

2010

Autism in the US: Social Movement and Legal Change

Daniela Caruso

Boston University School of Law

Follow this and additional works at: https://scholarship.law.bu.edu/faculty_scholarship



Part of the [Education Law Commons](#)

Recommended Citation

Daniela Caruso, *Autism in the US: Social Movement and Legal Change*, 36 *American Journal of Law and Medicine* (2010).

Available at: https://scholarship.law.bu.edu/faculty_scholarship/571

This Article is brought to you for free and open access by Scholarly Commons at Boston University School of Law. It has been accepted for inclusion in Faculty Scholarship by an authorized administrator of Scholarly Commons at Boston University School of Law. For more information, please contact lawlessa@bu.edu.



**AUTISM IN THE US:
SOCIAL MOVEMENT AND LEGAL CHANGE**

36 American Journal of Law and Medicine__ (2010)

Boston University School of Law Working Paper No. 10-07

(March 23, 2010)

Revision of June 1, 2010

Daniela Caruso

This paper can be downloaded without charge at:

<http://www.bu.edu/law/faculty/scholarship/workingpapers/2010.html>

DANIELA CARUSO*

AUTISM IN THE US:

SOCIAL MOVEMENT AND LEGAL CHANGE

36 AMERICAN JOURNAL OF LAW AND MEDICINE __ (2010)

Abstract - The social movement surrounding autism in the US has been rightly defined a ray of light in the history of social progress. The movement is inspired by a true understanding of neuro-diversity and is capable of bringing about desirable change in political discourse. At several points along the way, however, the legal reforms prompted by the autism movement have been grafted onto preexisting patterns of inequality in the allocation of welfare, education, and medical services. In a context most recently complicated by economic recession, autism-driven change bears the mark of political and legal fragmentation. Distributively, it yields ambivalent results that have not yet received systemic attention. This article aims to fill this analytical vacuum by offering, first, a synoptic view of the several legal transformations brought about or advocated for by the autism movement and, second, a framework for investigating their distributive consequences.

* Professor of Law, Boston University. Thanks for insights and comments to Bill Alford, George Annas, Paulo Barrozo, Glen Cohen, Kris Collins, Fengming Cui, Michael Harper, Allison Hoffman, Duncan Kennedy, Pnina Lahav, Gillian Lester, Linda McClain, Silvio Micali, Fran Miller, Martha Minow, Abby Moncrieff, Maureen O'Rourke, Kevin Outterson, Vlad Perju, Chris Robertson, Sarah Robinson, David Rossman, Talha Sayed, Miguel Schor, Kate Silbaugh, Ken Simons, Michael Stein, Helen Tager-Flusberg, Katie Young, students and guest-lecturers in the inter-disciplinary seminar "Autism and Society" (Boston University, Spring 2009), participants in faculty workshops at the law schools of Boston University and Suffolk University, in a workshop of the Harvard Project on Disabilities, and in the conference *Autism: Science, Law & Public Policy* (Boston University, Spring 2009). Thanks to Aaron Schue, Daniel Devoe, Hannah Lubin, Joan Bennett, Patrick Jiang and Caroline Bruno for excellent research assistance. This work, ever in progress, is dedicated to my children, one of whom has a diagnosis of autism. Errors are mine.

I. INTRODUCTION

II. AUTISM AND SOCIAL MOVEMENT.....

 A. DEFINING AND COUNTING.....

 B. IMAGES OF AUTISM

 C. EVOLUTION AND SPLINTERING

 D. AUTISM AND DISABILITY DISCOURSE

III. JUDICIAL DISCOURSE: CONFLICT MANAGEMENT AND AFFIRMATION

 A. THE OMNIBUS AUTISM PROCEEDING

 B. CRIME AND AUTISM

 1. EMPATHY AND MORAL AGENCY.....

 2. AUTISM AS IDENTITY

 C. AUTISM AND EMPLOYMENT DISCRIMINATION.....

IV. THE QUEST FOR TREATMENT AND LEGAL CHANGE.....

 A. EDUCATION.....

 1. LITIGATING AUTISM IN SCHOOL.....

 2. SCHOOL LITIGATION AND THE PROBLEM OF DISTRIBUTIVE EQUITY

 3. AUTISM AND VOUCHERS

 4. NORMALIZATION.....

 B. THE HEALTH SECTOR

 1. ABA REIMBURSEMENT CLAIMS IN COURT

 2. MANDATED BENEFITS.....

 3. MEDICAID AND RECESSION

 4. RETRENCHING

V. AN INTERIM ASSESSMENT

I. INTRODUCTION

A 1950s masterpiece of science fiction — *The Invasion of the Body Snatchers* — tells the unsettling story of a town occupied by aliens.¹ Due to mysterious forces, androids take the place of real human beings.² Semblances are identical, but souls are gone. In the last and most terrifying scene of the movie, the main character realizes that his girlfriend – his only companion in the desperate struggle to repel the invaders – is also gone.³ In her place is left an equally beautiful woman, whose eyes look elsewhere and whose voice is distant. The scene depicts solitude at its deepest.

Until recently, autism prompted similarly tragic feelings.⁴ The diagnosis of an autism spectrum disorder meant that your baby, the person with whom you expected to have the closest possible connection in this world, would never understand why you were crying.⁵ The impossibility of emotional bonding, understood as central to the diagnosis,

¹ *INVASION OF THE BODY SNATCHERS* (Walter Wanger Productions 1956).

² *Id.*

³ *Id.*

⁴ See STUART MURRAY, REPRESENTING AUTISM: CULTURE, NARRATIVE, FASCINATION 209 (2008). “Like cancer, autism is often seen as a remorseless attacker of innocents, a destroyer of lives and families.” *Id.* See also SUSAN SONTAG, *ILLNESS AS METAPHOR* (1978), reprinted in SUSAN SONTAG, *ILLNESS AS METAPHOR AND AIDS AND ITS METAPHORS* 3, at 68 (1990). Sontag refers to the movie “*Invasion of the Body Snatchers*” to describe, critically, a common image of cancer in the 1970s. *Id.*

⁵ The fourth edition of the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders (DSM-IV), now under revision, listed among the marks of autism a “lack of ... emotional reciprocity,” *id.* at 20. See also Michael E. Waterstone & Michael Ashley Stein, *Disabling Prejudice*, 102 NW. U. L. REV. 1351, 1352 (2008) (reporting, critically, an instance of the common assumption that people with autism do not feel).

made it so heart-wrenching as to evoke science-fictional scenarios: alien invasions and snatched bodies.⁶

Advances in psychiatric science are proving such analogies misguided.⁷ Autism, while affecting one's ability to understand others' viewpoints,⁸ leaves ample room for shared emotions.⁹ Accordingly, many commentators have opposed the portrayal of autism as a catastrophe¹⁰ or as a condition that is not fully human.¹¹ But the metaphor of

⁶ ROY RICHARD GRINKER, *UNSTRANGE MINDS: REMAPPING THE WORLD OF AUTISM* 5 (2007) (noting that the talk of an "autism epidemic" "implies danger and incites fear, calling up associations with plagues that can sweep through the streets . . . threatening the ones you love. With autism, the label of "epidemic" sounds both frightening and tragic.").

⁷ The fifth edition of the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders (DSM), currently in draft form, refers to "lack of social reciprocity" but no longer lists deficits in "emotional reciprocity" among the diagnostic criteria for autism. DSM-5 Proposed Revisions, 299.00 Autistic Disorder, <http://www.dsm5.org/ProposedRevisions/Pages/proposedrevision.aspx?rid=94>.

⁸ A prevailing theory of the primary deficits of autism is the "Theory of Mind" thesis, which holds that autism results in a failure to recognize intentional states of others. See DEBORAH R. BARNBAUM, *THE ETHICS OF AUTISM: AMONG THEM, BUT NOT OF THEM* 19, 21 (2008).

⁹ Jim Sinclair, *Don't Mourn for Us*, OUR VOICE (Autism Network Int'l, Syracuse, N.Y.), 1993, available at <http://www.autistics.org/library/dontmourn.html>. "[T]he child doesn't respond in any way you can recognize as being part of [your] system. That does not mean the child is incapable of relating at all. It only means you're assuming a shared system, a shared understanding of signals and meanings, that the child in fact does not share." *Id.*

¹⁰ Michelle Dawson, *The Many Varieties of Being Written Off: An Argument About Autism As Catastrophe*, NO AUTISTICS ALLOWED: EXPLORATIONS IN DISCRIMINATION AGAINST AUTISTICS, http://www.sentex.net/%7Enexus23/naa_wro.html. Ms. Dawson was one of the interveners in the case *Auton v. British Columbia* [2004] 3 S.C.R. 657, 2004 SCC 78 (Can.), [2004] S.C.J. No. 71 QUICKLAW (Nov. 18, 2004).

¹¹ See, e.g., the protests launched by the Autistic Self Advocacy Network (ASAN) against the "ransom notes" of the NYU Child Study Center in 2007, <http://www.autisticadvocacy.org/modules/smartsection/item.php?itemid=21>. See also Claudia Wallis, *I Am Autism: An Advocacy Video Sparks Protest*, TIME, Nov. 6, 2009 (discussing analogous protests launched against a video produced for Autism Speaks by Billy Mann and Alfonso Cuarón in 2009).

alien invasion has an enduring grip on collective consciousness¹² and survives in popular accounts as well as personal narratives.¹³

Tragic tropes are not the only source of autism's importance in public discourse. In contrast to the image of invasion is another, equally important picture, which is utterly peaceful and inspiring. In his pioneering work, Austrian psychiatrist Leo Kanner gave an aesthetic dimension to the diagnosis of autism by noticing how beautiful his patients often were.¹⁴ His casual remarks originated the belief that beauty, talent for music, and graceful movements were normal complements to the autistic child's fascination with himself.¹⁵ Autism is also quite prevalent in Silicon Valley, and according to some it runs in families of great musicians and mathematicians.¹⁶ Part of its appeal rests upon the belief that it is home to genius, and that each of us would benefit from having bits of it – extraordinary ability to focus, untrammelled concentration, or perception of patterns that escape everyone else. In this light, autism sits comfortably on a spectrum that comprises

¹² Ian Hacking, *Humans, Aliens & Autism*, 138 DAEDALUS 44 (2009) (recalling that “[a] nasty variant [of the alien trope] was used in a disturbing autism awareness sound bite given wide distribution a couple of years ago by the advocacy group CAN: Cure Autism Now. 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.” This is the ancient myth of the changeling, the troll child substituted in the dead of night for an infant sleeping in his cot at home.”).

¹³ Parents often reported that their children seemed to be thriving until age 18-24 months. Then, they became withdrawn, unhappy, often non-verbal, and “slipped away.” See, e.g., Helia Garrido Hull, *Induced Autism*, 34 CAP. U. L. REV. 1 (2005) (describing the experience of regressive autism as follows: “[T]he little angel was quickly slipping into the darkness of his own deteriorating ability to communicate . . .”).

¹⁴ Leo Kanner, *Autistic Disturbances of Affective Contact*, in 2 NERVOUS CHILD, 217-50 (1943), reprinted in CHILDHOOD PSYCHOSIS: INITIAL STUDIES AND NEW INSIGHTS (Leo Kanner ed., 1973).

¹⁵ Emilio Rodrigué, *The Analysis of a Three-Year-Old Mute Schizophrenic* (1952) in NEW DIRECTIONS IN PSYCHOANALYSIS: THE SIGNIFICANCE OF INFANT CONFLICT IN THE PATTERN OF ADULT BEHAVIOR 140, 178 (Melanie Klein et al. eds., 2003) (noting that “[t]he autistic child, like Narcissus, is beautiful.”). The overlap of beauty and disability is a remarkable prerogative of autism discourse. Cf. SUSAN SCHWEIK, *THE UGLY LAWS: DISABILITY IN PUBLIC* (2009) (discussing laws enacted with the explicit purpose of keeping disability out of sight).

¹⁶ Arthur Kaplan, *Would You Have Allowed Bill Gates To Be Born?* MSNBC, May 31, 2005 <http://www.msnbc.msn.com/id/7899821>.

the entire human condition, not just a subset of it. It replaces the old and ugly label of mental retardation with something that is both terrifying and terrific – a mental condition that is incapacitating and yet flirts irresistibly with genius.¹⁷

Susan Sontag argues effectively that metaphors may vilify suffering and ultimately impede a rational, purposeful approach to the reality of pathology.¹⁸ On the other hand, Sontag herself lays the ground for understanding the tremendous cognitive salience of metaphors, and the massive mobilization of resources that images of illness may prompt.¹⁹ Autism's unusual combination of conceptually opposite but equally powerful images – terror and innocence, incapacity and genius, handicap and excellence – has already impacted the legal system in multiple ways and is likely to do more so in the coming decades.

Autism is transforming the way we think about disability; it is affecting the balance between medical insurance coverage and educational services; it is creating new markets that beg for regulatory intervention; it is challenging traditional assumptions about retribution and punishment; it is prompting a massive investment of public and private resources; it is changing the aesthetics of suffering, and in so doing, it is rearranging legislative priorities. These pages are devoted, in the first place, to setting the stage for studying this phenomenon. And if indeed it is the case that autism has warped law as we have known it, then it is time to ask what the law of autism reveals about the

¹⁷ MURRAY, *supra* note 4, at 65. The movie RAIN MAN (GUBER/PETERS CO. 1988) put great emphasis on the savant qualities of its main character.

¹⁸ SONTAG, *supra* note 4, at 68.

¹⁹ SONTAG, *supra* note 4, at 103-04. In the first chapter of AIDS AND ITS METAPHORS, Sontag acknowledges that her earlier predictions about the negative impact of breast cancer metaphors did not materialize. *Id.* at 103.

nature of our legal system as a whole. Changes have been occurring in multiple and often unrelated sectors of the legal system, prompted at times by collective deliberation and, at other times, by mere political contingencies. The field needs mapping, cross-references and conceptualization.²⁰ What follows is in the first place an attempt to correct the fragmentation of the autism picture by bringing together its many pieces.

A further goal of this essay is to focus on the distributive implications of granting autism special recognition at law. From the viewpoint of Richard Roy Grinker, anthropologist and parent of a child with autism, the story of autism in the US legal system at the dawn of the new millennium is one of great egalitarian momentum. In his view,

the newer, higher, more accurate statistics on autism are a sign that we are finally seeing and appreciating a kind of human difference that we once turned away from[.] The result of the new rates is that we are fortunately seeing more research, more philanthropy, and more understanding of how families struggle to cope.²¹

In the same vein, philosopher Ian Hacking refers to the increasing integration of autistic people in society as “a very substantial human achievement” and asserts that “the social history of this progress is a promising tale of hard work, a ray of light.”²²

Indeed, at several points in the following pages, we shall see how autism lends strength to truly progressive claims, directing resources to the neediest pockets of our

²⁰ The law of autism might seem to mirror the law of the horse – an unnecessary effort to bring together unrelated and duly self-contained bodies of law. See Karl N. Llewellyn, *Across Sales on Horseback*, 52 HARV. L. REV. 725 (1939). Autism, however, is not just another quadruped in Llewellyn’s world, and is already, for better or for worse, prompting system-wide legal changes, calling for panoramic investigation.

²¹ GRINKER, *supra* note 6, at 5. It is often the case that “social movements in health” target “health and inequality based on race, ethnicity [and] class.” See Phil Brown and Stephen Zavetoski, *Social Movement in Health: An Introduction*, SOCIAL MOVEMENTS IN HEALTH 1 (2004).

²² Hacking, *supra* note 12, at 45.

society. Advocates' tireless quest for pediatric screening, aimed at identifying developmental disabilities as early as possible in children of all social backgrounds, is a most vivid instantiation of the movement's redistributive strength.²³ At a more general level, autism can be credited with a veritable advancement in the understanding of difference.²⁴ 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.²⁵ The post-modern concept of neuro-diversity, with its promise of inclusion and its philosophical acceptance of variation, may find in autism a perfect home. This is indeed a ray of light.

But a comprehensive reading of the "social history of this progress" reveals a more nuanced and multi-layered scenario – one in which the body of policy-making generated by the autism movement oscillates uncomfortably, at times pursuing broader redistributive objectives, and at other times retrenching by necessity behind narrower advocacy goals. Some of the socio-legal transformations advocated for by the movement are symptoms of a higher commitment to inclusion of traditionally marginalized individuals and groups. Other changes fail to yield adequate redistribution even within

²³ The impetus for generalized early screening for developmental disabilities is to be found in the Children's Health Act of 2006, Public Law 106-310, 42 USC Title I, Section 102, in itself a product of autism advocacy (*see infra*, fn 63 and corresponding text).

²⁴ MURRAY, *supra* note 4, at 212. *See also*, Elizabeth F. Emens, *Integrating Accommodation*, 156 U. PA. L. REV. 839 (2008) (discussing more generally the "third-party benefits" that may result from the accommodation of disabilities in education and at work).

²⁵ *See Genius Locus: Autism and Extraordinary Ability*, ECONOMIST, Apr. 16 2009.

the pool of children on the autism spectrum. Autism's call for difficult policy choices and intelligent allocation of finite resources bears the marks of this distributive ambiguity.

Towards the dual goal of this article – mapping autism onto the legal system and highlighting the distributive implications of autism-driven changes in law and policy, — Part II analyzes the birth and growth of the autism social movement, investigates the reasons for its relative success, and explores its internal dynamics. Part III analyzes conflicts among the various strands of the movements through the lens of judicial opinions in matters of torts, crimes, and ADA claims. The discussion of a few recent cases is meant to highlight the role played by courts in reinforcing the visibility of the movement and in articulating its often conflicting goals.

Part IV delves into the fields of education law and health care reform – both politically hot terrains where the battle for autism-specific benefits is being fought. Here, the autism movement interacts with underlying political dynamics and is significantly affected by market forces. I track the particular flow of money generated by the phenomenology of autism in the US, including funding of research and treatment, investment in special education, legislative regulation of health insurance, and market responses to the rise of autism rates.

Part V provides an assessment of the legal and judicial developments surveyed in Parts II to IV, commenting on ongoing policy shifts and on the trends which the autism movement is setting in motion or simply reinforcing. These pages offer no single policy proposal, no univocal solution to the distributive dilemmas raised by autism in matters of education, health, and welfare law, research funding, and societal inclusion of diversity.

This is rather a plea for a broader and deeper reflection on the legal and political meaning of autism advocacy. Autism is here to stay for the medium or long term, and if we fail to understand the way it marbles our legal system, we will ultimately hurt its cause. Without panoramic analysis, autism may fall prey to the cycle of embrace and rejection that has historically characterized the American approach to mental illness.²⁶ It may become, at best, an area of true care and understanding, but one that nests distributive inequalities among individuals with autism, or that legitimizes the neglect of other miseries. Dissecting the “ray of light” and critically exploring its reach may be the only way to keep it shining.

II. AUTISM AND SOCIAL MOVEMENT

This Part sketches the story of the autism movement with an eye to its impact on law making, both in court and in the legislative arena.²⁷ Autism emerged as a distinct psychiatric phenomenon in the 1940s and has since acquired much cognitive salience.²⁸ The movement’s growth into an established center of advocacy has brought about its splintering into sub-groups, each marked by a distinct agenda. Unsurprisingly, courts have been vehicles of articulation for such multiple viewpoints and, by giving them voice, have prevented their splintering away from the movement.

²⁶ See Robert A. Burt, *Promises to Keep, Miles to Go: Mental Health Law Since 1972*, in THE EVOLUTION OF MENTAL HEALTH LAW 11, 18 (Lynda E. Frost & Richard J. Bonnie eds., 2001) (discussing “historical cycles of public attention”).

²⁷ See Irene Barnett & Trudy Steuernagel, *U.S. Health Social Movements and Public Policy: Autism and Alzheimer’s Disease* (2007), available at www.allacademic.com/meta/p198556_index.html, for a comparison of the autism social movement and analogous forms of political mobilization around Alzheimer’s disease.

²⁸ Christine Jolls et al., *A Behavioral Approach to Law and Economics*, 50 STAN. L. REV. 1471, 1518-19 (1998) (discussing cognitive salience and law).

A. Defining and Counting

An article written by Dr. Leo Kanner of the Johns Hopkins Hospital in 1943 marks the birth of autism in the world of psychiatry.²⁹ Kanner used the label ‘infantile autism’ to describe an unusual psychiatric syndrome, characterized by an inability to relate to people, a failure to develop speech or an abnormal use of language, deviant responses to environmental objects and events, excellent rote memory, and an obsession with repetition and sameness.³⁰

Hans Asperger, like Kanner, was born in Austria and wrote his seminal contribution to the understanding of autism spectrum disorders in the mid 1940s.³¹ His take on autism, however, was different. He focused on the most high-functioning end of the spectrum and observed that certain individuals, while lacking common intuition, empathy, and flexibility, were capable of turning their difficulties into gifts, their obsessions into skills, and their perseveration into talent. Asperger’s work, written in German, remained unknown to most for several decades, but was translated into English in the early 1990s and quickly gained popularity among autism researchers and activists.³²

²⁹ Kanner, *supra* note 14. Swiss psychiatrist Eugen Bleuler had coined the term “autism” in 1910 to indicate a characteristic of patients with schizophrenia. EDWARD SHORTER, *THE HISTORICAL DICTIONARY OF PSYCHIATRY* 34 (2005).

³⁰ D. V. M. Bishop, *Autism, Asperger's Syndrome and Semantic-Pragmatic Disorder: Where Are the Boundaries?* BRIT. J. DISORDERS COMM. 24, 107-21 (1989).

³¹ Hans Asperger, ‘*Autistic Psychopathy*’ in *Childhood* (published in 1944 in German and translated into English by Uta Frith in 1991 in *AUTISM AND ASPERGER SYNDROME* 37, Uta Frith ed., 1991).

³² In the English literature on the subject, Lorna Wing from the Institute of Psychiatry in London was the first to use and divulge the term “Asperger's syndrome.” See Lorna Wing, *Asperger Syndrome: A Clinical Account*, 11 PSYCHOL. MED. 115-29 (1981), available at <http://www.mugsy.org/wing2.htm>.

Not everyone agrees that autism and Asperger's syndrome are manifestations of the same pathology (differing in degree but not in substance).³³ While severe autism is completely incapacitating, individuals with Asperger's syndrome can be well integrated in their community, and oftentimes make fundamental contributions in their professional fields. Post-mortem diagnoses are doubtful, but Albert Einstein's life story, which begins with tales of delayed speech and abysmal performance at school, suggests that the most accomplished scientist of all time might have suffered from Asperger-like symptoms.³⁴ Yet, severe autism and Asperger's syndrome remain closely linked in popular and political discourse, and scientists are increasingly inclined to subsume both under a common spectrum of disorders (ASD).³⁵ The figures illustrating both incidence and prevalence of autism are alarming. Whether or not autism qualifies as an epidemic,³⁶ numbers are unsettling: today, one in 110 children in the US have a diagnosis of ASD.³⁷

Such figures, however, are aggregate, while a diagnosis of autism can mean a number of different things. Autism is an undefined and variable cluster of multiple

³³ David G. Amaral et al., *Neuroanatomy of Autism*, 3 TRENDS NEUROSCI. 137 (2008) "Autism is a heterogeneous disorder with multiple cause and courses, a great range in the severity of symptoms, and several associated co-morbid disorders. Increasingly, researchers refer to 'the autisms' rather than a simple autism phenotype." *Id.*

³⁴ See generally DON BROWN, ODD BOY OUT: YOUNG ALBERT EINSTEIN (2004).

³⁵ The current version of the DSM (*supra* note 5), is currently undergoing revision and will ultimately be replaced by the DSM-V. See www.DSM5.org. It is possible that Asperger's syndrome will no longer be a separate label and that autism spectrum disorders will remain the only overarching diagnosis. See Susan Swedo, *Report of the DSM-V Neurodevelopmental Disorders Work Group*, available at <http://www.psych.org/MainMenu/Research/DSMIV/DSMV/DSMRevisionActivities/DSM-V-Work-Group-Reports/Neurodevelopmental-Disorders-Work-Group-Report.aspx>.

³⁶ Ka-Yuet Liu et al., *Social Influence and the Autism Epidemic*, 115 AM. J. SCI. 1387 (2010) (providing an up-to-date discussion of the debate around the epidemic proportions of autism.) According to a recent study of the Centers for Disease Control, "Although improved ascertainment accounts for some of the prevalence increases documented in the ADDM sites, a true increase in the risk for children to develop ASD symptoms cannot be ruled out." Centers for Disease Control and Prevention, *MMWR Surveillance Summaries, Prevalence of Autism Spectrum Disorders*, December 18, 2009, available at <http://www.cdc.gov/mmwr/preview/mmwrhtml/ss5810a1.htm>.

³⁷ *Id.*

symptoms: cognitive, communicative, and sensory.³⁸ Individuals identified as autistic may suffer acutely from some symptoms and mildly from others, so that it is very hard to know where to place them along the spectrum. The movement draws strength from all camps, including those of parents who have been waiting for years for their children's first words, and those who demand extra care for their socially impaired adolescents.

Gauging the relative prevalence of autism in any given race is also a difficult task.³⁹ There is no blood test or genetic marker for autism,⁴⁰ and diagnoses are based only on neuro-psychological tests and clinical observations. Defining a person as more or less neuro-typical is a function of both lay and medical culture, and cultural variations are so extreme as to escape modeling.⁴¹ The shape and structure of the autism movement are heavily impacted by the still nebulous and impressionistic definition of autistic disorders.

B. Evolution of the Movement

Kanner's 'discovery' became an object of great interest for psychoanalysts. Kanner's work blamed "refrigerator mothers" – women incapable of bonding with their

³⁸ See DSM-IV, *supra* note 5, Diagnostic Criteria for 299.00 Autistic Disorder. The Centers for Disease Control (CDC) website excerpts the relevant criteria. *Autism Spectrum Disorders*, CDC, <http://www.cdc.gov/ncbddd/autism/hcp-dsm.html>. See also <http://www.dsm5.org/ProposedRevisions/Pages/proposedrevision.aspx?rid=94>.

³⁹ See *Prevalence of Autism Spectrum Disorders – Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2006*, MMWR SURVEILLANCE SUMMARIES, Dec. 18, 2009, available at <http://www.cdc.gov/mmWR/preview/mmwrhtml/ss5810a1.htm>. The study reveals that Black and Hispanic children were less likely to be identified as having ASD in 2006, but variations may be due to later and fewer diagnoses of ASD in children of ethnic minorities. See Catherine Lord and Somer L. Bishop, *Autism Spectrum Disorders: Diagnosis, Prevalence, and Services for Children and Families*, 24 SOC. POL'Y REP. 9 (2010).

⁴⁰ Liu, *supra* note 36, at 1387 ("As there are no definitive biological markers for the vast majority of cases, diagnosis relies on the recognition of a range of behavioral symptoms that vary greatly from case to case[.]")

⁴¹ See David S. Mandell et al., *Racial/Ethnic Disparities in the Identification of Children with Autism Spectrum Disorders*, 99 AM. J. PUB. HEALTH 493 (2009).

babies and teaching them the basics of empathy.⁴² Through the later work of child psychologist Bruno Bettelheim, Kanner's theory became popular and remained unchallenged through the mid-60s.⁴³ Another reading of the syndrome came from the myth of Narcissus, used in psychology to describe self-absorbed personalities whose overgrown egos interfere with relational abilities.⁴⁴ This approach did not emphasize poor parenting, but it did continue to analyze autism within the boundaries of psychoanalysis. It was only in 1964 that Bernard Rimland put forth an alternative explanation of the syndrome, based not on psychodynamics but rather on neurobiology.⁴⁵ In 1965, Rimland founded the American Society for Autism (ASA) which is, to this day, a major center of advocacy.

Following Rimland's work, activism in the name of autism began to flourish thanks to both grassroots efforts and power houses. Some groups – most visibly Cure Autism Now (CAN) and the National Alliance for Autism Research (NAAR) – coalesced around genetic research and investigation of toxic substances potentially related to the surge of autism.⁴⁶ It is no coincidence that such movements emerged in a context of

⁴² BRYAN JEPSON & JANE JOHNSON, CHANGING THE COURSE OF AUTISM: A SCIENTIFIC APPROACH FOR PARENTS AND PHYSICIANS 11-17 (2007) (describing Kanner's theory and its development).

⁴³ BRUNO BETTELHEIM, THE EMPTY FORTRESS: INFANTILE AUTISM AND THE BIRTH OF THE SELF (1967).

⁴⁴ Rodrigué, *supra* note 15, at 178.

⁴⁵ BERNARD RIMLAND, INFANTILE AUTISM: THE SYNDROME AND ITS IMPLICATION FOR A NEURAL THEORY OF BEHAVIOR (1964).

⁴⁶ See *NBC Nightly News: Meet Founders of "Cure Autism Now"* (NBC television broadcast Feb. 22, 2005), available at <http://www.autismspeaks.org/video/index.php>, under "Meet Founders of 'Cure Autism Now'" (describing the rise from grassroots to a full-blown organization). CAN started the Autism Genetic Resource Exchange (AGRE), <http://www.agre.org/>. NAAR spearheaded the Autism Genome Project. <http://www.autismspeaks.org/docs/agp1a.pdf>. Both initiatives are now subsumed under the umbrella of Autism Speaks activities.

burgeoning environmental activism.⁴⁷ Many other capillary initiatives focused instead on the reality of living with autism by developing information centers for parents of newly diagnosed children, and starting awareness campaigns aimed at educating the public about this poorly-understood phenomenon.⁴⁸

Today, the core of the autism movement is characterized by the presence of large organizations such as Autism Society of America (ASA) and Autism Speaks.⁴⁹ The former retains with pride its ‘senior’ status.⁵⁰ The latter, Autism Speaks, was founded in 2005 and later merged with both Cure Autism Now (CAN) and the National Alliance for Autism Research (NAAR) to become “the nation’s largest autism advocacy organization.”⁵¹ Within Autism Speaks, divergences have arisen around the issue of vaccines-related research.⁵² As the organization leans towards supporting further

⁴⁷ See, e.g., Paul B. Sears, *Ecology: A Subversive Subject*, 14 *BIOSCIENCE* 11 (1964) (laying the groundwork for the environmental social movement that would take off in the 1970s).

⁴⁸ One especially important effect of the awareness campaign is that police and medical emergency responders are increasingly being trained to deal with persons with autism in order to prevent possibly fatal misunderstandings. See Elizabeth Hervey Osborn, *What Happened to "Paul's Law"?: Insights on Advocating for Better Training and Better Outcomes in Encounters Between Law Enforcement and Persons with Autism Spectrum Disorders*, 79 *U. COLO. L. REV.* 333 (2008).

⁴⁹ ASA and Autism Speaks are the two centers of autism activism that the Combat Autism Act of 2006 lists as members of the Interagency Autism Coordinating Committee. CAA 2006, § 399 CC., 42 U.S.C. § 280i-2. The Committee is entrusted with the task of coordinating all efforts within the Department of Human Health Services concerning autism spectrum disorders. *Id.*

⁵⁰ Carin Yavorcik, *ASA and Kirkman Honor Dr. Bernard Rimland with a Memorial Challenge*, *AUTISM SOCIETY*, Nov. 19, 2007, <http://www.autism-society.org/site/News2?page=NewsArticle&id=9943> (last visited Feb. 22, 2010) (reminding us that Bernard Rimland “was among the first to realize the importance of combining a focus on medical interventions with support services and advocacy, inspiring him to found ASA.”).

⁵¹ *Autism Speaks Launches National University Program*, *AUTISM SPEAKS*, Oct. 9, 2008, http://www.autismspeaks.org/press/autism_speaksu_launched.php (last visited May 24, 2010).

⁵² In 2007 Bob and Suzanne Wright, the founders of Autism Speaks, did not subscribe to the vaccine theory of causation, while their daughter Katie (mother of their autistic grandson Christian) did. See Jane Gross & Stephanie Strom, *Autism Debate Strains a Family and Its Charity*, *N.Y. TIMES*, June 18, 2007.

investigation of this issue, other groups take distance from it and promote markedly different lines of scientific queries.⁵³

The strategy of Autism Speaks is one of broad information and mobilization.⁵⁴ Walks for autism, organized both nationally and locally, help generate awareness, and also bring meaningful subsidies to the cause. Until recently, funding for autism lagged behind when compared to other disabling conditions.⁵⁵ Today, donations to the cause are pouring in, and several celebrities are involved in very effective fund-raising.⁵⁶ Predictably, “political contingency and the vagaries of fashion” also contribute to the relative success of the autism movement.⁵⁷ The fact that media moguls have become personally involved in autism matters certainly has helped the cause.⁵⁸ The movement, once peripheral and radical in tone, has now espoused stable organizational models and achieved main-stream status.⁵⁹

⁵³ See, e.g., Autism Science Foundation (ASF) (co-founded in April 2009 by Alison Singer, formerly executive vice president of communications and awareness at Autism Speaks). Eric London, who had founded NAAR, now serves on the science advisory board of ASF. *See* <http://www.autismsciencefoundation.org/>; *See* also the independent work of the Simons Foundation Autism Research Initiative, <https://sfari.org/>.

⁵⁴ *See About Us*, Autism Speaks, http://www.autismspeaks.org/about_us.php (outlining Autism Speaks’ activities).

⁵⁵ In 2005, the privately raised budget for research in matters of muscular dystrophy, leukemia, and child diabetes (conditions whose incidence is much less alarming) totaled \$500 million, while only \$15 million were devoted to autism research. See graph at min. 5:38 of the video *Suzanne and Bob Wright: Autism Speaks*, on *Today Show* (NBC television broadcast Feb. 25, 2005) available at <http://www.autismspeaks.org/video/index.php>.

⁵⁶ In February 2010, Sumner Redstone donated \$1 million to Autism Speaks. Celebrities who have brought attention to autism include Sylvester Stallone, Jenny McCarthy (founder of the organization Generation Rescue), Jim Carey, Joe Mantegna, Brad Whitford, Dan Marino, and Doug Flutie. “In the US in particular, the power of celebrity has become vital in drawing attention to the condition.” MURRAY, *supra* note 4, at 134.

⁵⁷ STANLEY COHEN, *STATES OF DENIAL* 171 (2001).

⁵⁸ Bob Wright, co-founder of Autism Speaks, used to be chairman of NBC Universal.

⁵⁹ A chief lobbyist for Autism Speaks, Craig Snyder, used to be chief of staff to Pennsylvania Senator Arlen Specter. *See* Alex Wayne, *Spending Surge on Autism Outpaces Understanding*, CONG. Q. WKLY., Dec. 16, 2007; *see also* Dana Lee Baker & Trudy Steuernagel, *Comparative Policy Entrepreneurship: The Case of Autism Related Policy in North America*, 11 J. COMP. POL’Y ANALYSIS 233, 240 (2009). “To date, most

Most recently, autism has adopted the language of civil rights.⁶⁰ Rhetorically, the move functions to link the autism movement to an old tradition of political activism, aimed at granting oppressed minorities legal status and entitlements.⁶¹ The goal is then one of resource mobilization, which requires working “side by side – sometimes in competition, sometimes in collaboration, with traditional political institutions.”⁶²

Steeped in economic utility and rights discourse, the movement has been able to make important strides in matters of federal funding for research and treatment options. The Children’s Health Act of 2000 (Health Act),⁶³ its first tangible victory at the federal level, directed federal agencies to undertake a long-term national study of children’s health and development as related to environmental exposures. The Health Act explicitly identified autism as a major target of research;⁶⁴ CAN’s advocacy was instrumental to its passage.⁶⁵ The 2006 Combating Autism Act (CAA) was an even more momentous

federal autism policy in the United States has been a product of the relationship between Congress and advocacy groups with policy entrepreneurs as catalysts.” *Id.* This bureaucratic progression of social movements into social movement organizations (SMOs) is a well-known phenomenon. *See* Eduardo Canel, *New Social Movement Theory and Resource Mobilization Theory: The Need for Integration*, in *COMMUNITY POWER AND GRASSROOTS DEMOCRACY: THE TRANSFORMATION OF SOCIAL LIFE* 189 (Michael Kaufman & Haroldo Dilla Alfonso eds., 1997).

⁶⁰ *See* Vanda Marie Khadem, Esq., Autism Higher Education Foundation, <http://www.autismhighereducationfoundation.org/board-of-directors/vanda-marie-khadem-esq/> (explaining that “[t]he lack of lifelong learning opportunities for individuals with autism is a civil rights issue and the next frontier in human rights which demands immediate redress.”).

⁶¹ Martha Minow, *Interpreting Rights: An Essay for Robert Cover*, 96 *YALE L.J.* 1860 (1987); LAURA SCHREIBMAN, *THE SCIENCE AND FICTION OF AUTISM* 258-59 (2005) (noting that “there is no rational ‘con’ argument against the civil rights of [autistic] children.”).

⁶² *See* Canel, *supra* note 59. More than social movement theory, resource mobilization theory emphasizes groups’ strategic and instrumental alliances with political forces, and is therefore better suited to deciphering the dynamics of autism activism. *See* *Editors’ Introduction*, *COMPARATIVE PERSPECTIVES ON SOCIAL MOVEMENTS: POLITICAL OPPORTUNITIES, MOBILIZING STRUCTURES, AND CULTURAL FRAMINGS* 1 (Doug McAdam et al. eds., 1996).

⁶³ Public Law 106-310 Sec. 1004 (2000).

⁶⁴ *Id.*, Division A, Title I.

⁶⁵ *See* Barnett & Steuernagel, *supra* note 27, at 12.

achievement⁶⁶ as it focused on autism only. The CAA provided for approximately \$950 million in spending on autism over five years, divided among research and other programs, and was subsequently funded accordingly.⁶⁷ The new administration is on the same track. 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.⁶⁸ In addition, the US Department of Defense has established its own Autism Research Program.⁶⁹ The involvement of the Department of Defense curiously highlights the military emergency mode that pervades the dominant strand of the autism social movement. The force of the autism movement is, in relative terms, remarkable.⁷⁰

C. Splintering and Cohesion

⁶⁶ Combat Autism Act, Pub. Law No. 109-416, 120 Stat. 2821 (2006).

⁶⁷ *President Signs CAA Funding, AUTISM SPEAKS*, http://www.autismspeaks.org/government_affairs/president_signs_caa_funding.php (last visited May 24, 2010). Signed by President Bush in December 2007, the Fiscal 2008 Omnibus Appropriations Act provided for an annual spending of approximately \$162 million, of which approximately \$108.5 million was to be devoted to NIH-funded autism research. *Id.*

⁶⁸ See http://www.aaas.org/news/releases/2010/0318rd_clemins_briefing.shtml.

HHS Secretary Kathleen Sebelius's press release of February 1st, 2010 on the President's Fiscal Year 2011 Budget included the following statement:

There is a \$222 million, an increase of \$16 million, included in the Budget to address Autism Spectrum Disorders (ASD). NIH research will pursue comprehensive and innovative approaches to defining the genetic and environmental factors that contribute to ASD, investigate epigenetic changes in the brain, and accelerate clinical trials of novel pharmacological and behavioral interventions. CDC will expand autism monitoring and surveillance and support an autism awareness campaign. HRSA will increase resources to support children and families affected by ASD through screening programs and evidence-based interventions.

<http://www.hhs.gov/news/press/2010pres/02/20100201a.html>

⁶⁹ Press Release, Department of Defense, Department of Defense Autism Research Program (ARP) Funding Opportunities for Fiscal Year 2009 (FY09) (January 28, 2009), *available at* <http://cdmnp.army.mil/pubs/press/2009/09arppreann.htm> (noting that the Fiscal Year 2009 Defense Appropriations Act provides \$8 million to the Department of Defense Autism Research Program (ARP)). Funding was renewed for another \$8 million for FY 2010. <http://cdmnp.army.mil/arp/default.htm>

⁷⁰ See the 2010 Interagency Autism Coordinating Committee Strategic Plan for Autism Spectrum Disorder Research - January 19, 2010, *available at* <http://iaacc.hhs.gov/strategic-plan/2010/index.shtml> (“[Autism] research has become a national priority, receiving a massive surge in funding through the American Recovery and Reinvestment Act (ARRA) of 2009.”)

When a social movement embraces the rhetoric of civil rights, or when, in Janet Halley's words, a movement starts to rely on "race-like arguments," issues of identity are bound to arise.⁷¹ Autism can be and has been defined as a closed class – a finite set of human beings possessing immutable characteristics.⁷² Clear advantages to this strategy are the strength of the group's claim to equality, the resonance of large numbers, and the power of well-oiled argumentation. The drawback is the emergence of a stereotype that is not intrinsically negative and may well be poetic and romanticized, but is nonetheless undesirable for two reasons. First, it does not do justice to all those on the autistic spectrum who feel misrepresented by the dominant image of the syndrome. Second, it locks in the idea that autistic individuals are different from the rest of humanity.⁷³ Campaigning in the name of a group brings the group to life as a "discrete and insular" entity.⁷⁴ Activism creates difference at the same time as it calls for sameness at law.⁷⁵

With the promise of special recognition and ad-hoc entitlements comes disagreement within the autism movement.⁷⁶ At one extreme end of the spectrum of opinions one finds the "neuro-diversity" or "autism rights" camp, where autism simply is

⁷¹ Janet Halley, "Like Race" Arguments, in WHAT'S LEFT OF THEORY? NEW WORK ON THE POLITICS OF LITERARY THEORY 40, 50 (2000).

⁷² See Regents of Univ. of Cal. v. Bakke, 438 U.S. 265, 360 (1978) (discussing the legal treatment of immutable characteristics). Autism is deemed treatable but non-curable. The minority group model of disability policy is conceptually opposite to a "universal" understanding of disability, which by contrast posits that disability-specific policies are undesirable, and rather puts forth "general rule[s] of flexibility to recognize that all people are different." SAMUEL R. BAGENSTOS, LAW AND THE CONTRADICTIONS OF THE DISABILITY RIGHTS MOVEMENT 21 (2009).

⁷³ MARTHA MINOW, MAKING ALL THE DIFFERENCE 31 (1990) (remarking that "making differences matter singles out the disabled child.").

⁷⁴ The expression "discrete and insular minority" famously originated in footnote four of the opinion in U.S. v. Carolene Products Co., 304 U.S. 144, 152 (1938) and was later referred to in the Americans with Disabilities Act of 1990, 42 USC par 12101, Findings and Purpose, A (7). The 2008 amendments of the ADA eliminated such a reference.

⁷⁵ Minow, *supra* note 72 at 108. "Special rights, justified by difference, undermine claims of equal treatment predicated on sameness." *Id.*

⁷⁶ BAGENSTOS, *supra* note 72, at 20-33 (discussing internal tensions among disability rights activists).

not an illness, and where the very idea of cure is an assault on identity.⁷⁷ First epitomized by Jim Sinclair's "don't mourn for us" message,⁷⁸ this group deems the attempt to cure autism by means of behavioral intervention as hideous as the 1960s psychiatric treatment of homosexuality.⁷⁹ Several websites espouse this view, which is of particular appeal to individuals on the milder end of the autism spectrum.⁸⁰ In a way that closely resembles the plea of deaf-culture advocates, self-identified bearers of autism spectrum disorders demand acceptance and even admiration for autism's most appealing traits, which range from savant-like musicality to a philosophical detachment from most mundane matters.⁸¹

The relation between the movement's large core and this relatively young neurodiversity group is uncomfortable. It is now generally accepted that it is important to let persons with disabilities speak with their own voice. The Interagency Autism Coordinating Committee (IACC), established in 2000 and further empowered by the Combat Autism Act of 2006, includes among its members two adults with autism

⁷⁷ See Mark Osteen, *Autism and Representation: A Comprehensive Introduction*, in *AUTISM AND REPRESENTATION* 1, 6 (Mark Osteen ed., 2008) "Certain high-functioning autists and those diagnosed with Asperger's syndrome (self-described 'Aspies') . . . [proclaim] that they are not sick and don't need to be 'cured.'" The origin of the neurodiversity strand within the autism movement is usually traced to Judy Singer, "Why can't you be normal for once in your life?" in *DISABILITY DISCOURSE* (Mairian Corker & Sally French eds., 1999).

⁷⁸ Sinclair, *supra* note 9.

⁷⁹ Michelle Dawson, *An Autistic at the Supreme Court. The Auton Case: The Intervener's Factum* (reminding readers that Dr. Lovaas, a pioneer of behavioral autism treatment, advocated behavior modification therapy for homosexual persons) (quoting G.A. Rekers, P.M. Bentler, A.C. Rosen & O.I. Lovaas, *Child Gender Disturbances: A Clinical Rationale for Intervention*, 14 *PSYCHOTHERAPY: THEORY, RES. & PRAC.* 2, at 9 (1977)); see also Kenji Yoshino, *Covering*, 111 *YALE L.J.* 769 (2002).

⁸⁰ Osteen, *supra* note 77, at 6. Mark Osteen refers to "a flourishing online community devoted to disseminating information about autistic people and their lives." See, e.g., The Autistic Self Advocacy Network, <http://www.autisticadvocacy.org>; Aspies for Freedom, <http://www.aspiesforfreedom.com>; Autistics.org.: The Real Voice of Autism, <http://www.autistics.org>; see also Andrew Solomon, *The Autism Rights Movement*, *N.Y. MAG.*, May 25, 2008, available at <http://nymag.com/news/features/47225/>.

⁸¹ David Wolman, *The Advantages of Autism*, *NEW SCIENTIST*, May 4, 2010.

spectrum disorders.⁸² But when members of the neuro-diversity group undermine the value of treatments and of research aimed at eradicating autism, the rest of the movement distances itself from this strand.⁸³ The critique of behavioral interventions and the downplaying of autism's tragedy find no room in the manifesto of the movement's large base.

At the other end of the movement are activists invested in challenging the findings of established science and in pushing autism research beyond its currently dominant parameters.⁸⁴ Among its most vocal expressions are the on-line publication "Age of Autism"⁸⁵ and the organization "Generation Rescue."⁸⁶ These advocates stress that we are in the presence of an organic illness of epidemic proportions and vehemently disagree with those who portray autism in lighter tones.⁸⁷ In this camp, the focus is on autism as a biomedical (as opposed to psychogenic, psychiatric or behavioral) condition, a source of deep physical and mental suffering whose cause must be eradicated. Vaccines, mercury, and other man-made poisons are the main suspects.⁸⁸ Currently, this

⁸² IACC members include Stephen Shore, Executive Director of Autism Spectrum Consulting, and most recently Ari Ne'eman, Founding President of Autistic Self Advocacy Network.

http://www.iacc.hhs.gov/news/news_updates/2010/news_2010_iacc_new_members.shtml.

⁸³ President Obama nominated Mr. Ne'eman to the National Council on Disabilities, but his nomination proved controversial within the autism movement and is now on hold. See Amy Harmon, *Nominee to Disability Council Is Lightning Rod for Dispute on Views of Autism*, NY Times March 28, 2010, at A16.

⁸⁴ See e.g. the work of the Autism Research Institute and its project "Defeat Autism Now" (DAN), <http://www.defeatautismnow.com/>

⁸⁵ Age of Autism, <http://www.ageofautism.com>.

⁸⁶ Generation Rescue, <http://www.generationrescue.org>.

⁸⁷ See Dan Olmstead, *Roy Grinker's Unright Facts*, AGE OF AUTISM, July 29, 2009, <http://www.ageofautism.com/2008/07/olmsted-on-au-2.html>.

⁸⁸ See Philip J. Landrigan, *What causes autism? Exploring the environmental contribution*, 22 CURRENT OPINION IN PEDIATRICS 219 (2010) (encouraging further study of environmental triggers for autism). See also DAVID KIRBY, EVIDENCE OF HARM: MERCURY IN VACCINES AND THE AUTISM EPIDEMIC: A MEDICAL CONTROVERSY (2005). Cf. PAUL A. OFFIT, AUTISM'S FALSE PROPHETS: BAD SCIENCE, RISKY MEDICINE, AND THE SEARCH FOR A CURE (2008).

is the most militant strand of the movement.⁸⁹ It blames the medical establishment for too quickly dismissing the hypothesis of a causal link between autism and vaccines, and openly accuses researchers of colluding with the pharmaceutical industry.⁹⁰ In this camp, detoxifying diets and ‘natural’ remedies, which include nutritional supplements, are judged favorably.⁹¹ By contrast, psychiatric drugs are labeled as band-aid solutions that only mask underlying biomedical problems.⁹²

At times, very vocal fights have occurred between anti-vaccine (or anti-toxins) advocates and other strands of the movement.⁹³ This splintering, potentially fatal to the movement, has not yet undermined the larger mission of autism advocacy. The two extreme approaches – anti-vaccine and neuro-diversity – do not engage each other directly. In fact, they have so little in common that they seem to be talking about different phenomena altogether, and they may well be. As a result, their profound philosophical disagreements have knocked each other out of the center stage and have not managed to shake the foundations of the movement’s core. In a way, their forceful interventions in the forum of public opinion serve the mainstream cause of keeping autism in the spotlight and yield paradoxical synergies. The core of the autism movement remains, as a result,

⁸⁹ Representatives of associations like TACA (talkaboutcuringautism.org/), National Autism Association (NAA), Generation Rescue, and SafeMinds (Sensible Action For Ending Mercury-Induced Neurological Disorders) have so far been kept outside of the Inter-Agency Autism Coordination Committee.

⁹⁰ See e.g. Russell L. Blaylock, *The Truth Behind the Vaccine Cover-up*, <http://www.generationrescue.org/blaylock/Truth-behind-vaccine-cover-up.pdf>

⁹¹ See e.g. Treatment: Generation Rescue Action Plan, Generation Rescue, <http://www.generationrescue.org/action.html>; see also Jill Neimark, *Autism: It’s Not Just in the Head*, DISCOVER, April 2007, available at <http://discovermagazine.com/2007/apr/autism-it2019s-not-just-in-the-head>.

⁹² See e.g. *Chelation: The Story Behind the Headlines*, 19 AUTISM RESEARCH REVIEW INTERNATIONAL 3 (2005) (asserting that psychiatric drugs “only suppress symptoms, while causing a host of horrific and sometimes lethal side effects.”), available at http://www.autism.com/ari/editorials/ed_chelationstory.htm.

⁹³ For a glimpse of such disputes, see Kim Stagliano, *Suzanne Wright Speaks. Does Autism Speaks Listen?*, HUFFINGTON POST, Aug. 20, 2007, http://www.huffingtonpost.com/kim-stagliano/suzanne-wright-speaks-do_b_61202.html.

sufficiently broad-based to bring about legal change. The power of initiative and money allies with the despair of all those struck by autism, with a primitive fear of epidemics, with the promise of a window into the mysteries of the brain, and with the aesthetic appeal of extraordinary minds, to produce a model of 21st-century activism.

D. Autism and Disability Discourse

Taken at face value, the extreme strands of the autism movement might seem to mirror the nature/culture divide that we observe in general disability discourse. In the nature camp, just as within the ‘cure’ fringe of autism activism, the emphasis is on impairment – the physical or mental difference that justifies differential treatment in fact and at law. Difference is “medicalized” and conceived of as pathology.⁹⁴ The culture camp of disability advocacy, by contrast, de-emphasizes the biological impairment, celebrates diversity, and attacks the very idea of disability as a purely social construction.⁹⁵ The implication of the latter viewpoint is that the impairment – say, the inability to walk – would no longer be a disability if society were ready to replace stairs with ramps.⁹⁶ As observed, the neuro-diversity strand of the autism movement, which is mostly made of self-identified autistic adults, embraces this viewpoint entirely.

⁹⁴ See Shelley Tremain, *On the Government of Disability. Foucault, Power, and the Subject of Impairment*, in *THE DISABILITY STUDIES READER* 185 (Lennard J. Davis ed., 2nd ed. 2006).

⁹⁵ See LENNARD J. DAVIS, *BENDING OVER BACKWARDS: DISABILITY, DISMODERNISM, AND OTHER DIFFICULT POSITIONS* 12, 41 (2002).

⁹⁶ Mary Crossley, *The Disability Kaleidoscope*, 74 *NOTRE DAME L. REV.* 621, 654 (1999).

Of course, the discourse on disability can hardly be reduced to such dichotomies and the social model, while prevalent, is laden with internal contradictions.⁹⁷ In general, the nature/culture (or biology/society) divide does not map well onto the field of cognitive impairment.⁹⁸ Intellectual disability advocates have actually struggled to emphasize, rather than downplay, the biological root of what could otherwise be perceived as despicable behavior.⁹⁹ As observed above, at the heart of the autism movement is Bernard Rimland's effort to eradicate the perception that autism is caused by bad parenting, and to replace it with a quest for biological etiology.

But not even the context of intellectual disabilities provides a good lens for studying the autism movement, which proves again and again to be following a trajectory of its own.¹⁰⁰ According to certain accounts of social justice, people with severe intellectual disabilities seem to have a lesser claim to public resources than other groups.¹⁰¹ In a contractarian perspective, for instance, they do not count as net contributors and are therefore excluded from the paradigm of reciprocity.¹⁰² Advocacy

⁹⁷ See Vlad Perju, *Impairment, Discrimination, and the Legal Construction of Disability in the United States and Europe*, forthcoming — CORNELL J. INT'L L. (2010).

⁹⁸ “[T]he social model of disability tends to have somewhat less purchase in the realm of psychiatric disabilities.” Elizabeth F. Emens, *Against Nature* (forthcoming NOMOS 2010, manuscript at 9, on file with author).

⁹⁹ See Osteen, *supra* note 76, at 3 (arguing that “Disability studies’ adherence to the social-constructionist model, with its heavy debt to Foucault, has helped to foster a set of biases and misrepresentations [...], thereby excluding the intellectually disabled just as mainstream society has done.”)

¹⁰⁰ Brigitte Chamak, *Autism and Social Movements: French Parents' Associations and International Autistic Individuals' Organizations*, 30 SOCIOLOGY OF HEALTH & ILLNESS 76 (2007). “If the disability movement is considered as the latest generation of social movements, the action of autistic persons can be viewed as the latest generation of the disability movements.” *Id.*

¹⁰¹ Martha Nussbaum identifies the root of the lesser status of people with mental disabilities in the “Kantian conception of the person, which makes possession of the mental and moral powers central both to equality and to the key idea of reciprocity.” MARTHA NUSSBAUM, *FRONTIERS OF JUSTICE: DISABILITY, NATIONALITY, SPECIES MEMBERSHIP* 130 (2006).

¹⁰² David Gauthier, *Justice as Mutual Advantage*, in COLIN FARRELLY, *CONTEMPORARY POLITICAL THEORY: A READER* 89, 97 n.20 (2004). Even in the writings of authors who espouse a more strongly

for those with severe mental impairments, therefore, ends up relying on philosophical notions of human dignity¹⁰³ and universal human rights,¹⁰⁴ which may have less redistributive pull in policy-making circles.¹⁰⁵

This is not the case with autism advocacy. Its pitch is *also* grounded upon morality and universal values of inclusion, but pure economic logic is central to the movement in at least four ways. First, there is much emphasis on the fact that autism is expensive, because it saps the strength of adult caregivers and generates long-term burdens on society.¹⁰⁶ Finding ways to cure it or alleviate its symptoms is advertised as a cost-saving proposition. Second, autism is often perceived as the unavoidable flip-side of

redistributive approach, persons with very low IQs remain somehow beyond philosophical reach. Rawls expressly leaves disabilities out of his theory of justice, leaving others with the task of elaborating “Rawlsian” approaches to disability and distribution. For Martha Nussbaum, severely mentally impaired persons lead an unfortunate existence that a just society should, if scientifically possible, genetically re-engineer. NUSSBAUM, *supra* note 100, at 193. The limits of Nussbaum’s theory of justice when it comes to persons with severe mental impairments are highlighted by Michael Ashley Stein in *Disability Human Rights*, 95 CAL. L. REV. 75, 110 (2007) (noting critically that “Nussbaum’s approach continues to use functional ability as a metric to justify distribution.”). *See also* Mark S. Stein, *Nussbaum: A Utilitarian Critique*, 50 B.C. L. REV 489, 501-02 (2009).

¹⁰³ *See* Eva Feder Kittay, *Equality, Dignity and Disability*, in PERSPECTIVES ON EQUALITY: THE SECOND SEAMUS HEANEY LECTURES 93 (Lyons & Waldron eds., 2005) (discussing dignity as an entitlement for persons with severe mental disabilities).

¹⁰⁴ *See* Michael Stein, *Disability Human Rights*, *supra* note 102.

¹⁰⁵ *See, e.g.*, Louis Kaplow & Steven Shavell, *Fairness Versus Welfare*, 114 HARV. L. REV. 961, 968-69 (2001) (positing that “notions of fairness like corrective justice[, rights, and cognate concepts] should receive no independent weight in the assessment of legal rules.”).

¹⁰⁶ Michael L. Ganz, *The Costs of Autism*, in UNDERSTANDING AUTISM: FROM BASIC NEUROSCIENCE TO TREATMENT 475, 496 (Moldin & Rubenstein eds., 2006). A comprehensive 2006 study reports that the total annual societal per capita cost of caring for and treating a person with autism in the US amounts to \$3.2 million. *Id.* The distribution of these costs over time was further detailed in Michael L. Ganz, *The Lifetime Distribution of Incremental Societal Costs of Autism*, 161 ARCHIVES PEDIATRICS & ADOLESCENT MED., Apr. 2007, at 343-49. Autism appears to be more expensive than other forms of childhood special needs. Lisa A. Croen et al., *A Comparison of Health Care Utilization and Costs of Children With and Without Autism Spectrum Disorders in a Large Group-Model Health Plan*, 118 PEDIATRICS n. 4 Oct. 2006, at e1203-11. Children with autism reportedly need more medication, more doctors’ visits, and in general more care than children with other emotional, developmental, or behavioral problems. *See* Michael D. Kogan et al., *A National Profile of the Health Care Experiences and Family Impact of Autism Spectrum Disorder Among Children in the United States, 2005–2006*, 122 PEDIATRICS n. 6 Dec. 2008, at e1149-58.

the precious coin of genius.¹⁰⁷ The force of this positive message is astonishing in fundraising and political activism. If society has a chance to gain remarkably from children with autistic traits, then early therapy is an investment in the interest of progress and civilization.¹⁰⁸ Third, because there is no known way to prevent autism and because of its epidemic dimensions, subsidizing autism-related research and other public expenditures can be seen as a mechanism of insurance, one that would be deemed legitimate even by libertarian policy makers.¹⁰⁹ Fourth, the mystery of autism is most attractive to the analytical mind. Autism offers neuroscientists unprecedented insights, based on the scientific intuition, now widely popularized, that deviations from the biological norm can teach us much about the norm itself.¹¹⁰ Given that emotions, empathy, and communication are so different in autistic individuals, perhaps autism research can lead to identifying the genetic bases of feelings and relations. Gender stereotypes are also implicated. Considering that most autistic children are boys, what in the brain explains

¹⁰⁷ See *Autism and Extraordinary Ability*, *supra* note 25.

¹⁰⁸ In the words of Temple Grandin, perhaps the most prominent example of autism self-advocacy, “[i]f the genetic factors that cause autism were eliminated from the human race, we would pay a terrible price. The way I see it, it is likely that the genetics that produce autism are the same genetics that create an Einstein or a Mozart.” TEMPLE GRANDIN, *THE WAY I SEE IT: A PERSONAL LOOK AT AUTISM AND ASPERGERS* 241 (2009). As is well known, utilitarianism has often been the driving engine of disability law reforms. See Mark S. Stein, *DISTRIBUTIVE JUSTICE AND DISABILITY. UTILITARIANISM AGAINST EGALITARIANISM* (2006). What is peculiar to autism, however, is its ability to give a utilitarian spin even to profound intellectual disabilities, which have traditionally scored poorly in coarse cost/benefit analyses.

¹⁰⁹ See RICHARD A. EPSTEIN, *FORBIDDEN GROUNDS: THE CASE AGAINST EMPLOYMENT DISCRIMINATION LAWS* 481 (1995). “There is thus a powerful insurance feature that leads everyone to think that some assistance for the disabled may not be solely an act of disinterested benevolence but one of prudent self-interest as well.” *Id.* The idea that the level of compensation for disabilities should be based on what individuals themselves would have wanted to insure for is articulated in RONALD DWORKIN, *SOVEREIGN VIRTUE* 76-83 (2000).

¹¹⁰ See, e.g., MARK S. BLUMBERG, *FREAKS OF NATURE: WHAT ANOMALIES TELL US ABOUT DEVELOPMENT AND EVOLUTION* (2008).

such a remarkable gender difference?¹¹¹ Is it true, after all, that women, by a process of Darwinian selection, are more likely to display the warm and fuzzy features that the autistic mind seems to lack? Or is the correlation between autism and maleness something other and more interesting than the popular belief that “Men are from Mars”?¹¹² Such questions could hardly be more appealing to the scientific community, and investigating them may prove a cost-effective proposition.

Interestingly, this utilitarian theme pervades autism discourse in either of its main manifestations. When autism is framed as invasion and catastrophe, advocacy stresses its astonishing costs, the urgency of research, and the long-term savings that may come from treatment. When the emphasis is on beauty and genius, spending on autism is touted as a wise investment. In either case, autism seems to possess a utilitarian extra-gear vis-à-vis other types of conditions.

The legislative history of a health-insurance mandate in Florida speaks volumes about the relative power of this image. The House had favored a broad mandate that would cover intensive therapeutic services for young children afflicted by developmental disabilities, such as autism and Down syndrome. Down syndrome, however, is not mysterious; it cannot be cured, but it is detectable *in utero*; it is heart-wrenching, but it does not evoke a fear of uncontrollable forces. In the Senate, alleged financial constraints led to the refocusing of the bill around autism only. Governor Crist responded to ensuing criticism with the vague prediction that the ongoing “momentum and spirit of

¹¹¹See SIMON BARON-COHEN, *THE ESSENTIAL DIFFERENCE: MALE AND FEMALE BRAINS AND THE TRUTH ABOUT AUTISM* (2004). Autism occurs about 4 times more often in boys than in girls. See Lord & Bishop, *supra* note 39 at 4.

¹¹²JOHN GRAY, *MEN ARE FROM MARS, WOMEN ARE FROM VENUS: A PRACTICAL GUIDE FOR IMPROVING COMMUNICATION AND GETTING WHAT YOU WANT IN YOUR RELATIONSHIPS* (1993).

compassion” would soon “do more for those with Down syndrome.”¹¹³ But for the time being, Down syndrome was left behind. The dual frame of beauty and invasion carries more weight than other conditions when it comes to distributing finite resources.

III. JUDICIAL DISCOURSE: CONFLICT MANAGEMENT AND FRAMING

In a culture as dominated by law as the American one, autism’s growing presence in the judicial forum is a natural consequence of its notoriety. In turn, the movement draws strength from the fact that courts are increasingly busy figuring out what role to carve out for autism in the context of legal disputes. Judicial opinions play an important expressive function¹¹⁴ insofar as they contribute to the portrayal of autism as a phenomenon of growing importance, calling for individualized attention and ad-hoc solutions. Courts have also performed the role of umpires in highly politicized disputes concerning the biomedical causes of autism, and have taken part in the controversy on the moral agency of persons with autism. While the conflicting strands of the movement have never resorted to legal action against one another, courts have unquestionably been involved in the discursive management of their disagreements.

This Part explores three areas of autism-related litigation which have variously polarized, expressed and channeled dissent within the movement. The first type of litigation pertains to the above mentioned split between the mainstream and the anti-vaccine camp. The forum for such diatribes is the Omnibus Autism Proceeding, a subdivision of a federal Vaccine court established to adjudicate the question of a causal

¹¹³ Josh Hafenbrack, *Plan for Autism Insurance Coverage Passes*, SUN-SENTINEL, May 3, 2008, at 10B.

¹¹⁴ See Richard H. McAdams, *The Expressive Power of Adjudication*, 2005 U. ILL. L. REV. 1043, 1062.

link between vaccines and the autism epidemic. Here, specialized judicial panels face the difficult task of signaling systemic concern for the still mysterious causes of autism while at the same time deflecting mass hysteria and clinging to scientific evidence.

A second line of autism-related adjudication deals with criminal cases in which the defendant has autism. In such matters, the mainstream frames autism as a *problem* in need of attention and ad-hoc solutions. Autism rights advocates, by contrast, abhor the discursive association of autism spectrum disorders with criminal conduct. Here, again, courts are called to strike a difficult balance between conflicting demands stemming from the movement by acknowledging the specificities of autism in matters of capacity and culpability, thereby making room for exculpatory or mitigating doctrines while concurrently avoiding damning stereotypes.

Remarkably parallel issues are raised by a third line of cases: the judicial attempt to define autism in matters of employment discrimination. ADA litigation is bound to become a salient forum for discussing the relation between autism and the work-force and for fine-tuning the balance of protection and autonomy required in this particular context.

When observed together, these seemingly divergent sets of cases share the important task of articulating the multi-layered and non-linear relationship between the various strands of the movement. At this stage, there are no losers, as the few cases that have been decided or settled, when considered together, do not uniformly endorse one view or another. Rather, as a result of judicial engagement in such matters, the movement

as a whole grows stronger and gains in notoriety. In all such cases, autism emerges as a problem with its own brand name, distinct and special.

A. *The Omnibus Autism Proceeding*

One of the few known facts about autism is that it is at least in part hereditary.¹¹⁵ If one child is autistic, the chances of autism or other neurological disorders in siblings are significantly higher than in the general population.¹¹⁶ It is notoriously hard for parents to accept genetic liability for their children's medical problems. Discovering that their child's autism was brought about by something other than procreation does not alleviate parents' grief, but may at least lift the weight of genetic guilt off their shoulders.¹¹⁷ Autistic symptoms often become visible at age 18 months, exactly when children are routinely vaccinated against measles, mumps, and rubella. According to many parents and also to a minority of scientists,¹¹⁸ the MMR vaccine is somehow responsible for the increased incidence of autism either per se or because of a mercury-based preservative,

¹¹⁵ Claudia Wallis, *Autism Linked to Genes That Govern How the Brain Is Wired*, TIME, Apr. 28, 2009, available at <http://www.time.com/time/health/article/0,8599,1894409,00.html> (last visited May 24, 2010).

¹¹⁶ See, e.g., Marlene Briciet Lauritsen et al., *Effects of Familial Risk Factors and Place of Birth on the Risk of Autism: A Nationwide Register-Based Study*, 46 J. CHILD PSYCHOL. & PSYCHIATRY 9, 963-71 (2005).

¹¹⁷ See Stephen Sugarman, *Cases in Vaccine Court – Legal Battles over Vaccines and Autism*, 357 NEW ENG. J. MED. 13, 1275 (2007); Joelle Anne Moreno, *Toxic Torts, Autism, and Bad Science: Why the Courts May Be Our Best Defense Against Scientific Relativism*, 40 NEW ENG. L. REV. 409 (2006).

¹¹⁸ See Heather A. Young et al., *Thimerosal Exposure in Infants and Neurodevelopmental Disorders: An Assessment of Computerized Medical Records in the Vaccine Safety Datalink*, 271 J. NEUROL. SCI. 110 (2008). The hypothesis of a connection between vaccines and autism was first raised by Andrew Wakefield in *Ileal-Lymphoid-Nodular Hyperplasia, Non-Specific Colitis, and Pervasive Developmental Disorder in Children*, THE LANCET 351, Issue 9103, 637-41 (Feb. 28, 1998). This article was later found to be lacking in integrity and scientific rigor. See the Editors' *Retraction*, THE LANCET (February 2, 2010), available at <http://press.thelancet.com/wakefieldretraction.pdf>. The PBS show *Frontline: The Vaccine Wars*, aired in April 2010, explored the controversy (and generated more of it.). <http://www.pbs.org/wgbh/pages/frontline/vaccines/etc/script.html>.

Thimerosal, contained in MMR vaccine vials.¹¹⁹ Based on this theory, thousands of parents have sought damages before the “Vaccine Court,” a section of the United States Court of Federal Claims established in 1988 to handle, in non-adversarial fashion, all tort claims based on vaccine-induced illness or death.¹²⁰ In the Vaccine Court, causation is simply presumed¹²¹ for all cases listed in a “vaccine injury table.”¹²² But because the table does not contemplate autism, parents cannot rely on presumptions and must instead prove causation by a preponderance of the evidence. This standard is notoriously difficult to meet.¹²³ Expert testimony must be “not only relevant, but reliable” and “scientifically valid” according to stringent parameters (known as the *Daubert* standard) to be assessed at trial.¹²⁴

Because of the unique nature of autism litigation – the pressure of power-house activism, the skyrocketing incidence of the disease, and the political sensitivity of the issue, – a special proceeding was set up in July 2002 within the vaccine litigation system with the goal of addressing the enormous caseload of autism litigation.¹²⁵ The Omnibus

¹¹⁹ Thimerosal was banned from all over-the-counter drugs in 1998. In July of 2007 President Bush vetoed a bill that would have banned thimerosal from flu vaccines.

¹²⁰ H.R. REP. No. 99-908, at 18 (1986), reprinted in 1986 U.S.C.C.A.N. 6344, 6359.

¹²¹ Daniel A. Cantor, *Striking a Balance Between Product Liability and Product Safety: Lessons from the Vaccine Act*, 44 AM. U. L. REV. 1853, 1861 (1995).

¹²² The Vaccine Act contains a “Vaccine Injury Table” that lists several vaccines manufactured in the United States and a number of related injuries. Controversies falling clearly within the four corners of the table are easily handled. Causation is presumed if the symptoms occurred within the time period identified in the Table. 42 U.S.C. 300aa-13(a)(1)(A). Autism is not among the injuries listed in the table.

¹²³ See Margaret A. Berger & Aaron D. Twerski, *Uncertainty and Informed Choice: Unmasking Daubert*, 104 MICH. L. REV. 257, 259 (2005) (remarking that “significant changes in the doctrine are not in the offing”).

¹²⁴ *Daubert v. Merrell Dow Pharm., Inc.*, 509 U.S. 579 (1993) (establishing such high evidentiary standards).

¹²⁵ National Vaccine Injury Compensation Board: About the Omnibus Autism Proceeding, U.S. Dept. Health and Human Services, Health Resources and Services Admin., <http://www.hrsa.gov/vaccinecompensation/omnibusproceeding.htm> (discussing the establishment of the Proceeding and Office of Special Masters’ Autism General Order #1, which started the Proceeding).

Autism Proceeding was designed to start with general investigations on causal links between Thimerosal-containing vaccines and autism, based on a handful of test cases.¹²⁶ The next stage would consist of using general findings to answer questions of specific causation in each dispute.

This system was set up at a point when the whole scientific community was eager to investigate the vaccine-autism issue. The Vaccine Court became invested with the new task of addressing, for example, not only the sadly predictable chance of contracting polio after receiving oral polio vaccine, but a systemic, statistically impressive link that was shattering the modern world's faith in vaccination. In 2001, the Immunization Safety Review Committee of the Institute of Medicine of the National Academies found the hypothesis of a connection between Thimerosal-containing vaccines and developmental disorders to be "biologically plausible."¹²⁷ In that climate, the federally-recommended and state-mandated MMR vaccination became the main suspect among all possible causes of autism and even, according to some, an object of mass hysteria.¹²⁸

Things look different today. In May 2004, the same committee, based on further review of research, determined that "the body of epidemiological evidence favors

¹²⁶ The system is designed to test three different theories of general causation, each on the basis of three test cases. The three theories assume, respectively: 1) that the MMR vaccine can combine with Thimerosal-containing vaccines (TCV) to cause autism; 2) that TCVs alone cause autism; 3) that the MMR vaccine alone causes autism. *Id.*

¹²⁷ INSTITUTE OF MEDICINE OF THE NATIONAL ACADEMIES, NATIONAL ACADEMY OF SCIENCES, IMMUNIZATION SAFETY REVIEW: THIMEROSAL-CONTAINING VACCINES AND NEURODEVELOPMENTAL DISORDERS (Executive Summary) (2001). Because the evidence was "inadequate to accept or reject a causal relationship," the Committee recommended further research. *Id.*

¹²⁸ See Moreno, *supra* note 117, at 414-15 (blaming the vaccine scare on "conspiracy theorists").

rejection of a causal relationship between Thimerosal-containing vaccines and autism.”¹²⁹

More generally:

The CDC, American Academy of Pediatrics, Institute of Medicine and other prestigious medical organizations maintain there is no known link between vaccines and autism. Studies published in the *New England Journal of Medicine* and elsewhere also have found no link. Even after Thimerosal was removed from infant vaccines, the autism rate has continued to climb.¹³⁰

In product liability cases, as well, Thimerosal-containing products have been found to be unrelated to neurodevelopmental disorders.¹³¹ Most recently, three of the test cases were closed, with no finding of any causal link between vaccine and autism.¹³² The story, however, remains far from simple.

As observed, in the Omnibus Autism Proceeding the burden of proof for petitioners is to establish causation by a “preponderance of the evidence.” A simple finding that a biomedical connection between vaccines and autism is “plausible” will not

¹²⁹ INSTITUTE OF MEDICINE OF THE NATIONAL ACADEMIES, NATIONAL ACADEMY OF SCIENCES, IMMUNIZATION SAFETY REVIEW: VACCINES AND AUTISM (Executive Summary) (2004).

¹³⁰ *Vaccine Case Draws New Attention to Autism Debate*, CNN, Mar. 7, 2008, available at <http://www.cnn.com/2008/HEALTH/conditions/03/06/vaccines.autism/index.html>. See also Moreno, *supra* note 117, at 412 (criticizing politicians who pandered to anti-vaccine constituencies).

¹³¹ Some parents of children with autism have chosen to sue manufacturers of thimerosal-containing drugs along the lines of typical toxic tort litigation, but they have regularly been unable to meet the threshold of causation by preponderance of the evidence. See Note, *Toussaint v. Merck & Co.: Opening the Door to Thimerosal Vaccine Litigation in Civil Court?*, 21 GA. ST. U. L. REV. 773 (2005). Other types of thimerosal litigation also ended with plaintiffs’ defeat. See, e.g., *Redfoot v. B.F. Ascher & Co.*, 2007 U.S. Dist. LEXIS 40002 (N.D. Cal. June 1, 2007) (nasal spray, products liability), and *Doe v. Ortho-Clinical Diagnostics, Inc.*, 440 F. Supp. 2d 465 (M.D.N.C. 2006) (Thimerosal in Rhogam given to mother before birth). See also Gordon Shemin, *Mercury Rising: The Omnibus Autism Proceeding and What Families Should Know Before Rushing Out of the Vaccine Court*, 58 AM. U.L.REV. 459 (2008) (discussing the procedural difficulties of switching from the vaccine court to general tort litigation).

¹³² Editorial, *Vaccines Exonerated on Autism*, N.Y. TIMES, Feb. 12, 2009, at A30. See *Cedillo v. Sec’y of Health & Human Servs.*, No. 98-916V, 2009 WL 331968 (Fed.Cl. 2009); *Hazlehurst v. Sec’y of Health & Human Servs.*, No. 03-654V, 2009 WL 332306 (Fed.Cl. 2009); *Snyder v. Sec’y of Health & Human Servs.*, No. 01-162V, 2009 WL 332044 (Fed.Cl. 2009). The Special Master assigned to the *Cedillo* case concluded: “[T]he petitioners have failed to demonstrate that thimerosal-containing vaccines can contribute to causing immune dysfunction, or that the MMR vaccine can contribute to causing either autism or gastrointestinal dysfunction.” *Cedillo*, 2009 WL 331968.

suffice. But if the plausible biomedical theory is corroborated by facts, e.g., by a strong temporal connection between vaccination and symptoms, and by other specific circumstances, then petitioners are relieved of their burden of proof, and it is up to the respondents to prove, by a preponderance of the evidence, that factors other than the vaccine prompted the onset or worsening of the illness.¹³³ In November 2007, plaintiff Hannah Poling prevailed along such argumentative lines and was found entitled to compensation in the vaccine court.¹³⁴ In her case, aptly removed from the list of test cases of the Omnibus Autism Proceeding, the temporal connection between vaccination and symptoms was remarkable, and it was at least plausible that, given Hannah's particular mitochondrial disorder, the vaccine could have prompted the onset of autistic symptoms.¹³⁵ It is for this specific reason that respondent Secretary of Health and Human Services agreed to move the proceedings on to the stage of damage determination.¹³⁶ The case could be read narrowly – and was indeed read very narrowly by Dr. Julie Gerberding, Director of the U.S. Centers for Disease Control and Prevention, who was quick to say:

Let me be very clear that the government has made absolutely no statement indicating that vaccines are a cause of autism. That is a complete mischaracterization of the findings of the case and a complete mischaracterization of any of the science that we have at our disposal today.¹³⁷

¹³³ Golub v. Sec'y of Health & Human Servs., 2000 U.S. App. LEXIS 24858 (Fed. Cir. Oct. 3, 2000); Walther v. Sec'y of Health & Human Servs., 485 F.3d 1146 (Fed. Cir. 2007).

¹³⁴ Kent Heckenlively, *Full Text: Autism Vaccine Case*, AGE OF AUTISM, Feb. 26, 2008, <http://www.ageofautism.com/2008/02/full-text-autis.html>.

¹³⁵ *Id.*

¹³⁶ See Claudia Wallis, *Case Study: Autism and Vaccines*, TIME, Mar. 10, 2008, available at <http://www.time.com/time/health/article/0,8599,1721109,00.html>.

¹³⁷ Gardiner Harris, *Deal in an Autism Case Fuels Debate on Vaccine*, N.Y. TIMES, Mar. 8, 2008, at A9.

It is nonetheless remarkable that the Polings were able to negotiate a sort of settlement at a time when the scientific community was in large part rejecting the ‘general theory of causation’ propounded by autism activists. The case spurred a renewal of interest in the vaccine-autism theory.¹³⁸ Many had criticized *Daubert* and argued for a smoother path to compensation whenever evidence seemed compelling in terms of epidemiology. It took autism, however, to bring the very idea of mandatory vaccination under unusually strict scrutiny¹³⁹ and to bypass gate-keeping evidentiary rules.¹⁴⁰

Another judicial victory for the anti-vaccine strand of the movement made news in February 2009.¹⁴¹ Here, the family of Bailey Banks obtained not just a settlement but a proper award of damages totaling over one million dollars.¹⁴² Special Master Abell found that plaintiffs had established a causal link between the MMR vaccination and the child’s acute disseminated encephalomyelitis (ADEM).¹⁴³ ADEM, in turn, caused pervasive developmental delay, or PDD,¹⁴⁴ which is, according to many, a type of autism spectrum

¹³⁸ See, e.g., *Poling Case Intensifies Debate; Vaccine-Autism Link Worth Investigating, Says Former NIH Director*, AAPSONLINE, May 24, 2008, www.aapsonline.org/newssoftheday/0027; Gardiner Harris, *Experts to Discuss One Puzzling Autism Case, as a Second Case Has Arisen*, N.Y. TIMES, June 28, 2008, at A15; see also David Kirby, *The Next Vaccine-Autism Newsmaker: Not Isolated, Not Unusual*, HUFFINGTON POST, Apr. 27, 2008, http://www.huffingtonpost.com/david-kirby/the-next-vaccine-autism-n_b_98807.html.

¹³⁹ Steve P. Calandrillo, *Vanishing Vaccinations: Why Are So Many Americans Opting out of Vaccinating Their Children?*, 37 U. MICH. J. L. REFORM 353, 398-99 (2003-2004).

¹⁴⁰ See Steven Novella, *Autism Court Ruling. Vaccines Didn’t Cause Autism*, NEUROLOGICABLOG, Feb. 12, 2009, <http://www.theness.com/neurologicablog/?p=478> (noting that “the standard of evidence for the compensation program has been significantly lowered recently.”).

¹⁴¹ *Banks v. Sec’y of Dep’t of Health and Human Servs.*, No. 02-0738V, 2007 WL 2296047 (Fed. Cl. 2007). The case received notoriety because the group Generation Rescue publicized it, purchasing a full-page advertisement in USA Today’s February 25, 2009 issue that read: “Court Again Concedes Vaccines Cause Autism.” See David Gorski, *The Incredible Shrinking Vaccine-Autism Hypothesis Shrinks Some More*, posting to SCIENCE-BASED MED., <http://www.sciencebasedmedicine.org/?p=393> (Mar. 2, 2009).

¹⁴² See Sharon Begley, *Vaccines and Autism: The Unending Story*, NEWSWEEK, <http://blog.newsweek.com/blogs/labnotes/archive/2009/02/25/vaccines-and-autism-the-unending-story.aspx> (describing the settlement terms).

¹⁴³ *Banks*, 2007 WL 2296047, *supra* note 141.

¹⁴⁴ *Id.*

disorder.¹⁴⁵ This case, like *Poling*, was removed from the deck of test cases. The result is that the net, loud and dramatic loss for the plaintiffs in the first three test cases, regularly decided in 2009 through the Omnibus Autism Proceeding, finds an unsettling counterpart in the atypical victories of *Poling* and *Banks*. The vaccine court is therefore the lynchpin of a complex dispute where established science sides with the medical community and with the pharmaceutical industry, while a small but highly vocal group reminds the public of a long history of toxic epidemics silenced by powerful economic interests. The very existence of this forum gives the extreme strand of advocacy enough voice to prevent complete fracture within the movement.

B. Crime and Autism

At age fourteen, Leonard D., a non-verbal adolescent with autism, was probably raped and certainly hurt while at summer camp.¹⁴⁶ His parents were never able to identify the perpetrator and failed to convince the court that the conduct of the camp personnel was in any way actionable.¹⁴⁷ Judge Melinda Harmon granted the school district summary judgment “despite clear evidence that someone mistreated Leonard.”¹⁴⁸ Students with disabilities, especially those who can’t speak for themselves, are common targets of bullying and crime, and children with autism are no exception to this tragic

¹⁴⁵ See e.g., Autism Spectrum Disorders, *supra* note 38. The CDC includes PDD criteria on its website in the Autism Spectrum Disorder section.

¹⁴⁶ See *Drye-Durden v. Stripling*, 2006 U.S. Dist. LEXIS 39817, at *13 (S.D. Tex. June 14, 2006).

¹⁴⁷ *Id.*

¹⁴⁸ *Id.*

rule.¹⁴⁹ In this respect, there is unfortunately nothing special about autism. But when the tables are turned, when the defendant on trial is a person with autism, courts are now faced with unprecedented questions raised by the arguably different nature of the autistic psyche.

1. Empathy and Moral Agency

While the capacity for empathy in individuals with autism is subject to debate,¹⁵⁰ autism is often associated with difficulty recognizing intentional states of others. The ethical implications of this alleged trait are startling and further complicate the already fuzzy logic of culpability.¹⁵¹

Even when very bright, individuals with autism are seriously handicapped by their inability to understand social cues or to reason intuitively in relational contexts.¹⁵² When they engage in criminal conduct, establishing their responsibility may be harder than in other cases of mental defect, because both cognition and volition may be intact, but perspective may be lacking in a way that cannot be dismissed as simply evil.¹⁵³ Autism's unique dissonance between self and other, its lack of perspective and mind-theory, has

¹⁴⁹ Massachusetts Advocates for Children, Report: *Bullying of Children with Autism Spectrum Disorder*, available at <http://www.massadvocates.org/uploads/44/a0/44a075940bd061eef73d72ec643c2762/Bullying-Report-final-s.pdf>.

¹⁵⁰ See BARNBAUM, *supra* note 8, at 19. According to Barnbaum, autism presents a novel challenge to Hume's and Kant's ethical theories. *Id.* at 113. Cf. Frédérique de Vignemont and Uta Frith, *Autism, Morality, and Empathy*, in W. SINNOTT-ARMSTRONG (ED), *THE NEUROSCIENCE OF MORALITY* 273, 275 (2007) (noting that emotional empathy can coexist with autistic traits.)

¹⁵¹ See BARNBAUM, *supra* note 8, at 6. "[T]he fact that autism challenges a person's ability to make intentional ascriptions presents startling ethical implications."

¹⁵² See Shelley Channon et al., *Punishment and Sympathy Judgments: Is the Quality of Mercy Strained in Asperger's Syndrome?* J. AUTISM DEV. DISORD. (2010), available at <http://www.springerlink.com/content/d8683778812814n0/fulltext.pdf>.

¹⁵³ See Stephen J. Morse, *From Sikora to Hendricks: Mental Disorders and Criminal Responsibility*, in *THE EVOLUTION OF MENTAL HEALTH LAW* 129, 134 (L.E. Frost & R.J. Bonnie eds., 2002) (reporting, critically, that the law considers those who lack empathy and guilt "particularly immoral and deserving of special condemnation.")

nothing to do with socio-pathology and can be, in fact, quintessentially innocent.¹⁵⁴ Many individuals with autism would certainly be capable of premeditation, competent to stand trial, and able to withstand punishment.¹⁵⁵ But does punishment respond to any ethical imperative or perform any desirable function besides incapacitation? Does retribution make sense when something other than free will is responsible for terrible actions?¹⁵⁶ If the autistic person is incapable of empathy or moral discernment, then there is no possibility of retribution or redemption.¹⁵⁷ If, on the other hand, there *is* empathy – a glimmer of consciousness, a touch of sensitivity – what do we make of it? Do we take compassion on the heart fallen captive to an ill-wired brain? Or does the finding that there is, after all, a soul enhance arguments for reproach and punishment?¹⁵⁸

These issues have been raised before in the general context of moral philosophy¹⁵⁹ or with regard to other mental disabilities,¹⁶⁰ but autism recasts them in a form that is interesting to neuroscientists, philosophers, and to the lay public. Criminal cases have polarized the movement and expressed profound epistemic divergences among its members.

¹⁵⁴ See BARNBAUM, *supra* note 8, at 65.

¹⁵⁵ See Nita A. Farahany, *Cruel and Unequal Punishments*, 86 WASH. U. L.R 859, 897 (2009) (observing that roughly 30% of people with autism do not have mental retardation). Farahany laments the injustice of depriving these persons of the mitigating effect of mental retardation in death penalty cases. *Id.* at 898.

¹⁵⁶ For a recent exploration of these questions, see Kenneth W. Simons, *Retributivists Need Not and Should Not Endorse the Subjectivist Account of Punishment, Response to: Adam J. Kolber, The Subjective Experience of Punishment*, 109 COLUM. L. REV. 182 (2009).

¹⁵⁷ Morse, *supra* note 153, at 133 (positing that “normative competence in the context of responsibility for wrongdoing should include the ability to empathize and feel guilt or some other reflexive reactive emotion.”).

¹⁵⁸ See BARNBAUM, *supra* note 8, at 110-11 (reporting on two (small and questionable) studies aimed at testing whether individuals with autism were able to tell right from wrong).

¹⁵⁹ See Meir Dan Cohen, *Responsibility and the Boundaries of the Self*, 105 HARV. L. REV. 959 (1992).

¹⁶⁰ See Steven K. Erickson, *The Myth of Mental Disorder: Transsubstantive Behavior and Taxometric Psychiatry*, 41 AKRON L. REV. 67 (2008) (discussing the difficulty of matching the metaphysical construct of free will, which takes center stage in criminal law, with psychiatric science, which relies on biomedical criteria).

On January 19, 2007, John Odgren, a sophomore in high school, stabbed to death 15-year old James Alenson, a fellow student whom he did not know.¹⁶¹ Odgren was a student with special needs, enrolled in a program called “Great Opportunities” but otherwise included in regular classrooms. He had been diagnosed with Asperger Syndrome, switched from one school to another over the years, and subjected to pharmacological treatment.¹⁶² The charge of first-degree murder, naturally central to the prosecutor’s case, involves premeditation and calls for a life sentence without possibility of parole. It has been argued that individuals with autism spectrum disorders are “unlikely to premeditate a crime and also ill equipped to assist in their own defense,”¹⁶³ but the assumption of the prosecution was that Odgren’s cognition was intact.¹⁶⁴ A state-hired psychologist determined in March 2007 that he did not need to stay in a psychiatric hospital,¹⁶⁵ that he could sit in jail, and that he would be competent to stand trial. By contrast, the defense argued that Odgren should be held not guilty by reason of insanity.¹⁶⁶

Within the Asperger community, John Odgren was immediately portrayed as an outcast (“This Odgren kid had something else going on in his brain besides [Asperger

¹⁶¹ Commonwealth vs. Odgren, 455 Mass. 171, 915 N.E.2d 215, 2009 Mass. LEXIS 664 (2009).

¹⁶² Patricia Wen and Milton J. Valencia, *Jury convicts Odgren of 1st-degree murder; Rejects insanity defense; life term mandatory*, BOSTON GLOBE, April 30, 2010 at 1.

¹⁶³ See Farahany, *supra* note 155, at 897. In Massachusetts, courts do not recognize the diminished capacity defense that is allowed in other states, but they permit defendants to submit “psychiatric evidence that would allow a jury to consider whether the defendant lacked the mental capacity to premeditate a killing.” Commonwealth v. Gaboriault, 785 N.E.2d 691, 699 (Mass. 2003).

¹⁶⁴ Andrew Ryan, *Odgren Hearing Focuses on Asperger’s*, BOSTON GLOBE, Mar. 7, 2008, at B1.

¹⁶⁵ Jonathan Saltzman, *Psychologist Says Teen Competent for Trial*, BOSTON GLOBE, Mar. 27, 2007, at 1A.

¹⁶⁶ Judge Botsford, in Commonwealth vs. Odgren (*supra* note 161) reports: “In January, 2008, the defendant notified the Commonwealth of his intent to rely on a defense of lack of criminal responsibility because of mental disease or defect.”

Syndrome]”),¹⁶⁷ and as one who must be distanced so as to avoid any association between ‘Aspies’ and crime. In this light, the villain was Odgren’s lawyer, who used the trendy label of AS to exculpate his client but in so doing branded many others with the mark of dangerousness. The Asperger’s Association of New England hurried to make the point that “physical violence is not at all typical of people with Asperger Syndrome,” and warned the public against buying into a “sweeping negative stereotype about all people with AS.”¹⁶⁸

A different view was held by Susan Senator, a notable activist in the battle for the rights of autistic children, with a focus on the more severe end of the spectrum.¹⁶⁹ Senator advocated acknowledging that impulsive and aggressive behaviors are sometimes a result of the autistic condition.¹⁷⁰ Acknowledgment of this truth, in her view, would lead to better policies, heightened services, preventive strategies, and extra help.¹⁷¹ This voice was echoed, albeit with much less empathy for autism, by those who focused on the

¹⁶⁷ Aspies for Freedom Message Board, www.aspiesforfreedom.com/showthread.php?tid=7330 (last visited May 24, 2010). The idea that something quite different from Asperger’s syndrome may be related to aggression finds support in Stewart S. Newman et al., *Violent Crime in Asperger Syndrome: The Role of Psychiatric Comorbidity*, 38 J. AUTISM DEV. DISORD. 1848 (2008).

¹⁶⁸ Autism Bulletin, <http://autismbulletin.blogspot.com/2007/01/aspergers-association-responds-to.html>. The website of the Autism Society of America explains:

In a review of the demographics of individuals with a developmental disability executed in the United States since 1976, of the 31 defendants that were executed no one had a diagnosis of autism . . . [W]here individuals with autism and related syndromes and conditions have been implicated in the death of others, i.e., ‘committed murder,’ they have not been a defendant in a homicide criminal action case. . . . [This is because] the majority of individuals with autism do not have premeditated intentions to harm others and do not understand the seriousness of their actions and therefore should be tried accordingly.”

See *The Criminal Justice System and Autism*, in AUTISM SOCIETY OF AMERICA, LIVING WITH AUTISM: CRIMINAL JUSTICE ISSUES, http://www.autism-society.org/site/PageServer?pagename=about_lwa_justice.

¹⁶⁹ Susan’s Blog: The Autism Blame Game, <http://susansenator.com/blog/2007/01/autism-blame-game.html> (Jan. 23, 2007).

¹⁷⁰ *Id.*

¹⁷¹ *Id.*

victim and on his family's tragedy. For the so-called neuro-typical majority of high-school students, living side by side with individuals whose ability to tell right from wrong is compromised can be unsettling. Some wondered whether the stereotypical traits of the autistic mind, its lack of empathy, its relational difficulties, might warrant an extra dose of precaution.¹⁷²

The jury eventually found Odgren guilty of first-degree murder and he was sentenced to life without parole.¹⁷³ Odgren's autism spectrum disorder fell out of the jurors' radar screen, but the chorus of conflicting voices aroused by the trial keeps echoing in the media.¹⁷⁴

2. Autism as Identity

Oscillation between the particular and the general is a feature of all legal endeavors. The judicial resolution of disputes requires both attention to the peculiarities of each case and elaboration of broad categories – an endless balancing of induction and deduction. The former responds to such principles as fairness, morality, and responsibility; the latter makes justice predictable, efficient, and manageable. In matters of criminal law, an inductive, case-specific approach prevails. When moral judgment,

¹⁷² The diagnosis of autism is so amorphous that it is hard to establish a direct correlation between autism and aggression. A study published in 2007 found “little evidence to support the notion that offending was a significant problem in people with Asperger.” David Allen et al., *Offending Behaviour in Adults with Asperger Syndrome*, 38 J. AUTISM DEV. DISORD. 748, 758 (2008). However, one often reads statements to the contrary. See e.g. Barbara G. Haskins & Arturo Silva, *Asperger's Disorder and Criminal Behavior: Forensic-Psychiatric Considerations*, 34 J. AM. ACAD. PSYCHIATRY & L. 374, 377 (2006) (suggesting that individuals with Asperger's syndrome appear more frequently in forensic populations than in the general public); see also Farahany, *supra* note 155, at 897. “Individuals with autism are easily manipulated, and therefore easily enticed into criminal behavior.” *Id.*

¹⁷³ Middlesex Superior Court, *Commonwealth v. Odgren* (April 29, 2010). On April 10, 2010 the defense had moved (in vain) to have the sentence of life without parole for a crime committed by a juvenile declared unconstitutional, and to have Odgren sentenced to life with the possibility of parole.

¹⁷⁴ See e.g. June Schwartz, *Justice Served in Odgren Case*, BOSTON GLOBE, May 8, 2010 at 10.

punishment, and redemption are involved, judicial focus is utterly individualized. Juries are asked to pay attention to case-specific circumstances and to behavioral and moral features of the offender only. Mental impairments of any kind are relevant to the final verdict and may lead to the conclusion that, given the absence of rationality, there is no punishable crime.¹⁷⁵ But there is no blanket excuse automatically connected to any given diagnosis. A case-by-case approach remains the rule.

The Model Penal Code of 1962 (the Code) was drafted in a way that would accommodate the evolution of brain science, and offers no definition of “mental disease or weakness.”¹⁷⁶ The language of the explanatory note attached to Section 4.01.1 of the Code is broad enough to include high-functioning autism or Asperger syndrome, i.e. cases in which cognition is intact but volition is distorted by an individual’s “failure to apprehend the significance of his actions in some deeper sense.”¹⁷⁷ In principle, therefore, defendants with autism must be judged like everyone else, that is, by means of a case-by-case investigation aimed at determining the mental state of each particular person. Accordingly, a survey of criminal law cases mostly collected between the 1970s and the 1990s reports that:

Persons with autism are judged as individuals rather than as members of a group. A diagnosis of autism does not categorically exempt a person from

¹⁷⁵ “A person is not responsible for criminal conduct if at the time of such conduct as a result of mental disease or defect he lacks substantial capacity either to appreciate the criminality [wrongfulness] of his conduct or to conform his conduct to the requirements of law.” MODEL PENAL CODE § 4.01.1 (1962).

¹⁷⁶ MODEL PENAL CODE § 4.01.1, explanatory note (1962).

¹⁷⁷ MODEL PENAL CODE § 4.01.1, explanatory note (1962)

[A finding of] irresponsibility does not require a total lack of capacity . . . An individual's failure to appreciate the criminality of his conduct may consist in . . . a failure to apprehend the significance of his actions in some deeper sense. . . . An individual is also not responsible if a mental disease or defect causes him to lack substantial capacity to conform his conduct to the requirements of the law. *This part of the standard explicitly reaches volitional incapacities.* [emphasis added].

prosecution and punishment. Rather, the nature and severity of the person's impairment are compared to legal standards for each particular rule (e.g., competency, capacity). As a general rule [. . .] the more severe the impairment, the more likely that an accused with autism will be able to successfully raise an autism-related defense.¹⁷⁸

This statement is in line with a well-established scholarly opinion that warrants focusing on the rationality of each individual offender, rather than on diagnostic labels.¹⁷⁹ In principle, individuals of all degrees of intelligence or rationality should be treated equally humanely in court.¹⁸⁰ In practice, however, awareness campaigns and advocacy strategies on behalf of persons with autism have produced catchy slogans, informational sound bites, and popular narratives. The discourse on crime is now increasingly characterized by the need to make sense of autism as a general phenomenon that defies the logic of individual free will, and yet does not really fit in the exculpatory language of mental retardation.¹⁸¹ When the perpetrator is allegedly autistic, the spotlight now extends to encompass the "autistic population."¹⁸² Judges face enhanced public scrutiny when they tackle the question of autism as excuse, and they are in a sense required to take

¹⁷⁸ Thomas A. Mayes, *Persons with Autism and Criminal Justice: Core Concepts and Leading Cases*, 5 J. POSITIVE BEHAV. INTERVENTIONS 92, 94, n.1 (2003).

¹⁷⁹ According to criminal law theorist Stephen Morse,

people try to create a new excuse every time [a new syndrome] is discovered that plays a role in behavior. But syndromes and other causes, including those of brain structure and function, do not have excusing force unless they sufficiently diminish rationality in the context in question. In that case, it is diminished rationality that is the excusing condition, not the presence of any particular type of cause.

Stephen J. Morse, *New Neuroscience, Old Problems: Legal Implications of Brain Science*, 6:4 CEREBRUM 81, 85-86 (2004). See also Morse, *supra* note 153, 131 (addressing volitional or compulsion problems, and concluding that they should be treated, just like cognitive problems, as rationality deficiencies).

¹⁸⁰ Joshua Greene & Jonathan Cohen, *For the Law, Neuroscience Changes Nothing and Everything*, PHIL. TRANS. R. SOC. LOND. B 359, 1775 (2004).

¹⁸¹ A recent CDC study shows that close to 60% of children with ASD have IQs over 70. Centers for Disease Control and Prevention, MMWR Surveillance Summaries, *Prevalence of Autism Spectrum Disorders*, December 18, 2009, available at <http://www.cdc.gov/mmwr/preview/mmwrhtml/ss5810a1.htm>.

¹⁸² Julie Berry, *Safety Doesn't Come From Stereotyping or Overreacting*, METROWEST DAILY NEWS, Feb. 2, 2007. See also Susan Spencer-Wendel, *Autism Defenses, Rare but Gaining Notoriety*, PALM BEACH POST, Apr. 18, 2009 (wondering whether "autism-made-me-do-it" is the "new defense du jour.").

crash courses in the psycho-dynamics of the autistic brain. The Supreme Court of New Jersey recently held that testimony from an expert who had diagnosed the defendant with Asperger's disorder was relevant to the defense and should have been admitted.¹⁸³

Lawyers like Jonathan Shapiro in the Odgren case are expected to delve into the neuroscience of autism to extract from it exculpatory evidence.¹⁸⁴ Whether or not they succeed, whether or not the court can be persuaded that rationality does not imply responsibility, the case becomes sensational because the defendant has autism.¹⁸⁵ The difficulty of integrating autism in a neuro-typical society is increasingly felt as a systemic problem, as crucial and impossible to ignore as race matters. As is the case with race, the form remains one of equal and individual accountability. The substance, though, is colored by issues of group identity.

C. Autism and Employment Discrimination

Because the spectrum of autistic disorders encompasses a multifarious range of abilities, many persons with autism – with or without a diagnosis – are seamlessly integrated in the workforce. The unforgettable portrayal of Bartleby the scrivener exemplifies the employee who never establishes a personal connection with his boss or

¹⁸³ State v. Burr, 948 A.2d 627 (N.J. 2008). By contrast, defense attorney Alan Margoles failed to persuade the court of the relevance of his client Michael John Anderson's Asperger's syndrome. Abby Simons, *Asperger's Diagnosis Is Rejected in Craigslist Trial*, STAR TRIBUNE (Minneapolis, MN) Mar. 14, 2009, at 2B.

¹⁸⁴ See Jeff Truesdell, *Should an Autistic Child be Charged with Murder?* 71:15 PEOPLE 87 (Apr. 20, 2009) (commenting on the murder of Gertrude "Trudy" Steuernagel allegedly committed by her severely autistic son, Sky Walker).

¹⁸⁵ See Michelle Dawson, *Autism Society Canada Speaks for Itself*, NO AUTISTICS ALLOWED http://www.sentex.net/~nexus23/naa_js.html (Open Letter of Oct. 23, 2003, denouncing the Autism Society of Canada's "denigration of autistics through sensationalism, condescension, and misrepresentation . . . [aimed at] fulfill[ing] the emotional and perceived financial needs of non-consumers.").

fellow workers, and whose repetitive speech and behavior seem to be determined by a mysterious internal logic rather than by incentives or consequences.¹⁸⁶ Anecdotes abound on the high prevalence of autism or Asperger's syndrome among math geeks – persons with relational difficulties and often superior analytic intelligence.¹⁸⁷ Engaging persons with autism in productive activities suited to their particular skills is indeed possible.¹⁸⁸ Channeling employees with high-functioning autism into high-tech enterprises, emphasizing savantism and mathematical wizardry, does pose ethical and legal dilemmas,¹⁸⁹ but experiments of this sort consolidate the utilitarian foundation of autism advocacy and positively change societal attitudes towards this type of disability. When, however, the focus shifts onto persons with more significant impairments, the challenge of embracing them in the workplace and keeping them employed suddenly appears more daunting. The case law on ADA claims brought by employees with autism against their employers is still sparse, but it already reveals discursive divides that will only grow wider and deeper.

In order to qualify for judicial protection against discrimination in the workplace, a person must be found to have “a physical or mental impairment that substantially limits

¹⁸⁶ Herman Melville, *Bartleby, the Scrivener: A Story of Wall Street*, Putnam's Monthly Mag. of Am. Literature, Sci. and Art, 546, July-Dec. 1853, at 546, 609-613.

¹⁸⁷ See, e.g., Steve Silberman, *The Geek Syndrome*, WIRED, December 2001 (discussing the prevalence of autistic characteristics amongst Silicon Valley programmers and their children, available at <http://www.wired.com/wired/archive/9.12/aspergers.html> (last visited May 24, 2010)).

¹⁸⁸ For the Danish company Specialisterne, hiring persons with autism is no less than a business plan, and other entrepreneurs around the world are following their example. http://specialisterne.com/html/english/specialisterne/specialisterne_mission.html (last visited May 24, 2010). See *Brave Thinkers*, ATLANTIC, November 2009, at __. Autelligent Laboratories is an example of one American company trying to expand the the Danish model. Autelligent Laboratories, <http://www.autlabs.com>.

¹⁸⁹ Wolman, *supra* note 81 (reporting that “Michelle Dawson, an autistic cognition researcher at the University of Montreal, Canada, [...] cautions against pigeonholing people: “Asking what kind of job is good for an autistic is like asking what kind of job is good for a woman,” she says.”)

one or more major life activities.”¹⁹⁰ Courts have disagreed on this issue, but there certainly is precedent for considering social interaction a “major life activity” for ADA purposes,¹⁹¹ and social interaction is by definition impaired in persons with autism.¹⁹² Secondly, the person must be qualified to perform the essential functions or duties of a job, with or without reasonable accommodation, and this requirement is obviously met by persons with autism in a variety of circumstances.¹⁹³ ADA protection is therefore theoretically available for individuals with autism.

On the ground, however, complications arise. Autism requires accommodations that are oftentimes counterintuitive,¹⁹⁴ and it may be hard to see why a person endowed with average or high intelligence is entitled to protection under the ADA. The case of Cathleen Comber, employed by a rehabilitation center in Maryland, exemplifies these difficulties. One day Cathleen refused to drive a company van because she smelled deodorant in it and could not stand it.¹⁹⁵ When reproached by a supervisor, she threw a fit

¹⁹⁰ [42 U.S.C. § 12102](#).

¹⁹¹ *McAlindin v. County of San Diego*, 192 F.3d 1226, 1232-35 (9th Cir. 1999) (finding that “interacting with others” is a major life activity under the ADA). *See also* *Francis v. Chem. Banking Corp.*, 213 F.3d 626, 2000 WL 687715 at *1 (2d Cir.) (assuming without deciding that “interacting with others” constitute[s] [a] major life activity”); *Doyal v. Oklahoma Heart, Inc.*, 213 F.3d 492, 496 (10th Cir. 2000) (same). *Cf.* *Soileau v. Guilford of Me., Inc.*, 105 F.3d 12, 15 (D. Me. 1996) (expressing doubt that “the ability to get along with others” is a major life activity under the ADA).

¹⁹² *Morgenthal v. AT&T*, No. 97 Civ. 6443 (DAB), 1999 U.S. Dist. LEXIS 4294, at *8 (S.D.N.Y. Apr. 5, 1999) (“[Autism] is recognized as a disability under the ADA. See 24 C.F.R. § 9.103 (1998).”); *Jakubowski v. Christ Hosp.*, No. 1:08-CV-00141, 2009 U.S. Dist. LEXIS 66847, at *23 (S.D. Ohio Aug. 3, 2009) (“Plaintiff’s Asperger’s Syndrome amounts to a “mental impairment.””)

¹⁹³ *Taylor v. Food World, Inc.*, 133 F.3d 1419, 1425 (11th Cir. 1998) (summary judgment for employer denied where there existed a genuine issue of material fact as to whether autistic grocery store clerk terminated for loud constant repetitive speech and inappropriate comments could nevertheless perform the essential functions of his clerk position with accommodation).

¹⁹⁴ Magda Mostafa, *An Architecture for Autism: Concepts of Design Intervention for the Autistic User*, 2 INT’L J. ARCHITECTURAL RESEARCH 189, esp. at 193 (2008).

¹⁹⁵ *Comber v. Prologue, Inc.*, No. JFM-99-2637, 2000 U.S. Dist. LEXIS 16331, at *3 (U.S. Dist. Md. Sept. 28, 2000).

and kicked a chair across the hall.¹⁹⁶ She was fired the next day.¹⁹⁷ Anyone familiar with autism knows that sensory responses can be particularly acute in persons with ASD.¹⁹⁸ For Cathleen, the very prospect of being stuck in a smelly vehicle with closed windows was probably enough to trigger a break-down.¹⁹⁹ Nonetheless, Cathleen was found not entitled to ADA protection and the case ended in summary judgment for the employer.²⁰⁰ The employer had accommodated her multiple disabilities in many ways.²⁰¹ Evidence of her hypersensitivity to smell did not satisfy the *Daubert* standard.²⁰² Since she had been capable of performing the job's many tasks for years and had also gotten along with most of her fellow workers, the altercation between Cathleen and her supervisor that followed the bus accident was read as a personality conflict, rather than as a manifestation of Cathleen's autism. She was therefore penalized, vis-à-vis other ADA-eligible workers, because of her extraordinary ability to compensate for her difficulties most of the time.

More recent cases signal a somewhat deeper understanding of autism.²⁰³ The case of Martin Jakubowski, a medical resident diagnosed with Asperger's syndrome, whose perseveration and difficulty communicating with patients caused him to be fired from the family medical practice where he had been working, indicates heightened judicial sensitivity to his disability, and a correspondingly heightened scrutiny of the employer's

¹⁹⁶ *Id.* at *4.

¹⁹⁷ *Id.*

¹⁹⁸ Joyce Davidson, *It Cuts Both Ways: A Relational Approach to Access and Accommodation for Autism*, SOCIAL SCIENCE & MEDICINE 305, 307-308 (2010).

¹⁹⁹ *Comber* at *4.

²⁰⁰ *Id.* at *33.

²⁰¹ *Id.* at *2.

²⁰² *Id.* at *13-15.

²⁰³ See e.g. *Burriola v. Greater Toledo YMCA*, 133 F. Supp. 2d 1034 (N.D. Ohio 2001) (concerning ADA Title III accommodations in an afternoon program for a child with autism).

conduct.²⁰⁴ It is clear that autism advocacy has changed the judicial discourse on autism, but the reality of integrating this particular disability in the workforce remains plagued by the endemic fuzziness of ADA standards, exponentially complicated by the fuzziness of autism science itself.

IV. THE QUEST FOR TREATMENT AND LEGAL CHANGE

Endowed with extraordinary energy and transformative potential, enriched by its many internal strands and well anchored to institutional moorings, the autism social movement is now busy making history. Having won some preliminary legislative battles, it is now working its way through the courts, pushing the envelope of existing social benefits, and inventing new avenues of entitlement for those on the autism spectrum and their families. Securely rooted in utilitarian turf, the movement can safely tout a message of empathy and morality. Voices of distinct beauty have emerged from all its quarters. The movement has already begun to affect the legal system as we know it, and is bound to bring about further changes.²⁰⁵

The question is, *which* changes. Autism is splendidly poised to be a catalyst for social justice. It is apt to knock out of existence the myth of able-minded dominance. It injects fresh utilitarian blood into the veins of disability advocacy at large. It puts extreme suffering in the spotlight and brings it so close to wealth and intelligence that we can no longer ignore it. It demands coordinated efforts, and in so doing it calls for institutional

²⁰⁴ Jakubowski, 2009 U.S. Dist. LEXIS 66847, at *25. The court was “sympathetic . . . to Plaintiff’s clearly-established disability” but found him not “otherwise qualified” for this job. *Id.*

²⁰⁵ See Jack M. Balkin & Reva B. Siegel, *Principles, Practices, and Social Movements*, 154 U. PA. L. REV. 927 (2006).

reforms. Autism seems set to contribute in a very real way to the transformation of our chaotic health care sector into a system – one that would work in synch with education and social services agencies.

Unsurprisingly, the way in which the movement’s history is unfolding is not always aligned with such rosy projections. Reva Siegel and Jack Balkin aptly remind us that “rarely can movements completely realize their aims in law. More often, a movement's aims are transformed in the quest.”²⁰⁶ Along the way, the autism movement is encountering difficulties and diversions. The textured analysis of autism-related legal changes in the following pages explores how the autism movement, its hands deep in the dough of law and politics, ends up producing distributive outcomes that may not always match the lofty goals of its advocates. There is, as is always the case for social movements of all kinds, the danger of cooptation,²⁰⁷ and the cause of autism may be hijacked by parallel political agendas. The autism movement may be intended as a wedge that will slowly bring about a more humane allocation of resources across the range of human conditions,²⁰⁸ but it may end up as a silo, with benefits parsimoniously tailored to one particular diagnosis. Thanks to autism, the tide of attention to neuro-diversity is rising. But will all the boats rise? And when the tide recedes, what will lie dead on the shore?

The following sections track recent developments in special education law, private insurance, and Medicaid assistance. The movement naturally attempts to secure

²⁰⁶ *Id.*

²⁰⁷ Orly Lobel, *The Paradox of Extralegal Activism: Critical Legal Consciousness and Transformative Politics*, 120 HARV. L. REV. 937, 948-58 (2007).

²⁰⁸ Caring about autism “is something from which all manner of people can and must benefit.” MURRAY, *supra* note 4, at 212.

access to services for individuals with autism spectrum disorders, at times by espousing general political messages of inclusion and social empathy, while at other times by focusing on autism's exceptionalism.

A. Education

The impact of the autism movement in the context of education law, namely its ability to channel resources towards children with autism and to reshape the culture of special education, must be assessed against the general backdrop of school funding.

The problem of unequal access to educational opportunities has vexed America since the times of Horace Mann²⁰⁹ and is a deeply embedded trait of the United States' school system. The resilient logic of local control over education makes it so that school funding remains tied in significant part to local property taxes.²¹⁰ Thus, per-pupil expenditures vary dramatically across districts and across states.²¹¹ Special education differs from this picture only slightly. The Individuals with Disabilities Education Act (IDEA) requires all educational agencies receiving federal funds to provide free and appropriate public education (FAPE) to all children with disabilities.²¹² As commonly interpreted, the FAPE requirement imposes upon schools the obligation to provide individualized educational programs, strictly tailored to the special needs of each eligible

²⁰⁹ See LAWRENCE A. CREMIN, *THE TRANSFORMATION OF THE SCHOOL: PROGRESSIVISM IN AMERICAN EDUCATION, 1876-1957* at 8-9 (1961). In the 1840s, Horace Mann launched the idea of free education as social equalizer. *Id.*

²¹⁰ See James E. Ryan & Michael Heise, *The Political Economy of School Choice*, 111 *YALE L.J.* 2043, 2087 (2002) (discussing the resilience of suburban interest in local control).

²¹¹ See MICHAEL J. KAUFMAN, *EDUCATION LAW, POLICY, AND PRACTICE* 119-22 (2005) (discussing the degree of funding inequality among and within the States).

²¹² IDEA is the current name of the original Education for Handicapped Children Act of 1975. See Wendy F. Hensel, *Sharing the Short Bus: Eligibility and Identity under the IDEA*, 58 *HASTINGS L.J.* 1147, 1153 (narrating the legislative history of this statute).

student. Special education, therefore, is a significant component of local school budgets. So far, federal funds have covered no more than 17-18% of the costs of special education, letting states and districts foot the rest of the bill.²¹³ The result is a profoundly uneven culture of special education across the country. The quality and the intensity of services range widely, depending on the wealth of states or districts and on the relative political clout of disability advocacy in each community.²¹⁴

A further source of variation and inequity, even within each district, is the relative power of each child's family to negotiate a strong individualized educational plan before the start of the school year. According to the IDEA, the parents or guardians of each student are both allowed and expected to work closely with the team of educators and therapists in the design of an appropriate range of services that meets that student's specific needs. The parents' role as advocates in the process is now a central feature of the law of special education. The tone of the battle for children with disabilities has

²¹³ See Glen Chang, *Caring for New Jersey's Children with Autism: A Multifaceted Struggle for Parity*, 60 RUTGERS L. REV. 997, 999 (2008). The IDEA authorizes appropriations up to 40% of the costs. The stimulus bill enacted in February of 2009 contains specific additional funding for special education. American Recovery and Reinvestment Act of 2009, Pub. L. No. 111-15, 123 Stat. 182-83 (2009). Its effectiveness remains to be seen.

²¹⁴ The distributive effect of IDEA in the context of school equity has been subject to debate. Opening the school doors to previously excluded children was undoubtedly a progressive move, but some posited that the federal mandate would disproportionately aide students with minor handicaps (such as newly labeled learning disabilities) at the expense of low-income or minority students. See MARK KELMAN & GILLIAN LESTER, *JUMPING THE QUEUE: AN INQUIRY INTO THE LEGAL TREATMENT OF STUDENTS WITH LEARNING DISABILITIES* 159 (1998) (positing that IDEA mandates, when applied in poor school districts, have "squeeze[d] the nondisabled students," with the result of "further compromising inadequate educational systems," rather than increasing political pressure for additional funding). Since their writing, newer mechanisms for the targeted allocation of federal funds to low-income and minority students have been introduced, and may have somewhat changed the distributive scenario envisaged by the authors. See No Child Left Behind Act of 2001, 20 U.S.C.S. §6301 et seq., tit. I.

changed accordingly: the class actions of the 1970s have given way to strictly individual disputes, fought by parents with their own means only, one IEP at a time.²¹⁵

Enter autism. At its start, the movement was poised to give the public education system a shake, at least towards the limited goal of opening up meaningful educational opportunities for all the children on the autistic spectrum. So far, results have been mixed. On one hand, children anywhere in the country are much more likely to be diagnosed and serviced. On the other hand, inequities persist and are even less likely than before to be addressed in court. Judicial conflict, acute and disruptive through the 1990s, has been somehow normalized into routine educational business. The distributive reach of educational services, even within the pool of children with autism, remains generally regressive.

1. Litigating Autism in School

The starting point was bleak. Throughout the 1960s, very few school programs would accept children with autism. Since their condition was neither a physical disability nor, in many cases, mental retardation, they “slipped right through the educational loophole.”²¹⁶ When the Education for Handicapped Children Act of 1975 (later renamed IDEA) came into force, the educational know-how in matters of autism was still virtually

²¹⁵ Martha Minow, *Response, Accommodating Integration*, 157 U. PA. L. REV. PENNUMBRA 1, 5-6 (2008), <http://www.pennumbra.com/responses/10-2008/Minow.pdf> (discussing the “resilience of the individualized focus,” and explaining that, while “[a]chieving recognition as rights-bearers is indeed an historic accomplishment for persons with disabilities,” the focus on individual rights makes it difficult to perceive and discuss “interactions, mutual benefits, relational gains, and interdependence.”).

²¹⁶ SCHREIBMAN, *supra* note 61, at 254. *See also* KARL TARO GREENFELD, *BOY ALONE: A BROTHER’S MEMOIR* 57 (2009) (referring to the late 1960s as to an “Era of Despair” for parents of children with autism).

null.²¹⁷ The machine of due process, however, was set in motion, and parents began to use it to create from scratch what is now a rich culture of autism education.

Autism was added to the IDEA in 1991.²¹⁸ By then, the class action mode that had prompted the 1970s' paradigm shift in special education²¹⁹ had run out of steam if not of *raison d'être*. After fifteen years of IDEA practice, with its principled emphasis on individualized educational plans and parental due process, special education litigation had already become what it is now – a myriad of unrelated, atomistic disputes, each focused by definition around one child only.²²⁰ Families have since engaged in elaborate negotiations with school administrators.²²¹ According to detailed provisions in the IDEA, when discussions and mediation fail, the parties present their respective arguments before hearing officers, who are required to verify that both school and parents followed all mandated procedures. In terms of substance, the hearing officer must determine whether a child's IEP was properly written and implemented, and whether the child received “free

²¹⁷ Following the Education of the Handicapped Act of 1970 (20 U.S.C. 1400 et seq. (2000), Pub. L. No. 91-230, 84 Stat. 121 (1970)), Congress specifically addressed the rights of students with disabilities in the Education for All Handicapped Children Act (EAHCA) of 1975 (20 U.S.C. 1400 et seq. (2000), Pub. L. No. 94-142, 89 Stat. 773 (1975)). In a 1990 reauthorization, EAHCA was renamed as the Individuals with Disabilities Education Act (IDEA) (Education of the Handicapped Act Amendments of 1990, Pub. L. No. 101-476 § 901(b), 104 Stat. 1103 (1990). 20 U.S.C. § 1401(3)(A)(i) (2000)). In the aftermath of the No Child Left Behind Act of 2001, (20 U.S.C. § 1412(a)(1) (2000)) which applies to both disabled and non-disabled students, the IDEA was reauthorized by the Individuals with Disabilities Education Improvement Act of 2004 (the 2004 Reauthorization) which emphasizes accountability. See Stacey Gordon, *Making Sense of the Inclusion Debate under IDEA*, 2006 BYU EDUC. & L.J. 189 (2006).

²¹⁸ Pub. L. 102-119, 105 Stat. 587 (1991), codified at 20 U.S.C. § 1401(3)(A)(i) (2006).

²¹⁹ Pa. Ass'n for Retarded Children v. Commonwealth, 334 F.Supp. 1257 (E.D.Pa. 1971).

²²⁰ A group of parents' attempt to file a class action against a school district, based on the district's inability to provide for students with autism in general, was recently rejected by the court: “[T]here are no factual issues common to all the plaintiffs. Though all of the plaintiffs fall along the autism spectrum, the severity of their disabilities varies widely.” *Nelson v. Bd. of Educ.*, 2009 U.S. Dist. LEXIS 123892 (D.N.M., Jan. 7, 2009).

²²¹ For IDEA litigation in matters of autism, see Terry Jean Seligmann, *Rowley Comes Home to Roost: Judicial Review of Autism Special Education Disputes*, 9 U.C. DAVIS J. JUV. L. & POL'Y 217 (2005).

and appropriate public education” (FAPE) in a “least restrictive environment” (LRE).²²² Such substantive benchmarks are never easy to assess, but when the disability happens to be autism, things can become particularly controversial.²²³

Parents’ demands vary a great deal, but they usually include “related services” such as occupational and speech therapy. In order to curb such requests, educational agencies have routinely tried to draw a distinction between medical and educational services for autistic children, and have offered to pay only for the latter.²²⁴

Another common ground of disagreement is inclusion. It is not clear how much time autistic children should spend in regular classrooms, where they can gain familiarity with neuro-typical peers, or in special education classrooms, where they benefit from better tailored education.²²⁵ This sort of dispute often revolves around the judicial interpretation of the LRE standard, which requires that children be kept as much as possible within the mainstream of general education. This standard was originally conceived of to remedy the historical isolation of students with special needs, but it may

²²² *Id.* at 221 (referring to these acronyms as IDEA’s “alphabet soup”).

²²³ *Id.* at 218 (positing that “these cases present a particularly timely and dramatic prism through which to examine [certain] aspects of IDEA). *See also* Mothers From Hell, www.mothersfromhell2.org (providing a sense of how acrimonious the conflict can be).

²²⁴ *See, e.g.*, *O’Dell v. Special Sch. Dist. of St. Louis County*, 503 F. Supp. 2d 1206 (E.D. Mo. 2007). “[T]here is a substantial difference between a medical diagnosis of autism and an educational diagnosis of autism. The latter involves considering the child’s specific abilities and limitations in areas of educational concern.” *Id.*

²²⁵ Anne Proffitt Dupre, *Disability and the Public Schools: The Case Against “Inclusion,”* 72 WASH. L. REV. 775 (1997); Conor B. McDonough, *The Mainstreaming Requirement Of The Individuals With Disabilities Education Act In The Context Of Autistic Spectrum Disorders*, 35 FORDHAM URB. L.J. 1225, 1227 (2008) (arguing that “Congress and the Department of Education should relax the mainstreaming requirement in the context of autistic spectrum disorders.”).

make no sense for those children with autism who can only learn by way of one-on-one instruction and whose sensory system shuts down in the presence of peers.²²⁶

Eligibility can also pose thorny problems. Many children with autism spectrum disorders have average or high intelligence, and their autism manifests itself more as a social disability than as an intellectual impairment.²²⁷ Even in the presence of an autism spectrum diagnosis (most often, Asperger's syndrome), schools have denied the need for individualized instruction.²²⁸

A fourth articulation of autism disputes in school settings relates to the definition of an "appropriate" education, which by law does not need to coincide with the "best" option available on the market for educational services. IDEA courts have traditionally required that schools provide only an "equal floor of opportunity" to children with disabilities, even when it is arguable that students could perform better if granted additional services.²²⁹ In the case of autism, the "equal floor" criterion is too vague to be of any use. Science is uncertain: autism is a huge spectrum of disorders calling for different styles and modes of intervention.²³⁰ Applied Behavioral Analysis (ABA) has

²²⁶ "Mainstreaming and full inclusion are positive words. They sound much better than saying that the school district can save money by partly or fully depriving a child of the special help he or she needs. . . ." BRYNA SIEGEL, *THE WORLD OF THE AUTISTIC CHILD* 226 (1996). See also Tamera Wong, Note, *Falling Into Full Inclusion: Placing Socialization Over Individualized Education*, 5 U.C. DAVIS J. JUV. L. & POL'Y 275, 275-76 (2001); Bernard Rimland, *Inclusive Education: Right for Some*, 7 AUTISM RES. REV. INT'L 3 (1993).

²²⁷ Mandell (2009), *supra* note 41.

²²⁸ See, e.g., *Mr. I. ex rel. L.I. v. ME. Sch. Admn. Dist. No. 55*, 480 F.3d 1 (1st Cir. 2007). For an in-depth discussion of such issues see Melissa J. Sullivan, *Brilliantly Disabled*, 29 CHILD. LEGAL RTS. J. 49 (2009).

²²⁹ The "floor of opportunity" standard was established by the US Supreme Court in *Bd. of Educ. v. Rowley*, 458 U.S. 176 (1982).

²³⁰ Applied Behavior Analysis (ABA), the most established of many known modes of intervention, relies on one-to-one therapy. Children are rewarded each time they perform a given task – such as stacking two blocks or assembling puzzle pieces. Quantitative assessments measure in detail children's ability to respond to prompts and develop basic skills, with goals becoming increasingly ambitious. Pioneering ABA work was conducted by O. I. Lovaas. See O. I. Lovaas, *Behavioral Treatment and Normal Educational and*

certainly demonstrated its efficacy, but there is tremendous disagreement on how much therapy is really necessary, or how much of it should be paid for by the school.²³¹

Lastly, private schools for autistic children have mushroomed all over the country and parents often find that their programs offer better chances of recovery.²³² Many disputes are about footing the bill of private placements unilaterally chosen by families.²³³

2. School Litigation and the Problem of Distributive Equity

Over the years, courts have variously articulated such points of contention. The system allows for families' bargaining power and resources to weigh heavily upon the process. The fact that the content of IEPs happens to depend on the bargaining power of each family is not specifically related to autism. It is, rather, a general feature, a side effect, so to speak, of IDEA's principled goal of letting parents take part in IEP drafting.²³⁴ The point with autism is that the room for disagreement with school personnel is enormous, dollar figures are astronomical, and the importance of money, strategy and

Intellectual Functioning in Young Autistic Children, 55 J. CONSULTING & CLINICAL PSYCHOL. 3 (1987). At the opposite end one finds looser and warmer methods, such as Floor Time, that 'take the lead from the child' and build upon the child's own initiative, without a pre-determined agenda. STANLEY GREENSPAN, *ENGAGING AUTISM: USING THE FLOORTIME APPROACH TO HELP CHILDREN RELATE, COMMUNICATE, AND THINK* (2006).

²³¹ See Erin Phillips, *When Parents Aren't Enough: External Advocacy in Special Education*, 117 YALE L.J. 1802, 1821-22 (2008) (referring to "a list of treatments, including applied behavior analysis (ABA), floortime therapy, occupational therapy, speech therapy, or the school-based method Treatment and Education of Autistic and Related Communication-Handicapped Children (TEACCH), and lamenting that "the vague descriptions of a FAPE in the text of the legislation fail to provide useful direction as to what services students are entitled to receive. One helpful benchmark would be an educational 'menu' of sorts for each child, or even for each type of disability. . . [N]o such menu exists, and . . . this omission often creates an insurmountable obstacle to advocacy for parents.").

²³² Schemo & Medina, *Disabilities Fight Grows as Taxes Pay for Tuition*, N.Y. TIMES, Oct. 27, 2007, at A1.

²³³ See, e.g., *J.P. ex rel. Peterson v. County Sch. Bd. of Hanover Country, Va.*, 516 F.3d 254 (4th Cir. 2008).

²³⁴ See Daniela Caruso, *Bargaining and Distribution in Special Education*, 14 CORNELL J.L. & PUB. POL'Y 171 (2005).

clout in the negotiation of school services is particularly acute. IDEA litigation is expensive. Victorious parents in IDEA disputes can recover lawyers' fees,²³⁵ but they are unlikely to recover anything if they voluntarily settle before going to trial.²³⁶ A second source of difficulty is the burden of proving that the IEP proposed by the school district does not meet all IDEA requirements — a burden now clearly placed on the parents.²³⁷ This burden can often be carried only with the help of skillful advocacy and external evaluations. Parents benefit greatly from hiring professional advocates, who are not lawyers but rather experts in special education and possibly very effective repeat players in school litigation, but the cost of such experts now bears firmly on their shoulders and cannot be shifted onto losing adversaries.²³⁸ The market of autism experts has plenty to offer to all, but not all families can afford independent educational consultations.²³⁹

Against this backdrop, the autism movement is poised to enhance the legal agency of all parents of children with autism in court. In 2007, the Supreme Court decided

²³⁵ Courts “may award reasonable attorneys’ fees as part of the costs” to parents who prevail in an action brought under the IDEA. 111 Stat. 92, 20 U. S. C. §1415(i)(3)(B).

²³⁶ *Buckhannon Bd. & Care Home v. West Virginia Dep’t. of Health*, 532 U.S. 598 (2001). See Christy Marlett, *The Effects of the Idea Reauthorization of 2004 and the No Child Left Behind Act on Families with Autistic Children: Allocation of Burden of Proof, Recovery of Witness Fees, and Attainment of Proven Educational Methods for Autism*, 18 KAN. J.L. & PUB. POL’Y 53, 69 (2008) (discussing the application of *Buckhannon* to IDEA disputes).

²³⁷ *Schaffer v. Weast*, 546 U.S. 49, 62 (2005) (holding that “the burden of proof in an administrative hearing challenging an [individualized education program] is properly placed upon the party seeking relief”). See Jennifer M. Saba, *Undue Deference: Toward a Dual System of Burdens Under the Individuals with Disabilities Education Act*, 57 DEPAUL L. REV. 133 (2007) (criticizing *Schaffer*).

²³⁸ See *Arlington Cent. Sch. Dist. Bd. of Educ. v. Murphy*, 548 U.S. 291 (2006) (finding that the fees paid to experts in the course of legal disputes are not the kind of costs whose recovery the IDEA allows and that only “explicit statutory authority” would authorize payment of expert witness fees). *Arlington* is generally considered a major obstacle to equity in the allocation of special education services. In November of 2007, a bill was introduced in Congress to amend the Individuals with Disabilities Education Act, so as to permit a prevailing party in an action or proceeding brought to enforce the Act to be awarded expert witness fees and certain other expenses. IDEA Fairness Restoration Act, H.R. 4188, 110th Cong. (2007).

²³⁹ *IDEA Fairness Restoration Act Introduced: Restoring Parents’ Rights to Expert Witness Fees*, Counsel of Parents, Attorneys and Advocates (hereinafter COPAA), http://www.copaa.org/news/IDEA_fairness.html (stating that approximately 36% of children with disabilities live in families earning less than \$25,000 a year; over 2/3 earn less than \$50,000).

Winkelman v. Parma and took what was perceived as a step towards equal rights for children of lesser financial means. Families who lack money but have enough time and energy can now avoid or reduce lawyers' fees by representing their children in federal courts directly.²⁴⁰ Bypassing legal counsel, not only do families save financial resources; they also make their own voices heard, convey the reality of their tragedy to the court, and bring their unique knowledge of the child to bear on the question of what counts as "appropriate" education. The Winkelmans' personal victory proved hollow, as they lost on the merits,²⁴¹ but the case remains a strong procedural breakthrough championed by the parents of a child with autism. Arguably (and again with the caveat that special education litigation remains beyond the reach of many) this holding realized in full the spirit of the IDEA by giving real meaning to parents' procedural rights.²⁴² It took autism to bring about this change. The issue of representation without counsel in IDEA cases had been litigated for decades, but only the Winkelmans, speaking for an autistic boy, managed to reverse a solid judicial trend. Undoubtedly, the powerful mobilization of autism networks around their case²⁴³ and the pro bono work of prestigious lawyers had

²⁴⁰ *Winkelman v. Parma City Sch. Dist.*, 550 U.S. 516 (2007) (holding that parents may "file these suits themselves, without legal representation, in order to enforce rights guaranteed by the Individuals with Disabilities Education Act (IDEA)."). See Barbara Etkind & Prashant Khetan, *Post-Winkelman v. Parma: Ensuring Good Education for Special Needs Children*, AUTISM ASPERGER'S DIGEST MAG., Nov.-Dec. 2007).

²⁴¹ *Winkelman v. Parma*, 294 Fed. Appx. 997 (6th Cir. Ohio 2008) (on remand after the spectacular victory on pro-se representation before the Supreme Court (affirming the holding of the district court (*Winkelman v. Parma City Sch. Dist.*, 411 F. Supp. 2d 722 (2005))).

²⁴² See *Winkelman v. Parma City Sch. Dist.*, 550 U.S. 516, 526 (2007). Justice Anthony Kennedy, writing for the majority, concluded that "parents have enforceable rights at the administrative stage, and it would be inconsistent with the statutory scheme to bar them from continuing to assert those rights in federal court at the adjudication stage." *Id.* at 517.

²⁴³ ASA's Ohio chapter, the Autism Society of Ohio, filed an amicus brief in support of the petitioner. Brief of the Ohio Coalition for the Education of Children with Disabilities & the Autism Society of Ohio as Amici Curiae Supporting Petitioners, *Winkelman v. Parma City Sch. Dist.*, 550 U.S. 516 (2007) (No. 05-983), 2006 WL 4643858.

much to do with the Winkelmans' break-through. The Bush administration supported the parents' cause. The Department of Justice opined that the Court should grant review of the case and the Solicitor General's brief favored the Winkelmans.²⁴⁴ Their success scored points for the whole autism movement.

Of course, the movement has impacted the field of autism-related educational services well beyond the boundaries of high-profile judicial disputes. Children of parents who are neither willing nor able to argue with school administrators may still obtain decent services simply because autism is much better known and understood today than it was in the 1990s. Autism has asserted itself as a reality that cannot be ignored either in the classroom or in budget computations. Because of the laudable work of autism networks, information on educational options for autistic children is increasingly available to concerned parents.²⁴⁵ Autism can be the label of choice for parents determined to obtain as individualized an educational plan as possible for their children.²⁴⁶ Administrators are now willing to concede that individualized behavioral intervention does make a positive difference, and school districts have become increasingly creative in designing autism programs that are cost effective and reasonable,

²⁴⁴ Brief for the United States as Amicus Curiae, *Winkelman v. Parma City Sch. Dist.*, 550 U.S. 516 (2007) (No. 05-983).

²⁴⁵ "Autism is more familiar and visible than ever before." GRINKER, *supra* note 6, at 19.

²⁴⁶ "[P]arents whose children have rare chromosomal disorders that involve social and language deficits or mental retardation . . . want them to be diagnosed with autism." GRINKER, *supra* note 6, at 6. That autism is an increasingly common label of choice for children with moderate developmental disorders can be inferred from available data. Among children receiving special education services outside the regular education classroom for less than 21% of the time (i.e. children substantially included in the general education classroom), the percentage of children identified as autistic went from 24 in 2001 to 31 in 2005. U.S. Department of Education, Office of Special Education Programs, Data Analysis System (DANS), Children with Disabilities Receiving Special Education Under Part B of the Individuals with Disabilities Education Act: 2001-2005, OMB #1820-0517 (July 17, 2006).

if not optimal.²⁴⁷ Lastly, because autism is de-stigmatizing, it is plausible that families who would resent other demeaning labels and therefore refuse IDEA services are more readily accepting special education interventions in favor of their children.²⁴⁸ The movement has therefore achieved some of its equity goals in this realm. But the story is not one of linear progress.

3. Autism and Vouchers

Another recent case²⁴⁹ of great interest in the camp of autism advocacy concerns the possibility of obtaining reimbursement for unilateral placement of the child in a private school, based on the parents' belief that the program offered by the school district is not even worth trying.²⁵⁰ The text of the IDEA makes it possible for families to obtain reimbursement of private tuition when there is a record of inappropriate education in the public school, but is less clear when applied to cases where the parents do not give the school district's IEP a chance.²⁵¹ The child whose family brought this issue all the way up to the Supreme Court in 2007 did not have autism, but his father, Tom Freston, was well

²⁴⁷ See Fran Smith, *Overcoming Autism: Public Schools Deal with a Growing Problem*, EDUTOPIA, Mar. 19, 2008 (reporting that "school administrators realize that it may be cheaper to beef up autism programs than continue to fight lawsuits.").

²⁴⁸ The historic over-representation of black children in special education classes has led ethnic minorities to resent testing and special education placement in public schools. See, e.g., *Larry P. by Lucille P. v. Riles*, 793 F.2d 969 (9th Cir. 1984). By contrast, middle-class white families have made large use of testing. See *KELMAN & LESTER, supra* note 214, at 4. "[T]he movement to secure rights for children with learning disabilities had its genesis in the grass-roots mobilization of largely white, middle-class parents in the late 1950s and early 1960s to gain resources for what they perceived as their 'underachieving' children." *Id.*

²⁴⁹ *New York City Bd. of Educ. v. Tom F.*, 552 U.S. 1 (2007).

²⁵⁰ Some parents of children with autism, who start attending special private schools years before kindergarten, do not want to shift to the less intensive programs offered by local school districts when the children turn five. See e.g. *County Sch. Bd. of Henrico v. Z.P. ex rel. R.P.*, 399 F.3d 298 (4th Cir. 2005).

²⁵¹ The statute allows tuition reimbursement when the child "previously received special education and related services under the authority of a public agency." 20 U.S.C. § 1412 (a)(10)(C)(ii) (2005). The statute does not explicitly rule out reimbursement when the child never attended public schools.

known and well off,²⁵² and autism advocates seized the opportunity of weighing in on this high-visibility dispute with an amicus brief.²⁵³ A New York Times front page article discussing the Freston case gave more prominence to the similar legal vicissitudes of another child who has autism.²⁵⁴ Again, the solicitor general of the Bush administration, Paul Clement, sided with the child’s family and, by implication, with Autism Speaks.²⁵⁵ The elephant in the room was, of course, school choice – a core issue in the pro-voucher agenda of the Bush administration.²⁵⁶ A victory for the plaintiff could encourage some families of eligible IDEA students to bypass the public school system altogether.²⁵⁷ A 4-4 vote, with Justice Kennedy recusing himself for unknown reasons, left the issue temporarily unresolved. But in the different context of *Forest Grove v. T.A.*,²⁵⁸ where a student with disabilities had never been offered any special education services by the school district, the US Supreme Court upheld parents’ claim to reimbursement for private school costs as in line with text and purpose of the IDEA.²⁵⁹ The solicitor general’s brief,

²⁵² See Joseph Berger, *Private Schooling for the Disabled, and the Fight Over Who Pays*, N.Y. TIMES, Mar. 21, 2007, at B7 (noting that “Tom Freston [is] the former chief executive of Viacom, the company that runs MTV and Comedy Central . . . [and] left with a golden parachute worth \$85 million.”).

²⁵³ Autism Speaks’s amicus brief focuses on the critical nature of early intervention for children with autism and explains that parents of children with autism should not be forced to “try out” ineffective IEP programs during what may well be a relatively narrow window of opportunity. Brief for Autism Speaks as Amicus Curiae Supporting Respondent, Bd. of Educ. of the City Sch. Dist. of the City of N.Y. v. Tom F., 552 U.S. 1 (2007) (No. 06-637), 2007 WL 2088642.

²⁵⁴ Schemo & Medina, *supra* note 232.

²⁵⁵ Brief for the United States as Amicus Curiae Supporting Respondent, Bd. of Educ. of the City Sch. Dist. of the City of N.Y. v. Tom F., 552 U.S. 1 (2007) (No. 06-637), 2007 WL 2115429.

²⁵⁶ Klint Alexander, *The Road to Vouchers: The Supreme Court’s Compliance and the Crumbling of the Wall of Separation Between Church and State in American Education*, 92 KY. L.J. 439, 482 (2003/2004) (“The Bush Administration’s support for [voucher] plans coupled with the movement for greater accountability in public schools are indicative of the continuing push to ensure that public aid is redirected away from public education toward private and religious education.”)

²⁵⁷ Robert Barnes & Daniel de Vise, *Court Weighs Funding For Special Education*, WASH. POST, Apr. 27, 2009, at A4.

²⁵⁸ *Forest Grove Sch. Dist. v. T.A.*, 129 S. Ct. 2484 (2009).

²⁵⁹ The statutory interpretation endorsed by the majority is grounded on established canons (conformity with the purpose of the statute and with its explicit mandate to grant parents “appropriate relief;” avoidance

this time written by Elena Kagan for the Obama administration, focused less on choice and more on the purpose of the IDEA,²⁶⁰ but was equally inclined to grant parents reimbursement²⁶¹ and aligned in substance with the views of autism activists. Autism Speaks had again filed a brief in support of T.A.’s family,²⁶² and immediately applauded the Court’s holding as a victory for the autism community.²⁶³

A corollary to this development is to be found in the legislative initiatives, now sprinkled in a few states, that allow parents of autistic children to opt entirely out of the public school system and use an “autism scholarship” (paid by their school district and usually equal in amount to what the school district would have spent for the child) to pay for private education.²⁶⁴ Read against the background of *Forest Grove v. T.A.*, such initiatives symbolize again autism’s power to bypass political resistance to school

of interpretation *ad absurdum*; presumption against implied repeal; and compliance with clear notice requirements in the application of spending clause legislation). Nonetheless, the opinion has been deemed “very creative” and somewhat surprising. See Terry Jean Seligmann, *Muddy Waters: The Supreme Court and the Clear Statement Rule for Spending Clause Legislation*, 84 TUL. L. REV. 1067, 1110 (2010) (footnotes omitted) (“That *Forest Grove* is a result that prioritizes the provision of a FAPE to children at the time they need it makes it a decision clearly consistent with the overall purposes of the IDEA. That it avoids absurd results - here, allowing the district’s own failure to recognize and properly evaluate a child as disabled to relieve the district of financial responsibility - is also true. What is somewhat remarkable is the willingness of the Court in *Forest Grove* to engage in some very creative statutory interpretation in order to sustain this result, interpretation that after [*Arlington v. Murphy*] might have been thought to be highly unlikely to draw a majority.”)

²⁶⁰ Brief of the United States as Amicus Curiae in Support of Respondent, *Forest Grove Sch. Dist. v. T.A.*, 129 S. Ct. 2484 (2009) (No. 08-305).

²⁶¹ On remand, parents lost on the merits. *Forest Grove Sch. Dist. v. T.A.*, No. CV 04-331-mo, 2009 WL 4884465, at 3-4 (D. Or. Dec. 8, 2009).

²⁶² Brief of Autism Speaks as Amicus Curiae in Support of Respondent, *Forest Grove Sch. Dist. v. T.A.*, 129 S. Ct. 2484 (2009) (No. 08-305), 2009 WL 906570.

²⁶³ Press Release, Autism Speaks, Autism Speaks Applauds U.S. Supreme Court Ruling Reaffirming Parents’ Rights to Due Process in Securing Appropriate Education for Children with Disabilities (June 23, 2009), http://www.autismspeaks.org/press/supreme_court_forest_grove.php.

²⁶⁴ Easter Seals, *2009 State Autism Profiles* (Feb. 2009), <http://www.easterseals.com> (referencing proposed or enacted state legislation that provides autism scholarships in Alabama, Colorado, Kansas, Kentucky, Ohio, Oregon, Virginia and Wisconsin). Scholarship programs are also available to students with various kinds of special need, not only for autism, in Arizona and Missouri, *id.*, and also in Florida, Georgia, and Utah. See Winters & Greene, *How Special Ed Vouchers Keep Kids From Being Mislabeled as Disabled*, Manhattan Institute for Policy Research, Civic Report No. 58, August 2009, available at http://www.manhattan-institute.org/html/cr_58.htm.

vouchers and to downplay the implications of such vouchers for the general financial organization of districts.²⁶⁵ From the viewpoint of parents stuck in incompetent districts, financially unable to pay tuition, and faced with the awful prospect of seeing their children doomed to poor functioning for lack of early intervention, school choice may be the only hope and is a sacrosanct advocacy goal. But from a broader societal perspective, developing publicly funded, state-of-the-art special education programs remains a far more desirable option – one that vouchers and scholarships inevitably undermine.

4. Normalization

While celebrating the breakthroughs of the autism movement in the realm of special education, one cannot help but notice the resilience of the status quo, and the inability of the movement's egalitarian impulse to knock down traditional bulwarks of inequity. The funding of public schools is notoriously refractory to deep restructuring. As observed above, decades of school funding litigation, grounded on equity, adequacy, or both, have simply been unable to dismantle the fundamental architecture of the system. Since the largest fraction of educational costs (including special education costs) is still paid for by local property taxes, in low-income areas there simply is not enough money for state-of-the-art education of students with autism. A survey recently conducted in Long Island reveals in stark terms that the "push to expand special-education help for

²⁶⁵ See, however, the discussion generated in Wisconsin after Rep. Kitty Rhoades (R-Hudson) introduced A.B. 700 in the 2005-2006 legislation. Easter Seals' *2009 State Autism Profiles* (*supra* note 264) (Wisconsin) reports that

[t]here was an attempt in July 2007 to include the creation of an autism scholarship program in the Assembly Republican budget. However, opponents noted that the autism scholarship program would be funded at \$3 million using monies allocated for the public education system, which they advocated should remain with the public education system and distributed to special education services for students with autism.

Id.

students with autism has largely bypassed [the] poorest communities.”²⁶⁶ Wide inequalities persist between contiguous neighborhoods. Children with autism in low income areas are often under-diagnosed and underserved. The accountability mechanisms introduced by the No Child Left Behind Act in 2001 mean little or nothing for the many children with autism who are not capable of taking standardized testing.²⁶⁷

The uneven and regressive reach of autism services in public schools is in a sense harder to fix today for at least two reasons. First, public schools have developed their own budget-conscious version of autism programs.²⁶⁸ It is therefore easier for courts to side with administrators.²⁶⁹ Deference to initial IEP determinations is the norm.²⁷⁰ Parents who take extreme adversarial postures are not rewarded in court and are often

²⁶⁶ John Hildebrand, *Gaps Seen in Communities' Student Autism Services*, NEWSDAY.COM, Jan. 10, 2008, <http://www.newsday.com/news/local/ny-liauti0111,0,5100120.story>.

²⁶⁷ Shima Kalaei, *Students with Autism Left Behind: No Child Left Behind and the Individuals with Disabilities Education Act*, 30 T. JEFFERSON L. REV. 723, 725, 736-43 (2008) (positing that “the interplay between IDEA and NCLB has resulted in the insufficient education of students with autism.”).

²⁶⁸ There is of course a wide divergence in quality among such programs. *See* Brief of Autism Speaks at 11-12, as Amicus Curiae in Support of Respondent, *Forest Grove Sch. Dist. v. T.A.*, 129 S. Ct. 2484 (2009) (No. 08-305) (“While some district's school systems do have adequately-staffed programs, many do not[.]”)

²⁶⁹ *See, e.g.*, *JG v. Douglas County Sch. Dist.*, 552 F.3d 786 (9th Cir. 2008) (parents complained that teacher was not competent to perform functional analysis and implement a discrete trial training program. District, however, had contracted with two private behavior analysts for support and supervision, and this was deemed sufficient). *See also* *Wagner v. Bd. of Educ., Montgomery County, MD*, 340 F.Supp.2d 603, 611 (D.Md. 2004); *A.C. ex rel. M.C. v. Bd. of Educ. of the Chappaqua Cent. Sch. Dist.*, 553 F.3d 165, 173 (2nd Cir. 2009); *Joshua A. by Jorge A. v. Rocklin Unified Sch. Dist.*, 52 IDELR 64 (9th Cir. 2009); *MW by Wang & Gao v. Clarke County Sch. Dist. (M.D. GA 2008)*; *Huffman ex rel. C.H. v. North Lyon County Sch. Dist.*, 53 IDELR 147 (D. Kan. 2009) (while a private school might have offered greater benefits, district's IEP allowed for progress and met FAPE standards).

²⁷⁰ *A.C. ex rel. M.C. v. Bd. of Educ.*, 553 F.3d 165 (2d Cir. 2009) (deferring to “the SRO's finding that the IEP adequately addressed the need for M.C. to develop independence, and thus was not substantively deficient under the IDEA.”); *K.S. v. Fremont Unified Sch. Dist.*, 2009 U.S. Dist. LEXIS 120902 (N.D. Cal., Dec. 29, 2009) (

faulted with procedural irregularities.²⁷¹ It is understood that autism is not necessarily a trump card when it comes to requesting services.²⁷²

A second agent of normalization is the wide availability of educational expertise on the private market. The business of special education schools is now much more diversified and sophisticated than it was only a few years ago. Much more is available today than the traditional restraint-based institutions for mentally and behaviorally challenged students. Architectural firms compete to come up with autism-friendly interior and exterior designs.²⁷³ The proliferation of private programs, combined with a growing judicial deference to school districts and with the high litigation costs necessary to rebut districts' findings, is set to 'skim' and deplete the pool of potential litigants. Those who can afford it may therefore decide to bypass the public school system altogether. The result is a transformation of the landscape of autism litigation. Up until the 1990s, the field was populated by families of all types, busy educating school districts about the benefits of intensive individualized instruction. But over the past few years, the proliferation of private options has led many families of high means to bypass public schools altogether. Those who still work within the public school system come to IEP meetings armed not only with lawyers, but also with (self-paid) neuropsychological evaluations and reports of educational consultants, and are therefore more likely to obtain

²⁷¹ See, e.g., *Smith v. James C. Hormel Sch. of the Va. Inst. of Autism*, 2010 U.S. Dist. LEXIS 29026 (W.D. Va., Mar. 26, 2010); *Marc V. v. N. E. Indep. Sch. Dist.*, 455 F. Supp. 2d 577 (W.D. Tex. 2006); *Schoenbach v. Dist. of Columbia*, 309 F. Supp. 2d 71 (D.D.C. 2004).

²⁷² See *O'Dell v. Special Sch. Dist. of St. Louis County*, 503 F. Supp. 2d 1206 (E.D. Mo. 2007) (“[D]iagnosis alone does not drive the services to be provided to a student.”)

²⁷³ See, e.g., Brian Libby, *Psychologically Accessible*, ARCHITECTUREWEEK, Jan. 19, 2005 at D1.1.

private therapeutic programs for their children paid for by the school district.²⁷⁴ In such cases, school budgets take a hit but at the same time buy the contentment of pro-active parents.

The Commonwealth of Massachusetts provides a relevant case study of the regressive reach of autism services. The Massachusetts Department of Education keeps data on the ethnic and income profile of autistic children receiving special education, but collects no information on exactly how much money school districts invest for the education of autistic children of racial/ethnic minorities or low-income families. Pending investigation of this lacuna, however, it is possible to cull the following piece of information (relative to enrollment in the years 2008-2010): 22 to 24% of all the students diagnosed with autism are from low-income families; but of those students with autism who obtained the most expensive type of service, i.e. placement in private settings, only approximately 7% come from low income families.²⁷⁵ These data come as no surprise to those acquainted with the IEP process highlighted above – a process in which parents contribute, in direct proportion to their means and availability, to the design of individualized educational plans for their autistic children.

The same pattern is repeated in all aspects of the market. For those with means, the dream of a family life that is still fulfilling and interesting need not be shattered by

²⁷⁴ Seligmann, *supra* note 221, at 220 (stating that “credible expertise . . . goes a long way” in autism litigation).

²⁷⁵ Massachusetts Department of Elementary and Secondary Education, Student Information Management System (SIMS). Numbers are as follows: 2008-2009: students with autism enrolled in public education: 9,793; students with autism from low income families: 2,145; sum of white, black and Hispanic students in private day or residential setting: 1,014; students from low-income families in private day or residential setting: 69.

2009-2010: Students with autism enrolled in public education: 10,781; students with autism from low-income families: 2,563; sum of white, black and Hispanic students in private day or residential placement: 1,077; students from low-income families in private day or residential setting: 85.

autism. With time and money, one can find autism-friendly versions of just about any kind of service or product, from ski lessons to special foods and cruises.²⁷⁶ When a child has autism, everything is therapy, and everything can be sold to parents for the right price. We are moving towards an increasingly market-based autism world, where the security net of publicly provided services bears no relation to the wealth of possibilities that cash can purchase.

B. The Health Care Sector

From the perspective of a family whose child presents with autistic symptoms in pre-school years, the goal is to obtain immediate access to all recommended services, most typically behavioral, occupational, and speech therapy, at rates proportional to the severity of the child's specific needs. Because autism is ordinarily diagnosed by pediatricians, in theory health insurance should pay for the therapeutic interventions medically necessary to improve the condition of patients. In practice, early treatment is still out of the reach of many and, unsurprisingly, the autism community faces the same sorts of problems that make health reform so urgent across the board.

Several public programs provide channels towards therapeutic options: Early Intervention, Medicaid, SCHIP,²⁷⁷ Head Start, and various forms of publicly subsidized assistance.²⁷⁸ But gaps remain, because many families are not poor enough to be eligible

²⁷⁶ Jane Margolies, *Bypassing the Roadblock of Autism*, N.Y. TIMES, Sept. 14, 2008 (Travel Section at 3).

²⁷⁷ In 1997 the State Children's Health Insurance Program (SCHIP) was added as Title XXI of the Social Security Act. SCHIP works as a supplemental measure when Medicaid or waivers would not apply. 42 U.S.C. §§ 1397aa-1397jj (1997).

²⁷⁸ See, e.g., Catastrophic Illness in Children Relief Fund, <http://www.mass.gov/cicrf/> (last visited May 24, 2010). The employees of the Department of Defense whose children have autism also benefit from a

for services, or because those who would be eligible have no knowledge of their options. Medicaid-eligible families often lack the ability to navigate the bureaucracy and secure timely services for their children with autism.²⁷⁹ Among racial and ethnic minorities, children with autism are more likely to be misdiagnosed as having mental retardation – a label that makes a much feebler case for behavioral therapy.²⁸⁰ Educational agencies may also provide resources as early as at age 3,²⁸¹ but their ability or political willingness to establish intensive therapy programs varies dramatically from place to place. As a result,

Access to care is limited for racial and ethnic minority families, with low parental education, living in non-metropolitan areas, and not following a major treatment approach. . . .

. . . .

. . . Children with ASD of minority race and ethnicity have been found to receive services at a later age and receive a different mix of services from white children. . . .

. . . .

Racial and ethnic minority families had half the odds of using a case manager, and only a quarter the odds of using a psychologist [and a developmental pediatrician²⁸²

particularly generous package of benefits. *See* Health and Special Education Services for Military Children with Autism, <http://www.wrightslaw.com/info/autism.mil.benefits.htm> (last visited May 24, 2010).

²⁷⁹ A multi-state investigation of racial and ethnic disparities among new SCHIP enrollees reported, six years into the program, that it yielded systemically lower advantages for children of racial and ethnic minorities. Laura P. Shone et al., *The Role of Race and Ethnicity in the State Children's Health Insurance Program (SCHIP) in Four States: Are There Baseline Disparities, and What Do They Mean for SCHIP?*, 112 PEDIATRICS e521, e529 n. 6 (2003).

²⁸⁰ David S. Mandell et al., *Race Differences in the Age of Diagnosis among Medicaid-Eligible Children with Autism*, 41 J. AM. ACAD. CHILD & ADOLESCENT PSYCHIATRY 1447-53 (2002). In the clearly racialized context of under-diagnosed autism, mental retardation qualifies as an “emergent disability,” ie a disability “which would not exist, or would not be substantial, but for a context of social inequity.” Beth Ribet, NAMING PRISON RAPE AS DISABLEMENT: A CRITICAL ANALYSIS OF THE PRISON LITIGATION REFORM ACT, THE AMERICANS WITH DISABILITIES ACT, AND THE IMPERATIVES OF SURVIVOR-ORIENTED ADVOCACY, 17 Va. J. Soc. Pol'y & L. 281, 285 (2010)

²⁸¹ Individuals with Disabilities Education Improvement Act (IDEA) of 2004, 20 U.S.C. § 1419 (2005) (Preschool Grants (ages 3-5)).

²⁸² Kathleen C. Thomas et al., *Access to Care for Autism-Related Services*, 37 J. AUTISM DEV. DISORDER 1902, 1902, 1906 (2007) (citations omitted) (discussing available services in North Carolina from 2003 to 2005).

It is also well documented that families with lower incomes or limited education have more difficulty entering the early intervention system,²⁸³ that significant racial/ethnic disparities exist in the recognition of autism spectrum disorders,²⁸⁴ and that there are systemic barriers to bringing IDEA entitlements to full fruition for school-aged children with autism in low income districts. Against this backdrop, advocates rightly demand a more coherent and consistent approach to the problem.

Strategies have been multiple. First, there has been a spate of law suits against public and private insurance providers, aimed at establishing that reimbursement claims for intensive behavioral treatments such as ABA for autistic children must be routinely paid for. The same battle is being fought even more forcefully in states' legislative arenas, where the movement is putting forth bills mandating insurance coverage of ABA as a matter of state law. Not as prominent on activists' agendas but, as we shall see, at least equally important is the movement towards expansion of public services by means of Medicaid waivers, coordination agencies, and programs for adults with autism. These battles, revolving around the specific diagnosis of autism, take place against the politically hot background of health care reform, and must be assessed in that context.

1. ABA, Medicaid, and recession

In the 1990s, behavioral therapy for young children with autism increasingly asserted itself as a commendable strategy of early intervention and came to be routinely

²⁸³ KATHLEEN HEBBELER ET AL., EARLY INTERVENTION FOR INFANTS & TODDLERS WITH DISABILITIES AND THEIR FAMILIES (2007), http://www.sri.com/neils/pdfs/NEILS_Report_02_07_Final2.pdf.

²⁸⁴ Mandell, *supra* note 41, at 496 table 3 (2009).

recommended by many pediatricians.²⁸⁵ As a consequence, parents began to demand that ABA costs be regularly covered by existing public programs.²⁸⁶ A primary recipient of such claims was the Early and Periodic Screening, Diagnosis and Treatment (EPSDT) program, administered by Medicaid state agencies since 1967.²⁸⁷ This program, characterized by comprehensive benefits and by a particularly generous standard of “medical necessity,” seemed especially apt to guarantee access to specialized services often needed by children with chronic and expensive medical needs.²⁸⁸ In 2008, Autism Speaks acknowledged that Medicaid plays a “critical role for Americans with autism” and that, in response to a growing demand for habilitative therapies not covered by private insurance, “Medicaid spending for people with [autism] . . . has increased substantially in recent years.”²⁸⁹

Today, the attitude of Medicaid administrators towards ABA reimbursement claims is described as erratic.²⁹⁰ In some states, Medicaid insurance appears to be a

²⁸⁵ See John McEachin et al., *Long-term Outcome for Children with Autism Who Received Early Intensive Behavioral Treatment*, 97 AM. J. ON MENTAL RETARDATION 359 (1993).

²⁸⁶ See, e.g., *French v. Concannon*, No. 97-CV-24-B-C (D. Me. July 16, 1998) (children with autism and other disabilities); *Chisholm v. Hood*, 133 F. Supp. 2d 894, 901 (E.D. La. 2001) (finding Louisiana’s Department of Health and Hospitals in breach of its Medicaid obligations, because “the availability of behavioral and psychological services, to class members diagnosed with autism, [was] more theoretical than actual”).

²⁸⁷ Social Security Act § 1905 (a) (4) (B), 42 U.S.C. § 1396(d).

²⁸⁸ Christie Provost Peters, *EPSDT: Medicaid’s Critical but Controversial Benefits Program for Children*, NATIONAL HEALTH POLICY FORUM, Issue Brief – No. 819, Nov. 20, 2006, at 10. See also Sarah Knipper, *EPSDT: Supporting Children with Disabilities*, 11 (2004). EPSDT is available not only to children who are eligible for SSI, but also (in roughly one third of the states) for those who qualify under the TEFRA or “Katie Beckett” option. *Id.* at 30.

²⁸⁹ Testimony of Autism Speaks before the Health Subcommittee of the U.S House of Representatives Committee on Energy and Commerce, *Helping Families with Needed Care: Medicaid’s Critical Role for Americans with Disabilities*, Jan. 16, 2008. Exact data on Medicaid spending for individuals with autism, by distinct clinical grouping, are difficult to track. See Robert J. Master and Carol Taniguchi, *Medicare, Medicaid, and People With Disability*, 18 HEALTH CARE FINANCING REV. 91, 92 (1996).

²⁹⁰ Thomas Reinke, *Filling in the Gaps: Medicaid Waivers Add to the Continuum of Resources for People with Autism*, EXCEPTIONAL PARENT MAG., Apr. 1, 2009, at 68. “There is wide variation in [Medicaid] coverage for autism from state to state.” *Id.*

generous source of reimbursement for autism treatments, to the point of generating the impression that the extremely poor are better off than the middle class.²⁹¹ In others, Medicaid administrators interpret the treatment services mandate so narrowly as to exclude autism therapies.²⁹² Recent litigation suggests that agencies still perceive ABA as outrageously expensive and not sufficiently grounded in science to justify public expenditures. One argumentative hurdle is the distinction between habilitative and rehabilitative therapies.²⁹³ The latter, usually covered by insurance, are meant to restore patients to their normal level of functionality in the aftermath of a traumatic event. Habilitation, by contrast, implies that the patient has been suffering from a structural condition since birth, so that there is no lost ability to restore. Another difficulty stems from the fuzzy distinction between medical and educational intervention, sometimes invoked by agencies to reject claims and refer parents back to their school district administrators.²⁹⁴

The lack of clear guidelines at the federal level has contributed to the present state of confusion. In early 2003, a directive from the federal Centers for Medicare and Medicaid Services (CMS) stated that ABA was habilitative in nature, and therefore not

²⁹¹ Chad Livengood, *Bill To Mandate Coverage for Autism Therapy*, SPRINGFIELD NEWS-LEADER (Springfield, MO), Feb. 25, 2009, at 6A. *See generally* Peters, *supra* note 288, at 4. “EPSDT benefits for Medicaid children are more generous than most private health insurance benefit packages.” *Id.*

²⁹² Parents’ League for Effective Autism Servs. v. Jones-Kelley, 565 F. Supp. 2d 905, 910 (S.D. Ohio 2008), *aff’d*, 339 Fed. Appx. 542 (6th Cir. Ohio 2009).

²⁹³ This distinction was at the heart of the dispute in Parents’ League for Effective Autism Servs. v. Jones-Kelley. *Id.*

²⁹⁴ The line between educational and medical services is a fuzzy one. The IDEA requires schools to provide free “related services” when they are needed to allow students with disabilities to learn. 20 U.S.C. § 1415. Such related services commonly include speech and occupational therapy, which are regularly delivered in medical centers and in many circumstances covered by health insurance. *See, e.g.*, Micheletti v. State Health Benefits Comm’n, 389 N.J. Super. 510 (2007) (finding state employee’s autistic child entitled to reimbursement of speech and occupational therapy costs that would have been covered by private insurance carriers). By the same token, ABA can equally be conceived of as strictly educational, as a “related service,” or as a rehabilitative practice of the type often covered by health insurance.

covered by the EPSDT mandate.²⁹⁵ The CMS has since sent multiple signals that federal financial participation to state expenditures on behavioral programs is no longer to be taken for granted.²⁹⁶ Such signals have not been translated into regulations,²⁹⁷ but state agencies, burdened by budget constraints, have taken them seriously and have acted accordingly.²⁹⁸

In response, parents' pleas have been forceful. Contrary to the discrete and structurally individualized litigation in the school setting, here the movement is turning to collective action, similar in flavor to the judicial battles fought by large classes of parents of children with special needs in the 1970s.²⁹⁹ When the State of Ohio tried to change its Medicaid regulations in such a way as to exclude reimbursement of ABA, the Parents' League for Effective Autism Services and the Ohio Legal Rights Service joined forces

²⁹⁵ See Paul T. Shattuck et al., *Utilization of a Medicaid-Funded Intervention for Children with Autism*, 60 PSYCHIATRIC SERVICES 549 (2009).

²⁹⁶ See Testimony of Autism Speaks, *supra* note 289, at 4 (referring to CMS's proposed rules that "would deny federal financial participation for habilitation services, as well as for rehabilitation services furnished as 'intrinsic elements' of educational programs" as well as regulations that "would limit claims for federal financial participation for case management services").

²⁹⁷ The 6th Circuit reports that "[o]n August 13, 2007 CMS filed proposed rules that would limit Medicaid's coverage of rehabilitative services. Parents' League for Effective Autism Servs. v. Jones-Kelley, 339 Fed. Appx. 542, 545 (6th Cir. Ohio 2009). However, Congress placed a moratorium on these and other proposed restrictions on Medicaid spending, and therefore these rules were never adopted. See Pub. L. No. 110-28 § 7001(a); Pub. L. No. 110-252 § 7001(a) (extending moratorium on regulations restricting coverage of rehabilitative services until April 1, 2009); Pub. L. No. 111-5 § 5003(a), (d)(3) (January 4, 2009) (noting a "sense of Congress" that the proposed regulations relating to rehabilitative services should not be promulgated as final regulations)."

²⁹⁸ In *Parents League for Effective Autism Services v. Jones-Kelley*, 565 F. Supp. 2d 905, 910 (S.D. Ohio, 2008), the court refers to a letter written by CMS in October of 2005 to the director of Ohio's Department of Job and Family Services, indicating that habilitation services should not be covered by Medicaid. In response, ODJFS proposed rules changing the definition of "rehabilitative services" and effectively excluding ABA coverage. Similar developments occurred in Wisconsin, which opted to discontinue ABA coverage under EPSDT. See Shattuck, *supra* note 295, at 549.

²⁹⁹ Pa. Ass'n for Retarded Children v. Commonwealth, 334 F. Supp. 1257 (E.D. Pa. 1971). The law firm Mantese & Rossman, based in Troy, Michigan, is seeking people who have been denied coverage for ABA in the past six years. See Jay Greene, *Blue Cross Plans Limited Coverage for Autism*, CRAIN'S DETROIT BUS., May 13, 2009, available at <http://www.crainsdetroit.com/article/20090510/SUB01/305109959#>. A class action was filed in February of 2009 in the Superior Court of California, County of Alameda. *Anderson v. Kaiser Found. Health Plan, Inc.*, No. RG09435560 (Cal. Super. filed Feb. 11, 2009), available at http://www.dralegal.org/downloads/cases/Autism/001_Complaint.pdf.

and sought judicial injunction against such changes.³⁰⁰ The district court's injunction was later affirmed by the Court of Appeals for the 6th Circuit, and the battle continues on the merits. A similar class action was endorsed by the US District Court for the District of Columbia.³⁰¹

Judicial victories against Medicaid agencies, however, do notoriously little to stem the contraction of public programs.³⁰² The case of Wisconsin exemplifies such contractions. In 2003, following CMS's directives, the state took the lead and opted to discontinue ABA coverage under EPSDT.³⁰³ A politically viable alternative was found in Medicaid's Home and Community Based Services waivers.³⁰⁴ HCBS waivers do not have the general scope of EPSDT, but are meant to address the needs of specific groups – namely, those that would require institutionalization if they did not receive adequate care at home and in the community.³⁰⁵ The waivers grant states the flexibility to expand services and include habilitation therapy.³⁰⁶ HCBS funding is by definition less than the cost of institutionalizing individuals with disabilities, and therefore politically more palatable than other Medicaid benefits. HCBS waivers are often perceived as a money-saving device, because they usually come with caps to the number of serviceable

³⁰⁰ Parents' League for Effective Autism Servs. v. Jones-Kelley, 565 F. Supp. 2d 895, *aff'd*, 339 Fed. Appx. 542 (6th Cir. Ohio 2009).

³⁰¹ In 2008, the US District Court for the District of Columbia endorsed a class action which aims at establishing that the Medicaid program in DC must cover ABA therapy for autistic children. Salazar v. D.C., 560 F. Supp. 2d 6 (D.D.C. 2008).

³⁰² BAGENSTOS, *supra* note 72, at 139 (“If states respond to [Medicaid] litigation by amending their Medicaid plans to cut back on the services they promise to provide, there is nothing in the statute to stop them.”)

³⁰³ Shattuck, *supra* note 295, at 549.

³⁰⁴ The waiver program was named Children's Long-Term Support Waiver and came into effect in January of 2004. See Wisconsin Legislative Reference Bureau, Wisconsin Briefs, Brief 08-14, November 2008, at 6, available at <http://www.legis.state.wi.us/lrb/pubs/wb/08wb14.pdf>.

³⁰⁵ Shattuck, *supra* note 295, at 549.

³⁰⁶ *Id.*

individuals and are more narrowly defined than the general EPSDT obligation.³⁰⁷ Today, however, with state budgets so severely under pressure, the future of waivers is also in jeopardy.³⁰⁸

As a result, the movement has begun to construct autism as a special category of Medicaid eligibility. This has been done in several states by way of establishing autism-specific waivers.³⁰⁹ While HCBS waivers focus in general on a vast group of candidates for long-term institutionalization,³¹⁰ the new spate of waivers is narrowly tailored around the diagnosis of autism spectrum disorders. The task of the movement, definitely uphill in the present economic climate, now consists of having such waiver programs re-authorized and possibly expanded by CMS.³¹¹ Several autism waiver programs have a precious few slots, and ongoing advocacy efforts are bringing to the attention of

³⁰⁷ H.S. Kaye et al., *Do Non-Institutional Long-Term Care Services Reduce Medicaid Spending?*, 28 HEALTH AFFAIRS 262 (2009).

³⁰⁸ See Robert L. Mollica et al., *Taking the Long View: Investing in Medicaid Home and Community-Based Services is Cost-Effective*, AARP POLICY CENTER, Mar. 2009, at 1, http://assets.aarp.org/rgcenter/il/i26_hcbs.pdf (reporting, critically, that in the present climate of deep budget cuts “many state policymakers are targeting Medicaid home and community-based services (HCBS) because they are optional Medicaid benefits”).

³⁰⁹ See GRINKER, *supra* note 6, at 133 (“The waiver permits a child to receive intensive supports and medical care even if his or her family is not near the poverty line.”). Autism waivers are to be found in the legislation of Colorado (2008), Illinois (2007), Indiana (2008), Kansas (2007), Maryland (2001), Massachusetts (2007), Missouri (2009), Montana (2008), Pennsylvania (2008), and Wisconsin (2003). Ellen W. Blackwell, MSW, Center for Medicaid and State Operations, Disabled & Elderly Health Programs Group, *A National View of Medicaid Home and Community-Based Waivers Serving People with Autism*, available at www.nasdds.org/Meetings/2008_Mid-Year_Meeting/2008_MYM_Presentations/Blackwell.ppt; Reinke, *supra* note 290.

³¹⁰ To be a waiver participant, an individual must be one “with respect to whom there has been a determination that but for the provision of such services the individuals would require the level of care provided in a hospital or a nursing facility or intermediate care facility for the mentally retarded the cost of which could be reimbursed under the State plan.” Social Security Act § 1915 (c), 42 U.S.C. 1396(n).

³¹¹ In Massachusetts, advocates’ efforts to double the number of autism waivers in 2008 (from just 80 to 160) was resisted by Governor Patrick, who brought the number of total eligible children only up to 100. The Massachusetts Chapter of Autism Speaks campaigned to override Patrick’s veto. See David Yas, *The Unlimited Dreams of a Child with Autism*, MASS. LAWS. WKLY., July 28, 2008, at 2; Massachusetts Advocates for Children, *Children’s Autism Medical Waiver Update*, http://www.massadvocates.org/uploads/4z/S3/4zS3qXJ-NPLq-nik7wPOvA/MAC_Website_Waiver_Update_final.pdf.

legislators the fact that many eligible children remain on waitlists for years, missing a precious window of opportunity for therapeutic intervention.³¹² Specific programs for adults with autism are also beginning to be funded.³¹³

The story reveals the built-in tension of the autism movement: autism enhances the public focus on mental disability and on the need to integrate neuro-diverse people into the community; but as the costs of such integration increases and budgets shrink, the movement is forced to pursue carve-out policies, and autism becomes a small island of resilience in a sea of contraction of public expenditures.

2. Retrenching

The story of autism advocacy in matters of access to Medicaid benefits parallels the trajectory observed above in the context of education: a movement endowed with strong redistributive potential targets, at first, broad-based methods of societal intervention (strong special education programs in all public schools on the one hand, and federal or state funding of in-home services for low income families, on the other); soon

³¹² See, e.g., Sebastian Montes, *Bills Target Coverage of Autism Therapy Costs, But Health Care Providers Question Validity of Treatments*, GAZETTE.NET, Mar. 18, 2009, http://www.gazette.net/stories/03182009/poolnew180938_32470.shtml (commenting on Maryland's Autism Waiver Program, which "leaves 2,700 people on a waiting list for the 900 slots"). See also Wisconsin Briefs 08-14, *supra* note 304, at 6 ("At the end of 2007, 366 children were waiting for services under the CLTS waivers due to insufficient funding."). A petition addressed to Indiana's legislators by the Indiana Autism Coalition and entitled "Preserve Funding for Indiana's Medicaid Autism Waiver Services" states that "those who do currently receive Medicaid waiver services represent a fraction of the more than 15,000 who need and have qualified for such services but have been placed on years-long waiting lists necessitated by insufficient funding." Preserve Funding for Indiana's Medicaid Autism Waiver Services, <http://www.petitiononline.com/inautism/petition.html>.

³¹³ Pioneering states are Connecticut and Pennsylvania. Connecticut (along with Alabama, Mississippi, and Virginia) is one of the states whose definition of Developmental Disabilities (for the purpose of DD waiver eligibility) excludes autism unless the individual also has mental retardation. See Saul Spiegel, *Medicaid Autism Waivers and State Agencies Serving People with Autism*, OLR Research Report, 2007-R-0319 (Apr. 10, 2007). Hence the particular necessity of establishing a special source of service funding. See Linda H. Davis, *Still Overlooking Autistic Adults*, WASHINGTON POST, Apr. 4, 2009, at A15 (decrying the paucity of such programs).

enough, however, the system's endemic resistance to redistribution redirects the movement towards narrower and more politically palatable scenarios.

The analysis of the education law landscape (Section A in this Part) ended with the recent establishment of autism scholarships – mini-vouchers granted to a specific segment of the IDEA population. By the same token, the analysis of Medicaid developments concludes with the rising of specific autism waivers – a small but earmarked and well-defined sub-category of home and community based services, on which the movement can spend focused political capital without evoking the system-wide implications of the Olmstead decision.³¹⁴

Peripheral autism task forces and centralized coordination agencies, now emerging at local and federal level, are intelligent mechanisms that can avoid cost duplication and promote the capillary reach of autism services. At the same time, steeped as they are in various loci of government, they represent bulwarks of autism advocacy – a foot in the door, firmly set to resist the shutting down of welfare provisions and market options in times of austerity.³¹⁵ Budget cuts, the message goes, must spare persons with autism. By necessity, pursuing this goal requires embracing a most classical tool of advocacy: emphasizing autism's unique needs, its urgency, its tragic difference more than its equally profound message of blending and inclusion.

³¹⁴ Olmstead v. L. C., 527 U.S. 581 (1999) (famously emphasizing the importance of creating opportunities for general community inclusion of persons with disabilities). See Ira A. Burnim and Jennifer Mathis, *The Olmstead Decision at Ten: Directions for Future Advocacy*, 43 CLEARINGHOUSE REV. 386 (2009).

³¹⁵ See, e.g., the 2009 budget of Delaware's Office of Developmental Programs, available at <http://www.mhmrpa.org/mhmr/lib/mhmr/ODPBudgFY2009-10.pdf> (devoting the first of its six items to autism intervention funds).

The status of legislative projects currently pending in Congress confirms the impact of strained public budgets on the movement's agenda. A 2007 bill aptly entitled "Expanding the Promise for Individuals with Autism Act" (EPIAA) contained generous provisions of "state and federal funds" meant to subsidize access to treatment, and was meant to complement the major accomplishments (particularly in matters of research funding and network building) of the 2006 Combat Autism Act.³¹⁶ The EPIAA's discursive emphasis on promises and public funding sounds now passé. There has been no legislative activity on EPIAA since April 2007.³¹⁷ Some of its provisions have been incorporated in the more recent Autism Treatment Acceleration Act (ATAA),³¹⁸ but the latter bill is clearly centered around insurance mandates and less exacting on fiscal revenue.³¹⁹

3. The Health Insurance Market

Private insurance providers have been even more hostile than public agencies to claims for ABA reimbursement.³²⁰ An argument commonly invoked to deny claims is

³¹⁶ EPIAA was introduced in the House on April 17, 2007 (H.R. 1881), and in the Senate on March 20, 2007 (S. 937). It would dramatically expand federal funding for life-long services for people with autism and authorize approximately \$350 million in new federal funding.

³¹⁷ Another recent "bill to increase housing, awareness, and navigation demonstration services (HANDS) for individuals with autism spectrum disorders" was introduced on March 25, 2009 (S. 706, H.R. 1707) but has generated no further activity in Congress.

³¹⁸ Autism Treatment Acceleration Act of 2009, S. 819, H.R. 2413, 111th Cong. (2009).

³¹⁹ *Id.* § 12.

³²⁰ Pamela B. Peele et al., *Exclusions and Limitations in Children's Behavioral Health Care Coverage*, 53 PSYCHIATRIC SERVICES 591-94 (2002). For examples and anecdotes, see, e.g., *Parents Fight for Autism Insurance Coverage* (National Public Radio broadcast Aug. 16, 2007), available at <http://www.npr.org/templates/story/story.php?storyId=12829221>; John & Jennifer Maloney, *Is it Time for Autism Insurance? Yes*, RICHMOND TIMES DISPATCH (Virginia), Jan. 4, 2009, at E1 (explaining that "[i]n Virginia, 95 percent of health insurance plans deny parents' claims because autism is excluded from coverage"). See also Lisa Girion, *Autism Patients in California Are Dealt Insurance Setback*, L.A. TIMES, Mar. 10, 2009 ("In 15 of 16 recent disputes over insurance denials of applied behavior analysis for individual children, state-impaneled physician-reviewers have declared the therapy to be medically necessary. Those decisions required the insurers to pay for the treatment. The 16th case is pending.").

that ABA is still experimental or investigative.³²¹ As evidence of ABA's efficacy piles up, this claim becomes less and less tenable,³²² but it is still made by such insurance giants as Blue Cross Blue Shield.³²³ ABA is not administered by medical or other licensed professionals.³²⁴ As discussed earlier in these pages, there are private mechanisms for ABA certification, but no state licenses of any kind have been set up yet. Insurance companies have at times denied coverage for this reason.³²⁵

Regulatory variations abound. In some states, coverage of ABA is mandated by statute.³²⁶ Such mandates are to be found either in the broad language of mental health parity bills³²⁷ or in specific recent enactments of autism insurance mandates. Pro-active

³²¹ Livengood, *supra* note 291 (reporting a recent dispute in Missouri where the insurer, United Behavioral Health, considered ABA "to be an experimental, investigational and/or unproven service").

³²² Press Release, Autism Votes, Autism Speaks Joins Kansas Families to Answer Legislator Questions Raised About Kate's Law (Feb. 20, 2009), *available at* <http://www.autismvotes.org/site/apps/nlnet/content2.aspx?c=frKNI3PCImE&b=3930723&ct=6778273> ("The Department of Defense's TriCare health insurance plan for military dependents is specifically prohibited by federal law from covering 'unproven care or special education.'"). Nonetheless, Tri-Care provides coverage of behavioral treatments with its Extended Care Health Option, deeming such treatments "medically necessary." *Id.*

³²³ *Johns v. Blue Cross Blue Shield of Mich.*, 2009 U.S. Dist. LEXIS 29030 (E.D. Mich. Mar. 31, 2009). BCBS agreed to pay for ABA treatment for all class members in a settlement approved on May 25, 2010. Order of Final Approval of Proposed Settlement at 4, *Johns v. Blue Cross Blue Shield of Mich.*, No. 2:08-cv-12272 (E.D. Mich. May 25, 2010); Settlement Agreement at 7, *Johns v. Blue Cross Blue Shield of Mich.*, No. 2:08-cv-12272 (E.D. Mich. July 23, 2009). A similar suit against BCBS is still pending in state court for denial of claims for ABA treatment. *Matthews v. Blue Cross Blue Shield of Mich.*, No. 09018750CK (Mich. Cir. Ct. Wayne County filed July, 2009).

³²⁴ Insurance Help for Autism: Step-by-Step Guide, Step 6, <http://insurancehelpforautism.com/guide.html>.

³²⁵ *See, e.g., McHenry v. PacificSource Health Plans*, 643 F. Supp. 2d 1236 (D. Or. 2009) (providing a detailed discussion of this issue and relaxing most accreditation and credentialing requirements, but concluding, in final analysis, that the particular ABA provider hired by plaintiffs for their child was not "authorized for reimbursement").

³²⁶ *See Council for Affordable Health Insurance, The Growing Trend Towards Mandating Autism Coverage*, 152 ISSUES & ANSWERS 1, 2 (2009), *available at* http://www.cahi.org/cahi_contents/resources/pdf/n152AutismTrend.pdf (explaining that it is difficult to determine exactly how many states mandate autism benefits, because mandates are phrased differently and cover different benefits).

³²⁷ California's Mental Health Parity Act of 1999 covers autism treatment. 1999 Cal. Legis. Serv. Ch. 534 (A.B. 1465) (codified at Health and Safety Code § 1374.72). It is reported, however, that insurers have "continued to avoid paying for one of the most expensive elements of autism care -- ABA therapy -- by denying requests on the grounds that it hadn't been proved effective." Lisa Girion, *Autism Patients'*

parents have been able to hold insurers to their statutory duties, often only after fighting tooth and nail.³²⁸ In what is still a majority of states, there is no mandate, and insurers often deem autism a diagnostic exclusion.³²⁹ Federal and states' Mental Health Parity statutes have failed to bring any clarity to the issue of autism treatment coverage.³³⁰

Against this background, litigation is slowly switching from individual-plaintiff to class-action mode. Until recently, class actions seemed to be hard to file against private insurers, because each plan reads differently and claims are not sufficiently uniform,³³¹ but recent judgments have favored the bundling of plaintiffs' pleas.³³² A large lawsuit is

Treatment is Denied Illegally, Group Says, L.A. TIMES, July 1, 2009, at B1, available at <http://articles.latimes.com/2009/jul/01/business/fi-autism1>.

³²⁸ Milt Freudenheim, *Battling Insurers over Autism Treatment*, N.Y. TIMES, Dec. 21, 2004, at C1. "Even in the 17 states where autism coverage is required by law, insurers often drag their feet on payment or avoid it in individual cases by questioning the qualifications of the therapist or even a doctor's affirmation that treatment is medically necessary." *Id. See, e.g.,* McHenry v. PacificSource Health Plans, 643 F. Supp. 2d 1236 (D. Or. 2009) (holding that de novo standard of review applies to insurer's denial of autism therapy coverage).

³²⁹ Such was the case, for instance, in the insurance plan litigated in *Morgenthal v. AT&T*, *supra* note 192 at *2. Autismvotes.org reports that "[i]n many states, insurers explicitly exclude coverage of these therapies from policies." Autism Votes, *Autism Speaks Applauds Nevada Governor Jim Gibbons for Enacting Autism Insurance Reform Bill* (May 29, 2009), <http://www.autismvotes.org/site/c.frKNI3PCImE/b.4432467/k.BC88/Nevada.htm>.

³³⁰ The Paul Wellstone and Pete Domenici Mental Health Parity and Addiction Equity Act (signed by President Bush on Oct. 3, 2008 as part of the Emergency Economic Stabilization Act) does not require health insurers to cover mental health care, but, if they do, they must treat psychological and addictive disorders just as other medical conditions. This Act and earlier equivalent statutes enacted at state level are not suited to answer the question of autism treatment coverage for many reasons, including the fact that, in the eyes of many, autism is not a mental illness but a biomedical condition. *See* Jill Rubolino, *Autism Is Not Mental Illness: Get it Out of the DSM*, AGE OF AUTISM, Apr. 20, 2009. The interpretation of California's Mental Health Parity Act is at the heart of an ongoing dispute involving California's Department of Managed Health Care and parents seeking ABA reimbursement.

³³¹ Class certification was denied for this reason in *Johns v. Blue Cross Blue Shield of Mich.*, 2009 U.S. Dist. LEXIS 29030 (E.D. Mich. Mar. 31, 2009), and also in *Graddy v. Blue Cross Blueshield of Tenn.*, No. 4:09-cv-84, 2010 WL 670081 (E.D.Tenn. February 19, 2010). For developments favoring plaintiffs, see *Tresa Baldas, Michigan Class Action Settlement on Autism Treatment Hailed as Landmark Case*, NAT'L L.J., June 23, 2009.)

³³² An important judicial move aimed at facilitating class actions against private insurers is to be found in *Arce v. Kaiser Found. Health Plan, Inc.*, 181 Cal. App. 4th 471 (Cal. App. 2d Dist. 2010) (finding that the challenged plan "had a uniform policy of categorically denying coverage for health care services to treat autism spectrum disorders without determining whether the services were medically necessary for individual plan members"). Kaiser tried to block the class action but the California Supreme Court recently denied review. *Arce v. Kaiser Found. Health Plan, Inc.*, 2010 Cal. LEXIS 4014 (Cal. Apr. 28, 2010).

now pending before the Los Angeles county Superior Court. At issue is the interpretation of the California Mental Health Parity Act, allegedly violated by the Department for Managed Health Care's policy of allowing health plans to deny reimbursement of ABA costs.³³³

4. Mandating Autism Coverage

Litigation strategies, while important to generate political momentum, are only a complement to legislative activism. In 2007, Autism Speaks and other organizations launched a multi-state, bi-partisan campaign to promote legislation that would mandate autism treatment coverage in all insurance plans.³³⁴ The move is bold and meets with the firm opposition of medical insurance giants. Nonetheless, in state after state, bills are being passed mandating the coverage of ABA therapies.³³⁵ The movement's internal disagreement on what counts as treatment and on the relative ethical merits of different

³³³ Girion, *supra* note 327. See also *Schwarzenegger Administration Sued for Allowing Health Insurance Companies to Deny Autism Care*, PR NEWSWIRE, <http://news.prnewswire.com/ViewContent.aspx?ACCT=109&STORY=/www/story/07-01-2009/0005053688>. An interim victory for the plaintiffs was obtained in *Consumer Watchdog v. Cal. Dep't of Managed Health Care*, available at <http://www.consumerwatchdog.org/resources/AutismOrderOnDemurrer.pdf>.

³³⁴ Autism Speaks, *Autism Speaks Announces Multi-State Insurance Legislation Campaign*, Dec. 27, 2007, http://www.autismspeaks.org/government_affairs/state_issues.php.

³³⁵ See, e.g., Pennsylvania's Autism Insurance Act 2008, Pa. Legis. Serv. Act 2008-62 (H.B. 1150) (amending 40 PA. STAT. ANN. § 764) (mandating "Autism Spectrum Disorders Coverage"). The statute provides \$36,000 a year for Applied Behavior Analysis and other necessary treatments up to age 21, with no lifetime cap. *Id.* A total of 19 states have similar legislation. Autism Votes, State Initiatives, http://www.autismvotes.org/site/c.frKNI3PCImE/b.3909861/k.B9DF/State_Initiatives.htm. See Erica Noonan, *Push on for Insurers to Share Autism Costs*, BOSTON GLOBE, Sept. 16, 2008, at 1. See generally JANET L. KAMINSKI LEDUC, PRIVATE INSURANCE COVERAGE FOR TREATMENT OF AUTISM, Connecticut OLR Research Report, July 31, 2008, 2008-R-0427, <http://www.cga.ct.gov/2008/rpt/2008-R-0427.htm>. "[I]t appears that 22 other states [besides Connecticut] mandate some amount of coverage for the treatment of autism. Of these, eight require coverage for behavioral treatment services for the treatment of autism (Arizona, Florida, Indiana, Kentucky, Louisiana, Pennsylvania, South Carolina, and Texas) and five require other coverage related to autism (Colorado, Georgia, Maryland, New York, and Tennessee). Nine other states include autism in their laws mandating coverage for mental illness (California, Illinois, Iowa, Kansas, Maine, Montana, New Hampshire, New Jersey, and Virginia)." *Id.* Easter Seals' 2009 State Autism Profiles, *supra* note 264, provides information on States' legislative activities of this type.

treatment options is likely to affect the future of insurance mandates, but not to stop the tide of reform.³³⁶ A federal bill – the Autism Treatment Acceleration Act (ATAA) – was also introduced in both House and Senate in 2009, with the main goal of making autism treatment a subject of federal insurance mandate and of closing the loopholes left open by state legislation.³³⁷

The gist of the argument in favor of expanded coverage is discrimination.³³⁸ Insurance companies, the argument goes, pay routinely for treatments of all kinds, including treatments of other “non-curable” chronic conditions, such as HIV and diabetes, and there is no principled reason to leave autism treatment off their lists. Denying autistic children the possibility of making great strides at an early age puts them in a permanent situation of inferiority, which could be avoided through timely services.

The stringent logic of this argument is making strides across the spectrum of political preferences and is proving to be the most potent tool in autism advocates’ shed. The literature on health law and policy is, of course, full of arguments against mandated benefits. In general, mandates fail to reach those without access to insurance, which are on average needier;³³⁹ make insurance less affordable for the poor;³⁴⁰ and their

³³⁶ Age-of-Autism activists would like insurance coverage to extend to biomedical treatments (including nutritional supplements and laboratory work) rather than being expressly confined to behavioral therapy. See, e.g., Theresa Wrangham & Vicky Debold, *Are Federal Research Dollars Being Spent Wisely?*, 32 AUTISM FILE (2009).

³³⁷ Autism Treatment Acceleration Act, *supra* note 318.

³³⁸ See AUTISM SPEAKS, ARGUMENTS IN SUPPORT OF PRIVATE INSURANCE COVERAGE OF AUTISM-RELATED SERVICES (2009), available at http://www.autismvotes.org/atf/cf/%7B2A179B73-96E2-44C3-8816-1B1C0BE5334B%7D/Arguments_for_private_insurance_%20coverage.pdf.

³³⁹ See Diane Rowland & Adele Shartz, *America's Uninsured: The Statistics and Back Story*, 36 AM. J.L. & MED. 618, 620 (2008) (remarking that “[p]ersons who are members of racial and ethnic minority groups are much more likely to be uninsured”).

³⁴⁰ See Christopher J. Conover, *Distributional Considerations in the Overregulation of Health Professionals, Health Facilities, and Health Plans*, 69 LAW & CONTEMP. PROBS. 181, 191 (2006). Autism

redistributive impact is derailed by loopholes and exemptions.³⁴¹ The autism mandate, however, especially if compared to legislation of very large scope such as the mental health parity statutes, can be packaged as a contained addition to (or natural integration of) existing benefits. Moreover, autism coverage is not cast as a new benefit to be added to the list of plans' obligations, but rather as a minimalist correction to an isolated instance of discrimination routinely perpetrated by insurers.³⁴² From this perspective, behavioral therapy for autistic children is *already* a natural object of insurance coverage, which happens to be denied due to contra-*legem* or praeter-*legem* policies. The proposed legislation is touted as declaratory, rather than constitutive of new entitlements. This move, made viable by the movement's power of persuasion, is managing to circumvent the classical arguments against new benefits. Insurance mandates seemed until recently an overly steep and ambitious goal. With time, however, states have come to see them as a way to "reduce state expenditures by shifting costs to the private sector."³⁴³ In the present socio-economic climate, insurance mandates have come to look as the most equitable move that autism advocates can pursue.

mandates are currently estimated to increase the cost of health insurance by approximately 1%, and further increases (up to 3%) are possible in the near future. Council for Affordable Health Insurance, *supra* note 326 at 2. See generally Amy B. Monahan, *Federalism, Federal Regulation, or Free Market? An Examination of Mandated Health Benefit Reform*, 2007 U. ILL. L. REV. 1361 (2007).

³⁴¹ For a discussion of such loopholes, see Sharon Hoffman, *Unmanaged Care: Towards Moral Fairness in Health Care Coverage* 78 IND. L.J. 659, 700 (2003). Self-funded employer-sponsored insurance plans are exempt from such mandates under the Employee Retirement Income Security Act of 1974. As a consequence, their employees (on average healthier and wealthier than others) do not necessarily contribute to subsidize the costs of autism treatment for the increasing plurality of privately-insured children. Furthermore, "[t]he laws most recently enacted (Arizona, Florida, Louisiana, Pennsylvania, and South Carolina) generally . . . do not apply to individual health insurance policies or policies issued to small employers (50 or fewer employees)." KAMINSKI LEDUC, *supra* note 335.

³⁴² Autism Votes, *Autism Speaks Launches TV Ad Campaign Calling on Congress to End Insurance Discrimination Against Children with Autism*, July 8, 2009, <http://www.autismvotes.org/site/apps/nlnet/content2.aspx?c=frKNI3PCImE&b=3930723&ct=7180013>.

³⁴³ MARLIA MOORE ET AL., WISCONSIN'S MEDICAID WAIVER AUTISM SERVICES 10 (2004), available at <http://www.lafollette.wisc.edu/publications/workshops/2003-2004/pa869/2004-Autism.pdf>.

A shift to mandated autism treatment coverage, if coupled with universal access to health insurance, with equitable risk pooling, and with tighter control on the market price of treatments,³⁴⁴ may indeed prove distributively desirable in the long term. The impact of such developments on the neighboring sectors of welfare and public education programs will depend on modalities of implementation, which will in turn require intense planning and coordination in order to prevent regressive distributive consequences. At a philosophical level, autism mandates affirm the triumph of anti-discrimination discourse, and also push the pendulum of disability away from the social and back towards the medical model.³⁴⁵ Such moves do not lack precedent in the history of disability law, and are known to nurse new tensions that are certain to unfold.³⁴⁶

V. AN INTERIM ASSESSMENT

The story of the autism movement is endowed with great transformative potential and inspired by ideals of justice, such as the end of discrimination against people with disabilities. Insofar as it promotes a true appreciation of neuro-diversity, autism discourse brings positive externalities everywhere and way beyond the limits of the autism spectrum community. Thanks to images of beauty and genius, autism redeems cognitive impairment and draws large cohorts of suffering humanity out of the woodwork of shame and neglect. It is impossible to quantify the actual distributive impact of this shift, but it is

³⁴⁴ See Health Care Reform: What Does it Mean for the Autism Community?, <http://blog.autismspeaks.org/2010/03/23/health-care-reform/> (Mar. 23, 2010) (outlining the synergic effects of the Health care Reform of 2010 and of proposed federal autism mandates).

³⁴⁵ See BAGENSTOS, *supra* note 72, at 18 (discussing the general shift from the medical to the social model among disability rights advocates).

³⁴⁶ *Id.* at 149 (positing that antidiscrimination “is simply too narrow a tool” and that the movement needs a renewed emphasis on universalism and social welfare programs).

clear that autism lends the moral-philosophical call for redistribution in favor of persons with mental disabilities, famously voiced by Martha Nussbaum,³⁴⁷ a firmer political grip. Autism breaks away from old images of retardation, de-stigmatizes cognitive impairment, and makes a compelling case for intervention and vocational opportunities. In hindsight, someone will perhaps link the autism movement of this decade with other instances of increased sensitivity to the large legal question of mental capacity, such as the Supreme Court's decision of 2007 to heighten the standard of competency required to be executed;³⁴⁸ the accelerated itinerary of the Mental Health Parity Bill in Congress;³⁴⁹ and the increasingly popular science of brain imaging, that eats away at the notion of free will and moral responsibility.³⁵⁰ But, at the end of this – by no means exhaustive – journey through the legal reality of autism, one is left with the impression that things are more complicated and that the progression is, in fact, not a linear one.

In tort law, the Omnibus Autism Proceeding touts the idea that vaccines are safe, but individually tried cases such as *Poling* and *Banks* feed and keep alive the hypothesis of a connection between autism and vaccination and undermine the policy of herd immunity. So far, autism has simply asked courts to do more of the same: to craft an unstable compromise between pharmaceutical producers, established bio-medical research, environmental movements, and tragic casualties. Pending further research, the distributive impact of this strand of judicial work is at best ambiguous.

³⁴⁷ See NUSSBAUM, *supra* note 101, at 188-90.

³⁴⁸ *Panetti v. Quarterman*, 551 U.S. 930 (2007).

³⁴⁹ The Paul Wellstone and Pete Domenici Mental Health Parity and Addiction Equity Act of 2008, Pub. L. No. 110-343, § 511-12, 122 Stat. 3765, 3881 (2008).

³⁵⁰ George J. Annas, *Foreword: Imagining a New Era of Neuroimaging, Neuroethics, and Neurolaw*, 33 AM. J. L. & MED 163 (2007).

In the adjudication of criminal cases, autism's frontal attack on the notion of moral responsibility might prompt welcome reflections on the general ethics of retribution and punishment, but it also might boil down to empty sensationalism attached to a particular diagnostic label, without any systemic step forward in the communication between neuro-science and criminology.

At several points along the way, the legal reforms prompted by the autism movement have been by necessity grafted onto preexisting patterns of inequality in the distribution of legal, social, educational, and medical services. In education law, the important breakthroughs brought about by autism in matters of inclusion and effective education of children with mental impairments are only part of the story. It is just as important to recognize that special education services (including those directed to students with autism) continue to have a structurally uneven reach across income and race. The picture is further complicated by the fact that the autism movement has found itself aligned with school-choice advocates – an unintended allegiance that may in turn decrease, rather than enhance, the financial viability of public educational programs. In matters of welfare, autism, for obvious reasons of urgency and efficacy, is now building its own silo of benefits, in the form of specific programs strictly tailored to an autism diagnosis. In the present legal system and in the current economic climate, this competitive retrenchment makes utmost sense, but its redistributive reach remains questionable. The enactment of statutes mandating insurance coverage of autism treatment costs may bring needed equity to the picture, but only if combined with a truly

accessible health care system and if adequately coordinated with education and welfare services.

Lastly, an unregulated market has developed an awesome array of therapeutic possibilities, but also money games and unintended policy pressure on publicly funded service providers. In sum, the loud arrival of autism onto the legal scene has in some ways furthered the goal of letting all boats rise. But there is a part of the autism revolution that could become no more than *déjà vu* – a replica of a story that the system narrates over and over again. Some of the discussed changes started off in the name of equality and then fell back into known patterns of regressive distribution. In the long term, without adequate reflection, autism could mirror the dark sides of gender, race, and immigration. It could become a story of ultimate marginalization, where principled equality is eroded by market forces, lobbying, and normalizing adjudication, to the point that one could wonder whether this was really the result intended by the early pioneers of this cause. It could be story with a happy ending, in which autism is fully embraced and deciphered, but only in the wealthier part of the world. And autism rights could prompt a serious backlash, just like gay rights had incendiary effects on homophobia, or desegregation mobilized racist groups.³⁵¹

It is to this worrisome and under-explored side of the story that autism, as an image, speaks loudly. Autism teaches us that we all think in pictures³⁵² and seek

³⁵¹ MICHAEL J. KLARMAN, FROM JIM CROW TO CIVIL RIGHTS: THE SUPREME COURT AND THE STRUGGLE FOR RACIAL EQUALITY 352-53 (2004); Michael J. Klarman, *Brown and Lawrence (and Goodridge)*, 104 MICH. L. REV. 431 (2005). See BACKLASH AGAINST THE ADA: REINTERPRETING DISABILITY RIGHTS (Linda Hamilton Krieger ed., 2003).

³⁵² TEMPLE GRANDIN, THINKING IN PICTURES (2005).

immediate rewards; that we can see many trees but perhaps not the forest;³⁵³ that we suffer from path dependence; that empathy is hard to grasp and nurture; that we aspire to reach out to others but are prisoners of self-reflective wiring. Autism offers, among other things, a metaphor for who we are and for the law we live with.

³⁵³ In neuro-psychological terms, this feature of autism spectrum disorders is termed “weak central coherence.” See BARNBAUM, *supra* note 8, at 27.