Increases in Identified Cases of Autism Spectrum Disorders

Policy Implications

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Autism is the term commonly used to refer to autism spectrum disorders, a group of neurodevelopmental disorders involving sensory processing problems and social and language difficulties. According to the National Institute of Mental Health (NIMH), the exact prevalence of autism is unknown. Estimates range from 1 person in 500 to 1 in 1,000 in this country; and the number of people diagnosed with autism is growing. This article assesses the policy implications of the autism “epidemic.” It begins with an overview of the disability policy–making process in the United States and its implications for autism policy and proceeds to a discussion of the social construction of autism as a policy issue. This is followed by an analysis of federal and state governments’ institutional capacity to respond to the autism epidemic.

The May 6, 2002, cover of Time magazine features an 11-year-old boy. His eyes are closed and his head is tilted slightly to the left. His arms are held to the right side of his body, and his hands are spread apart. To the average observer, he looks like he is about to catch a football. For some people, there is no need to read the picture’s caption to know what is really going on with him. He is “stimming,” that is, engaging in self-stimulatory behavior, as anyone familiar with autism can readily detect. “Inside the World of Autism,” proclaims the magazine’s cover. “More than one million Americans may have it,” it continues, “and the number of new cases is exploding. What scientists have discovered. What families should know” (Time, May 6, 2002).

In our culture, an issue that has made the cover of Time is an issue that has gained the public’s attention and made it onto the public agenda (McCombs, 1997). Autism is the term commonly used to refer to autism spectrum disorders (ASDs), a group of neurodevelopmental disorders involving sensory processing problems and social and language difficulties. According to the National Institute of Mental Health (NIMH), the exact prevalence of autism is unknown. Estimates range from 1 person in 500 to 1 in 1,000 in this country (NIMH, 2003). Although disagreement exists as to whether the increase in the number of children identified as having symptoms of autism is due to increases in the disorder itself, better diagnostic tests, more inclusive classification guidelines, misdiagnosis, or some combination of these, there is no disputing the fact that autism now affects a significant number of people in this country (American Academy of Pediatrics, 2001).

This article assesses the policy implications of the autism “epidemic.” Although the policy issues surrounding autism are not without precedent, autism does present a number of challenges to policymakers (Cohen, 2003; Havassey, Alvidrez, & Owen, 2004; Yell & Katsiyannis, 2003). To begin, there is little consensus as to the etiology of or best treatments for autism. Policymakers seeking to construct policies on the education of children with autism, for example, will not find a widely accepted set of best practice standards. Even though there is strong evidence that early intervention allows children with autism to develop better functional skills, the evidence to date suggests that there is not a single form of early intervention that will benefit all affected children (“Could New Changes,” p. 3). Although one child may show marked improvement with intensive speech therapy, another may show little, if any, increase in language acquisition. A school district or a state government that mandates 1 hour of speech therapy per week for all children with an autism diagnosis, for example, may not be making the best policy to address the autism epidemic. Feinberg and Vacca, in their discussion of the difficulties involved in creating policies on autism, also take note of the more general questions that can be addressed in the process of developing autism policies. In their words, “A basic question must be posed: how do stake-
holders plan policies and programs for a childhood disorder in which there may be a variety of etiologies, and in which there may be a variety of potentially promising intervention strategies, at a time when we do not yet know which strategies are most effective? (Feinberg & Vacca, 2000, p. 133).

The purpose of this article is to make a contribution to the development of policies to address the autism epidemic. It begins with an overview of the disability policy–making process in the United States and its implications for autism policy. This section also includes a discussion of the impact of the disability rights movement on the efforts to move disability policy to the state and national political agendas, and to move from a traditionally fragmented approach to a more comprehensive effort to address disability issues.

The second section of the article deals more specifically with the social construction of autism as a policy issue, including the policy implications of constructing autism as a mental health issue and the implications for autism policy of the emergence of the dominance of the vaccine narrative. An interesting aspect of autism policy making is the role of celebrities and public officials involved with autism policy. Actors Anthony Hopkins and Sylvester Stallone and football player Doug Flutie, for example, have used their visibility to increase autism awareness. Dan Burton (R-IN), who has a grandson with autism, is a leading figure in promoting autism issues in Congress and is a major force in advancing the vaccine narrative.

Part 3 focuses on federal and state governments’ institutional capacity to respond to autism. Included in this section is a discussion of the role of the states in providing access to autism services through the use of mandates. Currently, 33 states have some form of mental health parity legislation, some of which includes mandated coverage for autism, with mandates falling under one of three categories: mandatory inclusion, mandated benefits offering, and mandated if offered (National Mental Health Association, 2004). In 1985, researchers in disability policy studies noted that existing policy was a group of “mini-policies, diverse in the perceived needs it addresses, in the groups it seeks to benefit, in its legislative origins and purposes, and in the interest groups that battled over its enactment” (Erlanger & Roth, 1985, p. 320). Included in this section is a discussion of the specific policy implications of the rapid growth in the number of children identified with autism. Currently, for example, most states deliver services to children with autism through school systems, and the challenge will become how to deliver services when these children become adults and exit the schools. The established institutions, such as bureaus of vocational rehabilitation, must be ready to deal with the largest generation ever of autistic adults (Feinberg & Vacca, 2000).

The fourth and final section raises issues critical to the future of autism policy. We must decide what we want to accomplish with autism policy. Should we, for example, devote the bulk of available resources to finding a cure or to finding better treatments, such as behavioral and pharmacological interventions?

Part 1: Disability Policy and Autism

Any consideration of the policy implications of the autism epidemic must be placed in the overall context of United States disability policy. Or should it? Autism as a public policy issue is not historically rooted in one particular policy venue, and the governmental institutions, such as congressional committees, in which autism policy is developed and implemented are not routinized (Simpson, 2003). This is not to imply that most issues are neatly and cleanly encompassed by a single policy arena. Environmental policies are balanced with economic interests, for example, and trade policies are balanced with national security interests (Crabb, Antizzo, & Sarieddine, 2000; Switzer, 1994). Still, with these issues there is a general consensus as to what constitutes the problem and where it “fits” in the policy-making process (Bacchi, 1999). The ability of the policy-making process to respond to an issue such as the autism epidemic hinges on whether the issue can be defined, problems identified, and solutions found and implemented (Teays & Purdy, 2001). Although autism affects many aspects of an individual’s life, including communication abilities, fine and gross motor skills, and sociability, it has only recently become a matter of public policy (Children’s Health Laws, 2001). How and where it will enter the policy-making process is evolving. Although the “whys” of this are not completely discernible, some broad generalizations are possible. For the most part, autism was not seen as an issue to be systematically addressed by the policy process because it was not seen as affecting many people. If autism was on the radar screen, there was little consensus as to how it should be addressed. School districts were responsible for providing the available treatments, and individuals with autism had few opportunities for services once they left school. Insurance companies such as Aetna routinely refuse to cover speech and occupational therapy for people with autism (Aetna, 2003); and for the most part, families are forced to rely on their own resources for treatment. Moreover, there was and continues to be a lack of consensus concerning autism’s etiology and no agreement on a comprehensive treatment protocol (Feinberg & Vacca, 2000).

As the number of children diagnosed with autism has increased, the issue has become very real not just for parents but for school districts and vocational rehabilitation programs. As the autism issue is being translated into autism policy, it is more and more often becoming part of disability policy, itself a relatively new area.

I will briefly consider the emergence of disability policy in the United States and then offer a few remarks on its implications for autism. As Erlanger and Roth noted in 1985, disability policy was “moving to the top of the health and welfare agenda” (p. 319). Among the reasons offered for this were the increased awareness by the public of the disabled population as well as the perception that a large social cost was involved with their reduced productivity and that programs for the disabled were costly and needed to be monitored. In addition, Er-
langer and Roth noted the role played by an increasingly militant disabled population and their demands for recognition and services. The disability policy that emerged in the latter half of the twentieth century involved an effort to comprehensively address disability issues. This was in contrast to earlier times, when most public policy toward disability was a “subset” of some other policy domain, such as labor policy.

The most visible indicator of this new trend in disability policy was the 1990 Americans with Disabilities Act (ADA). Although not an unqualified success in terms of implementation, the ADA did bring official recognition to the disability community, which some consider the nation’s largest minority group (Switzer, 2001). In addition, the ADA, unlike previous efforts, was comprehensive federal legislation that expanded federal antidiscrimination law (Percy, 2001, p. 633). Overall, the ADA was a necessary but not sufficient factor in the development of autism policy. Every individual is unique, and every impairment affects an individual in a unique way. Autism is particularly challenging in this regard. Legislation that removes full barriers to participation in mainstream society is crucial, but it is here that the difficulties of addressing a spectrum disease in the policy process becomes apparent. The ADA reiterated the predominant federal definition of disability, first articulated in the Rehabilitation Act of 1973 (Pfeiffer, 1993, p. 730). According to the latter’s definition, the term “disability” means, with respect to an individual (a) a physical or mental impairment that substantially limits one or more of the major life activities of such individual; (b) a record of such impairment; or (c) being regarded as having such an impairment.

As noted by Pfeiffer, although this is not the only definition of disability in federal law, it is the key one. Ironically, the definition itself can be irrelevant to autism, which is frequently not detected until after a child’s third birthday and well past the time when early interventions should have been instituted. Autism is a spectrum disorder; individuals display widely different deficiencies, all of which may themselves change during an individual’s lifetime, and a definition readily applicable to one group of disabilities may well have the unintended consequence of marginalizing those whose conditions do not easily fit within the definition. An early possible indicator of autism, for example, is hyperlexia (What Is Hyperlexia?, 2004). For some children who will later be diagnosed with autism, hyperlexia displays itself as an early fascination with numbers and letters; some children with hyperlexia are able to read at a very young age. Clearly, this is not a condition that limits a life activity and would not in and of itself qualify a child for services, but it is a condition that may warrant early intervention. Furthermore, selective implementation of laws, not unexpectedly, is attractive to policymakers and public officials who must work from a position of limited resources. They may remove the obvious barriers to full participation in society through visible signs of compliance (e.g., curb cuts, ramps, and elevators) but allow the needs of individuals with autism to go unmet.

The construction of autism policy as a subset of disability policy, then, is not an unqualified blessing. This is apparent in the debates among disability advocates as to which model best serves the needs of the disabled and most effectively informs disability policy making. According to students of the evolution of public policy on disability (Pfeiffer, 1993; Scotch, 2002), most early disability policy research was based on a medical model. In this model, people with disabilities were acted on by professional experts who defined them in terms of their impairments. As such, the focus was on the individual and the impairment, not on the context in which the impairment was perceived by the society as a disability. In addition, the experiences of the persons with disabilities, including their feelings and emotions, were not considered, nor was there an expectation that they would act in their own name. As more people with disabilities became involved in advocacy efforts, the medical model began to be supplanted by alternatives, such as a minority group model, a sociopolitical model, or a disability studies perspective (Scotch, 2002). In general, these alternatives suggest a social model as opposed to a medical model.

Central to this newer social model was the belief that the experiences of people with disabilities, not the expertise of professionals, should be the critical factor in disability policy. The social model also stressed the difference between an impairment affecting an individual and the society that sees the impairment as a disability. This new approach emphasized self-advocacy and a resolve that the world should be altered, not the people who live in it. According to Scotch (2002), associated with this perspective was the conviction that most problems associated with disability could best be addressed through self-advocacy and the removal of disabling environmental barriers such as cultural beliefs that stigmatized, public policies that provided perverse incentives that made it difficult to live independently and technology and physical structures that effectively excluded people with disabilities. (p. 26)

This new model does not suggest that medical research should stop or that there is no role for those with professional expertise in fields such as health care, education, and vocational rehabilitation. The model does, however, stress the social construction of disability. An impairment in mobility, for example, is given meaning in the context of particular social images and practices. Unlike the medical model, which looks at the individual as a person with an impairment, the social model contends that the individual and the impairment are given meaning in the context of a particular society and its values. A person using a wheelchair in a society that is barrier free and values every person’s ability to access all venues, for example, would not be as “disabled” as a person in a society that...
makes little, if any, effort to ensure such access. Moreover, some supporters of the social model contend that efforts to correct an individual’s impairment devalue that person. There are people with disabilities, for example, who argue that gene therapy is a form of eugenics (Harris, 2000).

To date, there is, as noted, little scientific consensus as to the causes and treatments of autism; at best, there is an incomplete medical model of the disorder. Although individuals with autism display varying symptoms in the areas of socialization, communication, and behavior, autism is complex and our understanding of its causes is undeveloped. Current research suggests that the onset of autism is preceded by a reduced head size at birth followed by excessive growth in head size and brain volume between the ages of 1 to 2 months and 6 to 14 months. By the time individuals with autism reach adolescence and adulthood, their brains are comparable in size to those of individuals without autism, which suggests that autism emerges during these early periods of rapid brain overgrowth (Courchesne, Carper, & Akshoomoff, 2003). Although this research suggests avenues for the development of diagnostic tools to detect children at risk for autism, it does not address the causes of the brain overgrowth. In addition, there is evidence to suggest some genetic basis for autism. More specifically, autism is thought to be a complex genetic disorder. That is to say, the gene or genes involved do not directly cause autism but may contribute to an individual’s susceptibility. There is scientific evidence to suggest that autism is caused by multiple genetic risk factors or genes (see Note 1). Furthermore, different types of autism may be linked to different genes. Identification of the genetic components of autism holds out hope for better diagnostic measures as well as possible treatments and even cures. If, however, a social model is advanced suggesting that autism itself is not a disabling condition, but that the problem lies in how society constructs and treats people with autism, then a case could be made that fewer resources should be devoted, for example, to eradicating autism than to understanding the specific educational needs of children with autism. It is not that we need to “cure” autism, proponents of the social model would contend, but that we must understand that autism is a different way of being that society needs to value and accommodate.

Still, because autism is a more recent arrival on the policy-making agenda, it is worthwhile to consider whether the social model of disability policy best serves the needs of individuals with autism. Would the medical model, for example, lead to more resources to uncover the yet-unknown causes of autism? Would the medical model foster more resources for research for treatments for autism, including medications to ameliorate its symptoms? In addition, the social model stresses the empowerment of people with disabilities and their right to speak for themselves. Some individuals with autism, and not just young children of the autism epidemic, are unable to speak for themselves. The possibility presents itself that policymakers, eager and willing to listen to the voices of the disabled, will either inadvertently marginalize the issues of people with autism because they are not able to voice these needs on their own behalf or, at the very least, develop policies that better serve the needs of the vocal groups within the disabled community.

Part 2: The Social Construction of Autism as a Policy Issue

One of the more significant pieces of federal legislation illustrating the difficulties surrounding autism as a public policy issue is the Mental Health Parity Act of 1996 (P.L. 104-204). Intended to require insurance companies to provide parity for mental health coverage with medical/surgical benefits, the law states that an insurance plan that provides both medical/surgical and mental health benefits must cover them at the same levels. The law does not require a plan to offer mental health benefits, and it provides exemptions for small employers and some kinds of group plans (see Note 2). Loopholes in the law, however, render this significant piece of legislation all but useless in meeting the needs of individuals with autism. Some insurance companies have argued, for example, that mental health coverage under the Mental Health Parity Act must be provided only for biologically based severe mental illnesses, and a judgment of which cases qualify can be capricious and random. An insurance company that decides to cover only conditions such as schizophrenia, major depression, and bipolar disorder, arguing that these are biologically based and severe, can refuse to cover autism, arguing that it is not established as a biologically based condition (see Note 3). An effort to close this and other loopholes in the Mental Health Parity Act was a bill called the Mental Health Equitable Treatment Act (MHETA), sponsored by, among others, the late Sen. Paul Wellstone (D-MN). Congress did not enact MHETA but did extend until December 31, 2003, the deadline for the expiration of the Mental Health Parity Act. In addition, in the 108th Congress, the Senator Paul Wellstone Mental Health Equitable Treatment Act of 2003, a bill very similar to MHETA, was introduced in both the Senate (S. 486) and the House (H.R.953) (Library of Congress, 2003). If this act becomes law, insurance companies will still have some discretion concerning conditions, including autism, listed in the Diagnostic and Statistical Manual of Mental Disorders—Fourth Edition (DSM-IV; American Psychiatric Association, 1994). There would be no guarantee that autism would be included, but this would be an important step toward mandating coverage for all conditions in the DSM-IV. The Federal Employee Health Benefits Program, for example, provides parity coverage for all DSM-IV diagnoses. In addition, several states have mental health parity laws. Statutes in Connecticut, Kansas, Louisiana, Maine, Montana, New Hampshire, Texas, and Virginia specifically include coverage for autism. In 2001, Indiana enacted legislation requiring insurance companies and health maintenance organizations to provide treatment for autism and all pervasive development disorders (PDDs; National Alliance for the...
Mentally Ill, 2003). As is the case so often, the inclusion or exclusion of a condition is a function of the strength and effectiveness of a particular lobbying interest (Lee & Estes, 2003). In the case of autism, it is also quite clear that the policy, in this case mandated parity in coverage, is connected to how autism is defined. Golden Rule, an Illinois insurance company, objects to mandated coverage for autism, arguing, “Much of the typical autism mandate proposal is really intended to fund education, and we do not believe this is an appropriate item for health insurance to cover. We do believe, however, that it would be acceptable for insurers to provide coverage for medically necessary services or supplies related to the treatment of autism to the same extent as any other mental condition” (Golden Rule, 2003, para. 4). This translates into questions such as “Who should provide services such as speech therapy and occupational therapy?” and “Are these educational services or treatments?” As long as autism is defined as a mental health issue, it will continue, like all mental health issues, to be underinsured. Ironically, if autism were to be treated as a health issue rather than a mental health issue, and if the medical model was operative, individuals with autism would have greater access to services than they currently do.

Currently, access to treatments for autism is a function of an individual’s state of residency. As is often the case in the United States, federalism is a mixed blessing. Individuals living in states with mandated coverage for autism and excellent educational and vocational training programs, for example, are likely to have better outcomes than those residing in states with no mandated coverage and few services. Access to services also varies within states and can vary widely from school district to school district within a state (Gross, 2004; Sheehan, 2003). At the federal level, much of the credit for highlighting issues surrounding autism must be given to Rep. Dan Burton (R-IN). As already noted, Rep. Burton’s grandson has been diagnosed with autism, and the family, including Burton, believes the condition was caused by vaccination (see Note 4). Rep. Burton was subject to term limits as the chair of the Government Reform Committee, but he will head a newly created Government Reform Subcommittee on Human Rights and Wellness. As noted on his Web site, “Chairman Burton will continue his efforts to promote more research into autism, improve the safety of vaccines and reform the federal program that compensates victims of vaccine injuries” (Burton to Chair Subcommittee, 2003, para. 3).

Recently, media coverage of issues concerning autism have been linked to issues of homeland security. The selection of Sen. Bill Frist (R-TN), a physician and an individual with considerable backing from pharmaceutical companies, to succeed Sen. Trent Lott (R-MS) as majority leader of the Senate promises to keep autism on the public agenda. The “bundling” of autism and homeland security is itself a fascinating case study in American politics, which Huffington refers to as “Washington’s Hottest Whodunit” (Huffington, 2002, para. 1). There is agreement as to certain facts in the case, but in a city where lobbyists are quick to take credit for legislative provisions benefiting clients, the absence of a responsible voice is deafening.

Here is what is known. Negotiations between Republicans in the House and Senate on the Homeland Security bill took place in November 2002. It was at this time that a “Lilly-friendly” provision was inserted into the bill, which protects the pharmaceutical giant Eli Lilly and Company from suits claiming that thimerosal, a mercury-based preservative used in vaccines and manufactured by Lilly, causes autism (see Note 5).

The language was drafted by Sen. Frist, who had in March 2002 introduced legislation that contained this provision. Sen. Frist, who argues that such legislation is necessary so manufacturers will not be deterred from producing vaccines needed to combat bioterrorism, denies any connection to the insertion of the provision in the Homeland Security bill. The provision protects Lilly by requiring parents of children believed to have developed autism as a result of thimerosal to file claims in a federal vaccine compensation program that caps damages at $250,000 rather than in civil courts. It is thimerosal that Rep. Burton believes was responsible for his grandson’s autism. Lilly donated a great deal of money in the 2002 elections. The provision itself was originally drafted by Sen. Frist as part of a more comprehensive effort to address liability issues and vaccine manufacturers. According to the Center for Responsive Politics, Frist was instrumental in the fund-raising that contributed to Republican victories in the 2002 elections. The major contributors to Frist and his fund-raising organizations were doctors and other health professionals, hospitals, nursing homes, and pharmaceutical companies. Lilly was the top donor among pharmaceutical manufacturers in the 2001–2002 election cycle, giving $1.6 million in donations in the form of individual, PAC, and soft money. Seventy-nine percent of these funds went to Republicans (Center for Responsive Politics, 2002). Lilly also bought 5,000 copies of Frist’s book (Doctor as Dealmaker?, 2002). The CEO of Lilly, Sidney Taurel, is a member of the White House Homeland Security Advisory Council. Mitch Daniels, the White House budget director, is a former executive with Lilly, but he denies any involvement with the legislative provision. On November 25, 2002, the Bush administration went to federal court and requested the sealing of documents concerning hundreds of cases alleging a connection between thimerosal and autism. On December 4, 2002, Rep. Burton wrote to Attorney General John Ashcroft requesting that the agency withdraw its motion to seal records concerning vaccines and autism (Committee on Government Reform, 2003).

On December 19, 2002, the Department of Justice agreed to withdraw a motion to the U.S. Court of Federal Claims Office of Special Masters requesting the sealing of all documents related to thimerosal–autism claims. This move, supported by groups such as the Mercury Policy Project and SAFE MINDs, may help those currently involved in litigation (see the Web sites of these organizations for more information; they are located at http://www.mercurypolicy.org and http://www.safeminds.org). Rep. Burton, the point person on autism in the confer-
ence, indicated he had no knowledge that the provision was inserted into the legislation. Immediately after the Homeland Security incident, Burton wrote a letter to President Bush urging him to host a White House conference on autism (see Note 6). In December 2002, he scheduled additional congressional hearings on vaccines and the autism epidemic. In a communication with an intern for the Houston Chronicle, a high-ranking government official close to Sen. Frist noted,

It was Dick Armey who added that provision to the Homeland Security bill. Why Congressman Armey added this to the Homeland Security bill is unknown, but there is some concern that when we talk about creating vaccines for these upcoming possible biological weapons—and we don’t currently have vaccines for some of these agents—there was some concern that the vaccine companies don’t have the resources to research vaccines for some of these diseases. (A. Netzel, personal communication, February 10, 2003)

He also stated that Sen. Frist and his staff had not heard from Lilly or the White House, “At this point, we haven’t heard from either folks at this time. Rep. Armey had taken the provision earlier, and that was done behind closed doors. We were not involved” (A. Netzel, personal communication, February 10, 2003).

On January 10, 2003, an agreement brokered by Sen. Olympia Snowe (R-ME), Sen. Susan Collins (R-ME), and Sen. Lincoln Chafee (R-RI) was announced that commits the Senate to the repeal of the controversial provision. Sen. Frist supports the agreement, as do Senate Democrats; and the repeal of the provision was included in the 2003 omnibus appropriations bill.

Why has the vaccination issue dominated the public discourse of autism? Clearly, Sen. Burton’s advocacy and the Homeland Security bill are critical; but they alone cannot explain the visibility of the vaccine narrative, given the wealth of expertise suggesting that the vaccine theory is bad science. As Deborah Stone noted,

There is an old saw in political science that difficult conditions become problems only when people come to see them as amenable to human action. Until then, difficulties remain embedded in the realm of nature, accident, and fate—a realm where there is not choice about what happens to us. (Stone, 2001, p. 281)

Stone goes on to identify the factors that bring an issue from the private realm into the public one. She focuses on the concept of causal ideas and describes how political actors create stories that allow them to attribute blame and invoke government power to stop those individuals or organizations that are causing the problem (Stone, 2001, p. 282). There is a poignancy to the autism vaccination discourse. Focusing on vaccines, from the parents’ point of view, helps to alleviate two possible scenarios: that the cause of their child’s autism will never be known or that there is something the parents did, including having certain genes, that caused it. Blaming autism on vaccinations has much to recommend it. Parents who have their children vaccinated are doing something “good” for their children in protecting them against disease. The fact that the “bad” pharmaceutical companies lied to them does not make the autism any less real, but it does mitigate the guilt. In addition, the fact that there are campaign contributions flowing from these pharmaceutical companies to policymakers, contributions in amounts parents can barely conceive, suggests that even the most diligent and alert parents would not have been able to stop what happened. The brouhaha surrounding the Homeland Security Act and autism is just the kind of event that lends credence to the belief that there was a conspiracy to cover up the vaccine–autism connection. Without the presence of a key political actor such as Rep. Burton, however, the vaccine narrative would in all likelihood not have come to dominate the public agenda, despite the power it has exercised in the autism community.

Part 3: The Institutional Capacity of Federal and State Governments to Respond to Autism

Families and individuals living with autism are concerned that policies be in place whether there is an epidemic or not. A study sponsored by the Centers for Disease Control and Prevention was conducted in five metropolitan Atlanta, Georgia, counties and found autism rates higher than those found in the 1980s and early 1990s but consistent with rates found in more recent studies (Yeargin-Allsopp et al., 2003). A number of issues must be addressed, not the least of which involves what will happen as the large numbers of children now diagnosed with autism become adults and leave the school systems, the primary public institutions for the delivery of services. Two programs in particular face severe challenges: Medicaid and Supplemental Security Income (SSI) offered through Social Security. Currently, people with disabilities are 15% of all Medicaid recipients and account for 37% of expenditures. In addition, in the period from 1977 to 1992, Medicaid spending for mental retardation and developmental disabilities rose from $3.5 billion to $17.2 billion (Ronder, Kastner, Parker, & Walsh, 1999, p. 24). The long-term care components of these expenditures could rise dramatically if the autistic population of tomorrow requires the same kinds of care as today’s autistic population. States such as New Jersey and Oregon are experimenting with various forms of managed care, but it remains to be seen if states will be ready for the potential onslaught.

At this point in time, many children diagnosed with autism are not eligible to receive SSI because their family income is too high. This exclusion is referred to as “deeming.” When
these children reach the age of 18, however, their parents’ income is not counted, and they may be eligible for SSI. Unfortunately, the federal government does not provide data on the number of individuals with autism receiving SSI. Nonetheless, when the children who do not presently qualify for SSI reach 18, deeming will no longer apply. It is reasonable to expect that most or all of the under-18 individuals identified as autistic will apply for and receive SSI when they come of age and can no longer be excluded because of parental income. In addition, many of these individuals will become eligible for Medicaid.

A major move toward the development of a coordinated federal autism policy came in 2001 with the creation of the Interagency Autism Coordinating Committee (IACC). Mandated by P.L. 106-310 Title I, Section 104, of the Children’s Health Act of 2000, authority to create the IACC was given by Health and Human Services Secretary Tommy Thompson to the National Institutes of Health (NIH). In turn, the NIH gave the NIMH the lead role for the creation and administration of the IACC. According to the NIMH, the mission of the IACC is “to facilitate the efficient and effective exchange of information on autism activities among the member agencies” and “to coordinate autism-related programs and initiatives” (see Note 7). A number of organizations with a variety of different focuses, including education and health care, compose the IACC (see Note 8).

A review of the involved agencies reveals the federal government’s effort to bring together a wide range of offices that deal with autism from a number of different vantage points. With the inclusion of the Department of Education (DOE), for example, there is a clear effort to coordinate education issues with health issues. The IACC, moreover, does not embrace a single causal theory of autism. Among the agencies that compose the committee, for example, are the Agency for Toxic Substances and Disease Registry (ATSDR), which deals with possible environmental factors, as well as the Food and Drug Administration (FDA), which considers possible adverse drug reactions. The IACC, moreover, involves programs that span the life of the individual with autism, including child development issues under the National Center on Birth Defects and Developmental Disabilities (NCBD&D) and employment and community living opportunities under the Department of Education’s Office of Special Education and Rehabilitative Services (OSERS).

A promising policy response to the needs of individuals with autism is the Medicaid waiver program for the developmentally disabled. Part of the 1915(c) home and community-based waiver program passed by Congress in 1981, the waivers are designed to allow individuals who qualify to receive services outside institutions. States are attracted to the waivers and their potential cost savings because states can limit the number of individuals served by waivers. Under the regular Medicaid program, in contrast, states must serve all who are eligible. A 1996 study by the Government Accounting Office (GAO) of the use of the waiver program to serve the long-term needs of individuals with developmental disabilities characterized the results as “promising” but noted the program “poses some risks” (GAO, 1996). A few states have applied for and received 1915(c) waivers with autism-specific provisions (see Note 9). Part of the difficulty in tracking the utilization of waivers for the delivery of autism services is the lack of visibility of the category. The federal government database does not specifically identify autism waivers, and the organizations that track such programs do not either. The National Conference of State Legislatures routinely lists, based on data supplied by the Blue Cross and Blue Shield Association, all state health mandates (National Conference of State Legislatures, 2003). Although they have categories for conditions and services such as “hair prostheses” and “in vitro fertilization,” they have no specific category for autism.

Indiana is an example of a state that has been proactive in the development of autism policy. In 2001, for example, Indiana enacted legislation mandating that all state statutes define autism as a neurological disorder (H.B. 1047). In the same year, it made into law a bill, H.B. 1122, prohibiting the cancellation of insurance coverage or refusal to renew coverage after a person is diagnosed with a PDD, including autism, Asperger’s, and PDD–Not Otherwise Specified. Indiana also has a Commission on Autism as well as a Medicaid waiver program that is autism specific.

### Part 4: The Future of Autism Policy

Ironically, homeland security concerns have helped to advance the visibility of autism as a policy issue. Perhaps a less helpful development is the emerging dominance of the vaccine narrative as a causal explanation for the autism epidemic. As noted earlier, the appeal of the vaccine narrative is clear: If vaccines are responsible for the autism epidemic, then we can fix the problem. Unfortunately, the vaccine narrative can also lead to misplaced research funding and delay efforts to provide access to treatment for the symptoms of autism.

To arrive at the best policy response to the autism epidemic, it is necessary to have the best available information. More information as to the effectiveness of treatments will be needed. Despite the vilification of the pharmaceutical companies by many in the autism community, there is evidence that some drugs, although not a cure for autism, are useful in the treatment of autistic symptoms, including aggression and obsessive–compulsive behaviors (Aman, Lam, & Collier-Crespin, 2003; McCracken et al., 2002; “Newer Antipsychotic Medication,” 2002). Access to treatments, as noted in Part 1, is not guaranteed. Private insurers can continue to deny coverage for therapies such as speech therapy and occupational therapy as well as these medications because there is not a universally agreed on treatment protocol for autism. With the development of such a protocol, access to treatments for autism would improve.

The federal government has begun to coordinate a response to the autism epidemic and, as noted in Part 3, has
begun to develop and implement a federal government response. This should lead to the identification and elimination of barriers to treatments for the symptoms of autism and perhaps even the condition itself. Passage of the Senator Paul Wellstone Mental Health Equitable Treatment Act (H.R. 953, S. 486), despite the questionable construction of autism as a mental health issue, would be a welcome first step. Although it would not guarantee coverage for autism, it would be the basis for a move toward mandating coverage for all conditions in the DSM-IV, including autism.

It is also crucial that colleges and universities provide training for future teachers and that school districts provide in-service training for classroom teachers. This training must address the learning styles and behavioral challenges of children with autism and should be extended to all teachers, including those with a special education focus as well as those without one. Mainstreaming or including children with autism in typical classrooms, a placement that works well for some, will not be successful unless the classroom teachers are prepared to develop and implement individualized education plans for these students. Opportunities provided to teachers through two Michigan programs, the Autism Collaborative Endorsement (ACE) and the Interdisciplinary Certificate in Autism, are examples of how state government and state universities can work together to provide training for teachers who work with students with autism (“Personnel Development Grants Serve Students with Autism,” 2003).

As the cohort of today’s children moves through school systems and into adulthood, greater emphasis will need to be placed on increasing the capacity for vocational rehabilitation services, including, as noted above, the specialized training needed for those who work with individuals with autism. The success of programs such as Community Services for Autistic Adults and Children (CSAAC) demonstrates that adults with autism can be employed even in nonsheltered settings (Smith & Juhrs, 2004).

The policy response to the autism epidemic is in its early stages. Ideally, the recent interest in autism as a policy issue will continue, and scientists will arrive at a consensus as to the etiology of autism and what treatments are effective. Policy-makers will then have better information to use in the development of a response to the epidemic. Perhaps the best development would be for support for cross-involvement and treatments they want to use, and a combination of public and private resources would ensure access. At the same time, society would begin to understand the need to embrace all individuals, including those with autism.

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NOTES

1. For an article on genetics and autism easily accessible to the layperson, see Margaret A. Pericak-Vance, USA Today Magazine, Vol. 131, No. 2692, January 2003. For a complete discussion of genetics and autism, see the Web site developed by the Duke Center for Human Genetics (http://www.chg.duke.edu).
2. For further details, see the Web site of the Center for Mental Health Services, a component of the Substance Abuse and Mental Health Services Administration of the U.S. Department of Health and Human Services (http://www.mentalhealth.org/cmhs/ManagedCare/Parity).
3. For a more detailed discussion, see the Web site of the American Psychological Association (http://www.apa.org). Interestingly, in 1997 Indiana enacted legislation defining autism as a neurological and in 2001 passed additional legislation mandating the neuro- logical definition of autism to apply to all state statutes. For more information, see the report of the Indiana Commission on Autism (available at http://www.autismindiana.org/legis0101.html).
7. For more detail on these points, see the Web site of the NIMH (http://www.nimh.nih.gov/autism/autism.cfm).
8. Based on material provided by the NIMH at http://www.nimh.nih.gov/autism/autism.cfm, July 18, 2003. The organizations that compose the IACC are the Administration on Children and Families (ACF); Centers for Medicare and Medicaid Services (CMS); Centers for Disease Control and Prevention (CDC); Agency for Toxic Substances and Disease Registry (ATSDR); National Center on Birth Defects and Developmental Disabilities (NCBDDD); Department of Education (DOE); Office of Special Education and Rehabilitative Services (OSERS); Food and Drug Administration (FDA); Center for Biologics Evaluation and Research (CBER); Health Resources and Services Administration (HRSA); Maternal and Child Health Bureau, Division of Services for Children with Special Health Needs (DSCSHN); National Institutes of Health (NIH); National Institute of Child Health and Human Development (NICHD); National Institute on Deafness and Other Communication Disorders (NIDCD); National Institute of Environmental Health Sciences (NIEHS); National Institute of Mental Health (NIMH); National Institute of Neurological Disorders and Stroke (NINDS); and Substance Abuse and Mental Health Services Administration (SAMHSA).
9. Mary Jean Duckett, CMS, indicated that the waiver database does not track by an autism category (personal communication, February 11, 2003). She indicated that Maryland had such a waiver and that Kentucky had one pending. She also noted that some states receive waivers for developmental disabilities and that autism is included in these. A February 11, 2003, e-mail from Deidra
Abbott of CMS indicates that Florida, Indiana, and Maryland have autism waivers, but she too noted that the database cannot identify waivers that offer services to people with autism.

REFERENCES


Mental Health Parity Act of 1996, Public Law 104-204.


Senator Paul Wellstone Mental Health Equitable Treatment Act, H.R.953, S. 486


