

## Comparative Canadian and United States Autism: A Narrative Analysis

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**Abstract:** This article examines autism policy narratives in Canada and the United States. In both nations, meta-narratives emerged, establishing federal autism policy. Whereas the stories associated with these meta-narratives shared starting points, the stories unfolded in nationally distinct ways.

**Key Words:** Autism, Policy, Narrative Analysis

### Introduction

Policy narratives surrounding autism became more prevalent in Canada and United States during the past two decades (Baker & Stokes, 2007). This article explores stories, non-stories, counter-stories, and meta-narratives in autism policymaking using the narrative policy analysis approach presented by Roe (1994) with a specific focus on the 2006 Federal Autism Initiatives in Canada and the U.S. Combating Autism Act of 2006 (Lynch, 2006). The article begins with a brief overview of autism and then presents relevant aspects of narrative analysis. The introduction is followed by the Canadian case study and that, in turn, is followed by the United States case study. The article concludes with a comparative examination of the cases of Canada and the United States.

### Autism

The U.S. Centers for Disease Control and Prevention (CDC) defines autism as a “collection of neurologically-based developmental disorders in which individuals have impairments in social interaction and communication skills, along with a tendency to have repetitive behaviors or interests” (Centers for Disease Control 2008). There is no scientific consensus as to the cause of autism spectrum disorders (hereinafter referred to as autism). However, most research to date focuses on genetic or environmental explanations (see, for example, Morrow et al., 2008).

As a spectrum difference, autism presents differently in each individual identified as having autism (Miller 2009). Although symptoms may emerge in early infancy, autism may not be considered as a diagnosis until much later in a person’s life (Twyman et al., 2009). A young child who has major speech delays and sensory issues and avoids eye contact, for example, may be diagnosed with classical autism before his or her third birthday. However, a teenager with typical speech development but difficulties in social situations may not be diagnosed with high functioning autism (HFA) until the age of 16 or even later (Twyman et al., 2009). Diagnosis of

autism depends on observed behavior rather than a medical test. To further complicate the situation, over a person's lifespan, behaviors associated with autism may change (Miller 2009).

The inherent diversity and (perceived) mystery around autism complicate the creation of effective autism related public policy. For example, these factors complicate data collection on the prevalence and incidence of autism, both over time and across different contexts. They also complicate the work of incorporating input from multiple stakeholders, such as school systems, health care providers, and the families of people with autism. Finally, success of interventions is not consistent across the population of individuals with autism. What helps one person with autism cope with anxiety, for example, may do nothing for a person with the same diagnosis.

### Narrative Policy Analysis

Narrative policy analysis is particularly well suited to the case of autism policy. Autism-related policy is characterized by high degrees of uncertainty, ambiguity, complexity, and, in Roe's words, is an area "where most everyone is playing it by ear" (Roe, 1994, p. 13). In such instances, those involved in the policy process rarely agree on the criteria for success. Success can be constructed from movements within the narratives (Kaplan, 1986). Given this, an understanding of policy narratives is critical to an understanding of autism policymaking because these narratives provide the most cohesive framework around which policy can be developed.

Narrative policy analysis assumes language constructs the world. The approach focuses on the importance of language in constructing policy (Bridgman & Barry, 2002, p. 141). In this method, discourse surrounding an issue is the focal point rather than empirical data. Discourse can, in effect, "respond" to empirical data by shifting meanings without exiting the policy arena. Narrative policy analysis, as developed by Roe, employs a case study approach and focuses on "the scenarios and arguments on which policies are based" (Roe, 1994, p. 2). It examines the policy narratives or "stories" developing around a complex policy issue. Focus is placed on the stories or narratives that "dominate the issue in question" (Roe, p. 3).

Roe also stresses the need to identify stories not fitting the traditional definition of a story. These "nonstories" do not have beginnings, middles, and ends. Furthermore, if the narrative "run(s) counter to the controversy's dominant policy narratives," it is called a "counterstory" (Roe, p. 3). The narrative generated from a comparison of stories and nonstories or counterstories is the "metanarrative" (Roe, p. 4). The metanarrative may then "recast(s) the issue in such a way as to make it more amenable to decision making and policymaking" (Roe, p. 4). In polarized policy disputes, the metanarrative can make the issues more tractable by foregoing a search for compromise and consensus in favor of a story that all can accept and can be the basis for moving forward in the policy process. A metanarrative, as Roe reminds us, is a "small-a answer" providing "room to maneuver on an issue that has hitherto been treated as so uncertain, so complex, and so polarized that it affords little or no movement whatsoever" (Roe, p. 17). Power and politics are involved in shaping how the issue is perceived and communicated and how the narratives are created and communicated (Roe, p. 14).

On November 24, 2006, the Ministry of Health announced Federal Autism Initiatives. These initiatives included:

- sponsor an ASD stakeholder symposium in 2007 to further the development of ASD knowledge and dissemination among health care professionals, researchers, community groups, teachers, individuals, and family members;
- begin exploring the establishment of a research chair focusing on effective treatment and intervention for ASD;
- launch a consultation process on the feasibility of developing an ASD surveillance program through the Public Health Agency of Canada (PHAC) to help shape appropriate ASD programming and research;
- create a dedicated page on the *Health Canada Web site* to guide the public to ASD information available through the Canadian Health Network and other resources;
- designate the Health Policy Branch of Health Canada as the ASD lead for actions related to ASD at the Federal Health Portfolio level (Health Canada, 2006).

These initiatives were novel both because of the stated goals and the fact that they came from the national government as opposed to the provinces. Autism related groups welcomed the initiatives, even if they were not fully satisfied with their content, scope, or budget (approximately \$800,000). Autism Society Canada explained in a press release:

“We applaud the government for initiating some of the elements that ASC believes will help develop a comprehensive national autism strategy. These are modest first steps, and we will work to ensure that many more steps are taken by government to meet the multifaceted needs of our other partners across Canada.”  
(Anderson, 2006)

This creation of a national strategy broke from previous, provincially focused, autism policy trajectories. Primarily because autism issues were located in the health policy subsystem, defining autism as a federal concern had been no easy task. After all, Canadian provinces of the Canadian federation had been almost exclusively responsible for the design of health care systems under the Charter of Rights and Freedoms. Establishing a federal autism initiative necessitated careful balancing of federal leadership on the part of a newly elected government with respect for traditional provincial autonomies with regard to publicly provided health care. In the process of creating such a balance, different stories about autism were employed within Canadian public and government discourse.

### Medically Necessary

The Canadian medicare system receives funding from the federal and provincial governments. To receive federal funding, provincial and territorial health care insurance programs must meet the guidelines of the Canadian Health Act (adopted in 1984) (Canada Health Care Act Annual Report, 2008-2009). A fundamental component of the Act is the universally available provision of medically necessary health care delivered in hospitals and by physicians (Canada Health Care Act Annual Report, 2008-2009). Although strictly speaking,

provincial participation under the Canadian Health Act is voluntary, the value placed on the federal fiscal support on the part of provinces is high enough to generally ensure compliance on the part of provinces. No definition of “medically necessary” appears in the Canadian Health Act (Commission on the Future of Health Care in Canada, 2002). As a result, both the professional’s judgment and lists created by the provincial governments serve to discern which illnesses, differences, procedures, and treatments are covered.

One story expressed in the Canadian public discussion of autism revolved around the theme of medical necessity. Basically, the premise of this story was that autism is a treatable disease affecting a growing number of Canadian children. In keeping with this story, the incidence and/or prevalence growth of autism observed in Canada in recent years was described as an epidemic (Senate Standing Committee on Social Affairs, 2007).

In the version of the story most often told in Canadian discourse, autism can be effectively treated only by intensive behavior intervention, preferably applied behavior analysis. According to this story, for reasons ranging from miserly provincial governments to sheer lunacy on the part of other autism policy stakeholders, this medically necessary treatment had been withheld from children with autism. The FEAT BC website described an organization committed to achieving universal public provision of applied behavior analysis for all children with autism living in Canada:

“F.E.A.T. of B.C was established for another important reason – to publicize discrimination in B.C. against children with autism. Specifically, it is wrong that children with physical disabilities have access to government health insurance coverage, yet children with the mental, neurological disability of autism do not receive treatment.” (FEAT, 2010)

The penultimate expression of this story was the Supreme Court case *Auton (Guardian ad litem of) v. British Columbia (Attorney General)*, [2004] 3 S.C.R. 657, 2004 SCC 78. This case revolved around the question of whether or not the equality rights of children with autism under the Charter of Rights and Freedoms (the Canadian constitution) was violated if the children were not provided medically necessary treatment, particularly in the form of applied behavior analysis. The decision of the provincial Supreme Court supported the parents who brought the case (The Learning Disabilities Association of Canada, 2008).

However, the Supreme Court of Canada reversed the decision, finding that the provinces were not required to provide all medically necessary treatment except for the core medical services (Baker 2008). This finding created what Roe would call a “nonstory,” not providing a discernible beginning, middle, or end, or a redefinition of obligatory health care in Canada. The remaining controversy surrounding the treatment, particularly as connected to the story of autism as a different way of being human as opposed to an illness or disability, also cast influential doubt on the story presenting ABA as a virtual cure for autism. As is stated above, a key component of the 2006 Federal Autism Initiatives was the establishment of a research chair focusing on effective treatment and intervention for autism. This component of the initiatives connected back to the debates within the narratives on medical necessity left unsettled by the Supreme Court decision.

## Scientifically Proven

Another influential narrative surrounding autism was rooted in the concept of scientific proof. The “scientifically proven” presented intensive behavioral intervention (in particular ABA) as the only scientifically proven intervention for autism. As such, the story created extreme urgency for providing treatment, since ABA is generally expected to be most (if not only) beneficial to young individuals with autism.

Drawing primarily from the work of Dr. Ivar Lovaas, the story typically told in the Canadian public discourse was that little scientific evidence supporting the existence of other effective treatments for autism. In fact, expressions of this narrative typically did not address scientific studies of other options, such as dietary intervention. For example, an online dialogue called “Riding Talk” employed this narrative as follows:

“...since the 1980s the medical community has known that the application of Intensive Behavior Intervention (IBI) based on the principles of Applied Behavior Analysis (ABA) can help as many as 47% of children with autism develop to the extent that they are able to function as average children, indistinguishable from their peers. Such medically necessary autism treatment is the core healthcare need of children struggling to overcome the ravages of autism. Yet, even though the provision of this treatment is far less costly than a lifetime of social support and institutionalization for untreated children, there is not even one province in Canada that offers autism treatment under provincial public health insurance programs (Medicare).” (Canada Votes, 2006)

According to this narrative, the public policy challenges associated with autism were relatively easy to locate within the health care policy arena, and the blame for the problem was placed firmly on the shoulders of provincial governments failing to recognize a scientifically proven fact well established within the health care community.

The Canadian press frequently cited the only scientifically proven treatment narrative. Almost always, the narrative was expressed first with a statement of the cost of the treatment (in the range of tens of thousands of Canadian dollars per year), followed by the description of either intensive behavioral intervention or ABA as the only scientifically proven treatment, and concluding with a description of the government’s failure to provide the treatment.

After the Auton verdict, however, the scientific proof narrative slightly decreased its focus on identifying a unique treatment for autism. For example, the website for the Geneva Center for Autism in Toronto stated:

“While there is no one treatment which is entirely accepted by all professionals and parents as the 'only' approach to use, treatment based on the principles of Applied Behaviour Analysis (ABA) have been scientifically proven to facilitate the best outcomes for children with autism.” (Toronto Partnership for Autism Services, 2008)

Although the meaning of the quotes around “only” was open to interpretation, it appeared to reference Canadian public and government discourse surrounding the scientifically proven narrative.

The only scientifically proven narrative was controversial. Perhaps surprisingly, the counter-stories on scientific evidence usually did not come from or are motivated by providers or supporters of other types of therapies or interventions. Evidence regarding alternative treatments and interventions tended to appear in less well publicized nonstories in Canada and did not address the science backing to the intensive behavioral interventions (Baker, 2008). The leading counterstories to the scientifically proven narrative engaged the concepts of human individuality and human rights.

### Autistic Rights

The most common version of the autistic rights narrative was a counterstory to both the medically necessary, and, less frequently, the scientifically proven story. Whereas parents of children with autism and professionals in the behavioral intervention programs were the most fervent in expressing the scientifically proven and medically necessary stories, adults with autism who managed to integrate into the Canadian economy—if not society at large—were the most ardent in expressing the counterstory of autism rights.

The basic elements of the autistic rights counterstory were: 1) autism is not a disease or—in an inclusive society—even a disability; 2) behavioral intervention therapy is at best unnecessary and at worst an oppressive exercise robbing children with autism of their childhoods; and 3) other autism policy stakeholders, including the Canadian government, deliberately ignore and exclude the voices of adults with autism from related policy debates because they fear the truths revealed by the autistic-rights counterstory. As a result, these narratives were often expressed outside the formal policy debate (although individuals such as Michelle Dawson were not allowed to present evidence in settings including the Supreme Court debate of the *Auton* case).

Often autistic rights narratives were expressed in letters to members of government, and then the original letters and responses are posted on the World Wide Web. For example, Ralph Smith of The Autism Project, Ontario, wrote to his government representative liberal Minister of Parliament Karen Redman on October 4, 2004 to request she consider materials discussing the rights of autistic Canadians. She (or her office) responded in less than two weeks, citing her support for efforts to better identify and prevent autism. Michelle Dawson, a staunch advocate of neurodiversity,<sup>1</sup> wrote back to her, explaining their concern about rights of adults with autism. Karen Redman’s response expressed her support to the Minister of Health for the designation of one treatment (presumably ABA) as a medically necessary treatment for autism. Ralph Smith’s response read:

“Regarding your reply of November 18, 2004, I have not received a copy of your expected response from the Minister of Health. Also I do not support the request

which apparently you have made on my behalf. I do not support your request for an amendment to the Canada Health Act.” (Smith, 2004)

In another letter, Mr. Smith said the following:

“I believe you have mistaken me for the parent of an autistic child, rather than the independent autistic adult which I am. While mistaking current issues regarding autistic people is far more serious an error, I believe your oversight would equate to your assuming I am heterosexual when I am in fact a gay male, or in anyone assuming that you are heterosexual or lesbian.” (Smith, 2004)

Ironically, as seen in Smith’s letter, Redman’s formulaic response began with the story of autistic rights—individuals with autism who considered autism to be a formative element of their selves within society (the “autistics”) found themselves facing passive and active discrimination in society. Failing to recognize (or denying outright) the autistic identity was understood as an expression of bigotry similar to those experienced by all non-elite populations.

Such narratives have been a common element of modern disability studies. Much conversation on disability rights in both Canada and the United States began with the statement “nothing about us without us” (Shapiro, 2011). These narratives portray efforts *for* individuals with disabilities as oppressive and in line with understandings of disability that, for the most part, blame the individual with the disability for any associated disadvantage. Often these narratives have called for a replacement of organizations *for* individuals with disabilities (or with a particular disability) with organizations *of* individuals with disabilities (Shakespeare, 2005). In the Canadian public and government discourse surrounding autism, the autistic rights narrative tended to not be so separatist. This narrative has been heard, if not fully accepted or understood, in Canadian government discourse. For example, regarding government funding of autism treatment, the report of the Senate’s Standing Committee on Social Affairs stated the following:

“The second definition presented to the Committee was provided by other autistic individuals and researchers in the field. In their view, autism (or ASD) is not a mental disorder; it is rather a neurological difference classified as a developmental disability that begins in early childhood and persists throughout adulthood... In their view, autistic individuals have strengths and traits not seen in the general population, just like “non-autistics” have strengths and weaknesses of their own. Like non-autistic people, individuals with autism may suffer from mental health problems and illnesses, including for example depression, self-hate and suicidal ideation. Those mental health problems may be exacerbated by the lack of knowledge about and appreciation of autism among non-autistic individuals.” (Senate Standing Committee on Social Affairs, 2007)

The Canadian Government discourse tended to present a version of the autistic rights characterizing the story as an interesting (and arguably relevant) side note. After all, the 2006 initiatives listed individuals with autism alongside several other stakeholders (albeit towards end of the list) to be included in the anticipated national autism symposium. References to this narrative tended to be followed either by a return without comment to another narrative or a

discussion of the responsive viewpoint that autistic rights narratives were presented only by extremely high functioning individuals with autism who failed to understand the plight and needs of individuals who are more deeply affected by autism.

### Provincial Rights—Metanarrative

The three categories of policy stories discussed above encompass classic premises of public activity targeting disability—those of care, cure, cause and celebration. Juxtaposition of any pair of these premises created tensions capable of thwarting or stalling efforts to develop and implement new programs or policies. The presence of these premises in the culturally dominant autism policy stories underscores a necessity for the employment of a metanarrative for decisions to be made and for action to be taken. The 2006 Federal Autism Initiative demonstrated the federal autism policy, and the metanarrative emphasized the perfection and protection of Canadian federalism.

The Canadian federalism metanarrative began on a note of good intentions. Well-meaning citizens, groups, and even government officials wanting to improve conditions turned to the federal government to solve a problem. This problem in question, however, shaped daily lives and called for public policy sacrosanct to the provincial level of government. The challenge for the federal government, therefore, was to discern how to guide and support development of provincial programs and policies without becoming domineering or repressive. The conclusion of the metanarrative was to carefully protect the Canadian federalist system by maintaining a high degree of provincial autonomy in health care, despite perceived costs to individuals (particularly children) with autism. As Pat Lynch, a ministerial candidate, puts it:

“I am very reluctant to infringe on Provincial jurisdiction. I know the Liberals have done it repeatedly... but they are creating a real mess of things with all the side deals they are making...however, I do wonder why Medicare does not cover treatment of autism related disorders.” (Lynch, 2006)

The primary role of the federal government was, as a result, understood as to provide support for research, including \$15 from the Canadian Institutes of Health Research between 2000 and 2006, and to reach out to other countries to create joint research agendas (Scott, 2006).

### United States and the Combating Autism Act of 2006

In the case of the United States autism policy, a metanarrative emerged and led to the policy's success. The metanarrative of an autism epidemic formed the basis for Congressional action on autism and the passage and eventual funding of the Combating Autism Act of 2006 (Lynch, 2006). Moreover, the metanarrative of an autism epidemic was broad and encompassing and did not, as a “grand” or “master” narrative can do, marginalize other narratives or substitute a form of autism canon.<sup>2</sup> Equally importantly, the epidemic metanarrative supported powerful advocacy groups and members of Congress and was policy relevant.

Information on autism in the United States was important for establishing the context in which the metanarrative appears. There was no consensus in the United States as to the



prevalence or incidence of autism. The CDC, for example, reported prevalence rates between 2 and 6 per 1,000, or between 1 in 500 and 1 in 166. This placed the prevalence rate for autism lower than the rate for mental retardation but higher than the rates for cerebral palsy, Down syndrome, or childhood cancer (Volkmar et al., 2004). The National Institute of Neurological Disorders and Stroke (NINDS) placed the rate at 3 to 6 per 1,000 ([www.ninds.nih.gov](http://www.ninds.nih.gov)). The CDC used figures demonstrating a 600 percent increase, from 22,644 to 141,022, of children classified as autistic between 1994 and 2003 ([www.cdc.gov](http://www.cdc.gov)). More recently, the Autism Developmental Disabilities Monitoring Network (ADDM) suggested the prevalence may be as high as 1 in 110 (<http://www.cdc.gov/ncbddd/autism/index.html>).

### Mercury Story, Counter-Story, and Non-Story

As noted earlier, there was no scientific consensus as to the factors involved in the etiology of autism. In the United States, a vocal group, including national organizations such as Safeminds and celebrities such as Jenny McCarthy, supported the belief that autism was caused by thimerosal, a mercury-based preservative in vaccines (Baker & Stokes, 2007). This lack of consensus as to the cause of autism, coupled with the lack of consensus as to the prevalence or incidence, encouraged the epidemic metanarrative.

The status of organized autism advocacy and its efforts to gain federal passage of autism legislation also played a major role in developing the context of the epidemic metanarrative. The organized autism advocacy began in 1965, when Dr. Bernard Rimland founded the first nationwide group devoted to autism, the Autism Society of America (ASA). Rimland, a father of a child with autism, began ASA as a parent advocacy organization. It expanded to over 100,000 members and supporters and some 200 local chapters. The ASA, however, had no major federal legislative success until the emergence of other advocacy groups, arguably because of the low profile of autism as a low incidence difference. Indeed, significant policy impact at the federal level did not occur until 2000 with the passage of the Children's Health Act (Lynch, 2006). ASA supported the legislation, but the advocacy group Cure Autism Now (CAN) was largely responsible for the inclusion of autism in this omnibus bill.

Jonathan Shestack and Portia Iverson, parents of a son with autism, founded CAN in 1995. As Shestack and Iverson were members of the entertainment community, CAN used their connections to gain congressional attention for autism. Their efforts eventually resulted in the inclusion of autism in the Children's Health Act (Lynch, 2006). The Children's Health Act mandated the establishment of the Interagency Autism Coordinating Committee (IACC) to coordinate autism research, programs, and activities (Lynch). The IACC supported the federal policy response to autism and can enhance the government's response to autism.

As CAN was successfully advocating the inclusion of autism in the Children's Health Act, Rep. Burton (R-IN) was holding hearings on the mercury and vaccine connection to autism (Lynch). Altogether, Rep. Burton conducted over 20 hearings on topics related to mercury, vaccines, and autism, none of them led directly to major autism legislation. Nonetheless, his efforts were a major factor in placing autism on the congressional agenda.

The next major legislative initiative was the Combating Autism Act (CAA) of 2006. First introduced in 2005, the CAA became the focus of national controversy. From the perspective of its supporters, it was “held captive” by Rep. Joe Barton (R-TX), then Chair of the House Energy and Commerce Committee (Lynch, 2006). Barton argued he was interested in his bill to reform the NIH and was not willing to support single-issue legislation, such as the CAA, until the reform was enacted. Consequently, he became the object of intense pressure from autism advocacy groups. Also, radio host Don Imus relentlessly campaigned against Barton, in large part because of his friendship with Bob and Suzanne Wright and their new organization, Autism Speaks. Autism Speaks characterized Barton’s actions in particularly negative terms:

“(I)n his unwillingness to act on a bill meticulously crafted over 18 months and unanimously passed by the United States Senate, Congressman Barton has decided to put politics before the welfare of our children.” (Autism Speaks, 2006)

The statement, consistent with the Autism Speaks message, referred to autism as “an epidemic now affecting one in every 166 of our children, yet federal funding for autism remains woefully insufficient” (Barton, 2006). Barton’s speech about CAA to the floor before the House included the possible connection between autism and vaccines and did not refer to an epidemic, but did present figures on incidence.

Autism Speaks (now Autism Speaks, Inc.) was founded by Bob and Suzanne Wright, the grandparents of a child with autism, and friends of Don Imus and his wife Deirdre. Bob Wright was the chair and CEO of NBC Universal and vice chair and executive officer of General Electric Company. Autism Speaks quickly became a major player in autism advocacy and, along with CAN, lobbied for the passage of the CAA. The Wrights were thanked on the floor of the Senate when the CAA passed. Congress approved the bill, and President Bush signed it into law on December 19, 2006.

The CAA authorized spending for the early detection and treatment of autism as well as research and education and reauthorized and restructured the IACC. Bob Wright and Jon Shestack noted when the Senate and House of Representatives approved the final version of the CAA, “(T)he passage of this landmark single-disease legislation signals the federal government’s declaration of war on the epidemic of autism” (Cure Autism Now and Autism Speaks, 2006).

However, the discourse around legislative victory reflected controversy. Although Rep. Barton finally released the bill from the committee, the discussion from some in the autism community included objection to the version that became law, primarily because it removed earmark funding for research into the environmental causes of autism, including mercury in vaccines. Deirdre Imus, in a letter to *Newsweek*, advanced the epidemic metanarrative while not dismissing a possible mercury connection by writing:

“What has caused autism rates to grow so much in less than 20 years? The idea that it’s just better diagnosis is, to parents and supporters of the autistic community, like fingernails on the chalkboard. This epidemic is real and recent and cannot be explained by saying the diagnostic skills of doctors suddenly improved in the late 1990s. Perhaps the number of mercury-containing vaccines

given to children tripled in the '90s and resulted in a toxic tipping point, causing these children to regress into a disorder we call autism.” (Imus, 2006)

A-CHAMP withdrew its support for the CAA. Other organizations, such as Sensible Action for Ending Mercury-Induced Neurological Disorders (SAFE MINDS), supported the legislation, but expressed reservations. Even before the bill became law, there was dissension within the Wright family. Katie, the Wright's daughter, and mother of their grandson with autism, said on the Oprah Winfrey show in April 2007 that she believes mercury in his vaccinations was responsible for her son's autism. Autism Speaks responded with a disclaimer on its website, distancing themselves from Katie's views.

Nonetheless, the “mercury story” advanced by Rep. Burton and supported by a number of advocacy organizations accomplished what Roe predicted: when confronted with uncertainty concerning the etiology of autism, the mercury story simplified that reality (Roe, 1994, p. 35). For some, the mercury connection was discredited, and alternatives, including environmental and or genetic factors, were suggested. Some who refused to abandon the mercury story modified it. Still, others, mainly small parent organizations, continued to question the validity of the scientific research, basically constructing a story of deception and cover up.

The pressure from these groups was so great that the Senate Committee on Health, Education, Labor, and Pensions released the executive summary of a report on the allegations (Enzi, 2007).<sup>3</sup> The report made no conclusions concerning the safety of thimerosal and focused on whether or not there had been improprieties by government agencies or private entities, particularly the pharmaceutical companies. These allegations of improprieties included conflicts of interest, instances of compromised research, and cover-up of the dangers posed by thimerosal. The mercury story and the counterstory that autism was not caused by mercury in vaccines was joined by a nonstory, one that, following Roe, had no beginning, middle, or end and had no answer to what caused autism.

### Epidemic—Metanarrative

In this context, CAN and Autism Speaks turned to the metanarrative of the autism epidemic. In support of the 2005 version of the Combating Autism Act, Shestack, the founder of CAN, noted, “(w)e are determined to make the nation treat the autism epidemic as the crisis that it is” (Autism Speaks, 2008). The most dramatic and effective use of the epidemic metanarrative, however, was the Autism Speaks 1 in 166 message. This story was heavily publicized in public service announcements and print media.<sup>4</sup> As Fischer notes, “counting is also used as a tool of political mobilization” (Fischer, 2003, p. 171). Autism Speaks chose to use the metanarrative, including the 1 in 166 number. In an interview with *Autism Spectrum Quarterly*, Suzanne Wright, when speaking of lobbying on behalf of the CAA, noted,

“...This is an epidemic and they know how serious it is. The autism community is so committed to this and we really came together. As you know, since you've been involved with autism for so many years, the autism community can be a very disjointed

group. You might have your agenda and it might be worthwhile, but if you don't have one voice, nobody's going to pay attention to you." (Twachtman-Cullen, 2006, p. 2)

Wright went on to say:

"There are so many issues—research, genetics, the environment. We can't let the Senate and the full Congress point at us and say we are not together, because then we will not have a voice to their attention." (Twachtman-Cullen, p. 2)

As would be expected by narrative policy analysis, there was no consensus per se as to whether or not an autism epidemic exists. The Department of Health and Human Services (HHS) website, for example, notes:

"The question of whether there is an autism epidemic requires an understanding of trends in autism. Understanding autism trends is particularly difficult due to the lack of historical population-based tracking of autism rates and the fact that many early studies used different methods and a narrower definition of autism." (Department of Health and Human Services, 2005)

The Enzi report (2007) stated:

"Autism has been called a national epidemic by the media, medical science and many active in the autism community but stops short itself of endorsing the existence of an epidemic per se. The report accompanying the CAA presented data on the incidence and prevalence of autism but makes no mention of an epidemic." (Senate Committee on Health, Education, Labor and Pensions, 2006, pp. 2-3)

The report did state, however, "the committee encourages the CDC to examine specific trends of autism spectrum disorder over time" (Senate Committee on Health, Education, Labor and Pensions, p. 14). In addition, President Bush's signing statement did not mention an epidemic (White House, 2006, p. 1).

The epidemic metanarrative was successful because it managed to transcend the mercury narrative, and there were no competing narratives compelling enough to counter it. ASA's official stance rejected the finding that there of no connection between vaccines and autism (ASA, 2004). Both CAN and Autism Speaks carefully sidestepped the most radical form of the mercury narrative. CAN, for example, sponsored a number of research initiatives, including one focusing on the neurotoxicity of mercury. Autism Speaks' position was circumspect but not dismissive of a possible connection between mercury and autism. The official Autism Speaks position was as follows:

"Autism Speaks plans to strongly support a multidisciplinary research agenda on environmental exposures and autism. We believe that projects acknowledging the role of gene-environment interaction and incorporating markers of exposure susceptibility and etiologic heterogeneity will be the most productive in the long-term. Given present knowledge, there is a fairly broad array of neurotoxic

environmental exposures worthy of further study but, moving forward, the type and timing of exposures under investigation should continue to comport with emerging developments in autism neurobiology.” (Autism Speaks, 2010)

Autism Speaks and CAN were able to secure passage of federal legislation while acknowledging the need for research on more controversial issues, such as a mercury/vaccine connection to autism. Representative Burton supported the compromise legislation, referring to it as a “down payment” on what must be done to combat autism (Burton, 2008). In the same statement, he remained committed to the mercury story, but fully embraced the epidemic metanarrative.

The policy process could have responded to a known epidemic in ways not amenable to situations involving more uncertainty and ambiguity. Even the suggestion of an epidemic was important since policymakers seek to avoid appearing unresponsive or callous in the face of such concerns. The autism epidemic, in Roe’s terminology, became a “metanarrative that recasts a difficult policy problem in a more tractable way” (1994, p. 108).

### Discussion and Conclusion

Autism creates fascinating modern policy challenges in both Canada and the United States. Because of a relative lack of scientific understanding, there was significant room for the creation of stories to establish the consensus necessary for developing public policy. In both Canada and the United States, metanarratives emerged and helped to establish federal autism policy. Whereas the stories associated with these metanarratives shared starting points, they unfolded in distinct ways.

In both Canada and the United States, uncertainty surrounding current scientific evidence for autism-related theories created a starting point for policy stories. However, the dominant stories had different endings. This implied policy trajectories. In the United States, the narratives surrounding the source of an autism epidemic frequently drew on contested scientific evidence. In Canada, the more influential stories surrounded scientific proof in support of particular interventions for autism. In other words, whereas the predominant narrative on the theme of scientific proof surrounds causality in the United States, in Canada narratives tended to center on the concept and goal of a cure.

Autism is not a disease in the traditional sense of the word. In fact, many adults with autism (and quite a few other autism policy stakeholders) in both Canada and the United States take significant offense at this characterization (see, for example, the Autistic Self Advocacy Network at [www.autisticadvocacy.org](http://www.autisticadvocacy.org)). After all, the concept of a disease suggests wholly undesirable condition. It also implies an anticipated downward trajectory of functionality. Finally, a disease is often something a person catches, not a fundamental element of his or her personhood.

In both Canada and the United States, the elements of a disease narrative were invoked. They were not, however, fully embraced. As discussed above, in the United States, thimerosal was sometimes identified as the villain in the metanarrative of the autism epidemic by groups

such as Safeminds. Since childhood vaccines have been considered by policymakers, medical professionals and much of the general public to have been one of the greatest public health achievements of the twentieth century, this plot point of the story relatively quickly became divisive and politically counter-productive (Kirby, 2006). To become successful, proponents of the narrative became focused on the concept of epidemic growth itself. The epidemic narrative was also employed in Canada, though not as a metanarrative. In Canada, the question of contagion was largely sidestepped and the epidemic concept was present in legislative discourse as part of stories about treatment, including what (if any) treatments are necessary and the attempt to establish a treatment favored by some policy entrepreneurs as the most scientifically proven. Whereas the stories of both Canada and the United States depend on a starting point that characterizes autism as a disease, the stories diverge with regard to the middles and ends found most compelling.

This comparative study reinforces the importance of understanding the context in which narratives emerge and unfold. In Canada, the emphasis was on federal funding for intervention. In the United States, the narratives focused on what the federal government could do in the absence of national healthcare, such as regulate vaccines and fund research. These so-called medically necessary and scientifically proven stories, so crucial to the efforts in Canada to provide treatment for individuals with autism, were not the focus in the United States. The Canadian federalism metanarrative and the United States epidemic metanarrative were influenced as much if not more by the specific structures of government of the two countries as they were by the challenges presented by autism. As such, this history presents a useful reminder of the role of social construction in the creation of disability. It also demonstrates how the unfolding of the same scientific process can motivate markedly different policy outcomes in even quite similar democratic contexts.

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**Trudy Steuernagel** was a political science professor at Kent State University. Dr. Steuernagel passed away in February 2009. She is deeply missed and fondly remembered.

#### References

- Anderson, C. (2006, November). *Federal Government Announces New Autism Initiatives*. Retrieved from [http://www.communitylivingonctario.ca/Daily\\_News/2006/November/November24.htm](http://www.communitylivingonctario.ca/Daily_News/2006/November/November24.htm)
- Autism Society of America. (2004). *ASA Statement on May 2004 IOM Report on Vaccines and Autism*. (2004). Retrieved from <http://www.autism-society.org/site/PageServer?pagename=mmrvaccine>

- Autism Speaks (2010). Policy Statement on Mercury and Autism. Retrieved from [http://www.autismspeaks.org/press/mercury\\_autism\\_policy\\_statement.php](http://www.autismspeaks.org/press/mercury_autism_policy_statement.php).
- Baker, D.L., & Stokes, S. (2007). Brain Politics: Aspects of Administration in the Comparative Issue Definition of Autism-Related Policy. *Public Administration Review*, 67(4), 757-767.
- Baker, D.L. (2008). Issue Definition in Rights-Based Policy Focused on the Experiences of Individuals with Disabilities: An examination of Canadian Parliamentary Discourse. *Disability & Society*, 23(6) 571-583.
- Barton, D. (2006, December 6). Statement on S. 843 as Amended, the "Combating Autism Act." Retrieved from [http://www.autismspeaks.org/press/statement\\_on\\_combating\\_autism?act.php](http://www.autismspeaks.org/press/statement_on_combating_autism?act.php).
- Burton, D. (2008). Statement in Support of Combating Autism Act. Retrieved from [http://www.house.gov/burton/Issues/autism/support\\_of\\_combating\\_autism\\_act.htm](http://www.house.gov/burton/Issues/autism/support_of_combating_autism_act.htm).
- Bridgman, T., & Barry, D. (2002). Regulation is Evil: An Application of Narrative Policy Analysis in Regulatory Debate in New Zealand. *Policy Sciences*, 35, 141-161.
- Canada Votes 2006: Riding Talk (2006). Retrieved from <http://www.cbc.ca/canadavotes/ridingtaking/2005/11/019.htm>.
- Canada Health Care Act Annual Report 2008-2009. Retrieved from <http://www.hc-sc.gc.ca/hcs-sss/pubs/cha-lcs/2009-cha-lcs-ar-ra/index-eng.php>
- Centers for Disease Control (2008). Retrieved from <http://www.cdc.gov/ncbddd/autism/index.htm>.
- Commission on the Future of Health Care in Canada. (2002). *Medically Necessary: Who Decides? What is it?* Retrieved from [http://www.hcsc.gc.ca/english/pdf/romanow/pdfs/Medically\\_Nec\\_eng.pdf](http://www.hcsc.gc.ca/english/pdf/romanow/pdfs/Medically_Nec_eng.pdf)
- "Cure Autism Now and Autism Speaks Praise the Swift Approval of the Combating Autism Act by United States Senate," December 7, 2006. Retrieved from [http://www.autismspeaks.org/press/senate\\_combating\\_autism\\_act\\_php](http://www.autismspeaks.org/press/senate_combating_autism_act_php).
- Enzi, M. (2007, September). *Executive Summary of the Report of the Ranking Member on Alleged Misconduct by Government Agencies and Private Entities Related to Thimerosal in Childhood Vaccines*. Retrieved from [http://help.senate.gov/Min\\_press/autism.pdf](http://help.senate.gov/Min_press/autism.pdf).
- F.E.A.T. BC. (2010). History of FEAT. Retrieved from [http://www.featbc.org/history\\_of\\_feat/](http://www.featbc.org/history_of_feat/)
- Fischer, F. (2003). *Reframing Public Policy: Discursive Politics and Deliberative Practices*. New York: Oxford University Press.

- Health Canada (2006). Federal Autism Initiatives. Retrieved from [http://www.hc-sc.gc.ca/a-hc-asc/media/nr-cp/-2006/2006\\_111-eng.php](http://www.hc-sc.gc.ca/a-hc-asc/media/nr-cp/-2006/2006_111-eng.php).
- Imus, D. (2006, December 18). Letter to the Editor. *Newsweek*. Retrieved from <http://newsweek.com/id/44148/page/8>
- Kaplan, T. (1986). The Narrative Structure of Policy Analysis. *Journal of Policy Analysis and Management*, 5(4), 761-778.
- Kirby, D. (2006). *Evidence of Harm: Mercury in Vaccines and the Autism Epidemic*. New York: St. Martin's Press.
- The Learning Disabilities Association of Canada. (2008). *LD and the Law*. Retrieved from [http://www.Idac-taac.ca/LDandtheLaw/casesAuton\\_Law-e.asp](http://www.Idac-taac.ca/LDandtheLaw/casesAuton_Law-e.asp)
- The Lovaas Institute (2010). Retrieved from <http://www.lovaas.com/research.php>
- Lynch, P. (2006). *Canada Votes 2006: Riding Talk*. Retrieved from <http://www.cbc.ca/canadavotes/ridingtalk/2005/11/019.html>
- Miller, D. (2009). *Best Practices in School Neuropsychology: Guidelines for Effective Practice, Assessment, and Evidence-Based Intervention*, Hoboken, New Jersey: John Wiley.
- Morrow, E. M., Yoo, S.-Y., Flavell, S. W., Kim, T.-K., Lin, Y., Hill, R. S., . . . Walsh, C. A. (2008). Identifying Autism Loci and Genes by Tracing Recent Shared Ancestry. *Science*, 328(5886), 218-223.
- Roe, E. (1994). *Narrative Policy Analysis: Theory and Practice*. Durham, NC: Duke University Press.
- Scott, A. (2006). *Canada Votes 2006: Riding Talk*. Retrieved from <http://www.cbc.ca/canadavotes/ridingtalk/2005/11/019.html>
- Senate Committee on Health, Education, Labor and Pensions. (2006). *Report to Accompany S.843 Combating Autism Act of 2005*. Retrieved from <http://www.gpo.gov/fdsys/pkg/CRPT-109srpt318/html/CRPT-109srpt318.htm>.
- Senate Standing Committee on Social Affairs. (2007). *Final Report on: The Enquiry on the Funding for the Treatment of Autism PAY NOW OR PAY LATER Autism Families in Crisis*. Retrieved from <http://www.parl.gc.ca/39/1/parl>
- Shapiro, Joseph (2011). *No Pity: People with Disabilities Forging a New Civil Rights Movement*. New York: Random House.



- Smith, R. (2004). "Is Autism Prevention Government Policy?" Retrieved from [http://www.sentex.net/~nexus23/tap\\_red.html](http://www.sentex.net/~nexus23/tap_red.html)
- Toronto Partnership for Autism Services (TPAS) (2008). Welcome to Toronto Partnership for Autism Services (TPAS)--Intensive Behavior Intervention (IBI). Retrieved from <http://www.autism.net/content/view/97/260/>
- Twachtman-Cullen, D. (2006). *Suzanne Wright Takes on Autism*. Retrieved from Autism Spectrum Quarterly website, <http://www.asquarterly.com/articles/asq9excerpt.html>
- Twyman, K. A., Maxim, R. A., Leet, T. L., Ultmann, M. H. (2009). Parents' Developmental Concerns and Age Variance at Diagnosis of Children with Autism Spectrum Disorder. *Research in Autism Spectrum Disorders*, 3(2) 489-495.
- Volkmar, F. R., C. Lord, A. Bailey, R. Schultz, & A. Klin. (2004). Autism and Pervasive Developmental Disorders. *Journal of Child Psychology and Psychiatry* 45(1) 135-170.
- White House. (2006). *Fact Sheet: Combating Autism Act of 2006*. Retrieved from <http://www.whitehouse.gov/news/releases/2006/12/print/20061219-3.html>

#### Notes

<sup>1</sup> Examples can be seen online at [www.neurodiversity.com](http://www.neurodiversity.com) and [http://www.sentex.net/~nexus23/naa\\_02.html](http://www.sentex.net/~nexus23/naa_02.html).

<sup>2</sup> For more information on grand or master narratives see, for example, John Harley Warner, "Grand Narrative and Its Discontents: Medical History and the Social Transformation of American Medicine," *Journal of Health Politics, Policy and Law*, 29(4), 757-780.

<sup>3</sup> Only the executive summary was released. The full report was not made available to the public.

<sup>4</sup> A series of television commercials incorporating the 1 in 166 aired during this time. Interestingly, incidence figures at the time to 1 in 150, a figure Autism Speaks utilizes on its website and in public service announcements.