AUTISM IN THE US: SOCIAL MOVEMENT AND LEGAL CHANGE

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Daniela Caruso

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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 contingency 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 Otterson, 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 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.

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

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\(^1\) 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).
\(^6\) 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
Advances in psychiatric science are proving such analogies misguided. Autism, while affecting one’s ability to understand others’ viewpoints, leaves ample room for shared emotions. Accordingly, many commentators have opposed the portrayal of autism as a catastrophe or as a condition that is not fully human. But the metaphor of alien invasion has an enduring grip on collective consciousness and survives in popular accounts as well as personal narratives.

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.\textsuperscript{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.\textsuperscript{15} Autism is also quite prevalent in Silicon Valley, and according to some it runs in families of great musicians and mathematicians.\textsuperscript{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, untrammeled concentration, or perception of patterns that escape everyone else. In this light, autism sits comfortably on a spectrum that comprises 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.\textsuperscript{17}

Susan Sontag argues effectively that metaphors may vilify suffering and ultimately impede a rational, purposeful approach to the reality of pathology.\textsuperscript{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

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\item Leo Kanner, \textit{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).}
\item Murray, \textit{supra} note 4, at 65. The movie \textit{RAIN MAN} (GUBER/PETERS CO. 1988) put great emphasis on the savant qualities of its main character.
\item Sontag, \textit{supra} note 4, at 68.
\end{enumerate}
\end{footnotesize}
may prompt. 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 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. 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,

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19 SONTAG, supra note Error! Bookmark not defined., 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.

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.
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 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. At a more general level, autism can be credited with a veritable advancement in the understanding of difference.23 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

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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.
23 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).
helped to reach their potential without preconceptions. 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 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.

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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.\(^\text{25}\) 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.\textsuperscript{26} Autism emerged as a distinct psychiatric phenomenon in the 1940s and has since acquired much cognitive salience.\textsuperscript{27} 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.

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.\textsuperscript{28} 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.\textsuperscript{29}

\textsuperscript{28} Kanner, supra note 14. Swiss psychiatrist Eugen Bleuer had coined the term “autism” in 1910 to indicate a characteristic of patients with schizophrenia. EDWARD SHORTER, \textit{THE HISTORICAL DICTIONARY OF PSYCHIATRY} 34 (2005).
\textsuperscript{29} D. V. M. Bishop, \textit{Autism, Asperger's Syndrome and Semantic-Pragmatic Disorder: Where Are the Boundaries?} BRIT. J. DISORDERS COMM. 24, 107-21 (1989).
Hans Asperger, like Kanner, was born in Austria and wrote his seminal contribution to the understanding of autism spectrum disorders in the mid 1940s.\textsuperscript{30} 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.\textsuperscript{31}

Not everyone agrees that autism and Asperger’s syndrome are manifestations of the same pathology (differing in degree but not in substance).\textsuperscript{32} While severe autism is completely incapacitating, individuals with Asperger’s syndrome can be perfectly integrated in their community, and oftentimes make fundamental contributions in their professional fields. Post-mortem diagnoses can be 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


\textsuperscript{31} 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.

\textsuperscript{32} The current version of the Diagnostic and Statistical Manual of Mental Disorders, published by the American Psychiatric Association, is currently undergoing revision and will ultimately be replaced by the DSM-V. It is likely that Asperger’s syndrome will disappear from the DSM 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.
Asperger-like symptoms. Yet, severe autism and Asperger’s syndrome remain closely linked in scientific, popular, and political discourse. The figures illustrating the incidence or prevalence of autism are alarming. Whether or not autism qualifies as an epidemic, its prevalence is unsettling: today, one in 110 children in the US is diagnosed with autism.

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 symptoms: cognitive, communicative, and sensory. 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. There is no blood test or genetic marker for autism, 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

36 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.
extreme as to escape modeling.\textsuperscript{37} The shape and structure of the autism movement are heavily impacted by the still nebulous and impressionistic definition of autistic disorders.

\begin{center}
\textit{B. Evolution of the Movement}
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Kanner’s ‘discovery’ became an object of great interest for psychoanalysts. Kanner’s work blamed “refrigerator mothers” – women incapable of bonding with their babies and teaching them the basics of empathy.\textsuperscript{38} Through the later work of child psychologist Bruno Bettelheim, Kanner’s theory became popular and remained unchallenged through the mid-60s.\textsuperscript{39} 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.\textsuperscript{40} 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.\textsuperscript{41} In 1965, Rimland founded the American Society for Autism (ASA) which is, to this day, a major center of advocacy.

Following Rimland’s work, which abandoned the refrigerator stereotype and prompted neurobiological investigations, activism in the name of autism began to flourish thanks to both grassroots efforts and power houses. Some groups – most visibly Cure

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\item \textsuperscript{37} Christina Chew, \textit{Race, Immigrants, and Autism Rates}, AUTISM VOX, Jan. 11, 2008.
\item \textsuperscript{38} BRYAN JEPSON & JANE JOHNSON, \textit{CHANGING THE COURSE OF AUTISM: A SCIENTIFIC APPROACH FOR PARENTS AND PHYSICIANS} 11-17 (2007) (describing Kanner’s theory and its development).
\item \textsuperscript{40} Rodrigué, \textit{supra} note 15, at 178.
\item \textsuperscript{41} BERNARD RIMLAND, \textit{INFANTILE AUTISM: THE SYNDROME AND ITS IMPLICATION FOR A NEURAL THEORY OF BEHAVIOR} (1964).
\end{itemize}
Autism Now (CAN) and the National Alliance for Autism Research (NAAR) – coalesced around the fight against vaccines and toxic substances potentially related to the surge of autism.\(^{42}\) It is no coincidence that such movements emerged in a context of burgeoning environmental activism.\(^{43}\) 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.\(^{44}\)

Today, the core of the autism movement is characterized by the presence of two major organizations: Autism Society of America (ASA) and Autism Speaks.\(^{45}\) The former retains with pride its ‘senior’ status and its commitment to biomedical investigations.\(^{46}\) The latter, Autism Speaks, was founded in 2005 and later merged with both Cure Autism Now (CAN) and the National Alliance for Autism Research to become “the nation's largest autism advocacy organization.”\(^{47}\) Autism Speaks has been more


\(^{43}\) 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).

\(^{44}\) 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).

\(^{45}\) 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.

\(^{46}\) 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.”).

conservative, aligning itself with the recommendations of federally-funded research groups and with established medical expertise, in its advocacy for scientific investigations into the causes of autism.\textsuperscript{48} Autism Speaks and ASA seem to be competing for attention and prestige, but their activism is equally broad in scope and often overlaps in substance.

The strategy of these organizations is one of broad information and mobilization.\textsuperscript{49} Walks for autism, organized both nationally and locally, help generate awareness, and also bring meaningful subsidies to the cause. Until recently, funding for autism research lagged behind when compared to other disabling conditions.\textsuperscript{50} Today, donations to the cause are pouring in, and several celebrities are involved in very effective fund-raising.\textsuperscript{51} Predictably, “political contingency and the vagaries of fashion” also contribute to the relative success of any given cause.\textsuperscript{52} The fact that media moguls such as Bob Wright\textsuperscript{53} have become personally involved in autism matters certainly has

\textsuperscript{48} Bob and Suzanne Wright, the founders of Autism Speaks, do not subscribe to the vaccine theory of causation, while their daughter Katie (mother of their autistic grandson Christian) does. See Jane Gross & Stephanie Strom, \textit{Autism Debate Strains a Family and Its Charity}, N.Y. TIMES, June 18, 2007.

\textsuperscript{49} See \textit{About Us}, Autism Speaks, http://www.autismspeaks.org/about_us.php (outlining Autism Speaks’ activities).

\textsuperscript{50} 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 \textit{Suzanne and Bob Wright: Autism Speaks}, on \textit{Today Show} (NBC television broadcast Feb. 25, 2005) available at http://www.autismspeaks.org/video/index.php.


\textsuperscript{52} \textit{Stanley Cohen, States of Denial} 171 (2001).

\textsuperscript{53} Other celebrities who have brought attention to autism include 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.” \textit{Murray, supra} note 4, at 134.
helped the cause. The movement, once peripheral and radical in tone, has now espoused stable organizational models and achieved main-stream status.54

Most recently, autism has adopted the language of human rights.55 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.56 The goal is then one of resource mobilization, which requires working “side by side – sometimes in competition, sometimes in collaboration, with traditional political institutions.”57

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),58 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

54 The 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 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 (hereinafter 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).


57 See Canel, supra note 54. 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).

identifies autism as a major target of research;\textsuperscript{59} CAN’s advocacy was instrumental to its passage.\textsuperscript{60} The 2006 Combat Autism Act (CAA) was an even more momentous achievement\textsuperscript{61} as it focused on autism only. CAA provided for approximately $950 million in spending on autism over five years, divided among research and other programs, and was subsequently funded accordingly.\textsuperscript{62} The new administration is on the same track.\textsuperscript{63} In addition, the US Department of Defense has established its own Autism Research program.\textsuperscript{64} The involvement of the Department of Defense curiously highlights the military emergency mode that pervades the dominant strand of the autism social movement.

This increase in federal funding for research comes as no surprise. Because autism is presented in public discourse as an emergency, an epidemic of rapidly

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\textsuperscript{59} Id., Division A, Title I.
\textsuperscript{60} See Barnett & Steuernagel, supra note 26, at 12.
\textsuperscript{62} President Signs CAA Funding, AUTISM SPEAKS,
http://www.autismspeaks.org/government_affairs/president_signs_caa_funding.php (last visited May 27, 2009). 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.
\textsuperscript{63} See Fiscal Year Budget in Brief, Dept. of Health and Human Services, May 7, 2009, available at http://www.autismvotes.org/atf/cf/%7B2A179B73-96E2-44C3-8816-1B1C0BE5334B%7D/HHS%20FY2010budgetinbrief.pdf. The Brief contains the following language:
As part of a $211 million HHS-wide initiative that would invest an additional $1 billion over the next eight years in autism-related activities, the NIH budget includes $141 million in FY 2010 for research into the causes of and treatments for autism spectrum disorders (ASD). For NIH, this represents an increase of $19 million, or 16 percent above the estimated base FY 2009 level. NIH expects to use these funds to help implement the objectives of the Strategic Plan for ASD research, as developed by the Interagency Autism Coordinating Committee. These objectives include identifying biomarkers; improving ASD screening; establishing ASD registries; understanding genetic and environmental risk factors, as well as interactions between the immune and central nervous systems; and enhancing services that can help people with ASD across the lifespan.
\textsuperscript{64} Id. at 39-40.
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increasing proportions, a health scourge, and an avid guzzler of money and human resources, stopping it is and must be a political and scientific priority. The dollar figures in the CAA, when compared to funding for other biomedical conditions, convey the sense of a paradigm shift. Alzheimer’s disease is sometimes analogized to autism due to its alarmingly increasing prevalence and to the enormous amount of personal and medical care that Alzheimer’s patients demand. Experts talk about incidence rates of epidemic proportions and make gloomy predictions about the impact of Alzheimer’s disease on health care costs and on society in general. Alzheimer’s is no Cinderella when it comes to lobbying, is no less prevalent among Caucasians, and certainly affects many a prominent family. Yet, the United States government funding of Alzheimer's research has recently been cut. The force of the autism movement is, in relative terms, astounding.

65 But see Wayne, supra note 54 (describing skeptical attitudes).
66 See, e.g., Advances in Understanding Autism May Lead Towards Effective Treatment Drug Development, DRUG WEEK, June 25, 2004. “‘Autism is reaching epidemic proportions. The diagnosis can be made as early as 2 years of age, and autistic patients are expected to have a normal life span. Thus, in terms of the number of ‘patient years’, autism spectrum disorder (ASD) represents a market that is as large as that of the biggest neurological indication, Alzheimer's disease’’”) (quoting researchers at the University of Hawaii). See also Barnett & Steuernagel, supra note 26, at 3.
69 Steven Reinberg, 10 Million Baby Boomers Face Alzheimer's, Report Predicts, WASHINGTON POST, Mar. 18, 2008. According to Stephen McConnell, vice president for advocacy and public policy of The Alzheimer's Association, commenting on the 2008 Report of the Alzheimer association, “[r]ight now the government is spending about $640 million a year on Alzheimer's research . . . It seems like a lot, but we are spending over $5 billion a year on cancer, and more than $3 billion on heart disease each year. If we can just get that $640 million up to $1 billion a year, that would make a big difference.” Id. The website of the Alzheimer’s Association reports that: [f]unding for Alzheimer research peaked at $658 million in 2003. Since Congress completed the doubling of NIH, funding for Alzheimer’s research has dropped steadily in both real and
C. Splintering and Cohesion

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.⁷⁰ Autism can be and has been defined as a closed class – a finite set of human beings possessing immutable characteristics.⁷¹ 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.⁷² Campaigning in the name of a group brings the group to life as a “discrete and insular” entity.⁷³ Activism creates difference at the same time as it calls for sameness at law.⁷⁴

⁷² MARTHA MINOW, MAKING ALL THE DIFFERENCE 31 (1990) (remarking that “making differences matter singles out the disabled child.”).
⁷³ 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.
⁷⁴ Minow, supra note 72 at 108. “Special rights, justified by difference, undermine claims of equal treatment predicated on sameness.” Id.
With the promise of special recognition and ad-hoc entitlements comes disagreement within the autism movement. At one extreme end of the spectrum of opinions one finds the “neuro-diversity” or “autism rights” camp, where autism simply is not an illness, and where the very idea of cure is an assault on identity. First epitomized by Jim Sinclair’s “don’t mourn for us” message, this group deems the attempt to cure autism by means of behavioral intervention as hideous as the 1960s psychiatric treatment of homosexuality. Several websites espouse this view, which is of particular appeal to individuals on the milder end of the autism spectrum. 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.

The relation between the movement’s stable core and this more feebly organized neuro-diversity fringe is uncomfortable. It is now generally accepted that it is important to let persons with disabilities speak with their own voice. AutismSpeaks, for example,
has made sure to host persons on the autism spectrum in its organization, and federal legislation has also embraced the idea of giving voice and agency to adults with autism. But when members of the neuro-diversity group undermine the value of the core’s sought-after benefits or treatments, most notably applied behavioral analysis (ABA), the core distances itself from the neuro-diversity fringe. The critique of behavioral treatment and the downplaying of autism’s tragedy find no room in the manifesto of the movement’s large base.

At the other extreme end of the movement is the “cure” group. Among its most vocal representatives are Kim Stagliano, managing editor of the on-line publication “Age of Autism,” and Jenny McCarthy, founder of the organization “Generation Rescue.” Cure 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. In this camp, the focus is on autism as a biomedical (as opposed to psychological, psychiatric or behavioral) condition, a source of deep physical and psychological

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80 See CAA, Autism Interagency Coordination membership.
81 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 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).
82 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).
suffering whose cause must be eradicated. Vaccines, mercury, and other man-made poisons are the main suspects.\textsuperscript{86} Currently, this is the most militant strand of the movement. 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.\textsuperscript{87} In this camp, detoxifying diets and ‘natural’ remedies, which include nutritional supplements, are touted as the way to go.\textsuperscript{88} By contrast, psychiatric drugs are labeled as band-aid solutions that only mask underlying biomedical problems.\textsuperscript{89}

At times, very vocal fights have occurred between Autism Speaks and anti-vaccine groups. When autism research goals are defined for advocacy purposes, there are dramatic divergences, because the ‘cure’ fringe refuses to align with established medical science and accuses those who do of either idiocy or outright corruption.\textsuperscript{90}

This splintering, potentially fatal to the movement, has not undermined the larger mission of autism advocacy. The two fringe approaches – cure and neuro-diversity – do


\textsuperscript{87} See e.g., Russell L. Blaylock, The Truth Behind the Vaccine Cover-up, http://www.generationrescue.org/blaylock/Truth-behind-vaccine-cover-up.pdf


\textsuperscript{89} 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.

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 probably are. As a result, their profound philosophical disagreements knock each other out of the center stage and do not manage 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, cohesive and broad-based. 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. 91 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. 92 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. As observed, the neuro-diversity strand of the autism movement, which is mostly made of self-identified autistic adults, embraces this viewpoint entirely.

In matters of autism, however, the discourse on disability can hardly be reduced to such dichotomies. In general, the nature/culture (or biology/society) divide does not map well onto the field of cognitive impairment. Intellectual disability advocates have actually struggled to emphasize, rather than downplay, the biological root of what could otherwise be perceived as despicable behavior. 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 cognitive impairments provides a good lens for studying the autism movement, which proves again and again to be following a trajectory of its own. According to well-established accounts of social justice, people with severe intellectual disabilities seem to have a lesser claim to public resources than other groups. In a contractarian perspective, for instance, they can never count as net

94 “[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).
95 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.”)
96 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.
97 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).
contributors and are therefore excluded from the paradigm of reciprocity. Advocacy for those with severe mental impairments, therefore, ends up relying on philosophical notions of human dignity and universal human rights, which do not have as much redistributive pull in policy-making circles.

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. Finding ways to cure it or alleviate its symptoms is advertised as a

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100 See Michael Stein, *Disability Human Rights*, supra note 98.


cost-saving proposition. Second, autism is often touted as the unavoidable flip-side of the precious coin of genius. 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. 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. 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. 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 such a remarkable gender difference? Is it true, after all, that women, by a process of

103 See Autism and Extraordinary Ability, supra note 24.
104 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).
105 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).
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”? 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 incapacitating 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 compassion” would soon “do more for those with Down syndrome.” But for the time

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108 JOHN GRAY, MEN ARE FROM MARS, WOMEN ARE FROM VENUS: A PRACTICAL GUIDE FOR IMPROVING COMMUNICATION AND GETTING WHAT YOU WANT IN YOUR RELATIONSHIPS (1993).
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 function\(^\text{110}\) 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 ‘cure’ 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 link between vaccines and the autism epidemic. Here, specialized judicial panels face the difficult task

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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 very 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 Autism Omnibus Proceeding

One of the few known facts about autism is that it is at least in part hereditary.\(^{111}\) If one child is autistic, the chances of autism or other neurological disorders in siblings are significantly higher than average.\(^{112}\) 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.\(^{113}\) 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,\(^{114}\) the MMR vaccine is somehow responsible for the increased incidence of autism either per se or because of a mercury-based preservative, Thimerosal, contained in MMR vaccine vials.\(^{115}\) 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

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\(^{114}\) 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

\(^{115}\) 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.
vaccine-induced illness or death. In the Vaccine Court, causation is simply presumed for all cases listed in a “vaccine injury table.” 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. 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.

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. The Omnibus 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.

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118 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.
119 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”).
122 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.
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.”\(^{123}\) 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.\(^{124}\)

Things look different today. In May 2004, the same committee, based on further review of research, determined that “the body of epidemiological evidence favors rejection of a causal relationship between Thimerosal-containing vaccines and autism.”\(^{125}\)

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

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\(^{123}\) 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.

\(^{124}\) See Moreno, supra note 113, at 414-15 (blaming the vaccine scare on “conspiracy theorists”).

\(^{125}\) Institute of Medicine of the National Academies, National Academy of Sciences, Immunization Safety Review: Vaccines and Autism (Executive Summary) (2004).
Thimerosal was removed from infant vaccines, the autism rate has continued to climb.126

In product liability cases, as well, Thimerosal-containing products have been found to be unrelated to neurodevelopmental disorders.127 Most recently, three of the test cases were closed, with no finding of any causal link between vaccine and autism.128 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 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.\textsuperscript{129} In November 2007, plaintiff Hannah Poling prevailed along such argumentative lines and was found entitled to compensation in the vaccine court.\textsuperscript{130} 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.\textsuperscript{131} 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.\textsuperscript{132} 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.\textsuperscript{133}

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.\textsuperscript{134} Many had criticized \textit{Daubert} and argued for a

\begin{itemize}
\item Id.
\end{itemize}
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 scrutiny\(^{135}\) and to bypass gate-keeping evidentiary rules.\(^{136}\)

Another judicial victory for the “cure” strand of the movement made news in February 2009.\(^{137}\) Here, the family of Bailey Banks obtained not just a settlement but a proper award of damages totaling over one million dollars.\(^{138}\) Special Master Abell found that plaintiffs had established a causal link between the MMR vaccination and the child’s acute disseminated encephalomyelitis (ADEM).\(^{139}\) ADEM, in turn, caused pervasive developmental delay, or PDD,\(^{140}\) which is, according to many, a type of autism spectrum disorder.\(^{141}\) 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 Autism Omnibus Proceeding, finds an unsettling counterpart in the atypical victories of Poling and Banks. The vaccine court is therefore the lynchpin


\(^{136}\) 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.”).


\(^{139}\) Banks, 2007 WL 2296047, supra note 137.

\(^{140}\) Id.

\(^{141}\) See e.g., Autism Spectrum Disorders, supra note 35. The CDC includes PDD criteria on its website in the Autism Spectrum Disorder section.
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 cure fringe 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.\(^{142}\) 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.\(^{143}\) Judge Melinda Harmon granted the school district summary judgment “despite clear evidence that someone mistreated Leonard.”\(^{144}\) 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 rule.\(^ {145}\) 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

\(^{143}\) Id.
\(^{144}\) Id.
As observed above, one of the central features of autism as currently understood is the inability to recognize intentional states of others.\textsuperscript{146} The ethical implications of this trait are startling and further complicate the already fuzzy logic of culpability.\textsuperscript{147}

Even when very bright, individuals with autism are seriously handicapped by their inability to understand social cues or to reason intuitively in relational contexts.\textsuperscript{148} 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 empathy may be lacking in a way that cannot be dismissed as simply evil.\textsuperscript{149} Autism’s unique dissonance between self and other, its lack of perspective and mind-theory, has nothing to do with socio-pathology and can be, in fact, quintessentially innocent.\textsuperscript{150} Many individuals with autism would certainly be capable of premeditation, competent to stand trial, and able to withstand punishment.\textsuperscript{151} 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?\textsuperscript{152} If the autistic person is incapable of empathy or moral discernment, then there is no

\textsuperscript{146} See \textsc{Barnbaum}, \textit{supra} note 8, at 19. According to Barnbaum, autism presents a novel challenge to Hume’s and Kant’s ethical theories. \textit{Id.} at 113.

\textsuperscript{147} See \textsc{Barnbaum}, \textit{supra} note 8, at 6. “[T]he fact that autism challenges a person’s ability to make intentional ascriptions presents startling ethical implications.”


\textsuperscript{149} Stephen J. Morse, \textit{From Sikora to Hendricks: Mental Disorders and Criminal Responsibility}, in \textsc{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.”).

\textsuperscript{150} See \textsc{Barnbaum}, \textit{supra} note 8, at 65.

\textsuperscript{151} See Nita A. Farahany, \textit{Cruel and Unequal Punishments}, 86 \textsc{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. \textit{Id.} at 898.

\textsuperscript{152} For a recent exploration of these questions, see Kenneth W. Simons, \textit{Retributivists Need Not and Should Not Endorse the Subjectivist Account of Punishment, Response to: Adam J. Kolber, The Subjective Experience of Punishment}, 109 \textsc{Colum. L. Rev.} 182 (2009).
possibility of retribution or redemption. 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?

These issues have been raised before in the general context of moral philosophy or with regard to other mental disabilities, 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.

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. 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. The charge of first-degree murder, naturally central to the prosecutor’s case, involves premeditation and calls for a life sentence without possibility

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153 Morse, supra note 149, 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.”).
154 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).
156 See Steven K. Erickson, The Myth of Mental Disorder: Trans substantive 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).
158 Id.
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,” but the assumption of the prosecution is that Odgren’s cognition was intact. A state-hired psychologist determined in March 2007 that he did not need to stay in a psychiatric hospital, that he could sit in jail, and that he would be competent to stand trial. While we wait for the Odgren case to be resolved judicially, other similarly stirring cases continue to pile up in the news.

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 Syndrome]”), and as one who must be distanced so as to avoid any association between ‘Aspies’ and crime. In this light, the villain is Odgren’s lawyer, who uses the trendy label of AS to exculpate his client but in so doing brands all others suffering from it 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.”

159 See Farahany, supra note 151, at 897.
161 Odgren had spent twenty days at Westborough State Hospital. Jonathan Saltzman, Psychologist Says Teen Competent for Trial, BOSTON GLOBE, Mar. 27, 2007, at 1A.
163 See Jeff Truesdell, Should an Autistic Child be Charged with Murder? 71:15 PEOPLE 87 (Apr. 20, 2009) (discussing the issue of Sky Walker’s mental competence in the wake of his mother’s violent death).

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
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. Senator advocated acknowledging that impulsive and aggressive behaviors are sometimes a result of the autistic condition. Acknowledgment of this truth, in her view, would lead to better policies, heightened services, preventive strategies, and extra help.

In the Odgren case, there were, of course, the voices of those who focused on the 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 is unsettling. The problem is that with high-functioning autism one never knows, before the facts, to what extent relational capacity and moral intuition have been affected. One cannot help wondering whether the stereotypical traits of the autistic mind, its lack of empathy, its relational difficulties, might warrant an extra dose of precaution.

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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, 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.169 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.”170 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.”171 In principle, therefore,

169 “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).
171 MODEL PENAL CODE § 4.01.1, explanatory note (1962)
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 criminal. 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 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.172

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.173 In principle, individuals of all degrees of intelligence or rationality should be treated equally humanely in court.174 In practice, however, awareness campaigns and advocacy strategies on behalf of autistic persons have produced catchy slogans, informational sound bits, and popular narratives. The discourse on autistic crime is now increasingly

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[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].


173 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.

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. When the perpetrator is allegedly autistic, the spotlight now extends to encompass the “autistic population.” Judges face enhanced public scrutiny when they tackle the question of autism as excuse, and they are in a sense required to take 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. Lawyers like Jonathan Shapiro in the Odgren case are expected to delve into the neuroscience of autism to extract from it exculpatory evidence. 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. 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,

175 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.”).
176 Julie Berry, Safety Doesn’t Come From Stereotyping or Overreacting, METROWEST DAILY NEWS, Feb. 2, 2007.
179 See, e.g., Thomas J. Sheeran, Autism is a Challenge in Murder Case; An 18-year-old Awaits a Decision on Whether He Can Stand Trial for his Mother's Death, L.A. TIMES, Mar. 29, 2009, at A8 (commenting on the murder of Gertrude “Trudy” Steurnagel allegedly committed by her severely autistic son, Sky Walker).
the form remains one of equal and individual accountability. The substance, though, is colored by issues of group identity. Autism is a category in itself.

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 fellow workers, and whose repetitive speech and behavior seem to be determined by a mysterious internal logic rather than by incentives or consequences. Anecdotes abound on the high prevalence of autism or Asperger’s Syndrome among math geeks – persons with relational difficulties and often superior academic intelligence. Engaging persons with autism in productive activities suited to their particular skills is indeed possible and desirable. Channeling employees with high-functioning autism into high-tech enterprises, emphasizing savantism and mathematical wizardry, does pose ethical dilemmas and logistic problems, but experiments of this sort consolidate the utilitarian foundation of

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180 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.

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 autistic employees 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 one or more major life activities.” Courts have disagreed on this issue, but there certainly is precedent for considering social interaction a “major life activity” for ADA purposes, and social interaction is by definition impaired in persons with autism. 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. ADA protection is therefore theoretically available for individuals with autism.

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183 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).
184 Morgenthal v. AT&T, No. 97 Civ. 6443 (DAB), 1999 U.S. Dist. LEXIS 4294, at *8 (S.D.N.Y. Apr. 5, 1999) (refusing employee’s benefits for his son’s autism because the disorder is recognized as a disability within the meaning of the ADA); 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."”)
185 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).
On the ground, however, complications arise. Autism requires accommodations that are oftentimes counterintuitive and altogether puzzling, and it may be hard to see why a person endowed with average or high intelligence is entitled to protection under the Americans with Disabilities Act. 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.\(^{186}\) When reproached by a supervisor, she threw a fit and kicked a chair across the hall.\(^{187}\) She was fired the next day.\(^{188}\) Anyone familiar with autism knows that sensory responses can be particularly acute in persons with ASD. For Cathleen, the very prospect of being stuck in a smelly vehicle with closed windows was probably enough to trigger a break-down.\(^{189}\) Nonetheless, Cathleen was found not entitled to ADA protection and the case ended in summary judgment for the employer.\(^{190}\) The employer had accommodated her multiple disabilities in many ways.\(^{191}\) Evidence of her hypersensitivity to smell did not satisfy the \textit{Daubert} standard.\(^{192}\) 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

\(^{187}\) \textit{Id.} at *4.
\(^{188}\) \textit{Id.}
\(^{189}\) \textit{See id.}
\(^{190}\) \textit{Id.} at *33.
\(^{191}\) \textit{Id.} at *2
\(^{192}\) \textit{Id.} at *13-15.
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 deeper and more nuanced understanding of autism. 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 conduct.193 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.

193 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.
The movement has already begun to affect the legal system as we know it, and is bound to bring about further changes.\textsuperscript{194}

The question is, \textit{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-bodied and 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 reforms. Autism seems set to contribute in a very real way to the transformation of our chaotic health 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.”\textsuperscript{195} 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,\textsuperscript{196} and the cause of autism may be hijacked by parallel political agendas. The autism movement may be intended as a wedge

\textsuperscript{195} Id.
that will slowly bring about a more humane allocation of resources across the range of human conditions, 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 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, including 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 Mann 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

197 Caring about autism “is something from which all manner of people can and must benefit.” Murray, supra note 4, at 212.
198 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.
funding remains tied in significant part to local property taxes. Thus, per-pupil expenditures vary dramatically across districts and across states.\textsuperscript{199} 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.\textsuperscript{200} 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 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.\textsuperscript{201} 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.\textsuperscript{202}

\textsuperscript{199} See Michael J. Kaufman, \textit{Education Law, Policy, and Practice} 119-22 (2005) (discussing the degree of funding inequality among and within the States).

\textsuperscript{200} IDEA is the current name of the original Education for Handicapped Children Act of 1975. See Wendy F. Hensel, \textit{Sharing the Short Bus: Eligibility and Identity Under the IDEA}, 58 Hastings L.J. 1147, 1153 (narrating the legislative history of this statute).


\textsuperscript{202} 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, \textit{Jumping the Queue: An Inquiry Into the Legal Treatment of Students with Learning Disabilities} 159 (1998) (posing 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. \textsection 6301 et seq., tit. I.
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 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.203

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 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

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203 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.”).
nor, in many cases, mental retardation, they “slipped right through the educational loophole.” 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 null. 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. By then, the class action mode that had prompted the 1970s’ paradigm shift in special education 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 around one child only. Families have since engaged in elaborate negotiations with school administrators. According to detailed provisions in the IDEA, when discussions and mediation fail, the parties present their respective arguments before

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208 See Erin Phillips, When Parents Aren’t Enough: External Advocacy in Special Education, 117 YALE L.J. 1802, 1821-22 (2008) (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.”).

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

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.

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. 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

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210 Id. at 221 (referring to these acronyms as IDEA’s “alphabet soup”).
211 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).
212 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.
conceived of to remedy the historical isolation of students with special needs, but it makes 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.  

Eligibility can also pose thorny problems. An estimated 30% of 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. Even in the presence of an autism spectrum diagnosis (most often, Asperger’s syndrome), schools have denied the need for individualized instruction.

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. 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. Applied Behavioral Analysis has certainly

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214 “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).


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

217 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
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.

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

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. 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 clout in the negotiation of school services is particularly acute. IDEA litigation is expensive. Victorious parents in IDEA disputes can recover lawyers’ fees, but they are...
unlikely to recover anything if they voluntarily settle before going to trial.\textsuperscript{222} 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.\textsuperscript{223} 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.\textsuperscript{224} The market of autism experts has plenty to offer to all, but not all families can afford independent educational consultations.\textsuperscript{225}

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

\begin{itemize}
  \item \textsuperscript{224} \textit{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). \textit{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. \textit{IDEA Fairness Restoration Act}, H.R. 4188, 110th Cong. (2007).
  \item \textsuperscript{225} \textit{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).
\end{itemize}
energy can now avoid or reduce lawyers’ fees by representing their children in federal courts directly. 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, but the case remains a strong procedural breakthrough championed by the parents of a child with autism. Arguably, this holding realized in full the spirit of the IDEA by giving real meaning to parents’ procedural rights. It took autism to bring about this momentous 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 case and the pro bono work of prestigious lawyers had 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


228 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.

the case and the Solicitor General’s brief favored the Winkelms. 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. Autism can be the label of choice for parents determined to obtain as individualized an educational plan as possible for their children. Administrators are now willing to concede that individualized behavioral intervention does make a positive difference and argue only about how much of it is appropriate in each case. School districts have become increasingly creative in designing autism programs that are cost effective and reasonable, if not optimal. Lastly, because autism is de-stigmatizing, it is plausible that families who would resent other demeaning

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231 “Autism is more familiar and visible than ever before.” Grinker, supra note 6, at 19.
232 “[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).
233 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.”).
labels and therefore refuse IDEA services are more readily accepting special education interventions in favor of their children.\textsuperscript{234} 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 case\textsuperscript{235} 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.\textsuperscript{236} 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 at best ambiguous when applied to cases where the parents do not give the school district’s IEP a chance.\textsuperscript{237} 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 known and well off,\textsuperscript{238} and autism advocates seized the opportunity of

\textsuperscript{234} 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. \textit{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. \textit{See} \textit{Kelman & Lester}, supra note 202, 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.” \textit{Id.}

\textsuperscript{235} New York City Bd. of Educ. v. Tom F., 552 U.S. 1 (2007).

\textsuperscript{236} Many 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. \textit{See} County Sch. Bd. of Henrico v. Z.P. \textit{ex rel.} R.P., 399 F.3d 298 (4th Cir. 2005).

\textsuperscript{237} 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.

weighing in on this high-visibility dispute with an amicus brief.\textsuperscript{239} 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.\textsuperscript{240} Again, the solicitor general of the Bush administration, Paul Clement, sided with the child’s family and, by implication, with Autism Speaks.\textsuperscript{241} The elephant in the room was, of course, school choice – a core issue in the pro-voucher agenda of the Bush administration. A victory for the plaintiff could encourage families of eligible IDEA students to bypass the public school system altogether.\textsuperscript{242} A 4-4 vote, with Justice Kennedy recusing himself for unknown reasons, left the issue temporarily unresolved. But in the somewhat different context of \textit{Forest Grove v. T.A.}, where a student with attention deficit disorder had not been found eligible by the school district and had never been offered an IEP, the US Supreme Court most recently upheld parents’ claim to reimbursement for private school costs as in line with text and purpose of the IDEA.\textsuperscript{243} Autism Speaks had again filed a brief in support of

\textsuperscript{239} 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.

\textsuperscript{240} Schemo & Medina, \textit{supra} note 218.


\textsuperscript{243} \textit{Forest Grove Sch. Dist. v. T.A.}, 129 S. Ct. 2484 (2009). The holding enhances the pressure on school districts to lean towards a finding of special education eligibility in case of doubt.
T.A.’s family, and immediately applauded the Court’s holding as a victory for the autism community.

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. Read against the background of Forest Grove v. T.A., such initiatives symbolize again autism’s power to bypass political resistance to school vouchers and to downplay the implications of such vouchers for the general financial organization of districts. 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 a sacrosanct advocacy goal. But from a broader societal perspective,

246 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..
247 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 246) (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.
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 students with autism has largely bypassed [the] poorest communities.” 248 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.249

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

249 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.”).
own budget-conscious version of autism programs. It is therefore easier for courts to side with administrators. Deference to initial IEP determinations is the norm. Parents who take extreme adversarial postures are not rewarded in court and are often faulted with procedural irregularities. It is understood that autism is not necessarily a trump card when it comes to requesting services.

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. 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.

250 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).

251 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.”).


253 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.”

254 See, e.g., Brian Libby, Psychologically Accessible, ARCHITECTUREWEEK, Jan. 19, 2005 at D1.1.
result is a transformation of the landscape of autism litigation. Up until the 1990s, the field was populated by power-house families, 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 such families 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 private therapeutic programs for their children paid for by the school district.\(^{255}\) 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 accurate data on the racial and financial 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: in 2007-2008, 1,746 students identified as autistic came from low income families, but only 64 such families (i.e. less than 4%) obtained the most expensive type of service – placement in specialized private schools.\(^{256}\) The average rate of private

\(^{255}\) Seligmann, supra note 209, at 220 (stating that “credible expertise . . . goes a long way” in autism litigation).

placement, calculated with no reference to family income, is much higher (11%). 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 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. When a child is autistic, everything is therapy, and everything can be sold to parents of autistic children 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 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 defined by many as a biomedically based condition ordinarily diagnosed by pediatricians, in theory health insurance should pay for the therapeutic interventions medically necessary to improve the

257 The total number of white, black, and Hispanic families whose autistic children were awarded private placement in 2007-2008 is 908, i.e. approximately 11% of 8,126. Id.
258 Jane Margolies, Bypassing the Roadblock of Autism, N.Y. TIMES, Sept. 14, 2008 (Travel Section at 3).
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,260 Head Start, and various forms of publicly subsidized assistance.261 But gaps remain, because many families are not poor enough to be eligible 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.262 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.263 Educational agencies may also provide resources as early as at age 3,264 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

260 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).
262 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 n. 6 e521, e529 (2003).
264 Individuals with Disabilities Education Improvement Act (IDEA) of 2004, 20 U.S.C. § 1419 (2005) (Preschool Grants (ages 3-5)).
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 [or a] developmental pediatrician[.] 265

It is also well documented that families with lower incomes or limited education have more difficulty entering the early intervention system, 266 that significant racial/ethnic disparities exist in the recognition of autism spectrum disorders, 267 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 Reimbursement Claims in Court

The quest for clarity and uniform coverage of behavioral intervention has first been directed to Medicaid administrators, whose attitude towards ABA claims is, to this day, erratic.\(^{268}\) In some states, Medicaid insurance appears to be a 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.\(^{269}\) In others, Medicaid administrators interpret the treatment services mandate so narrowly as to exclude autism therapies.\(^{270}\) 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.\(^{271}\) 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.\(^{272}\)


\(^{271}\) This distinction was at the heart of the dispute in PLEAS. Id.

\(^{272}\) 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.
On such matters, parents’ pleas have been forceful and abundant. 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. 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 and sought judicial injunction against such changes. Having prevailed before a district court, they are presently continuing their battle in the Court of Appeals for the 6th Circuit. A similar lawsuit is now pending before the Los Angeles county Superior Court. At issue is the interpretation of the California Mental Health

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.

Lisa Girion, Autism Patients in California Are Dealt Insurance Setback, L.A. TIMES, Mar. 10, 2009 (reporting that “[i]n 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.”). 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).


OLRS Presents Oral Argument in the Parents’ League for Effective Autism Services (PLEAS) Case, OHIO LEGAL RIGHTS SERVICE, http://olrs.ohio.gov/asp/PLEASUpdate5_7.asp. On January 12, 2009, the Ohio Legal Rights Service (OLRS) filed a brief in the U.S. Court of Appeals for the Sixth Circuit. Id. OLRS argued that the defendants' proposed rules were properly enjoined and asked the Court to uphold the preliminary injunction order. Response Brief of Plaintiffs-Appellees, PLEAS v. Jones-Kelley, No. 08-3931 (6th Cir. Jan. 12, 2009).
Parity Act, allegedly violated by the Department for Managed Health Care’s policy of denying reimbursement of ABA costs.  

Private insurance providers have been even more hostile than public agencies to claims for ABA reimbursement. An argument commonly invoked to deny claims is that ABA is still experimental or investigative. As evidence of ABA’s efficacy piles up, this claim becomes less and less tenable, but it is still made by such insurance giants as Blue Cross Blue Shield. ABA is not administered by medical or other licensed professionals. 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.

279 Livengood, supra note 269 (reporting a recent dispute in Missouri where the insurer, United Behavioral Health, considered ABA “to be an experimental, investigational and/or unproven service.”).
280 “The Department of Defense’s TriCare health insurance plan for military dependents is specifically prohibited by federal law from covering ‘. . . special education.’” Autism Votes, http://www.autismvotes.org/site/apps/nlnet/content2.aspx?c=frKN13PCImE&b=3930723&ct=6778273. Nonetheless, Tri-Care provides coverage of behavioral treatments with its Extended Care Health Option, deeming such treatments “medically necessary.” Id.
Class actions proper may be hard to file against private insurers, because each plan reads differently and claims are not sufficiently uniform, but the few cases decided so far have consistently favored the plaintiffs. These cases portray a landscape of great confusion. In some states, coverage of ABA is mandated by statute. Such mandates are to be found either in the broad language of mental health parity bills or in specific recent enactments of autism insurance mandates. Pro-active parents have been able to hold insurers to their statutory duties, often only after fighting tooth and nail. In what is still a majority of states, there is no mandate, and insurers often deem autism a diagnostic exclusion. Federal and states’ Mental Health Parity statutes have failed to bring any clarity to the issue of autism treatment coverage.

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287 California’s Mental Health Parity Act of 1999 covers autism treatment (1999 Cal. Legis. Serv. Ch. 534 (amending 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.” Girion, supra note 277.

288 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.


290 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*
The patchwork-like quality of this state of affairs is often invoked by the autism movement as a reason for legislative intervention. Litigation strategies, while important to generate political momentum, are only a complement to legislative activism.

2. Mandated Benefits

Because the current response of insurance companies to the plea for reimbursement of therapy costs is at best unpredictable, legislative intervention would certainly be welcome for the sake of clarity. In 2007, Autism Speaks and other organizations launched a multi-state, bi-partisan campaign to promote such legislation.291 The proposed switch is at times radical 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.292 A federal bill – the Autism Treatment Acceleration Act (ATAA) – was also introduced in both House and Senate in 2009, with the main goal of

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*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.


making autism treatment a subject of federal insurance mandate and of closing the loopholes left open by state legislation.\textsuperscript{293}

The gist of the argument in favor of expanded coverage is discrimination.\textsuperscript{294} 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 early ABA intervention.

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;\textsuperscript{295} make insurance less affordable for the poor;\textsuperscript{296} and their redistributive impact is derailed by loopholes and exemptions.\textsuperscript{297}

\textsuperscript{294} See e.g. Autism Speaks, Strongest Mandate, supra note 291.
\textsuperscript{295} See Diane Rowland & Adele Shartzer, America's Uninsured: The Statistics and Back Story, 36 AM. J. L. & MED. 618, 620 (remarking that “[p]ersons who are members of racial and ethnic minority groups are much more likely to be uninsured.”).
\textsuperscript{297} For a discussion of such loopholes, see Sharona 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
This particular mandate, however, is not cast as a new benefit to be added to the list of coverage obligations, but rather as a minimalist correction to an isolated instance of discrimination routinely perpetrated by insurers. 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 rhetorical 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.” In the present socio-economic climate, insurance mandates have come to look as the most equitable move that autism advocates can pursue.

3. 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 recommended by many pediatricians. As a consequence, parents began to demand, in

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300 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).
court if necessary, that ABA costs be regularly covered by existing public programs.\textsuperscript{301} A primary target of parental advocacy was the Early and Periodic Screening, Diagnosis and Treatment (EPSDT) program, administered by Medicaid state agencies since 1967.\textsuperscript{302} 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\textsuperscript{303} and was for years a source of ABA coverage.\textsuperscript{304} The organization Autism Speaks acknowledges that Medicaid has played 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.”\textsuperscript{305}

In early 2003, objections to the high costs imposed by such services prompted a number of policy changes at state level. A directive from the federal Centers for Medicare and Medicaid Services (CMS) stated that ABA was habilitative in nature, and


\textsuperscript{302} Social Security Act § 1905 (a) (4) (B), 42 U.S.C. § 1396(d).

\textsuperscript{303} Peters, \textit{supra} note 269, at 10.

\textsuperscript{304} Sarah Knipper, \textit{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. \textit{Id.} at 30.

therefore not covered by the EPSDT mandate.\textsuperscript{306} As a response, Wisconsin took the lead and opted to discontinue ABA coverage under EPSDT.\textsuperscript{307} A politically viable alternative was found in Medicaid’s Home and Community Based Services waivers.\textsuperscript{308} 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.\textsuperscript{309} The waivers grant states the flexibility to expand services and include habilitation therapy.\textsuperscript{310} HCBS funding is by definition less than the cost of institutionalizing individuals with disabilities, and therefore politically more palatable than other Medicaid benefits. Medicaid waivers are often perceived as a money-saving device, because they usually come with caps to the number of serviceable individuals and are more narrowly defined than the general EPSDT obligation.\textsuperscript{311} Today, however, with state budgets so severely under pressure, the future of waivers is also in jeopardy.\textsuperscript{312} The CMS has sent states multiple signals that

\begin{footnotes}
\textsuperscript{306} See Paul T. Shattuck et al., Utilization of a Medicaid-Funded Intervention for Children with Autism, 60 \textit{PSYCHIATRIC SERVICES} 549 (2009). The CMS has since sent many such signals to state Medicaid administrators. In Parents League for Effective Autism Servs. 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. The court also reports that in August of 2007, CMS filed a proposed rule that would limit the services covered under the "rehabilitative" services category. In response, ODJFS proposed rules changing the definition of "rehabilitative services" and effectively excluding ABA coverage.

\textsuperscript{307} Shattuck, \textit{supra} note 306, at 549.


\textsuperscript{309} Shattuck, \textit{supra} note 306 at 549.

\textsuperscript{311} H.S. Kaye et al., \textit{Do Non-Institutional Long-Term Care Services Reduce Medicaid Spending?}, 28 \textit{HEALTH AFFAIRS} 262 (2009).

\textsuperscript{312} See Robert L. Mollica et al., \textit{Taking the Long View: Investing in Medicaid Home and Community-Based Services is Cost-Effective}, AARP POLICY CENTER, Mar. 2009, http://assets.aarp.org/rgcenter/il/i26 hcbs.pdf, at 1 (reporting, critically, that in the present climate of deep

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federal financial participation to state expenditures on behavioral programs is no longer to be taken for granted.\textsuperscript{313}

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.\textsuperscript{314} While HCBS waivers focus in general on a vast group of candidates for long-term institutionalization,\textsuperscript{315} 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.\textsuperscript{316} Several autism waiver programs have a precious few slots, and ongoing advocacy efforts are bringing to the attention of legislators the fact that many eligible children remain on waitlists for years, missing a

\textsuperscript{313}See Testimony of Autism Speaks, supra note 305, 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.”).

\textsuperscript{314}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.” Id. 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.nasddds.org/Meetings/2008_Mid-Year_Meeting/2008_MYM_Presentations/Blackwell.ppt, and Reinke, supra note 268.

\textsuperscript{315}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).

\textsuperscript{316}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; Children’s Autism Medical Waiver Update, Mass Advocates for Children, http://www.massadvocates.org/uploads/4z/S3/4zS3qXJ-NPLq-nik7wP0vA/MAC_Website_Waiver_Update_final.pdf.
precious window of opportunity for therapeutic intervention. Specific programs for adults with autism are also beginning to be funded.

When read together, these stories sketch an interesting trajectory: for a while, especially in the aftermath of the 1999 Olmstead decision, autism enhanced 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 increased and budgets shrunk, the movement was forced to pursue carve-out policies and autism became a small island of resilience in a sea of contraction of public expenditures.

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. The EPIAA’s discursive

317 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, available at 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 308, at 6. “At the end of 2007, 366 children were waiting for services under the CLTS waivers due to insufficient funding.” Id. 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.

318 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).
emphasis on promises and public funding sounds now passé.\textsuperscript{319} There has been no legislative activity on EPIAA since April 2007.\textsuperscript{320} Some of its provisions have been incorporated in the more recent Autism Treatment Acceleration Act (ATAA),\textsuperscript{321} but the latter bill is clearly centered around insurance mandates and less exacting on fiscal revenue.\textsuperscript{322}

4. Retrenching

These developments of autism advocacy in matters of access to health care parallel 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 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 – and of schools specifically designed to serve the needs of students with autism. By the same token, the Section on health law concludes by signaling the relevance, within the labyrinth of Medicaid possibilities, of specific autism

\textsuperscript{319} 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.

\textsuperscript{320} 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.

\textsuperscript{321} Supra note 293.

\textsuperscript{322} Id., § 12.
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. Also, the battle for autism mandates, as difficult as it may seem against the opposition of the insurance industry, is proving politically possible. These mandates, 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. 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.323 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.

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

323 See, e.g., the most recent budget of Delaware’s Office of Developmental Programs (devoting the first of its six items to autism intervention funds), available at http://www.mhmrpa.org/mhmr/lib/mhmr/ODPBudgFY2009-10.pdf.
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 clear that autism lends the moral-philosophical call for redistribution in favor of persons with mental disabilities, famously voiced by Martha Nussbaum, 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, the accelerated itinerary of the Mental Health Parity Bill in Congress, and the increasingly popular science of brain imaging, that eats away at the notion of free will and moral responsibility. 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 Autism Omnibus 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

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324 See Nussbaum, supra note 97, at 188-90.
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. 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 neuroscience 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 cognitive disabilities 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 in bed 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 health care, autism, for obvious reasons of urgency and efficacy, is now building its own silo of benefits, in the form of specific insurance mandates for a single diagnosis. In the present legal system and in the current economic climate, this
competitive retrenchment makes utmost sense, but its redistributive reach remains questionable.

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.328

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 pictures329 and seek

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immediate rewards; that we can see many trees but perhaps not the forest; 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.

\[330\] In neuro-psychological terms, this feature of autism spectrum disorders is termed “weak central coherence.” See BARNBAUM, supra note 8, at 27.