

Autism Politics: A Research Agenda

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Abstract

Autism has gained a great deal of attention from policymakers and journalists. But there has been little scholarly research into autism policy and politics. This paper sketches what we know about the topic and raises questions for future research. It follows the stages of the policy process.

Initiation is the first stage. Psychologists have known of autism since the 1940s, but why has it become a major national issue only in the past decade?

Estimation is the second stage. One possible reason for increased attention is the sharp rise in the reported prevalence of autism. But such data raise another question: how much of the increase reflects changing diagnostic criteria and how much is “real”?

Mobilization is the third stage. Emerging issues attract the attention of existing groups or spawn the formation of new ones. In the case of autism, why do these groups form? How and why do they clash or cooperate?

Selection and implementation are the fourth and fifth stages. The policy response involves education, health care, and disability policy at the national, state, and local levels. To what extent do policymakers in these fields work together -- or do they work at cross-purposes? What interest group pressures affect policymaking?

In the evaluation stage, policymakers reckon how well a policy is working. Are they tracking how much help is reaching people with autism? And is this assistance producing good long-term outcomes?

Researchers are seeing more and more cases of autism. A quarter-century ago, the best estimate was that only one child in 2,000 suffered from what we now call autism spectrum disorders. In 2007, a study published by the Centers for Disease Control (CDC) found a prevalence of one in 150.¹ Just three years later, another CDC study put the figure at one in 110.² No one knows how much is a true increase, and how much stems from changes in how we identify and classify autism.

Either way, autism has become a prominent political issue. The 2008 election marked the first time that presidential candidates seriously talked about it. But apart from some fine work by Dana Baker, the late Trudy Steuernagel and a few others, political science has barely begun to analyze autism policy and politics. This inattention is unfortunate because the discipline can tell us much about how the issue has emerged and what government is doing about it. Conversely, study of autism politics can contribute to a more sophisticated understanding of policymaking.

Lasswell identified several stages of the policy process in 1957.³ Brewer and deLeon revised the list in 1983, and I shall organize this paper around their version.⁴ There are a couple of changes, however. Unlike them, I omit “termination” as a separate phase, for in spite of recent budget cuts, the story here has largely been one of adding

¹ Catherine Rice, “Prevalence of Autism Spectrum Disorders — Autism and Developmental Disabilities Monitoring Network, 14 Sites, United States, 2002,” *Morbidity and Mortality Weekly Report* 56 (February 9, 2007): 12-28, at <http://www.cdc.gov/mmwr/pdf/ss/ss5601.pdf>. An *incidence* rate is the number of *new* cases divided by the number of persons at risk. A *prevalence* rate is the *total* number of cases divided by the total population.

² Catherine Rice, “Prevalence of Autism Spectrum Disorders — Autism and Developmental Disabilities Monitoring Network, United States, 2006,” *Morbidity and Mortality Weekly Report* 58 (December 18, 2009): 1-20, at <http://www.cdc.gov/mmwr/pdf/ss/ss5810.pdf>.

³ Harold D. Lasswell, *The Decision Process: Seven Categories of Functional Analysis* (College Park, Maryland: University of Maryland Press, 1956).

⁴ Garry D. Brewer and Peter deLeon, *Foundations of Policy Analysis* (Monterey: Brooks/Cole, 1983).

new policies and programs, not scrapping old ones. This paper also adds “mobilization” as phase. Accordingly, here are the six phases:

- *Initiation*: the recognition of a problem and its emergence onto the policy agenda.
- *Estimation*: the effort to define the problem, measure its contours, and reckon the cost of potential policy responses.
- *Mobilization*: the creation of new interest groups concerned with the new issue, along with the reorientation of existing organizations.
- *Selection*: the choice of options by policymakers.
- *Implementation*: the “on the ground” administration of the chosen policy.
- *Evaluation*: appraisal of how effectively and efficiently the policy is achieving its intended results.

This list suggests more order and logic than real-world policymaking displays, so some cautions are in order. First, the phases overlap with one another. For instance, policy estimation may start as the issue is still entering the agenda, and it continues throughout subsequent phases. Second, issues are always linked. Autism is part of set of issues involving developmental disabilities (e.g., cerebral palsy), and these issues in turn engage broader policy fields such as education, health care, civil rights, and law enforcement -- to name just a few. Developments in these fields can have big and unanticipated consequences for the specific issue in question. Third, even within that issue, there is seldom just one “policy” in play. Decisionmakers in all three branches and at all levels may be working on different parts of the problem all at the same time. Fourth, governments rarely “solve” a problem once and for all. Instead, the unanticipated consequences of a policy may result in new problems. And because of analysis and

interest group activity, new problems or new aspects of the existing problem may enter the agenda.

Much of the important policymaking on autism takes place at the state level. Outside of the structure established by federal education law, states provide various services to children and adults with autism.⁵ A number of states have set up autism task forces, commissions or councils to make recommendations for legislative and executive action.⁶ States have also enacted laws requiring insurance companies to pay for the diagnosis and treatment of autism spectrum disorders.⁷ But for the sake of brevity and simplicity, this paper concentrates on federal policy, analyzing the process in two broad policy areas. The first is the provision of therapy and other services to autistic people. The second is scientific research on autism, including the search for its causes, and the effort to develop medical treatments.

Initiation: Autism Becomes an Issue

It is likely that autism has always been with us, but only in 1943 did a researcher name it as a distinct disorder. Dr. Leo Kanner, a child psychiatrist at Johns Hopkins University Hospital, reported on eleven children who seemed to have more interest in certain inanimate objects than in other people.⁸ In listing symptoms, Kanner employed terms that are still in use today, including *echolalia* (repetition of words or phrases spoken in the autistic person's presence) and *stereotypy* (repetitive movement such as

⁵ For a database of state activities, see: Easter Seals, "2009 State Autism Profiles." Online: http://www.easterseals.com/site/PageServer?pagename=ntlc8_autism_state_profiles

⁶ National Conference of State Legislatures, "Autism," January 2010. Online: <http://www.ncsl.org/IssuesResearch/Health/AutismPolicyIssuesOverview/tabid/14390/Default.aspx>

⁷ Autism Speaks, "Autism Speaks State Insurance Reform Initiatives," February 2010. Online: http://www.autismvotes.org/site/c.frKNI3PCImE/b.3909861/k.B9DF/State_Initiatives.htm

⁸ Leo Kanner, "Autistic Disturbances of Affective Contact," *Nervous Child* 2 (1943): 217-250, at <http://affect.media.mit.edu/Rgrads/Articles/pdfs/Kanner-1943-OrigPaper.pdf>

hand flapping). Though he got some important things right, he also made mistakes with long-lasting consequences. He noted that all of the children came from “intelligent families,” suggesting a causal link. But what he actually saw was a referral bias, meaning those most likely to seek out a university psychiatrist in the 1940s were the most highly educated.⁹ More ominously, he observed that the children’s families tended to lack warmth and that several of the parents had divorced. Here he confused cause and effect, overlooking the emotional toll that autism can take on family members.¹⁰

In 1964, psychologist Bernard Rimland published *Infantile Autism: The Syndrome and Its Implications for a Neural Theory of Behavior*, which identified autism as a neurological problem. Kanner, who had revised his thinking, wrote the foreword. Though a milestone work, Rimland’s study had relatively few readers. Three years later, another book reached a wider audience and shaped the development of the issue. In *The Empty Fortress* (1967) noted author Bruno Bettelheim took up Kanner’s original theme and popularized the “refrigerator mother” theory of autism.¹¹ Bettelheim had little psychological training (his Ph.D. was in aesthetics) and many researchers were skeptical, but his skill at self-promotion helped him win favorable attention for the book in the mass media.¹² Editors and producers were receptive because Bettelheim seemed to convey a sense of authority.¹³

⁹ Roy Richard Grinker, *Unstrange Minds: Remapping the World of Autism* (New York: Basic Books, 2007), 73.

¹⁰ Laura Schreibman, *The Science and Fiction of Autism* (Cambridge: Harvard University Press, 2005), 81.

¹¹ “Throughout this book I state my belief that the precipitating factor in infantile autism is the parent’s wish that the child should not exist.” Bruno Bettelheim, *The Empty Fortress: Infantile Autism and the Birth of the Self* (New York: Simon and Schuster, Free Press, 1967), 125.

¹² Richard Pollak, *The Creation of Dr. B: A Biography of Bruno Bettelheim* (New York: Simon and Schuster, Touchstone, 1997), 270-272.

¹³ Katherine DeMaria Severson, James Arnt Aune, and Denise Jodlowski, “Bruno Bettelheim, Autism, and the Rhetoric of Scientific Authority, in Mark Osteen, ed., *Autism and Representation* (New York: Routledge, 2008), 65-77.

Students of agenda-setting have long known that mass-market books can help put an issue onto the political agenda. Examples include Rachel Carson's *Silent Spring* (pollution and pesticides) and Ralph Nader's *Unsafe at any Speed* (auto safety). Like these earlier works, *The Empty Fortress* did indeed raise the profile of a problem affecting many people. But whereas agenda-setting books convince readers that a policy response is necessary,¹⁴ *The Empty Fortress* pointed in the *opposite* direction by blaming maternal coldness. Instead of spurring demands for effective public action, it made a generation of autism mothers feel guilty. Its fraudulent research and bogus conclusions spread popular misunderstandings that would take years to correct.

By the 1980s, rigorous medical research had debunked the “refrigerator mom” theory and confirmed Rimland's argument that autism is a neurological disorder. Gradually, clinical practice caught up. These advances, however, were not enough to put autism onto the policy agenda. Several other developments helped increase its prominence and turn it into a public issue.

The entertainment media can sometimes stir curiosity or concern about social afflictions. In the 1960s, for instance, millions of Americans became more aware of child abuse when the problem inspired plotlines in television soap operas and prime-time dramas.¹⁵ In the case of autism, a key episode was the 1988 movie *Rain Man*, which won several Academy Awards and performed strongly at the box office. Its depiction of an autistic savant (Dustin Hoffman) likely had mixed effects. On the one hand, it spread autism awareness and exposed millions to the term “high-functioning.” On the other

¹⁴ Deborah Stone, *Policy Paradox: The Art of Political Decision Making*, rev. ed. (New York: Norton, 2002), 198-199.

¹⁵ Barbara J. Nelson, *Making an Issue of Child Abuse: Political Agenda Setting for Social Problems* (Chicago: University of Chicago Press, 1986), 56-57.

hand, it reinforced an old stereotype when one of its characters said – incorrectly -- that most autistic people “can’t speak or communicate.” It also created the false impression that high-functioning autism entails superhuman memory and math abilities.¹⁶ In fact, true savant syndrome is rare.¹⁷

Media portrayals helped make people more alert to the difficulty of autism. But as Aaron Wildavsky wrote, “a difficulty is a problem only if something can be done about it.”¹⁸ Identifying autism as a neurological problem was a key step that opened the way for more scientific research. In the 1980s, this research did not point to any effective medical treatment (and it still remains out of reach in 2010). Autism could not move from “difficulty” to “problem” until there was at least a plausible answer to the question: “What is to be done?” In 1987, O. Ivar Lovaas supplied one answer in the form of what would become known as applied behavior analysis (ABA). After applying more than 40 hours a week of behavioral training to very young children, he reported that nearly half had recovered normal intellectual and educational functioning.¹⁹ His work got widespread attention in clinical circles, and parents eventually learned of it, too. Despite criticisms that he had exaggerated ABA’s effectiveness, there was now something to be done: a specific course of therapy with at least some empirical justification.

The rise of “disability” as a distinct set of policy issues also helped autism get onto the agenda. In 1963, Congress passed a developmental disabilities act that

¹⁶ In 2008, Professor Stanley Fish illustrated the persistence of this misunderstanding when he likened autistic people to the mutant superheroes of *X-Men*. Stanley Fish, “Norms and Deviations: Who’s To Say?” *New York Times Opinionator Blog*, June 1, 2008, at <http://opinionator.blogs.nytimes.com/2008/06/01/norms-and-deviations-whos-to-say/>.

¹⁷ Schreibman, *The Science and Fiction of Autism*, 45-46.

¹⁸ Aaron B. Wildavsky, *Speaking Truth to Power: The Art and Craft of Policy Analysis*, 2d ed. (New Brunswick, NJ: Transaction, 1987), 42.

¹⁹ O. Ivar Lovaas, “Behavioral Treatment and Normal Educational and Intellectual Functioning in Young Autistic Children,” *Journal of Consulting and Clinical Psychology* 55(February 1987): 3-9. Online: <http://rsaffran.tripod.com/lovaas1987.html>

supported community mental health centers. In its 1975 reauthorization of the law, Congress specifically listed autism as a disability and providing for its representation on state developmental disability councils.²⁰ Also in 1975, the Education for All Handicapped Children Act required that states receiving federal special-education funds must provide a “free appropriate public education” to handicapped children. In contrast to past practices of isolation and marginalization, the new trend was to accommodate people with various disabilities so that they could take part in mainstream society. As Steuernagel pointed out, the most visible sign of this new trend was the 1990 passage of the Americans with Disabilities Act (ADA). This legislation brought official recognition to the disability community and included it in federal antidiscrimination law.²¹

In the same year, Congress also reauthorized the Education for All Handicapped Children Act, renaming it the Individuals with Disabilities Education Act (IDEA). The new law changed “handicapped children” to “children with disabilities” and specifically named autism as one of these disabilities. The lawmakers did not spend much time discussing autism, nor did they define it. Indeed, they left room for administrators to use a fairly expansive definition of the disorder. In his remarks on the conference report, Representative George Miller (D-CA) said: “The bill makes clear that children with an autistic condition or traumatic brain injury, *regardless of its severity* [emphasis added], are entitled to a free, appropriate public education and related services.”²²

With a greater public awareness of general disability issues, and with the new language of IDEA, parents of autistic children began pressing local school districts for

²⁰ Ruth Christ Sullivan, “The Politics of Definitions: How Autism Got Included in the Developmental Disabilities Act,” *Journal of Autism and Developmental Disorders* 9 (June 1979): 221-231.

²¹ Trudy Steuernagel, “Increases in Identified Cases of Autism Spectrum Disorders: Policy Implications,” *Journal of Disability Policy Studies* 16 (Winter 2005): 138-146.

²² *Congressional Record* (daily), October 15, 1990, H9632.

more services. As we shall see shortly, advocacy groups sprang up to enlist public support. By the end of the decade, the political community was taking more and more notice. One crude indicator of the issue's emergence onto the national political agenda is the number of *Congressional Record* items mentioning the words *autism* or *autistic*.²³

101 st	(1989-90)	43
102d	(1991-92)	15
103	(1993-94)	15
104	(1995-96)	32
105	(1997-98)	41
106	(1999-00)	108
107	(2001-02)	95
108	(2003-04)	159
109	(2005-06)	159
110	(2007-09)	188

As we noted at the outset, the reported number of autism cases has been on the rise. So perhaps the increase in political attention stems in part from the increase in the problem: people are more concerned about autism because there is more of it. But the reverse might also be true: that the growth in the reported size of the problem reflects greater public awareness.

Questions for Future Research

- Kingdon writes of the role of “policy communities” in agenda formation.²⁴ How did the autism policy community take shape? What role did academic experts and government officials play in sounding the autism alarm?

²³ The measure is rough and ready at best. It is simply the result of a Lexis-Nexis search of *The Congressional Record*, and includes all items (speeches, extensions of remarks, cosponsorship) that include variants of the word *autism*

²⁴ John W. Kingdon, *Agendas, Alternatives, and Public Policies*, 2d ed. (New York: HarperCollins, 1995).

- To what extent did early media coverage of autism stem from the efforts of autism advocates to publicize the disorder?

Estimation

In the estimation phase, the policy process moves beyond a general sense that a problem exists to efforts at defining and quantifying its contours. Estimation may sound dry and technical, but it has serious consequences. Autism is a vivid case study.

Consider data from the National Center for Education Statistics on the number of autistic children aged 3 to 21 in federally supported programs for the disabled:²⁵

	Number (thousands)	Percent of enrollment in programs for disabled	Percent of total enrollment
1995-1996	28	0.5	0.1
1996-1997	34	0.6	0.1
1997-1998	42	0.7	0.1
1998-1999	53	0.9	0.1
1999-2000	65	1.0	0.1
2000-2001	94	1.5	0.2
2001-2002	114	1.8	0.2
2002-2003	137	2.1	0.3
2003-2004	163	2.5	0.3
2004-2005	191	2.8	0.4
2005-2006	223	3.3	0.5
2006-2007	258	3.9	0.5
2007-2009	296	4.5	0.6

So whether the figure has risen sixfold (percent of total enrollment), ninefold (percent of enrollment in programs for the disabled) or tenfold (total number), the data suggest a startling growth in the autistic population. But the trend is less clear-cut than it

²⁵ U.S. Department of Education, Institute of Education Sciences, *Digest of Education Statistics*, 2009, Table 50: Children 3 to 21 years old served under Individuals with Disabilities Education Act, Part B, by type of disability: Selected years, 1976-77 through 2007-08. Online: http://nces.ed.gov/programs/digest/d09/tables/dt09_050.asp

seems at first, since there is no simple way to determine who is autistic. As opposed to people with Down Syndrome, most people with autism lack distinctive physical characteristics.²⁶ Despite strides in medical research, there is as yet no test that can confirm an individual case of autism. And because diagnosis involves people who are pre-verbal or non-verbal, questionnaires have limited value. Diagnosis mostly hinges on observation of behavior.

But what behavior?

The authoritative *Diagnostic and Statistical Manual of Mental Disorders* failed to provide any answers in its first (1952) or second (1968) editions, not even including autism as a separate diagnostic category. In 1980, the third edition (DSM-III) did so, listing six symptoms that had to be present for a diagnosis of “infantile autism.”²⁷ A 1987 revision dropped the word “infantile” in favor of “autism disorder.” The DSM-IV (1994) was more specific in language, offering a checklist of symptoms under several headings: “qualitative impairment in social interaction,” “qualitative impairments in communication,” and “restricted repetitive and stereotyped patterns of behavior, interests and activities.” Just as important, the book now listed five related disorders: Autistic Disorder, Rett’s Disorder, Child Disintegrative Disorder, Asperger’s Disorder, and Pervasive Developmental Disorder- Not Otherwise Specified (PDD-NOS). Together, the five would soon come under the common heading of “autism spectrum disorder” (ASD).

Because of the shifts in criteria and definition, at least some of the increase reflects diagnostic substitution. The basic idea is that children who today receive a

²⁶ People with Rett’s Disorder have small hands and feet, and experience a slowdown in head growth. People with Fragile X syndrome have distinctive facial characteristics. But Rett and Fragile X account for only a small proportion of people with ASD.

²⁷ Grinker, *Unstrange Minds*, 136-138.

diagnosis of autism spectrum disorder would have gotten a different diagnosis decades ago.²⁸ Some on the higher-functioning end of the spectrum would have received no diagnosis at all. (In 2000, at the age of 46, Pulitzer Prize-winning music critic Tim Page learned that he had Asperger’s Disorder, which was not even in the DSM when he was growing up.²⁹) Diagnostic substitution may also reflect greater sensitivity on the part of parents and professionals. Poor attention may cause autistic people to get low scores on standardized tests, so some individuals once classified as “retarded” were probably autistic – and possibly quite intelligent. Autistic self-talk and odd gestures mimic symptoms of schizophrenia, so others on the spectrum may have received thiorazine and other medications that did them no good.

Furthermore, the law encourages parents to seek a diagnosis of ASD for troubled children, since it can trigger thousands of dollars in assistance. Grinker quotes a leading scientist who also has a clinical practice: “I am incredibly disciplined in the diagnostic classifications in my research, but in my private practice, I’ll call a kid a zebra if it will get him the educational services I think he needs.”³⁰

Few would deny the role of diagnostic substitution – but does it account for *all* of the increase in autism? Data from California suggest otherwise. The state was a leader in autism treatment, and has been keeping detailed statistics for many years. Studying these data, Hertz-Picciotto and Delwiche concluded:

[T]he incidence of autism rose 7- to 8-fold in California from the early 1990s through the present. Quantitative analysis of the changes in diagnostic criteria, the

²⁸ Nestor Lopez-Duran, “Diagnostic Substitution Unlikely to Explain Increases in Autism in California,” Child Psychology Research Blog, June 4, 2009. Online: <http://www.child-psych.org/2009/06/diagnostic-substitution-in-autism-california-effect.html>

²⁹ Tim Page, *Parallel Play: Growing Up with Undiagnosed Asperger’s* (New York; Doubleday, 2009).

³⁰ Grinker, *Unstrange Minds*, 130.

inclusion of milder cases, and an earlier age at diagnosis during this period suggests that these factors probably contribute 2.2-, 1.56-, and 1.24-fold increases in autism, respectively, and hence cannot fully explain the magnitude of the rise in autism. Differential migration also likely played a minor role, if any. Wider awareness, greater motivation of parents to seek services as a result of expanding treatment options, and increased funding may each have contributed, but documentation or quantification of these effects is lacking. With no evidence of a leveling off, the possibility of a true increase in incidence deserves serious consideration.³¹

This possibility has serious implications for public policy. If there were no true increase, we might conclude that autism is primarily a genetic disorder. In that case, prevention efforts would focus primarily on genetic testing for autism predisposition.³² But if autism is really on the rise, then something other than genetics is at work, and a prime goal of autism policy must be to find that cause. In 1998, an article in *The Lancet* seemed to finger a suspect. Andrew Wakefield and his colleagues examined a dozen children with gastrointestinal and developmental disorders, concluding that the MMR (measles, mumps, rubella) vaccine might be to blame.³³ Wakefield held a news conference on his findings, and significant press coverage followed. Within a couple of years, studies disconfirmed any link between MMR and autism. Proponents of the vaccine theory then said that the problem lay not with MMR per se but with thimerosal,

³¹ Irva Hertz-Picciotto and Lora Delwiche, "The Rise in Autism and the Role of Age at Diagnosis," *Epidemiology* 20 (January 2009): 84-90, at 89.

³² Gary E. Marchant and Jason S. Robert, Genetic Testing for Autism Predisposition: Ethical, Legal and Social Challenges," *Houston Journal of Health Law and Policy* 9 (2010): 203-235.

³³ Andrew Wakefield, et al, "Ileal-Lymphoid-Nodular Hyperplasia, Non-Specific Colitis, And Pervasive Developmental Disorder In Children," *The Lancet* 351 (February 1998): 637-641. Online: <http://www.thelancet.com/journals/lancet/article/PIIS0140673697110960/fulltext>

the mercury-based preservative present in a number of vaccines. A significant number of parents have developed a passionate belief that vaccines with thimerosal caused their children's autism, and they have enjoyed support from members of Congress, prominent journalists, and celebrities. As we shall see in the next section, vaccine theory has become a fault line among autism advocacy groups

Mainstream science, however, has come down hard against the theory.³⁴ For instance, one study found that autistic children had no more mercury in their blood than typical children.³⁵ Another found that prevalence among young children did not decrease after the removal of thimerosal from vaccines.³⁶ In a landmark case before the United States Court of Federal Claims (“the vaccine court”), the special masters drew upon this literature to reject the thimerosal theory – with a thump. One wrote:

I conclude that the evidence is overwhelmingly contrary to the petitioners' contentions. The expert witnesses presented by the respondent were far better qualified, far more experienced, and far more persuasive than the petitioners' experts, concerning the key points. The numerous medical studies concerning the issue of whether thimerosal causes autism, performed by medical scientists worldwide, have come down strongly against the petitioners' contentions.³⁷

³⁴ For summaries of the literature, see: U.S. Centers for Disease Control, “MMR and Autism Research Agenda,” January 30, 2009. Online: http://www.cdc.gov/ncbddd/autism/documents/vaccine_studies.pdf

³⁵ Irva Hertz-Picciotto, “Blood Mercury Concentrations in CHARGE Study Children With and Without Autism,” *Environmental Health Perspectives* 118 (January 2010): 161-166.

³⁶ Robert Schechter and Judith K. Grether, “Continuing Increases in Autism Reported to California's Developmental Services System,” *Archives of General Psychiatry* 65 (January 2008): 19-24.

³⁷ *King v. Secretary of Health and Human Services* Case No. 03-584V. Special Master Hastings, March 12, 2010. Online: <http://www.uscfc.uscourts.gov/sites/default/files/Hastings.King%20Decision.pdf>.

In 2009, *The Times* of London published an investigative report charging that Andrew Wakefield had “changed and misreported results in his research.”³⁸ Early in 2010, a British medical disciplinary panel concluded that Wakefield had been dishonest and was misleading in describing his work. It said he had failed to disclose that he had received payment to advise lawyers acting for parents who thought that vaccine had harmed their children.³⁹ And then *The Lancet* took the extraordinary step of retracting the article, acknowledging that it had made false claims.⁴⁰

Nevertheless, many in the autism community continue to warn against vaccines. And about 25 percent of parents agree with the statement: “Some vaccines cause autism in healthy children.”⁴¹ Why?

First, if there is a true increase in autism, no one has a solid alternative theory to account for it. In their efforts raise to public consciousness of autism, advocacy groups frequently refer to it as an “epidemic.”⁴² The term connotes something that spreads wildly, and for which someone is to blame. The drug industry is a logical target: in a 2009 Gallup poll, 49 percent of American had a negative view of it, compared with only 31 percent with a positive view.⁴³

³⁸ Brian Deer, “MMR Doctor Andrew Wakefield Fixed Data on Autism,” *The Times*, February 8, 2009. Online: http://www.timesonline.co.uk/tol/life_and_style/health/article5683671.ece

³⁹ General Medical Council, Fitness to Practise Panel Hearing, January 28, 2010. Online: <http://www.rescuepost.com/files/facts-wws-280110-final-complete-corrected.pdf>

⁴⁰ “Retraction—Heal-Lymphoid-Nodular Hyperplasia, Non-Specific Colitis, and Pervasive Developmental Disorder in Children,” *The Lancet*, February 2, 2010. Online: <http://download.thelancet.com/flatcontentassets/pdfs/S0140673610601754.pdf>

⁴¹ Gary L. Freed et al., “Parental Vaccine Safety Concerns in 2009,” *Pediatrics* 125 (April 2010): 654-659. Online: <http://www.pediatrics.org/cgi/content/full/125/4/654>.

⁴² Trudy Steuernagel and Irene Barnett, “U.S. Health Social Movements and Public Policy: Autism and Alzheimer’s Disease,” paper presented at the annual meeting of the Midwest Political Science Association, Chicago, April 12-15, 2007. Online: http://www.allacademic.com/meta/p_mla_apa_research_citation/1/9/8/5/5/pages198556/p198556-1.php.

⁴³ Gallup Poll, “Business and Industry Sector Ratings,” August 6-9, 2009. Online: <http://www.gallup.com/poll/12748/Business-Industry-Sector-Ratings.aspx>.

Second, the “epidemic frame” is a natural for the mass media, which tend to look for stories with villains, heroes, and victims. Singh, Hallmayer, and Illes compared peer-reviewed autism articles in scientific journals with coverage in the mass media. Whereas scientific literature emphasized studies of behavior, genetics, and the brain, the popular press focused on environmental causes and epidemiology research, including the vaccine theory.⁴⁴ The entertainment media have weighed in, too. Britain’s Channel Five ran “Hear the Silence,” a pro-Wakefield docu-drama.⁴⁵ The 2008 premiere of the ABC series “Eli Stone” was a story about a child who had become autistic because of “mercuritol” – a fictional name for thimerosal.⁴⁶

Third, since most Americans lack the training to evaluate medical research studies for themselves, popular support for the findings depends on acceptance of scientific authority. In recent years, that authority seems to have eroded, in part because of the Internet. A study of health blogs found that autism was the primary subject of one-quarter of the disease-specific blogs on the Internet.⁴⁷ According to Grinker:

Information is accessible, but it is often difficult to discriminate between different genres. A blogger’s opinion and a scientific article may have equal weight to an average Internet user. But while doctors tend to access scientific articles, families, aided by the media, tend to access anecdotes, many of them convincing testimonials about unproven therapies. The celebrity becomes more of an “expert”

⁴⁴ Jennifer Singh, Joachim Hallmayer and Judy Illes, “Interacting and Paradoxical Forces in Neuroscience and Society,” *Nature Reviews Neuroscience* (February 2007): 153-160, at 157. Online: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1885680/>

⁴⁵ Paul A. Offit, *Autism’s False Prophets* (New York: Columbia University Press, 2008), 22-24.

⁴⁶ Edward Wyatt, “ABC Drama Takes on Science and Parents,” *New York Times*, January 23, 2008. Online: <http://www.nytimes.com/2008/01/23/arts/television/23ston.html>

⁴⁷ Edward Alan Miller, Antoinette Pole, and Clancey Batemen, “Diagnosis Blog: Checking Up on Health Blogs in the Blogosphere,” paper presented at the annual meeting of the Midwest Political Science Association, Chicago, April 2-5, 2009.

on autism than the scientist. It is indeed extraordinary to hear, as I did, a television advertisement for CNN's "Larry King Live" in which King said, "Is there an autism epidemic? Join us tonight with comedian Bill Cosby and singer Toni Braxton."⁴⁸

In the case of autism, scientific authority has special challenges. At least until recently, many pediatricians failed to screen for autism, or overlooked early signs of the disorder during patient visits.⁴⁹ When parents finally get the diagnosis of autism and realize that their pediatricians could have flagged it much earlier, they come to question the doctors' subsequent advice. Many parents know that clinicians once operated on the basis of Bettelheim's "refrigerator mother" theory. If he proved to be a fraud, they reason, will not the same fate meet today's scientists? Moreover, a small but prominent group of researchers dissent from the consensus. Bernard Rimland, who eventually gained fame for refuting Bettelheim, spent the last years of his life arguing for the vaccine theory. The support of people with M.D. and Ph.D. degrees, some of whom have done serious work on autism, enables adherents of the vaccine theory to claim a measure of credibility.

Issues of estimation extend far beyond basic questions of definition and causation. The disorder involves a range of other co-occurring or "co-morbid" conditions:⁵⁰

- Intellectual disabilities;

⁴⁸ Roy Richard Grinker, "Commentary: On Being Autistic, and Social," *Ethos* 38 (March 2010): 172-178, at 175. Online: <http://www3.interscience.wiley.com/cgi-bin/fulltext/123320144/PDFSTART>. There was at least some reason for their appearance. Cosby has a doctorate in education, and Braxton has an autistic son.

⁴⁹ The signs of autism should be clear to a trained professional when the child is two. According to one recent study, the average age of diagnosis is six. Paul T. Shattuck, et al, "Timing of Identification among Children with an Autism Spectrum Disorder: Findings From a Population-Based Surveillance Study," *Journal of the American Academy of Child and Adolescent Psychiatry* 48 (May 2009): 474-483.

⁵⁰ Susan E Levy, David S Mandell, Robert T Schultz, "Autism," *The Lancet* 374 (November 2009): 1627 – 1638.

- Delays in gross motor skills (e.g., walking, throwing) and fine motor skills (e.g., writing);
- Attention problems and hyperactivity;
- Anxiety;
- Self-injurious behavior;
- Unusual sensitivity to certain sounds, smells, or feelings;
- Extreme food selectivity;
- Sleep disorders.

These conditions may be hard to measure (or even notice, especially when the autistic person is not verbal), so it is difficult to reckon the aggregate need for services, and the cost of providing them. The families of autistic people bear significant burdens as well. To the extent that government or private insurance does not foot the bill, Sharpe and Baker have documented, families must pay for costly treatments out-of-pocket, often at risk to their financial futures.⁵¹ The time that goes into the care of an autistic person means less time for earning money, and one study put the resulting average loss of annual income at \$6200, or 14 percent of reported income.⁵² Michael Ganz of the Harvard School of Public Health estimated that the annual social per capita cost for each autistic person in the United States is \$3.2 million and about \$35 billion for a birth cohort of people with autism.⁵³ Ganz acknowledged that his figures are tentative, relying on simplified assumptions and incomplete information.

⁵¹ Deanna L. Sharpe and Dana Lee Baker, "Financial Issues Associated with Having a Child with Autism," *Journal of Family and Economic Issues* 28 (June 2007): 247-264.

⁵² Guillermo Montes and Jill S. Halterman, "Association of Childhood Autism Spectrum Disorders and Loss of Family Income," *Pediatrics* 121 (April 2008): 821-826.

⁵³ Michael L. Ganz, "The Lifetime Distribution of the Incremental Societal Costs of Autism," *Archives of Pediatrics and Adolescent Medicine* 161 (April 2007): 343-349. Online:

In short, autism represents a huge problem for policy estimation, involving uncertainty and disagreement over its definition, extent, causes, and cost.

Questions for Future Research

- If there has been no true increase in autism, what happened to the previous generations of autistic people who did not receive a proper diagnosis?
- If there has been a true increase, and if vaccines are not to blame, then what is? Possibilities include viruses, pollutants, and changes in the age at which parents have children.
- Despite the expansion of the autism population in special education, one study finds that the number is still lower than one might expect in light of prevalence estimates, in part because of under-identification of high-functioning children.⁵⁴ With correct identification, how would the special-education numbers change, and what would be the budgetary impact?
- Early behavioral intervention reduces the need for special education services later in the child's life. One Texas study says that early behavioral intervention could save the state up to \$208,500 per child across 18 years of education.⁵⁵ Is this estimate valid, and would it apply to other states as well?

<http://archpedi.ama-assn.org/cgi/reprint/161/4/343>

⁵⁴ Stephen P. Safran, "Why Youngsters With Autistic Spectrum Disorders Remain Underrepresented in Special Education," *Remedial and Special Education* 29 (March/April 2008): 90-95.

⁵⁵ Gregory S. Chasson, Gerald E. Harris, and Wendy J. Neely, "Cost Comparison of Early Intensive Behavioral Intervention and Special Education for Children with Autism," *Journal of Child and Family Studies* 16 (June 2007): 401-413

Mobilization

Many interest groups have a stake in the issue. Some examples are: the American Academy of Pediatrics, the American Psychological Association, the National Education Association, and professional groups representing occupational therapists and speech therapists. Easter Seals, originally the National Society for Crippled Children, is perhaps best known for its work with paraplegics, but in the past 20 years has become the nation's largest nonprofit provider of autism services.⁵⁶ In this section, however, we focus on interest groups whose main original purpose was to deal with autism. Factionalism and infighting are common within social movements – think of civil rights and environmentalism – and autism is no exception.

With the important exception of high-functioning autistic adults, the key stakeholders are parents of autistic children. Mobilization is a challenge for them. Because their children's needs take up so much of their time and money, they have very little left over for political activity. Nevertheless, some have managed. National autism advocacy began in 1965, when Bernard Rimland and Ruth Sullivan founded the National Society for Autistic Children (NSAC), the first major group focusing on the issue. NSAC did play a central role in persuading Congress to include autism in the 1975 developmental disabilities act.⁵⁷ It later changed its name to the Autism Society of

⁵⁶ Easter Seals, "Why Easter Seals and Autism?" Online:
http://www.easterseals.com/site/PageServer?pagename=ntlc8_whyES

⁵⁷ Sullivan, "The Politics of Definitions."

America (ASA) to acknowledge the problems of autistic teens and adults. It claims more than 120,000 “members and supporters” with nearly 200 chapters nationwide.⁵⁸

In spite of action on broader disability policy (e.g., the 1990 passage of ADA and IDEA), ASA did not have a major legislative success until other groups entered the field.⁵⁹ In 1995 autism parents Jonathan Shestack and Portia Iverson founded Cure Autism Now (CAN). Both are in the entertainment industry, and they used their connections to build celebrity support.⁶⁰

Even with famous supporters, interest groups must grapple with the problem of gaining and maintaining financial resources. One solution to the problem is to find patrons in the form of government agencies, nonprofit foundations, or wealthy individuals.⁶¹ For autism, that solution arrived in 2005 when Bob and Suzanne Wright, the grandparents of an autistic child, founded Autism Speaks. Wright was chair and CEO of NBC Universal, so the organization could benefit from his personal wealth and his connections to the entertainment industry and the top ranks of American business. With this access to large contributors and A-list fundraisers, Autism Speaks was instantly a major player. It became the issue’s leading organization when it merged with Cure Autism Now and two other groups: the National Alliance for Autism Research and the Autism Coalition for Research and Education. Autism Speaks funds research into causes

⁵⁸ Autism Society of America, “History.” Online: http://www.autism-society.org/site/PageServer?pagename=asa_princip_history

⁵⁹ Trudy Steuernagel and Dana Lee Baker, “Comparative Canadian and U.S. Autism Policy: A Narrative Analysis,” paper presented at the annual meeting of the Midwest Political Science Association, April 3, 2008. Online:

http://www.allacademic.com//meta/p_mla_apa_research_citation/2/6/8/6/7/pages268673/p268673-1.php

⁶⁰ Ibid.

⁶¹ Jack Walker, “The Origins and Maintenance of Interest Groups in America,” *American Political Science Review*, 77 (June 1983): 390-406

and treatments, seeks to increasing awareness of the disorder through public service announcements, and advocates public policies to help autistic people.

The group's prominence has spawned controversy. On the one hand, it has funded research into vaccines and other environmental causes, which prompted one of its executives to resign in 2009. Alison Singer, executive vice president of communications and awareness, said: "In general, I disagree with a policy that says, 'Despite what this study shows, more studies should be done.' At some point, you have to say, 'This question has been asked and answered and it's time to move on.'"⁶² On the other hand, it refrained from endorsing the vaccine theory, which was not enough for Katie Wright, Bob Wright's daughter and mother of the boy whose autism inspired the group. A passionate adherent of the theory, she attacked skeptics so strongly that her parents issued a statement that she did not represent Autism Speaks.⁶³

Several national groups support the vaccine theory. Rimland founded the Autism Research Institute two years after founding ASA, and since 1995, it has organized meetings for scientists and clinicians – a project called Defeat Autism Now! The "DAN doctors" advocate biomedical interventions such as special diets, nutritional supplements, and chelation (a controversial therapy that uses chemicals to remove mercury and other heavy metals from the body). The Coalition for SafeMinds (Sensible Action For Ending Mercury-Induced Neurological Disorders, founded in 2000) works "to change policy and focus national attention on the growing evidence of a link between mercury and neurological disorders such as autism, attention deficit disorder, language delay and

⁶² Claudia Kalb, "This Question Has Been Asked and Answered," *Newsweek*, January 16, 2009. Online: <http://www.newsweek.com/id/179998>

⁶³ Jane Gross and Stephanie Strom, "Autism Debate Strains a Family and Its Charity," *New York Times*, June 18, 2007. Online: <http://www.nytimes.com/2007/06/18/us/18autism.html>

learning difficulties.”⁶⁴ The National Autism Association (founded in 2003) seeks to raise “public and professional awareness of environmental toxins as causative factors in neurological damage that often results in autism or related diagnoses.”⁶⁵ Andrew Wakefield serves on its scientific advisory board. Generation Rescue (founded 2005) promotes the vaccine theory and “the goal of recovering children with autism using biomedical intervention.”⁶⁶ Actress Jenny McCarthy, mother of an autistic child, is the celebrity spokesperson for the group. Katie Wright serves on its board, as well as the boards of SafeMinds and the National Autism Association.

Other organizations have emerged to oppose the vaccine theory. The Association for Science in Autism Treatment (founded in 1999) backs evidence-based therapy and opposes “improbable theories about causation and treatments.”⁶⁷ After leaving Autism Speaks in 2009, Alison Singer co-founded the Autism Science Foundation to support scientific research and public education about autism. One of its premises is that the vaccine theory does not warrant “further investment of limited autism research dollars.”⁶⁸

The vaccine theory is not the only point of contention. The “neurodiversity” movement consists of people with Asperger’s and high-functioning autism who favor de-institutionalization, educational inclusion, and employment, but scorn the idea that they have an illness requiring a cure. Founded by Ari Ne’eman in 2006, the Autistic Self-Advocacy Network (ASAN) seeks to organize autistic people and make sure that they have a voice in public policy. Its mission statement puts forward “the concept that the

⁶⁴ SafeMinds, “Mission and Goals.” Online: <http://www.safeminds.org/about/mission-and-goals.html>

⁶⁵ National Autism Association, “Mission Statement.” Online: <http://www.nationalautismassociation.org/mission.php>.

⁶⁶ Generation Rescue, “Jenny McCarthy’s Autism Organization – Generation Rescue.” Online: <http://www.generationrescue.org/>

⁶⁷ Association for Science in Autism Treatment, “Mission and History.” Online: http://www.asatonline.org/about_asat/mission.htm

⁶⁸ Autism Science Foundation, “About Us.” Online: <http://www.autismsciencefoundation.org/aboutasf.html>

goal of autism advocacy should not be a world without Autistic people. Instead, it should be a world in which Autistic people enjoy the same access, rights and opportunities as all other citizens”⁶⁹ ASAN has flayed Autism Speaks for failing to include autistic people in its governing structure, and for portraying them as victims and burdens.

Perhaps not realizing that he was wading into a fight, President Obama nominated Ne’eman to the National Council on Disability. Ne’eman, who has Asperger’s Syndrome, was to be the first person on the autism spectrum to serve on the Council. But his nomination provoked a backlash among elements of the autism community. Said Jonathan Shestack: “Why people have gotten upset is, he doesn’t seem to represent, understand or have great sympathy for all the people who are truly, deeply affected in a way that he isn’t.”⁷⁰ An anonymous “hold” has stalled the nomination in the Senate.

The conflicts within the autism community are harsh and personal. Dr. Paul Offit, a leading expert on infectious diseases and opponent of the vaccine theory, receives hate mail and death threats.⁷¹ Asks Liane Kupferberg Carter, a writer and autism parent: “How can we expect Congress to listen to us, when we are so divided among ourselves?”⁷²

Questions for Future Research

- What is the relationship between autism groups and organizations dealing with other disabilities such as Down Syndrome?

⁶⁹ Autistic Self-Advocacy Network, “Mission Statement.” Online: <http://www.autisticadvocacy.org/>

⁷⁰ Amy Harmon, “Nominee to Disability Council Is Lightning Rod for Dispute on Views of Autism,” *New York Times*, March 27, 2010. Online: <http://www.nytimes.com/2010/03/28/health/policy/28autism.html>.

⁷¹ Offit, *Autism’s False Prophets*, xi-xxi.

⁷² Liane Kupferberg Carter, “Autism: Time for Civility,” *The Huffington Post*, April 1, 2010. Online: http://www.huffingtonpost.com/liane-kupferberg-carter/autism-time-for-civility_b_521521.html

- How have autism groups used blogs and social media to organize and share information?
- To what extent do autism groups cooperate and communicate with one another?
- How do the groups organize their lobbying operations? That is, how do they allocate resources between grassroots mobilization and traditional face-to-face lobbying of public officials?
- How much do grassroots members influence the autism organizations?
- What is the political role of providers of autism services? Although applied behavior analysis (ABA) is the best-known and most-validated therapy, there are other approaches as well. Do practitioners of these other therapies come into political conflict with ABA providers?

Selection

As mentioned earlier, autism groups had only a limited role in the passage of earlier federal legislation on special education and disability. Things changed in 2000, when Congress passed the Children’s Health Act of 2000 (P.L. 106-310).⁷³ The new law mandated the establishment of the Interagency Autism Coordinating Committee (IACC), which was to coordinate federal autism research and programs.

Cure Autism Now helped draft the autism portions of the legislation and was a major force in its enactment. Founder Jonathan Shestack lobbied for three years for the autism provisions and testified before a congressional subcommittee.⁷⁴ As mentioned earlier, his Hollywood connections enabled him to get celebrity support, and he arranged

⁷³ Steuernagel and Barnett, “U.S Health Social Movements and Public Policy.”

⁷⁴ Congress, House, Committee on Commerce, Subcommittee on Health and the Environment, *Children’s Health: Building Toward a Better Future*, 106th Congress, 1st session, October 12, 1999.

for actress Rene Russo to testify with him. Although her only link to the issue was her acquaintance with Shestack and his wife, her fame drew considerable attention and her emotional delivery gained the panel's sympathy.⁷⁵

Cure Autism Now, along with the newly-formed Autism Speaks, set their sights higher a few years later. They pressed for passage of the Combating Autism Act, to increase federal support for screening, public education and scientific research. In 2006, Congress enacted the measure, the first major federal legislation specifically addressing autism. There were some disagreements along the road to passage. Some lawmakers, such as Representative Dan Burton of Indiana, who had once invited Wakefield to testify before his committee, thought that the measure should mandate investigation into vaccines. Such a requirement, however, would have triggered opposition from the pharmaceutical industry. The final version instead said that the research "shall investigate the cause (including possible environmental causes)."⁷⁶ Senator Mike Enzi (R-WY), chair of the Health, Education, Labor, and Pensions Committee, used a floor colloquy to placate adherents of the vaccine theory. Research into environmental causes, he said, should indeed include vaccines: "I want to be clear that, for the purposes of biomedical research, no research avenue should be eliminated, including biomedical research examining potential links between vaccines, vaccine components, and autism spectrum disorder."⁷⁷

The bill won approval by unanimous consent in the Senate and voice vote in the House. With all of the splits in the autism community, why did it pass so handily?

⁷⁵ Csar G.Sciorano, "Ms. Russo Goes to Washington," *USA Today*, October 13, 1999, 2D.

⁷⁶ P.L. 109-416. Online: http://frwebgate.access.gpo.gov/cgi-bin/getdoc.cgi?dbname=109_cong_public_laws&docid=f:publ416.109.pdf

⁷⁷ *Congressional Record*, August 3, 2006, S8772.

Although the five-year \$945 million authorization seemed gratifyingly large to autism advocates, it accounted for a minuscule fraction of annual federal outlays, which came to nearly \$3 trillion in fiscal 2008. For lawmakers, it simply was not a big ticket item. By passing the bill, they associated themselves with a popular cause in a way that did not impose any direct burdens on identifiable constituencies. In the language of political science, it was a valence issue, not a position issue.

The same did not apply to special education. In 2004, when Congress reauthorized the Individuals with Disabilities Education Act, educators sought to ease its procedural burdens – which parents tended to see as an important safeguard. Organizations representing teachers and school districts were well-organized with large numbers of professional lobbyists. Groups representing parents of children with autism and other disabilities were at a competitive disadvantage, relying mostly on volunteers who had never worked together before. Autism Speaks did not yet exist, and other autism groups were focusing more on medical issues. In the end, the changes were not as far-reaching as the parents had feared. But as one put it, “We jumped in front of a moving train and we slowed it down. But we didn’t stop it.”⁷⁸

An ongoing issue involves money. IDEA is one of the largest programs in the Department of Education, with fiscal 2009 outlays of more than \$11 billion.⁷⁹ In 1975, when Congress passed IDEA’s predecessor legislation, the best estimate was that it cost twice as much to educate a child with disabilities than one without. The lawmakers

⁷⁸ Brian Friel, “School of Hard Knocks,” *National Journal*, November 13, 2004. Online: http://www.nationaljournal.com/njmagazine/nj_20041113_19.php.

⁷⁹ U.S. Department of Education, Institute of Education Sciences, *Digest of Education Statistics*, 2009, Table 375. Federal on-budget funds for education, by level/educational purpose, agency, and program: Selected fiscal years, 1970 through 2009. Online: http://nces.ed.gov/programs/digest/d09/tables/dt09_375.asp

decided that the federal government should pay part of this additional cost, so the statute authorized grants to states equal to 40 percent of national average per-pupil expenditure (APPE) times the number of children with disabilities served. This total is the “full funding” amount – which Congress has never appropriated.⁸⁰ Senator Tom Harkin (D-IA) has introduced legislation (S 1652) that would mandate full funding, but it remains in committee.

Questions for Future Research

- How did autism groups assist in the drafting of the Combating Autism Act?
- To what extent do autism groups involve themselves in special education issues on Capitol Hill? Have they increased their activities since the 2004 IDEA reauthorization?
- How active are autism groups in lobbying the congressional appropriations committees?
- Because many autistic children spend all or part of their school day in mainstream classrooms, changes in broader education policy affect them, too. To what extent do lawmakers take their needs into account when making policy for the general school population?

Implementation

The Children’s Health Act created the Interagency Autism Coordinating Committee (IACC), and the Combating Autism Act expanded its membership and

⁸⁰ Richard N. Apling and Nancy Lee Jones, “The Individuals with Disabilities Education Act (IDEA): Overview and Selected Issues,” Congressional Research Service, January 14, 2008. Online: http://assets.opencrs.com/rpts/RS22590_20080114.pdf

responsibilities. In 2009, after consulting with public officials, scientists, and stakeholders in the autism community, IACC released its first blueprint for autism research. The IACC organized its strategic plan around six issues: diagnosis, the biology of autism, risk factors, treatments and interventions, services and supports and questions about issues faced by adolescents, adults and seniors with autism and their families.

In its 2010 strategic plan, the committee tried to thread the vaccine needle. It acknowledged that “the link between autism and vaccines is unsupported by the epidemiological research literature.” But it also suggested that “the existing population-based studies were limited in their ability to detect small susceptible subpopulations that could be more genetically vulnerable to environmental exposures.” Accordingly, it proposed to support at least two studies “to determine if there are subpopulations that are more susceptible to environmental exposures (e.g., immune challenges related to infections, vaccinations, or underlying autoimmune problems).”⁸¹

Predictably, the committee’s position caught fire from both sides. When the committee voted to strike more extensive recommendations on vaccine research, SafeMinds director Mark Blaxill said both the committee and the Combating Autism Act (CAA) had failed. “CAA was meant to hold the NIH [National Institutes of Health] accountable. It’s very clear that they have hunkered down behind the old school orthodoxy. The committee is overtaken by conflicts.”⁸² Conversely, Yale neurologist Steven Novella, a skeptic of the vaccine theory, criticized the committee for allowing

⁸¹ U.S. Department of Health and Human Service, Interagency Autism Coordinating Committee, “The 2010 Interagency Autism Coordinating Committee Strategic Plan for Autism Spectrum Disorder Research,” January 19, 2010. Online: http://iacc.hhs.gov/strategic-plan/2010/print_version.jsp.

⁸² Elizabeth McBreen, “Insel: IACC Has Lost the Trust of the Autism Community,” *Spectrum*, April/May 2010. Online: http://www.spectrumpublications.com/index.php/news/insel_iacc_has_lost_the_trust_of_the_autism_community.

“anti-vaccinationists” to infiltrate the process. At his NeuroLogica Blog, he wrote: “This decision by the IACC represents the fruits of that infiltration – a distortion of funding for autism research to suit their anti-vaccine agenda. In fact, two members of the IACC – Lyn Redwood and Lee Grossman, were added specifically to represent the anti-vaccine movement in the (probably misguided) hope of placating that group.”⁸³

The overall level of funding is another issue. NIH estimates that it will spend \$143 million on autism research in fiscal 2011. That figure exceeds what it will devote to cerebral palsy (\$22 million), cystic fibrosis (\$90 million), or Down Syndrome (\$19 million).⁸⁴ Groups seeking funding for these diseases are less pleased than autism advocates. “Why is Down’s syndrome funding low? Autism I think is a big contributor,” Jon Colman, the chief operating officer of the National Down Syndrome Society told *Nature* in 2007. “It’s dominating priorities.”⁸⁵

Money is also an issue with special education. Because the federal government has never provided full funding, states and localities rely heavily on their own resources to educate autistic children. The 2009 economic stimulus bill promised temporary relief by providing funds for special education, but there was a catch. Under IDEA, whenever the federal government increases funding for special-needs students, districts meeting certain standards may cut local spending on special education by up to half of the amount of the increase – and then spend the freed-up money for other things. The Government Accountability Office explains that many school districts are taking advantage of this

⁸³ Steven Novella, “IACC Statement on Autism Research,” NeuroLogica Blog, November 12, 2009. Online: <http://www.theness.com/neurologicablog/?p=1220>. Grossman is the president and CEO of the Autism Society of America. Redwood is the vice president of SafeMinds.

⁸⁴ U.S. National Institutes of Health, Estimates of Funding for Various Research, Condition, and Disease Categories (RCDC), February 1, 2010. Online: <http://report.nih.gov/rcdc/categories/>

⁸⁵ Meredith Wadman, “Autism Speaks, the United States Pays Up,” *Nature* 449 (August 9, 2007): 629-629.

provision, not only because they face budget pressures, but also because they worry about creating unsustainable commitments. It would be hard to reduce services after stimulus funds are gone.⁸⁶ “This is a slap in the face,” said Candace Cortiella, director of the Advocacy Institute, a nonprofit that advises students with disabilities. “This is historic funding that could have had a huge impact with [special-education] students, and states and districts have instead chosen to minimize the amount of good.”⁸⁷ Local education officials respond that they simply have no choice.

IDEA requires a “free and appropriate public education” (FAPE) in the “least restrictive environment” (LRE). Facing this federal condition of aid, schools do not want to spend more than is necessary, especially in light of chronic fiscal constraints and a growing population of autistic children. Accordingly, their definition of what level of service is “appropriate” is less generous than parents would prefer. They cite the U.S. Supreme Court, which ruled in 1982 that appropriate” need not mean “best possible.” From the decision:

While Congress sought to provide assistance to the States in carrying out their constitutional responsibilities to provide equal protection of the laws, it did not intend to achieve strict equality of opportunity or services for handicapped and nonhandicapped children, but rather sought primarily to identify and evaluate handicapped children, and to provide them with access to a free public education.

⁸⁶ U.S. Government Accountability Office, “Recovery Act: Status of States’ and Localities’ Use of Funds and Efforts to Ensure Accountability,” GAO 10-231, December 2009. Online: <http://www.gao.gov/new.items/d10231.pdf>.

⁸⁷ Anne Marie Chaker, “Special-Ed Funds Redirected,” *Wall Street Journal*, January 6, 2010. Online: <http://online.wsj.com/article/SB126274303415617219.html>

The Act does not require a State to maximize the potential of each handicapped child commensurate with the opportunity provided nonhandicapped children.⁸⁸

The battleground for defining FAPE in specific cases is the Individualized Education Program (IEP), which lays out the child's unique needs and specifies the services that the school district will provide. At least once a year, parents meet with teachers, providers and school officials to review the IEP. These meetings can get adversarial, and parents often bring lawyers or paralegals. If the IEP meeting fails to reach an agreement, the parties may try informal negotiation or mediation. And if that approach does not work, they "go to due process," formally presenting their cases before a hearing officer. In such proceedings, which feature witnesses, exhibits and other trappings of a trial, parents usually need lawyers who specialize in this field.⁸⁹ They may recover attorneys' fees if they win, but not necessarily if they settle "out of court." In any case, they may also have to hire consultants to show why the school district's FAPE offer is inadequate. Affluent professionals are obviously in a better position to wage such fights than poor and under-educated parents.⁹⁰

Some IEPs end happily, with first-rate educational services. Sometimes, schools lack the resources and knowledge to carry out a satisfactory program. Occasionally, they fail completely, resorting to seclusion and restraints to deal with students who behave disruptively. A disturbing GAO report on the subject is worth quoting at length:

⁸⁸ *Board of Education v. Rowley*, 458 US 176, at 177. Online: <http://supreme.justia.com/us/458/176/case.html>

⁸⁹ Terry Jean Seligmann, "Rowley Comes Home to Roost: Judicial Review of Autism Special Education Disputes," *UC Davis Journal of Juvenile Law and Policy* 9 (Summer 2005): 217-288.

⁹⁰ Daniela Caruso, "Autism in the US: Social Movement and Legal Change," Boston University School of Law Working Paper No. 10-07, March 23, 2010. Online: <http://www.bu.edu/law/faculty/scholarship/workingpapers/documents/CarusoD032310.pdf>

GAO found no federal laws restricting the use of seclusion and restraints in public and private schools and widely divergent laws at the state level. Although GAO could not determine whether allegations were widespread, GAO did find hundreds of cases of alleged abuse and death related to the use of these methods on school children during the past two decades. Examples of these cases include a 7 year old purportedly dying after being held face down for hours by school staff, 5 year olds allegedly being tied to chairs with bungee cords and duct tape by their teacher and suffering broken arms and bloody noses, and a 13 year old reportedly hanging himself in a seclusion room after prolonged confinement. Although GAO continues to receive new allegations from parents and advocacy groups, GAO could not find a single Web site, federal agency, or other entity that collects information on the use of these methods or the extent of their alleged abuse.⁹¹

On March 3, 2010, the House of Representatives passed HR 4247, to forbid the use of seclusion and restraint, except in case of imminent danger. The bill is pending in the Senate.

Questions for Future Research

- How have autism groups shaped IACC's research priorities? How does their influence compare with that of groups in other research fields (e.g., cancer)?
- How much of the stimulus money will actually reach special education?
- To what extent do autism groups or other organizations help needy families with due process under IDEA?

⁹¹ U.S. Government Accountability Office, "Seclusion and Restraints: Selected Cases of Death and Abuse at Public and Private Schools and Treatment Centers," GAO-09-719T, May 19, 2009. Online: <http://www.gao.gov/new.items/d09719t.pdf>

- How have lawmakers attempted to “fix the implementation game,” that is, guide the administration of laws such as CAA and IDEA?⁹²

Evaluation, and Conclusion

The key question in autism policy evaluation is simple to pose, hard to answer: How do autistic people benefit? How much better off are they as a result of government action? While there are studies of the short-term impact of various therapies, there is surprisingly little research about the long term, which is really what autistic people and their families care about. Few studies have focused on the educational attainments of autistic youths. We do not know much about what happens to them in high school, apart from the kinds of classes that they take.⁹³ And as for older people with autism, our knowledge is even more limited. While IDEA requires a free appropriate public education only to people between the ages of 3 and 21, the requirement does not apply to adults. Author Karl Taro Greenfield wrote in *The New York Times*:

Low-functioning adult autistics are viewed with sympathy but not much scientific inquiry. No one has broken down how many dollars are actually flowing to adult autistics, but at the International Meeting for Autism Research in Seattle in May 2007, I counted more than 450 papers and presentations and three dozen talks on autism given by academics and specialists; of those, only two dealt with low-

⁹² Eugene Bardach, *The Implementation Game: What Happens After a Bill Becomes a Law* (Cambridge, MA: MIT University Press, 1977).

⁹³ National Center for Special Education Research, “Secondary School Experiences of Students with Autism,” April 2007. Online: <http://ies.ed.gov/ncser/pdf/20073005.pdf>,

functioning adults, and neither included a cohort large enough to be statistically relevant.⁹⁴

As for what autistic people experiences over their lifetimes, the literature provides minimal guidance for people with ASD across the spectrum. Parents and professionals assume that children who behave well and have good language skills can grow to be highly productive adults. Conversely, the assumption is that children who have difficulty with language and self-control will grow up to need extensive supports and services. Yet there is little hard evidence for these ideas.⁹⁵ Similarly, there has been scant research on such measures as employability, self-sufficiency, and social support – and that thin literature is discouraging.⁹⁶ One very useful snapshot of the state of autistic America is the 2008 “Living with Autism” study by Easter Seals. Based on a Harris survey of 1,652 parents of children with autism and 917 parents of typically developing children, the study offers some sobering statistics. Relatively few autism parents thought that their children will be able to:

- Make his or her own life decisions (14% compared to 65% of parents with typically developing children)
- Have friends in the community (17% compared to 57% of typical parents)
- Have a spouse or life partner (9% compared to 51% of typical parents)
- Be valued by their community (18% compared to 50% of typical parents)
- Participate in recreational activities (20% compared to 50% of typical parents)

⁹⁴ Karl Taro Greenfield, “Growing Old with Autism,” *New York Times*, May 23, 2009. Online <http://www.nytimes.com/2009/05/24/opinion/24greenfeld.html>:

⁹⁵ Interagency Autism Coordinating Committee, “2010 Strategic Plan.”

⁹⁶ Audrey F. Burgess and Steven E. Gutstein, “Quality of Life for People with Autism: Raising the Standard for Evaluating Successful Outcomes,” *Child and Adolescent Mental Health* 12 (May 2007): 80–86

Confirming the findings of Sharpe and Baker, the study found that many parents report they're "financially drowning." Seventy-four percent of parents of children with autism fear their children will not have enough financial support after they die, while only 18% of typical parents share this fear. Seventy-six percent worry about their child's future employment, when only 35% of typical parents share this fear.⁹⁷

Medical research continues apace, thanks to government funding under the Combating Autism Act, together with private fundraising by organizations such as Autism Speaks. None of this research has yet yielded an effective medical treatment. A 2010 study did find that oxytocin might help high-functioning autistic people respond more strongly to others and exhibit more appropriate social behavior and affect.⁹⁸ But in spite of widespread publicity, this finding merely opens an avenue of research and will not result in any clinical applications for years, if ever.

Meanwhile, the reported prevalence of autism continues to grow, and the policy issues persist.

Questions for Future Research

- What kinds of behavioral interventions produce the best results for the cost?
What gives us the most bang for the autism buck?
- In March 2010, Los Angeles police officers shot and killed an unarmed man with autism. How common are such incidents? Do social disabilities cause autistic

⁹⁷ Easter Seals, "Living with Autism Study," December 16, 2008. Online: http://www.easterseals.com/site/DocServer/Study_FINAL_Harris_12.4.08_Companded.pdf?docID=83143

⁹⁸ Elissar Andari, et al, "Promoting Social Behavior with Oxytocin in High Functioning Autism Spectrum Disorders," *Proceedings of the National Academy of Sciences* 107 (March 2, 2010): 4389-4394.

people to get in trouble with law enforcement? What happens to them within the criminal justice system?

- How available are community supports and services for autistic adults?
- Do any medications help autistic people with co-occurring conditions such as anxiety?

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