

Use of science in autism policy development

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Abstract

Though ultimately beneficial for society, relations between science and politics require careful tending. Because science is an exercise in trial and error, public policy development can be affected by both scientific missteps and the length of time it takes to produce reasonable scientific certainty. Introduction of scientific findings, especially more preliminary ones, into the political process has a mixed record. Understanding how these tensions play out in contemporary politics is important for both disability studies and policy studies generally. This article explores how science and scientific evidence is employed by stakeholders engaged with autism policy development in the United States.

Keywords: public policy, science, autism, politics

Introduction

Science and politics share a storied history. Nevertheless, in recent decades, a shared understanding of the ideal relationship between science and politics has been taken a degree more for granted. Scientists work to provide unbiased insights to enlighten political discourse. In return, those engaged in politics provide resources and protected intellectual space necessary for scientists to act as honest brokers of sophisticated human knowledge (Pielke, 2007). Though still often violated, a common understanding of distinction between normative political discussion and objective scientific inquiry supposedly exists.

For those with even the most passing interest in disability history, however, achieving comfort about relations between science and politics would be difficult at best (McRuer & Berube, 2006). While recognizing benefits of science is vital (particularly with regard to survivability of some disabling conditions), the past is replete with intrusions, insults and injuries to individuals with disabilities¹ conducted in the name of science (Silverstein, 2010) (Fine & Asch, 1998). Furthermore, some scientists--though certainly not all-- continue to disregard preferences and rights of people with disabilities (McRuer & Berube, 2006). Given these circumstances, how science is discussed in disability policy development becomes intriguing. Using samples drawn from legislative testimony and from statements from organizations in the United States, this article explores how science is employed in political discourse on autism.

Literature review

What is science?

Definitions of science vary across time, place and stakeholder. Agreement exists that science should be distinct from political endeavors. As Hans Kenslen put it in a 1951 article on science and politics “science is a function of cognition; its aim is not to govern, but to explain” (p. 642). However, more recent scholarship has argued “science is political and politics are technical” (Konefal & Hatanaka, 2011). Furthermore, heated debate remains as to boundaries of science. For some, science is limited either to “hard” sciences or results of data collected through replicable experimental procedures using a positivist approach. For others science incorporates any analysis of data collected empirically using a generally repeatable process including specific consideration of the role of human subjectivity. In this article, science is defined closer to the latter definition, including any knowledge derived from an empirical rather than purely creative exercise.

Two types of science are often distinguished: basic and applied science. Basic science involves analysis of data collected in response to a question posed exclusively for discovery. In other words, those conducting basic science isolate their work from other human goals including contemporary social, economic and political agendas. Importantly, basic science also includes an assumed lack of concern for commercial potential of products which might come about as a result of the endeavors (Drolet & Lorenzi, 2010). Basic science is often associated with open science, meaning a preference for making findings as widely available, even to the point of

¹ This article employs people first language unless discussing disability as a consciously embraced element of political or social identity or as found in context of cited documents.

actively refusing to apply for patents (David, 2008). Basic science is vital, especially because of lack of predictability about what knowledge will become urgently needed in the future.

The second type of science, applied science, has sometimes been considered inferior (Tijssen, 2010). Applied science embraces politically or economically directed pursuit of knowledge. In the United States, science became generally more applied over the past several decades (Oreskes, 2011). In particular, emphasis on grants to support research conducted at universities promotes applied science. Grant applications are increasingly required to articulate broader and immediate impacts of research both when proposed and when reported at the end of the funding period (Pielke, 2007).

Both types of science share defining characteristics inspiring some to question the utility of the dichotomy (Tijssen, 2010). First, science is conducted predominantly by experts trained in specific fields. The general trend has been for these fields to be increasingly focused (Oreskes, 2011). Secondly, science involves an expectation of long term commitment to an area (Driscoll, et al., 2012). Some scientific discoveries appear sudden and may be followed by an avalanche of other discoveries in the relatively short term. However, progress at this pace tends to be separated by long periods of normal science (Kuhn, 2012).

Politicization of science

Part of science's politicization involves increasing public participation in science (Felt & Fochler, 2008). This involves attention to rights related to biological materials or information taken from human beings (Skloot, 2011). Consideration of extension of these rights beyond the moment of actual participation in research contributes to the politicization of science. For example, such considerations have led to increased pressure to involve participants or the public in research design, interpretation of findings and dissemination of results (Boote, Baird, & Beecroft, 2010). This approach to science embraces a more democratic scientific method than the one born of the Enlightenment. Such efforts represent an important counterweight against a history of oppression against targeted individuals and groups, including people with disabilities.

At the same time, efforts to capitalize on confusion about science have grown increasingly influential. A campaign to confuse both the public and elected officials about scientific methods has been executed in the United States for the past several decades (Oreskes, 2011). In particular, lobbyists representing products found damaging to human health misrepresented the meaning of peer review as ex post facto changes to scientific results and the fact that positivist science never claims certainty to mean findings are unreliable (Oreskes, 2011). Furthermore, because esteemed scientific findings tend to be presented in peer reviewed journals and assertions less firmly supported tend to appear in popular presses, internet or the media, less reliable findings tend to be better known in a democratic setting (Brooks, 2009). Finally, mechanisms for translating basic science into clinical or applied science and then commercial efforts remain ambiguous (Drolet & Lorenzi, 2010). As a result, "many policies seem to fall short of or, indeed, directly contradict what the available evidence suggests is required...existing literature highlights how this particularly occurs in the conditions of uncertainty" (Juntti, Duncan, & Turnpenney, 2009, p. 208).

Finally, science has been politicized through changes in funding mechanisms, especially for publicly funded universities. Over the past several decades, the proportion of research funding expected to come from competitive grant processes consistently increased. While one anticipated benefit of this shift might be a move toward higher quality and relevant research, this assumption has two main flaws. First, it ignores the fact that most major human discoveries—especially those that proved most marketable—resulted from astute, unexpected observations made during the normal course of research (Taleb, 2007). Second, creation of competitive funding processes integrates increased politics into science. The majority of requests for proposals address contemporary, politically salient issues.

Making politics scientific

Scientific discoveries have elevated capacity for democratic governance and implementation of high quality public programs. Activities ranging from mass delivery of potable water to more effective compilation of government budgets result from scientific research. These innovations create conditions allowing humans to better practice democracy. Human existence is largely more comfortable now than in the past, largely because of sustained investment in discovery (Pinker, 2011).

Nevertheless, building scientific discoveries into public infrastructures is a fundamentally messy process. Identifying the moment at which scientific discovery becomes certain enough to integrate into policy is inherently difficult (Tijssen, 2010). Both science and democratic policy develop over long time spans. Politics within a democracy involves a shorter event horizon, largely understood as tied to election cycles (McIvor, 2010). This event horizon shortens as democracies mature and citizens acclimate to voicing discontent and organized, well-funded interest groups refine their ability to wield political influence (Oreskes, 2011). In addition, as democracies mature, they take on more complicated challenges. Current challenges targeted by democratic systems include many “wicked problems” (Jentoft & Chuenpagdee, 2009). Such challenges are difficult to define and elude technical solution. Addressing wicked problems involves near-constant calibration with social and political conditions as well as a need to continually rebalance attention between short and long term goals (Stace, 2011). Addressing wicked problems depends more artistic exercise of politics than implementation of rigidly and rigorously tested solutions discovered through the analysis of highly specified formal research questions.

Autism and public policy

Attention to autism spectrum differences (hereinafter referred to as autism)² has increased dramatically in the last twenty years. Its place on the formal and systemic agendas of contemporary democracies makes autism an excellent case from which to examine use of science in disability policy discourse (Kingdon, 2010). In addition, the number of unresolved scientific questions about etiology and, in fact, nature, of autism also increased the potential for

² During the time of this writing, the *Diagnostic and Statistical Manual of Mental Disorders V (DSM-V)* was in development. This manual is the most commonly used source of a scientific definition of autism employed in the creation of public policy in the United States. During the period examined in this article Asperger’s syndrome was formally considered part of the autism spectrum both in the DSM-IV and by most issue stakeholders.

involvement of scientists in issues surrounding autism (Bumiller, 2009). The increase in the population of individuals indentified as having autism inspired a definite and deliberate increase in scientific efforts targeting autism (Grinker, 2008). Finally, contemporary autism related policy highlights wicked problem characteristics found in disability policy (Stace, 2011).

Method

This article employs content analysis using data drawn from both legislative and issue stakeholder sources. First, a search for congressional testimony during the 107th to 112 Congresses (which met between 2000 and 2012) including the words “autism, autistic, or Asperger’s” was conducted. This time period was selected to include several years before and after the passage of the *Combating Autism Act of 2006*, which was the first federal legislation specific to autism. A sample of 150 documents was selected for analysis. The sample included 20 documents randomly selected from each Congress and a purposive sample of 5 documents per Congress added to ensure that pivotal policies were not excluded. This sampling strategy balances concerns related to bias coming from the tradition of falsifiability in positivist approaches with the appreciation of built knowledge more prevalent in other empirical traditions (Silverstein & Auerbach, 2003). Documents included in the legislative sample were of quite varied length ranging from text of one minute speeches to thousands of pages of discussion.

To triangulate findings using data of a slightly different kind, statements from autism related nonprofit organizations were also examined. The sample of organizations was collected using a purposive sampling followed by snowball sampling. The sampling targeted federal level organizations and included organizations from diverse perspectives, especially with regard of acceptance of neurodiversity versus pursuit of cure. This is important because most autism organizations were founded by either caregivers or professionals who tend toward association with cure oriented agendas (Baker, 2011). The sample included 30 organizations of varied size, formality, and tenure. Research oriented organizations inside the academy were excluded from the sample.

Data analysis

In the legislative sample, all references to autism in the full text of the documents were located and catalogued using textual analysis software. Discussion relating to autism was then coded for keywords (and close synonyms) typically involved in the discussion of science including: data, evidence, expert, grants, findings, hypothesis, research, science, scientists, study and theory. In the sample collected from nonprofit organizations, the full text of the collected statements was coded for the same keywords (since all of the statements focused on autism). The full sentence in which the keyword was located was employed s the unit of analysis. When “autism’ appearance more than once in a sentence, it was coded as a single reference.

Reference appearance patterns were examined and quotes were thematically catalogued. Coding was conducted by the author with a subsample of documents separately coded by two other individuals. No major differences were detected. Furthermore, the full text of 30 documents was coded to ensure the breadth of discussion was captured in the search strategy. Although this exercise generated a large number of references, it yielding no additional discussion related to

specifically to autism. For example, over a hundred references to grants focusing on student loans appeared in a document on the *Affordable Health Care Act*.

Findings & discussion

Legislative testimony

The vast majority of legislative discussion about autism did not focus on science. This is expected as not all political questions are inherently scientific. For example, statements urging celebration of groups or individuals were common. In one such a speech on March 8, 2011, Representative Lou Barletta (R-Pennsylvania) explained “Mr. Kossuth founded 12/24, a Christmas holiday seasonal band dedicated to raising funds for autism research.” Such mentions primarily included parents, physicians, service providers, and people working with nonprofits.

Much autism policy discourse including discussion of science sought to establish autism as an urgent public issue. The strategy generally employed centered on increased prevalence of autism. As a result, the most frequently discussed statistic (or more explicitly scientific finding) was rate at which autism appears in the population. In particular, rates amongst children were compared with those recorded a generation ago. Sometimes autism was described as part of a conglomerate of such challenges. For example, Representative Louise McIntosh Slaughter (D-New York) in an extension of her remarks on July 14th 2005 on the *Environmental Health Research Act*, said ““Over the last 30 years, the U.S. has seen a steep rise in the occurrence of childhood cancers, testicular cancer, juvenile diabetes, attention deficit disorder, learning disabilities, thyroid disorders, cognitive impairment, and autoimmune disorders...Autism cases alone rose 210 percent between 1987 and 1998.”

As time went on, autism was more typically described as a stand-alone challenge. For example, on October 6th 2009 Representative Dan Burton (R-Indiana) stated “It used to be 1 in 10,000 was autistic; then it went to 1 in 150; and *in the Journal of Pediatrics* this week, they said now more than 1 in 100 children are autistic.” Similarly Representative Danny K. Davis (D-Illinois) made a speech during consideration of the *Training and Research for Autism Improvements Nationwide Act of 2010* in which he explained “this bill expands federal support for understanding and treating the Autism Spectrum Disorders which affect as many as 1 in 110 children born in the United States” (111th Congress, September 22nd, 2010). Furthermore, autism was presented as “the fastest growing developmental disability in the United States” (James P. Moran, before the House of Representatives on April 27th, 2012). The most famous specifically referenced study involved the population of Brick Township, New Jersey. For example, in discussion of *Expanding the Promise for Individuals with Autism Act of 2007* on April 19th, 2007 Representative Christopher H. Smith (R-New Jersey) recalled “the results of this investigation, one of the first federal studies on autism, were quite alarming... Higher rates of autistic disorder and autism spectrum disorders, ASDs, were found in Brick Township relative to rates from previously published studies”

Occasionally entire academic articles or abstracts are submitted to the record in an effort to establish a pressing public issue. The only instances in which this agenda positioning strategy was found in legislative discourse examined for this article involved use of thimerosal in childhood vaccines as a potential causal factor of autism. This strategy was employed several

times by Representative Dan Burton (R-Indiana). For example on December 11, 2007, he stated ““now we have scientific evidence by two leading doctors in the *Journal of Child Neurology* that says without doubt, the mercury in the vaccines does cause autism, is a major contributing factor.” Representative Burton goes on to say ““in November 2007, the well-respected scientific journal, the *Journal of Child Neurology*, published an article authored by Drs. M. Catherine DeSoto and Robert T. Hiltlan (PhDs), detailing their findings on the relationship between mercury and autism spectrum disorders...The article was entitled ‘Blood Levels of Mercury are Related to Diagnosis of Autism: A Reanalysis of an Important Data Set.’”

Representative Burton also made general statements about scientists agreeing with his position including comparisons of knowledge expectations for scientists and other professionals. For example, on May 1st, 2001, Representative Burton stated:

I got a vaccination here by the doctor at the Capitol and I found out, he did not know it, he is a great doctor, a fine fellow, but he did not know there was mercury in the vaccine. How many of my colleagues got vaccines this year to protect themselves against the flu, flu vaccine? If you got one, you got mercury in your vaccination. That is a contributing factor according to a lot of scientists and doctors to Alzheimer's and to autism in kids.

Notably this scientific argument enjoys little (and diminishing) popularity within more established science, especially in the United States. From the perspective of the relationship between science and democracy, Congressional hearings become an audience of last resort for scientific theories (or discoveries) discerned to be less than credible by the majority of the members of the relevant scientific communities. As Burton stated in testimony entitled *Blood Levels of Mercury are Related to Diagnosis of Autism* on December 11, 2007, ““We simply cannot dismiss or downplay scientific research, which has the potential to unlock the mysteries surrounding what is causing our Nation's autism crisis.” In the same statement he goes onto say ““We owe it to the thousands of families living with autism to follow the science wherever it may lead.” This argument is, of course, fundamentally correct. However, discerning who is leading and who is following becomes an ever more complicated challenge in the absence of a strong norm of separation between science and politics. Such a norm may, ultimately, prove impossible to maintain in the absolute in the context of an engaged, complex democracy without consistent attention to protection of the principle on the part of politicians, scientists and, to the fullest extent possible, the general public.

Congress also focused significant attention on relative amounts of funding for autism research as compared to other issues. For example, during the 107th Congress, in a statement before the House of Representative regarding the *Homeland Security Act of 2002*, Representative Burton (R-Indiana) argued:

The CDC is spending \$932 million a year on the AIDS epidemic, and AIDS deserves attention. So does diabetes. This year we are going to spend \$62 million on diabetes, and we probably ought to spend more than that. But do you know how much they are spending on research for our children who are autistic? About \$10 million. So we are spending 80 times more on AIDS research than we are on

autism, yet it is the fastest-growing problem in America. And we are spending five to six times more on diabetes than we are on autism.

Comparisons over time were also employed. For example, Christopher H. Smith (R-New Jersey) in a speech concerning the *Expanding the Promise for Individuals with Autism Act of 2007* pointed out ““In 1995, NIH invested about \$10.5 million into autism research...the estimated budget for autism research in fiscal year 06 is nearly 10 times that amount--\$108 million” (April 19th, 2007).

Discourse surrounding grant programs addressed balance between funding for scientific research and those for services. For example, during the 111th Congress, Michael Doyle (D-Pennsylvania) discussed "The first type of grant would go to University Centers for Excellence in Developmental Disabilities Education, Research, and Service to provide training, continuing education, technical assistance, and information to children and adults on the autism spectrum, as well as the families of such individuals and the professionals working with those individuals" (September 22, 2010). During the 110th Congress, on May 19th 2008, Albert Wynn (D-Maryland) expressed “support for designation of April 2008 as ‘National Autism Awareness Month’ and supporting efforts to devote new resources to research into the causes and treatment of autism and to improve training and support for individuals with autism and those who care for individuals with autism.” Similarly, during discussion of the *Combating Autism Act* on December 8th 2006, Senator Mike Enzi (R-Wyoming) stated, “This is a comprehensive piece of legislation that will take the next steps toward providing, greater research so that we can provide children with autism early intervention to enable them to grow and reach their full potential.” Connected to such discussion this was the recognition of that the pace of scientific discovery will be slower than current need for services. For example, Representative James P. Moran (D-Virginia) reminded the House of Representatives on April 27th, 2012 that “while scientists work on the causes of and treatments for ASD, children on the spectrum deserve the best possible education.”

Promoting autism related research through provision of grants and contracts was discussed as a fundamental responsibility of government with regard to both science and society. For example, during a reading of the *Combating Autism Act* on December 6, 2006 one best practice described was that “the Secretary shall promote research, through grants or contracts, to determine the evidence-based practices for interventions for individuals with autism spectrum disorder or other developmental disabilities, develop guidelines for those interventions, and disseminate information related to such research and guidelines.” Similarly, in written testimony before the House Committee on Government Reform, Lee Grossman, the President of Autism Society of America, stated “ASA also recommends that there is a need to increase the number of scientists involved with research and treatment grants...We request that NIH develop programs that encourage researchers to enter into fields associated with autism research and to stimulate new research protocols” (107th Congress, April 18th, 2002).

Some of discourse examined supported intervening more forcefully in the direction of scientific efforts. Examples of this include Representative Christopher H. Smith’s (R-New Jersey’s) statement about the *Expanding the Promise for Individuals with Autism Act of 2007* on April 19th 2007 that "Many members of the C.A.R.E. caucus joined in supporting and passing last December the ‘Combating Autism Act,’ important legislation which focused on improving

autism-related research funded through the National Institutes of Health, autism surveillance, and early screening and diagnosis." In an earlier reading of the *Combating Autism Act* on December 6th 2006, one of the best practices described was to "promote research into the development and validation of reliable screening tools for autism spectrum disorder and other developmental disabilities and disseminate information regarding those screening tools." Representative Dan Burton (R-Indiana) expressed concern regarding the potential for Congress to micromanage science when he said during discussion of the *Combating Autism Act* on December 6, 2006:

The right funding and the right minds will cure autism, but even staggering amounts of money won't do the job if our efforts are not focused on the most promising research. I think it is important to let scientists decide how to conduct the medical research. They must be held accountable, too, but this is a job for science, not politics.

Though some would question whether Burton's concern is about science in general or the perception of his preferred science, concern about the degree to which science and politics is held distinct is not without cause. For example, though explicitly stated, there were some instances in the discourse in which research and advocacy were presented as conceptually similar, if not the same. For example, a reading of the *Combating Autism Act* on December 6, 2006 focused on the constitution of a board included the statement that "at least one such member shall be a representative of leading research, advocacy, and service organizations for individuals with autism spectrum disorder."

Another element of discussion involved lauding scientists for their recent efforts while reminding Congress that there was still quite a bit of as yet-undiscovered knowledge about autism. For example, in a speech regarding the *Training and Research for Autism Improvements Nationwide Act of 2010* Representative Danny K. Davis (D-Illinois) stated "Recently, scientists have made advances in understanding Autistic symptomatology...yet there remains limited understanding about its causes and course" (September 22, 2010). Similarly, during discussion before the Senate of the proposed *Advancement in Pediatric Autism Research Act* on March 9, 1999 Senator Slade Gorton (R-Washington) said:

The facts about autism can be sobering--but there is hope. Early intervention and treatment has helped many children. Science has also made great strides in understanding this disorder. We now know that autism is a biological condition, it is not an emotional problem and it is not caused by faulty parenting. Scientists believe that autism is one of the most heritable developmental disorders and is the most likely to benefit from the latest advances in genetics and neurology. Once the genetic link is discovered, the opportunities for understanding, treating, and eventually curing autism are endless.

Not all discussions of implementation were congratulatory, however. Concern was raised about failure to help limit potentially dangerous use of unproven treatments for autism on one side and heavy handed responses to use of less conventional treatments on the other. For example, Senator Daniel Inouye (D-Hawaii) sent an explanatory statement to the 111th Congress encouraging more informed government input into the information provided to the public about treatments for autism which read "'in addition, an increase of not less than \$2,000,000 is

provided for research on evidence-based practices for interventions for individuals with autism and other developmental disabilities, for development of guidelines for those interventions, and for information dissemination" (December 14th, 2010). On the other hand, on September 13, 2011, Representative Ron Paul (R-Texas) objected to government intervention into use of less proven therapies for autism by reporting "just this year, armed federal agents raided the headquarters of Maxam Nutraceuticals, a company that produces and sells nutritional supplements for people with autism."

Some of the discourse also took up the meaning of science directly. In particular, attempts were made to clarify interpretations of preliminary findings. For example, during discussion of the *Homeland Security Act of 2002* on November 22, 2002 Representative Dan Burton (R-Indiana) said "It is important to remember that the absence of proof of a correlation between vaccines and autism is far different than having a test and proving no vaccine causation." Since distinguishing between correlation and causality depends on theory and sustained observation rather than a single scientific finding, maintaining an understanding of this distinction is crucial for public policy development. On the other hand, this can also deter action in a democratic system. Representative Mike Doyle (D-Pennsylvania) expressed such frustrations before the House of Representatives on July 2th 2008 when he said "there have been decades of peer-reviewed, scientific research on autism, and the evidence is clear." Progress in both politics and science involves, at times, on taking leaps of faith toward a theoretically based conclusion made in the necessarily perennial absence of scientific certainty.

Organizations

Organizations dedicated to advancing or serving autism related causes often articulate a purpose oriented toward science. Sometimes this connection is obvious. For example, the mission statement of the Organization for Autism Research includes "to apply research to the challenges of autism." The Organization for Autism Research also provided a definition of applied research "In simplest terms, applied autism research is "practical research that examines issues and challenges that children and adults with autism and their families face everyday." Many organizations described providing funding for research as a key goal. For example, one of the National Autism Association's dedicated programs is called "Progress Research" described as follows: "Along with these services, NAA provides autism research funding, ongoing advocacy, support and education." Similarly, the Autism Society states ""The Autism Society advocates for multi-disciplined approaches to autism research focused on improving the quality of life for individuals across the autism spectrum and their families." The Autism Science Foundation's mission also includes "to support autism research by providing funding and other assistance to scientists and organizations conducting, facilitating, publicizing and disseminating autism research." Of course, in not for profit organizations, research funding is usually preferential, going to support research preferred by the organization's designees. For example, Autism's Speaks grant program description reads, "Autism Speaks is committing substantial effort and resources to fund definitive research to ensure that the final definition of ASD meets the following criteria..."

As was found in the legislative testimony, focal points of discussion of scientific findings related to autism included prevalence statistics. For example, Unlocking Autism reported "the number of children diagnosed with autism has increased exponentially since our children were diagnosed

back in the late 90's and the inception of UA.” Similarly, the Autism Coalition reported findings from Centers for Disease Control and Prevention that “assuming the prevalence rate has been constant over the past two decades, we can estimate that about 730,000 individuals between the ages of 0 to 21 have an ASD.” Organizations’ materials also include more general allusions to prevalence such as National Autism Association’s goal of “raising awareness about the autism epidemic and the environmental components that have contributed to the rise in cases.”

Organizations understood themselves as brokers of scientific insights, helping the general public to determine research quality. Autcom states this simply in declaring “When using any source of information about autism, it is vital to enquire what that source considers autism to be.” As an encouraging indication of both democratic discourse and—and least potentially— protection of scientific objectivity, such assertions were also found in organizations with dramatically different goals and understandings of autism than those of Autcom. For example, the Autism Society describes itself as “the leading source of trusted and reliable information about autism.” Similarly, Autism United states “By becoming a quality resource of information, Autism United allows millions of people to develop a better understanding of Autism and what people are experiencing.” Similarly, the National Autism Association articulates a key responsibility as “providing our members and community with the latest information pertaining to research, education, legislation, safety, and therapy and treatment trends.” ASAT describes this purpose even more explicitly in saying “Our mission is to educate parents, professionals, and consumers by disseminating accurate, scientifically-sound information about autism and its treatment and by combating inaccurate or unsubstantiated information.”

Other organizations express no intention toward scientific neutrality. As was the case with the congressional discourse statements of this sort most often connect to science an organization perceives as unfairly discredited or ignored. For example, example Unlocking Autism states “We educate the general public on the issues of autism, as well as work to provide educational information regarding the safety of vaccines, which we believe could provide an environmental trigger for a cohort of these children.” Similarly, Safeminds articulates the goal to “shift research focus from genetics to environment”. On a different issue, but taking a similar tack, Autism Speaks expresses deliberate intention with regard to the science of psychology in stating “Autism Speaks is concerned that planned revisions to the definition of autism spectrum disorder (ASD) may restrict diagnoses in ways that may deny vital medical treatments and social services to some people on the autism spectrum.”

Organizations also included statements of which voices were welcome participants in their deliberations about science and public policy relating to autism. Many organizations asserted a relatively broad base of issue stakeholders. For example, the Organization for Autism Research explained “The identification of priorities for OAR’s research will be undertaken with focus groups comprised of parents, educators, clinicians, and leading authorities whose life work is the promotion of autism research and the dissemination of information to the autism community.” Other times, limits on participation are expressed. For example, Autcom states “We welcome the participation of all family members, people with autism/PDD, caring professionals, and other friends who wish to implement, not debate, the right to self-determination by hearing and heeding the voices of people with autism.”

Also akin to the legislative discourse are statements which express frustration with or state an intention to address the (perceived) slow pace at which scientific research is being disseminated to the general public. For example, “Unlocking Autism was founded in February of 1999 by two mothers and a grandmother who came together for one primary purpose – to obtain information about how to help children with autism and to get that information as quickly as possible to the parents of newly diagnosed children.” Generation Rescue puts it somewhat more bluntly by stating “Generation Rescue brings to your attention scientists, physicians and community members who believe in recovery and are powerful advocates for families living with autism.” This responsibility also extends for some organizations to explicitly mandating how scientists funded by organizations disseminate the results of their work. For example, Autism Speaks requires posting on PubMed because “Once posted in PubMed Central, results of research become more accessible, prominent, and integrated, making it easier for scientists worldwide to pursue autism research.” Ultimately, from the perspective of some of the organizations, fundamental understandings about knowledge and expertise are questioned. As Autcom puts it, “many sources demonstrate a condescending attitude that rules out any possibility of learning from and with the real experts: people who have autism.”

Conclusion

As Debra Stone described, paradox defines policy making (Stone, 2001). One such paradox involves the tension in democratic politics between the responsibility to ensure the protection of unpopular science while respecting a boundary between science and politics which in the ideal firmly separates politics from the objectivity of science. The most passing reflection on the history of the twentieth century reveals the potential of both reliance on scientific objectivity and the politicization of science to at best set progress back and at worst lead to social injustice. In the case of autism related politics in the United States, negotiation of this paradox is demonstrated by the issue of thimerosal in vaccines. Intriguingly, the less popular science relied most ardently on the traditional hallmarks of scientific reputation.

Another paradox found in the roles of science in autism related policy involved the paradox of participation. Good practice in both democracy and science involves a broad basis of participation in which power of voice is ideally connected to the merit of the argument. Of course, both realms tend toward cementing of norms and power tied to money rather than evidence or persuasion. In part in response to the default norms which mainstream organizations engage as unquestioned truth, other autism related organization tend to advocate overt restriction participation in scientific discussion even while insisting that their voices should be better represented in autism policy discourse. The paradox strongly relates to the definition of science and the degree to which distinctions between basic and applied science have become more complicated in modern research. It is also a reflection of the expectation that public enjoy increased involvement in the articulation of scientific questions.

Finally, examination of use of science in autism related policy discourse turned up extremely limited discussion coming from the perspective of rights of individuals with autism, particularly outside of organizations explicitly committed to neurodiversity. The legislative discourse included no discussion of neurodiversity and limited discussion of rights. The discussion of rights that was found in the legislative discourse was generally set in opposition to science. Entitlements such as education or social services were mentioned as other important priorities

needed for individuals with autism that should also be attended to while society waits for answers about autism. Typically such discussion was exclusively about children with autism and their nuclear families. Given the decades-long history of rights based disability policy, the lack of such discussion in autism related policy discourse could be considered surprising, if not, disappointing. On the other hand, in discourse relating to specifically the role of science in autism related policy, this circumstance could be considered less discouraging and, instead, a recognition that normative elements of public policy, such as the provisions for protecting the rights of historically oppressed individuals lies beyond the realm of science. In the end, the interactive goal of science and democracy should be mutual reinforcement and improvement.

A key role of science in political discussion involves establishing a circumstances as either a new threat to (or opportunity for) society or a transcendent human challenge recently turned intolerable as a result of new discovery. Policy can, of course, also be made in response to changing norms and values, however, in such cases (social) science's role is interpreted as more exclusive to organizing, interpreting and communicating information about such changes, rather than directly such changes in most positivist interpretations of science.³ In the case of autism related policy, science was most frequently employed both in legislative discourse and in organizations documents in such a manner in order to argue that the incidence or prevalence of autism has increased dramatically in recent decades. Sometimes, such arguments include references to specific studies and scientists. More often the challenge was discussed as a matter of scientific consensus. As time goes on, this aspect of the interaction between science and politics is likely to become increasingly tense in autism related policy discourse. In part this will be due to more explicitly scientific discussion such as the revision of the DSM.

³ Other approaches to sciences (such as action research) and the humanities define and embrace a distinct role for the social sciences involving a more activist approach to defining social norms and values.

References

- Baker, D. (2011). *The Politics of Neurodiversity: Why Public Policy Matters*. Denver: Lynne Rienner.
- Boote, J., Baird, W., & Beecroft, C. (2010). Publicinvolvement at the design stage of primary health research: A narrative review of case examples. *Health Policy* 95(1), 10-23.
- Brooks, M. (2009). *Thirteen Things that Don't Make Sense: The Most Baffling Scientific Mysteries of our Time*. New York: Random House.
- Bumiller, K. (2009). The Geneticization of Autism: From New Reproductive Technologies to the Conception of Genetic Normalcy. *Signs* 34(4), 875-899.
- David, P. A. (2008). The Historical Origins of 'Open Science': An Essay on Patronage, Reputation and Common Agency Contracting in the Scientific Revolution. *Capitalism and Society* 3(2).
- Driscoll, C., Lambert, K. F., Chapin III, F. S., Nowak, D., Spies, T. A., Swanson, F. J., et al. (2012). Science and Society: The Role of Long-Term Studies in Environmental Stewardship. *Bioscience* 62(4), 354-366.
- Drolet, B. C., & Lorenzi, N. M. (2010). Translational research: understanding the continuum from bench to bedside. *Translational Research* 157(1), 1-5.
- Felt, U., & Fochler, M. (2008). The Bottom-up Meanings of the Concept of Public Participation in Science and Technology. *Science and Public Policy* 21(1), 17-35.
- Fine, M., & Asch, A. (1998). Disability Beyond Stigma: Social Interaction, Discrimination and Activism. *Journal of Social Issues* 44(1), 3-21.
- Grinker, R. R. (2008). *Unstrange Minds: Remapping the World of Autism*. Philadelphia: Basic Books.
- Jentoft, S., & Chuenpagdee, R. (2009). Fisheries and coastal governance as a wickedproblem . *Marine Policy* 33(4), 553-560.
- Juntti, M., Duncan, R., & Turnpenny, J. (2009). Evidence, Politics and Power in Public Policy for the Environment. *Environmental Science & Policy* 12(3), 207-125.
- Kenslen, H. (1951). Science and Politics. *The American Political Science Review* 14(3), 641-661.
- Kim, Y. S., Leventhal, B. L., Yun-Joo, K., Fombonne, E., Laska, E., Lim, E.-C., et al. (2011). Prevalence of Autism Spectrum Disorders in a Total Population Sample . *The American Journal of Psychiatry* 168(9), 904-912.
- Kingdon, J. (2010). *Agendas, Alternatives, and Public Policies, Update Edition, with an Epilogue on Health Care (2nd Edition)* . New York: Longman.

- Konefal, J., & Hatanaka, M. (2011). Enacting third-party certification: A case study of science and politics in organic shrimp certification. *Journal of Rural Studies* 27(2), 125-133.
- Kuhn, T. (2012). *The Structure of Scientific Revolutions: 50th Anniversary Edition*. Chicago: The University of Chicago Press.
- McIvor, D. (2010). The Politics of Speed: Connolly, Wolin, and the Prospects for Democratic Citizenship in an Accelerated Polity. *Polity* 43, 58-83.
- McRuer, R., & Berube, M. F. (2006). *Crip Theory: Cultural Signs of Queerness and Disability*. New York: New York University Press.
- Oreskes, N. (2011). *Merchants of Doubt: How a Handful of Scientists Obscured the Truth on Issues from Tobacco Smoke to Global Warming*. New York: Bloomsbury Press.
- Pielke, R. A. (2007). *The Honest Broker: Making Sense of Science in Policy and Politics*. Cambridge: Cambridge University Press.
- Pinker, S. (2011). *The Better Angels of Nature: Why Violence Has Declined*. New York: Viking Penguin.
- Roberts, N. C., & King, P. J. (1991). Policy Entrepreneurs: Their Activity Structure and Function in the Policy Process. *Journal of Public Administration Research and Theory* 2, 147-175.
- Silverstein, L. B., & Auerbach, C. (2003). *Qualitative Data*. New York: NYU Press.
- Silverstein, R. (2010). Anatomy of Change: The Need for Effective Disability Policy Change Agents. *Archives of Physical Medicine and Rehabilitation* 91(2), 173-177.
- Skloot, R. (2011). *The Immortal Life of Henrietta Lacks*. New York: Crown Publishers.
- Stace, H. (2011). *Moving Beyond Love and Luck: Building Right Relationships and Respecting Lived Experience in New Zealand Autism Policy*. Wellington: University of Victoria.
- Stone, D. (2001). *Policy Paradox: The Art of Political Decision Making (Revised Edition)*. New York: W.W. Norton & Company.
- Taleb, N. N. (2007). *The Black Swan*. New York: Random House.
- Tijssen, R. J. (2010). Discarding the 'basic science/applied science' dichotomy: A knowledge utilization triangle classification system of research journals. *Journal of the American Society for Information Science and Technology* 61(9), 1842-1852.
- Trickett, S. B., Trafton, J. G., & Schun, C. D. (2009). How Do Scientists Respond to Anomalies? Different Strategies Used in Basic and Applied Science. *Topics in Cognitive Science* 1(4), 711-729.