the semantics of construction—how impairment is constructed through naming and

254. See Areheart, *supra* note 18, at 364 (citing CHARLES E. ROSENBERG & JANET GOLDEN, *FRAMING DISEASE: STUDIES IN CULTURAL HISTORY*, at xiii (1992)).

255. *Id.* at 371; see also Bernstein, *supra* note 16 (contrasting diagnosis of mental disorders with “scientifically more mature (some would say less difficult) areas of medicine where diseases are identified by more ‘objectively’ ascertainable abnormalities of anatomy, physiology, or biochemistry and where genetic and environmental etiologies are increasingly certain”).

256. See Areheart, *supra* note 18, at 362.

257. *Id.* at 363 (quoting ROBERT A. ARONOWITZ, *MAKING SENSE OF ILLNESS: SCIENCE, SOCIETY, AND DISEASE* 171 (1998)).

258. One might nevertheless argue that these purportedly objective scientific measures of “impairment,” themselves, construct, as opposed to merely describe, “impairment.” See Tremain, *supra* note 202, at 188, 192 (arguing that “allegedly ‘real’ impairments” are “an effect of certain historical conditions and contingent relations of social power”). According to Professor Ron Amundson, “[T]he doctrine of biological normality is itself one aspect of a social prejudice against certain functional modes or styles. The disadvantage experienced by people who are assessed as ‘abnormal’ derive not from biology, but from implicit social judgments about the acceptability of certain kinds of biological variation.” Amundson, *supra* note 169, at 33.

259. See HACKING, *supra* note 19, at 121.

diagnosis. This argument focuses instead on the dynamics of construction—how impairments (once named and diagnosed) affect, and in turn are affected by, those who are named.²⁶⁰

As Professor Hacking states, “One of the defects of social construction talk is that it suggests a one-way street: society (or some fragment of it) constructs the [impairment] (and that is a bad thing because the [impairment] does not really exist as described, or would not really exist unless so described).”²⁶¹ My argument suggests “a two-way street” by which the meaning of impairment changes, and is changed by, those classified.²⁶²

B. Ideas and Objects

In arguing that impairment is socially constructed by those classified by it, an important distinction must be made. When we say that *something* is socially constructed (contingent), it is not always clear what that *something* is. According to Professor Hacking, things that are said to be socially constructed include both “objects” in the world, broadly speaking—people or material things—and “ideas” about those objects—classifications, kinds, categories, concepts, beliefs, and attitudes.²⁶³ This distinction matters; the answer to the question of whether something—such as impairment—is constructed depends on it. Therefore, it is necessary to distinguish between the “idea” of impairment and its referent, the “object” to which that idea refers.

1. Ideas

First consider ideas about objects. These ideas—take classifications (ideas) of people (objects), for instance—do not exist in a vacuum, in solely the “empty space of language.”²⁶⁴ Instead, they are formed within a social setting, a “matrix” of institutions and practices.²⁶⁵ This matrix in which ideas are formed is a mosaic; it is a complex of everything from laws, lawyers, court decisions, social workers, advocates, and newspaper articles to doctors’ offices, schools, health insurance, and fundraisers.²⁶⁶ Ideas are not inevitable—they are the product of social practices and institutions and are therefore socially constructed.

260. *Id.* at 123.

261. *Id.* at 116.

262. *See id.*

263. *Id.* at 22.

264. *Id.* at 10, 31.

265. *Id.* at 10.

266. *See id.* at 10, 31.

As noted above, the classification *disability* or *disabled person* might be said to be socially constructed—it came about as a result of the disadvantage experienced by people with certain physical or mental impairments.²⁶⁷ As Professor Hacking notes, the classification *woman refugee* is likewise constructed—it came about as a result of social events that led women to leave their homes under threat of violence and includes the laws that recognize these events as grounds for not returning women to their homelands.²⁶⁸ Similarly, the classification *child TV viewer* came about as a result of concerns expressed by researchers over the ills of obesity, poor socialization, and violence attributed to children watching television.²⁶⁹ And the classification *child abuse* emerged in the 1950s when radiologists and pediatricians “decried the evidence they were seeing of parents beating their children,” and when society responded by passing laws forbidding it, hiring social workers to investigate it, requiring schoolteachers to report it, and appropriating funds to study and raise awareness about it.²⁷⁰

None of these classifications was inevitable. As for *disability*, sidewalks never had to be built without curb cuts; schools never had to deem certain children uneducable; employers never had to refuse to hire certain people based on medical histories; and the medical establishment never had to institutionalize certain people. For *women refugees*, countries could have made any person crossing their borders a citizen with no questions asked, could have found some other way to protect women fleeing their homelands, or could have immediately returned them to their country of origin.²⁷¹ With respect to *child TV viewers*, researchers could have overlooked TV as a potential culprit for obesity, poor socialization, and violence, or parents could have ignored the purported threat to their children altogether.²⁷² And as for *child abuse*, pediatricians need never have called attention to unreported healed fractures in the legs and arms of children, and society could have continued to focus on other children’s issues, such as child poverty, infant mortality, child labor, and juvenile delinquency.²⁷³ The classifications *disability*,

267. See *supra* notes 205–11 and accompanying text.

268. See Hacking, *supra* note 2, at 10–11 (emphasis omitted).

269. *Id.* at 26.

270. Lane, *supra* note 151, at 172.

271. See HACKING, *supra* note 19, at 11.

272. See *id.* at 26–27.

273. See *id.* at 134–36.

women refugees, child TV viewer, and child abuse, and the matrix of institutions and social practices surrounding them, never had to be, or never had to be quite as they are. In this way, these classifications of people—these ideas about objects—can be said to be socially constructed.

The same might even be said, albeit with more difficulty, of classifications of things other than people. Consider the quark—a fundamental particle of matter. Professor Hacking suggests that a social construction account of the classification *quark* need not deny the existence of fundamental particles of matter.²⁷⁴ Instead, it would argue that the idea or concept of the quark was not inevitable—that “the evolution of physics, including the quark idea, is thoroughly contingent and could have evolved in other ways.”²⁷⁵ An equally successful physics could have proceeded in a nonquarky way with “different successes evolving in other ways that do not converge on the route that was in fact taken.”²⁷⁶ The same might also be said for ponies and plutonium: the former might have been classified as a “horse” and the latter, an artificial element, might never have been created at all.

Impairments can be thought of in much the same way. When commentators say that impairments are constructed, they are arguing that classifications such as *MR* and *learning disability (impairment X)* never had to be.²⁷⁷ The classification *impairment X* was formed within a social setting where certain characteristics were pathologized (named) and applied to people (diagnosed).²⁷⁸ Clinicians need not have named certain characteristics; or they need not have diagnosed people as they did. As commentators have noted, “[S]ocial forces affect the conceptualisation, recognition and visibility of disorders. A disorder in one place and at one time is not seen as such in another.”²⁷⁹ The classification *impairment X* is therefore not immune to social events; instead, it is the upshot of those events—the convergence of clinicians,

274. *See id.* at 70.

275. *See id.* at 31.

276. *Id.* at 32–33, 70.

277. *See supra* notes 247–57 and accompanying text.

278. *See id.*

279. OLIVER, *supra* note 10, at 13 (quoting M.W. SUSSER & W. WATSON, *SOCIOLOGY IN MEDICINE* 35 (2d ed. 1971)) (internal quotation marks omitted); *see id.* at 14 (“Beliefs about sickness, the behaviors exhibited by sick persons, and the ways in which sick persons are responded to by family and practitioners are all aspects of social reality. They . . . are cultural constructions, shaped distinctly in different societies and in different social structural settings within those societies.” (quoting ARTHUR KLEINMAN, *PATIENTS AND HEALERS IN THE CONTEXT OF CULTURE: AN EXPLORATION OF THE BORDERLAND BETWEEN ANTHROPOLOGY, MEDICINE, AND PSYCHIATRY* 38 (1980)) (internal quotation marks omitted)).

advocates, health insurance, drug makers, and others who decide what impairment X is.²⁸⁰

The classification *Asperger's syndrome* is a good example of the contingency of ideas. According to the proposed *DSM-V*, Asperger's will disappear as a diagnosis because of the inexactitude of its current criteria, which have been "used loosely with little agreement" among clinicians.²⁸¹ But inevitable things do not just disappear—Asperger's is disappearing because it is contingent.

The classification *autism* is also contingent. It need never have been named: its higher functioning manifestations could have remained mere oddities, while its lower functioning manifestations could have continued to be lumped under *childhood schizophrenia* or *MR*.²⁸² Furthermore, far from disappearing like Asperger's, autism is expanding under the *DSM-V* and swallowing a number of formerly named autistic subtypes along the way.²⁸³ Autism's appearance on the scene and proposed metamorphosis under the *DSM-V* are contingent.

Importantly, the contingency of impairment X does not stop there. The matrix in which impairment X derives meaning includes not only those contingent practices and institutions that *name* and *diagnose* impairment X but all of those other practices and institutions in the matrix that affect people classified as having impairment X.²⁸⁴ It includes those social elements that not only treat people with impairment X but also educate, legislate, employ, and entertain them. Therapists and advocates, laws and lawyers, summer camps, job coaches, and popular media—all give impairment X its meaning.²⁸⁵ None of these institutions and practices was inevitable.

2. Objects

So classifications of people, and even classifications of things in the natural world, might be said to be socially constructed. This is not that

280. See *supra* note 253 and accompanying text.

281. See *Asperger's Disorder: Rationale*, *supra* note 10.

282. See GRINKER, *supra* note 20, at 157–59.

283. See *Asperger's Disorder: Rationale*, *supra* note 10 (listing conditions subsumed by "autism spectrum disorder").

284. See *supra* notes 264–66 and accompanying text.

285. The ADA, for example, provides antidiscrimination protection only to those with an actual or perceived "impairment." See 42 U.S.C. § 12102 (2006 & Supp. II 2008); 29 C.F.R. § 1630.2(h) (2011) (defining *impairment*).

controversial. After all, such classifications are embedded within matrices that include many obvious social elements.²⁸⁶ Through social practices and institutions, these classifications are “debated, assessed, applied, and developed” and “proposed, criticized, entertained, [and] rejected.”²⁸⁷ In a word, they are contingent.

But now to the root of the matter. What about the *things* so classified—the things to which the classification refers? The people, the ponies, the pathologies, themselves. Might the point be extended—might the people or the material objects so classified, themselves, also be socially constructed? Or have we at last reached bedrock—those things that are inevitable, that are fixed? According to Professor Hacking, the answer depends on the thing so classified.²⁸⁸

a. “Interactive” Kinds: Classifications of People

Classifications of people are “interactive” kinds of classifications.²⁸⁹ These classifications interact with—and influence—the people they classify.²⁹⁰ This is so because people are self-conscious—they are aware of what is said about them, thought about them, and done to them.²⁹¹ As they move through the matrix of social practices and institutions affecting them, “people . . . become aware of how they are classified and modify their behavior accordingly.”²⁹² The classification, and the matrix within which that classification gets communicated, “changes how some [people] feel about themselves, their experiences, and their actions.”²⁹³ People may think of themselves as fitting within that classification, may transform the meaning of that classification, or may reject that classification altogether.²⁹⁴ Because one is indirectly affected by that classification, “the individual herself is socially constructed as a certain kind of person.”²⁹⁵ For interactive kinds of classifications, then, it

286. See *supra* notes 264–66 and accompanying text.

287. HACKING, *supra* note 19, at 10, 125.

288. See *id.* at 32, 103–05 (distinguishing between indifferent and interactive kinds of classifications).

289. *Id.* at 103–04.

290. *Id.*

291. *Id.* at 31–32, 102–03.

292. *Id.* at 32. While “[t]he awareness may be personal, [it] more commonly is an awareness shared and developed within a group of people, embedded in practices and institutions to which they are assigned in virtue of the way in which they are classified.” *Id.* at 104.

293. *Id.* at 11.

294. *Id.* at 31, 104.

295. *Id.* at 11.

“make[s] sense to say that the very individuals and their experiences are constructed within the matrix surrounding the classification.”²⁹⁶

Take the example of an individual disabled person. He may internalize the stigma directed toward him and believe himself incapable of doing certain things.²⁹⁷ He may not apply for a job or go to a grocery store because he does not want to burden others. Or he may react differently—he may challenge that stigma. He may embrace the term *disability*. If he uses a wheelchair, he may chain his wheelchair to a bus that is not accessible to him and yell, “Access now!”²⁹⁸ In either case, the classification *disabled* affects him. He has become a disabled person.

Consider also an individual woman refugee. Rather than go into hiding, the woman responds to questions and submits paperwork to government officials who hold her life in the balance.²⁹⁹ She takes her children to holiday camps for refugee children.³⁰⁰ She works with an immigrant advocacy group that helps usher refugees through the residence process.³⁰¹ This matrix of institutions and practices affects her, and the classification—embedded in that matrix—affects her.³⁰² As she interacts with the matrix surrounding the classification *woman refugee*, she is changed by being so classified. She acquires the characteristics of a woman refugee.³⁰³ “By living that life, she evolves, becomes a certain kind of person (a woman refugee).”³⁰⁴

The same is also true of the child TV viewer. Reacting to the reported ills of TV-watching, parents “start to interact, on occasion, with their children regarded not as their children but as child viewers.”³⁰⁵ Parents curtail TV-watching and embed parental guidance chips in their TVs.³⁰⁶ As a result, children may come to see themselves as child viewers and

296. *Id.*

297. See Samuel R. Bagenstos, “Rational Discrimination,” *Accommodation, and the Politics of (Disability) Civil Rights*, 89 VA. L. REV. 825, 843 (2003) (discussing “psychic harm” imposed by social stigmas).

298. Cf. TO RIDE THE PUBLIC’S BUSES: THE FIGHT THAT BUILT A MOVEMENT (Mary Johnson & Barrett Shaw eds., 2001) (chronicling American Disabled for Accessible Public Transportation’s use of nonviolent civil disobedience to draw attention to inaccessibility of public buses).

299. See HACKING, *supra* note 19, at 11.

300. See *id.* at 10.

301. See *id.*

302. See *id.* at 10–11.

303. See *id.*

304. *Id.* at 11.

305. *Id.* at 27.

306. *Id.* at 26.

may watch less TV or, in defiance, find ways to watch more.³⁰⁷ Similarly, after receiving counseling from social workers and even new (foster) parents and homes, children who are abused may come to see themselves not as ordinary children but rather as child abuse survivors.³⁰⁸ And as for child abusers, they are mentally ill, perpetrators of “the worst possible vice,” and possibly the victims of child abuse themselves.³⁰⁹

Importantly, this interaction between idea and object is a two-way street. Just as interactive kinds of classifications may cause people to change how they feel or behave, changes in people may cause classifications to be modified or replaced.³¹⁰ What was known about a certain classification of people, for instance, “may become false because people of that kind have changed in virtue of how they have been classified, what they believe about themselves, or because of how they have been treated as so classified. There is a looping effect.”³¹¹ As a result, classifications of people are not static—they are “on the move.”³¹² *Disabled* may come to mean “activist”; *woman refugee* may come to mean “patriot.”

b. “Indifferent” Kinds: Classifications of Material Things

Classifications of people are interactive kinds of classifications: they interact with the people they classify. But what about those classifications that do not involve interactions with the thing so classified, like classifications of things in the natural world, such as fundamental particles? According to Professor Hacking, these classifications are “indifferent” kinds of classifications.³¹³ They do not interact with the thing so classified because the thing is not aware of how it is classified.³¹⁴

Take quarks, for example. “Quarks are not aware that they are quarks and are not altered simply by being classified as quarks.”³¹⁵ As a result, “[t]he classification ‘quark’ is indifferent in the sense that calling a quark a quark makes no difference to the quark.”³¹⁶ The same can be said for plutonium, water, tigers, lemons, and the color yellow.³¹⁷ And

307. *See id.* at 27.

308. *See id.* at 162 (explaining that child abuse “has changed the past of many people, and so changed their very sense of who they are and how they have come to be”).

309. *See id.* at 125–26, 135, 137.

310. *Id.* at 103.

311. *Id.* at 104.

312. *See id.* at 108.

313. *See id.* at 104–05.

314. *See id.* at 32, 105.

315. *Id.* at 32.

316. *Id.* at 105.

317. *Id.* at 107.

because these things are not aware of how they are classified and do not change accordingly, it makes little sense to say that they are socially constructed.³¹⁸ At the very least, these things seem far more inevitable, far more determined by the nature of things, than *disability, woman refugee, child TV viewer, or child abuse*.

c. Impairment X: Classifications of People and Material Things

To summarize, classifications of *people*, such as *woman refugee*, are interactive kinds of classifications. These classifications affect people who are aware of how they are classified and, in turn, are affected by how people react to being classified (looping effect).³¹⁹ In this way, both the classification (*woman refugee*) and the thing classified (the individual woman) may be said to be socially constructed.³²⁰ They change. They are contingent.

Classifications of things *other than people*—things that are not aware of and therefore not affected by their classification—are indifferent kinds of classifications.³²¹ Although the classification *plutonium* may be said to be socially constructed (the idea of plutonium was not inevitable), the thing so classified (plutonium itself) is not socially constructed. It is very much with us, and it is not going anywhere.³²² The thing is inevitable.

Fair enough. But what happens if a classification is both interactive *and* indifferent—one that refers to both people and, say, the natural world?³²³ *Impairment* is such a classification. As seen above, the classification *impairment X* (or *disorder X, dysfunction X, deficit X, defect X, condition X*, or what have you) is socially constructed—it exists within a matrix of socially contingent institutions and practices that name and diagnose, educate and entertain, accommodate and legislate.³²⁴ But what about the thing to which impairment X refers?

On the one hand, the object to which the classification *impairment X* refers is some biological pathology that is indifferent, unaffected by its

318. See *id.* at 30 (“[Q]uarks, the objects themselves, are not constructs, are not social, and are not historical.”); see also *id.* at 119–20 (distinguishing between indifferent, biological kinds and interactive, socially constructed kinds).

319. See *supra* notes 291–95, 311–12 and accompanying text.

320. See HACKING, *supra* note 19, at 11.

321. See *supra* notes 314–19 and accompanying text.

322. See HACKING, *supra* note 19, at 105.

323. See *id.* at 108.

324. See *supra* notes 264–66, 277–80 and accompanying text.

classification.³²⁵ You can see it under a microscope. You can test for it. The pathology does not change because researchers have named it or clinicians have applied it to people.³²⁶ Pathologies are not aware of how they are classified and are therefore not constructed.³²⁷ They are inevitable.

But pathology is not impairment X's only referent. The classification *impairment X* also refers to *people*.³²⁸ Now, to head off an obvious objection at the outset, one could say that the classification *impairment X* refers *only* to pathology—it does not refer to people who share that pathology. “While people may experience and even *embrace* impairment X,” one might say, “the impairment does not refer to them.” This seems wrong for two reasons.

First, recall that the vast matrix surrounding the classification *impairment X* includes not only those practices and institutions that name and diagnose the impairment.³²⁹ It also includes those practices and institutions that act upon the impairment or, more particularly, on people classified as having the impairment.³³⁰ These practices and institutions “change the ways in which individuals experience themselves—and may even lead people to evolve their feelings and behavior in part because they are so classified.”³³¹ As people interact with this matrix of practices and institutions, they may also change how impairment X is understood (looping effect).³³² Therefore, the classification *impairment X* refers to both a pathology *and* the people whose lives shape, and are shaped by, the classification.

Consider again the example of Asperger's. In 2013, Asperger's will disappear from the lexicon of the APA and will be replaced by the *DSM-V*'s umbrella diagnosis, autism spectrum disorder.³³³ But Asperger's will most likely not disappear from autobiographies, blogs, and elsewhere.³³⁴ Notwithstanding the lack of coherent diagnostic criteria, the classification *Asperger's* will probably remain. Why? Because people currently classified as having Asperger's want it to. For them, it is a shared experience, a way of being.³³⁵ So there must be more to impairment X than pathology.

325. See HACKING, *supra* note 19, at 117.

326. *See id.*

327. *See id.*

328. *See id.* at 119.

329. *See supra* notes 285–86 and accompanying text.

330. *See id.*

331. HACKING, *supra* note 19, at 104.

332. *See supra* notes 311–13 and accompanying text.

333. *See DSM-V Proposed Revision, supra* note 3.

334. *See, e.g.,* SPIES FOR FREEDOM, *supra* note 74.

335. *See, e.g.,* Dave Angel, *Aspergers Diagnosis and the DSM 5 Proposed Changes*, PARENTING ASPERGERS BLOG (Apr. 7, 2010, 12:44 PM), <http://parentingaspergers.com/blog/other/aspergers-diagnosis-and-the-dsm-5-proposed-changes/> (objecting to *DSM-V*'s removal of Asperger's on grounds that, for people with Asperger's, “the

Consider also deafness. Although deafness refers to a pathology in the sense of hearing loss,³³⁶ it also refers to an experience, a way of being in the world.³³⁷ Resisting the institutions and practices that pathologize deafness—for example, school administrators, social workers, therapists, surgeons, otologists, hearing aid specialists—the deaf have redefined the classification, constituting themselves as a new ethnicity, a “linguistic minority” with their own “distinct manual language [ASL], culture, and social organization.”³³⁸

Second, and more fundamentally, one might argue that impairment X presumes at least some connection to the person. Pathologies, after all, do not exist outside of the person—they reside *in* the person, in their blood, in their brains. But for people, impairment X disappears.

C. Autism and Impairment

Because of the social setting in which impairment X derives its meaning, impairment X might be said to refer not only to a pathology but also to the experience of people classified as having the impairment.³³⁹ In this way, impairment X is constructed in part by those to whom it refers. It is a moving target that changes as people change.³⁴⁰

The social construction of impairment is important for three reasons. First, it means that impairment X is not inevitable, contrary to what both disability models say; impairment is in part contingent on the people it classifies.³⁴¹ As people experience and change in response to their classification, the social institutions and practices surrounding the classification *impairment X* may need to be changed.³⁴²

diagnosis is part of who they are, and changing that to Autism may be extreme and cause anxiety”).

336. See THE MERCK MANUAL OF DIAGNOSIS AND THERAPY, *supra* note 10, at 429–30.

337. See Lane, *supra* note 151, at 173 (construing the classification *deaf* as “designating a member of a linguistic minority”).

338. See *id.* at 174, 179. “[W]e’re more of an ethnic group because we speak a different language. . . . [D]eafness is a difference, not a deficiency.” *Id.* at 180.

339. See *supra* note 328 and accompanying text; *cf.* HACKING, *supra* note 19, at 121 (stating that one could well maintain that autism “is probably a definite unknown neuropathology that is the cause of prototypical and most other examples of what we now call childhood autism” but also includes “autistic children, actual human beings, whose way of being is in part constructed”).

340. See *supra* notes 311–13, 330–33 and accompanying text.

341. See *supra* notes 311–13, 330–33 and accompanying text.

342. See *supra* notes 311–13, 330–33 and accompanying text.

Second, by suggesting that impairment X has to do with peoples' experiences—how they are conceived of and how they conceive of themselves—not just their bodies,³⁴³ the social construction of impairment raises important moral questions that have policy implications.³⁴⁴ It does not matter to a pathology if we say we wish it never existed or was less pathological. But people are different. People are aware of how they are classified, either literally or because they interact with the matrix of social practices and institutions through which the classification gets communicated.³⁴⁵ It matters very much to people when we say that we wish they were not born or were different than they are.

Lastly, the social construction of impairment complicates disability, which, arguably, is itself a social construction.³⁴⁶ Disability refers to negative treatment based on impairment, and impairment refers both to some bedrock biological pathology and to the experience of people so classified.³⁴⁷ Although both disability and impairment have a social component, and although these waters are murky, there is a fundamental distinction between the two that offers some clarity. Disability is synonymous with disadvantage, and so the experience of being disabled is always a negative one.³⁴⁸ Disability is something to be gotten rid of.³⁴⁹ Being classified as having an impairment, on the other hand, is not always a bad thing. On the contrary, for those so classified, it may be a good thing. The classification may be something to be celebrated.

Autism is a case in point. The war raging over autism is not a war about disability. It is a war between those who believe that autism is a (still unidentified) biological pathology and inevitable (“I love my children, but I do not love autism”) and those who believe that it is an experience and therefore contingent (“Autism is a way of being”).³⁵⁰ Both may be right.³⁵¹ Autistic people share differences in social communication and behavior, and medical research may one day locate the source of those differences in a shared pathology.³⁵² But alongside these behavioral

343. See Areheart, *supra* note 18, at 379 (“[I]mpairment, rightly understood, is complicated—and is far more than just biology.”).

344. Cf. Samaha, *supra* note 18, at 1305 (“If the subordinated status of a group sharing a physical trait like deformity is the product of irrationally imposed social stigma, then one would think the social dynamic needs to be corrected without ‘fixing’ the subject of disadvantage.”).

345. See *supra* notes 292–94 and accompanying text.

346. See *supra* note 198 and accompanying text.

347. See *supra* notes 200–02, 326–29 and accompanying text.

348. See *supra* note 191 and accompanying text.

349. See *supra* note 216 and accompanying text.

350. See *supra* notes 37–38, 40–41 and accompanying text.

351. See HACKING, *supra* note 19, at 121.

352. See *id.* at 116.

features, autistic people share something else—an experience of being *different* from the norm.

As demonstrated by the neurodiversity movement, autistic people are shaped by, and are shaping, autism—resisting, embracing, and transforming it.³⁵³ Under their stewardship, autism has become something that, although challenging, is also mysteriously beautiful (a window into the wonders of the human brain), wildly liberating (not tethered to social niceties), and even radically transformative (defying social norms).³⁵⁴ Through their art, writing, and other modes of communication, the neurodiverse are challenging the conception of autism as some undiscovered pathology and pointing instead toward an understanding of autism as something akin to homosexuality, blue eyes, tallness, or shyness—a characteristic with its own brand of gifts and weaknesses.³⁵⁵ And if autism turns out to be a biological pathology, then, the neurodiverse might reasonably argue, it is a pathology in the sense that hearing loss is a pathology—not necessarily bad, and possibly quite good.³⁵⁶

With the Internet as its bricks and mortar, the neurodiversity movement has built a vibrant culture that prides itself on pushing the bounds of normality.³⁵⁷ Neurodiversity *is* autism. Pathology may be too.

As Professor Daniela Caruso notes:

[A]utism can be credited with a veritable advancement in the understanding of difference. Since the spectrum of autistic disorders is ample enough to include persons of high accomplishment, the line between the ill other and the healthy self is blurred. The very concept of cognitive impairment dissipates, leaving in its place a vision of a more advanced society, where human beings are allowed to flourish for who they are and are helped to reach their potential without preconceptions. The post-modern concept of neuro-diversity, with its promise

353. See NADESAN, *supra* note 43, at 204–05.

354. See *supra* notes 133–46 and accompanying text.

355. See Jim Sinclair, *Why I Dislike “Person First” Language*, CAFEMOM (Sept. 18, 2007), <http://www.cafemom.com/journals/read/436505/> (likening autism to traits such as blue eyes and left-handedness); cf. KUTCHINS & KIRK, *supra* note 16, at 90 & n.66 (calling “homosexuality . . . a normal variant [of sexual behavior]; the nearest analogy is that of left-handedness” (quoting Memorandum from Harold Lief, Member of DSM-III-R Advisory Comm. on Sexual Disorders, to Robert Spitzer, Chair of Work Grp. To Revise DSM-III (Jan. 15, 1986))).

356. See *supra* notes 337–39 and accompanying text.

357. See NADESAN, *supra* note 43, at 209–10.

of inclusion and its philosophical acceptance of variation, may find in autism a perfect home.³⁵⁸

VI. CONCLUSION

The oft-claimed binaries surrounding disability and impairment are not what they seem. As autism teaches, there is much gray here. Two conclusions emerge.

First, the medical-versus-social model binary is not as stark as it is often made out to be. The two models describe a debate over the cause of disability: the medical model holds that disability is a deficit in bodily functioning that inevitably results from impairment, while the social model holds that disability is negative treatment based on impairment and is contingent. Beyond this, disability's dueling models do not offer much. Both models regard disability as a limitation on ability—a disadvantage—and therefore something to be gotten rid of. Neither model requires a particular policy response, and both models acknowledge the inevitability of impairment.

The medical-versus-social model binary therefore does not explain the autism debate. Under both models, parents of autistic children and the neurodiverse seek the same thing: an end to disability—whether that disability is a negative medical state or negative treatment. Although the two sides clash over the pursuit of cures and certain treatments for autism, the medical-versus-social model binary does not explain their conflicting policy responses, which depend on moral frameworks independent of the models. Lastly, both models agree that impairment is inevitable, which turns out to be precisely what parents and the neurodiverse do not agree about. The social construction of disability therefore does not meaningfully distinguish autism's sides; the social construction of *impairment* does.

Second, impairment is not pathology *or* people's experience. It is both. Although impairment refers to pathology, which is inevitable, it also refers to those classified as having the impairment, whose experiences are contingent. Impairment is therefore not fixed; it is, in part, constructed. Again, the autism debate is instructive. A growing body of medical research suggests that autism is a biological pathology—some unidentified deficit in neurological functioning. But the neurodiversity movement shows that autism is also an experience, and a rich one. Through activism, the Internet, and art, autistic people are adapting to, resisting, and transforming the social practices and institutions that

358. Caruso, *supra* note 22, at 487 (footnotes omitted) (citing STUART MURRAY, REPRESENTING AUTISM: CULTURE, NARRATIVE, FASCINATION 212 (2008)).

classify them; they are constructing autism. Although this understanding of impairment as both pathology and experience does not make peace between autism's sides, it does help to explain *how* the sides are at odds and why they are likely to stay that way.

