

Brain Politics: Aspects of Administration in the Comparative Issue Definition of Autism-Related Policy

Procedural and Institutional Change: Four Perspectives from Abroad

The construction of public problems has a lasting influence on implementation in a given policy subsystem. National and sociopolitical contexts influence issue definition differently across nations. However, the degree to which nation-specific issue definition takes place has been insufficiently explored. In recent years, the growing incidence of autism has led to a quest for causal factors. One hypothesis posits that the use of mercury in vaccines may be a culprit. This paper examines the definition of the mercury and autism issue in Australia, Canada, the United Kingdom, and the United States. Insights into the comparative elements of issue definition are suggested by the case. These insights are of particular importance to administrators, as agencies are deeply involved as objects and actors in the process of issue definition and are often responsible for implementing new and redefined policies.

(hereafter referred to collectively as autism) and mercury is examined. A well-publicized surge in autism has been recorded by many nations since the mid-1990s (Bertrand et al. 2001; Chakrabarti and Fombonne 2001; Cowley 2003). Even the most conservative estimates report that the recorded incidence of autism has grown from 1 in 10,000 to 1 in 500 over the course of the last generation (Bargerhuff 2003; Simpson 2003). This incidence is most often recorded by government agencies in the process of administering civil rights–based policies to provide services for individuals with disabilities. As a result of this growth in the incidence of autism, agencies administering programs that address the needs associated with disability in children are facing continually changing demands for services for children with autism.

The framing of an issue is a political exercise rather than a self-governing natural phenomenon. Whether framing is discussed in terms of paradigmatic shifts (Kuhn 1996), agenda setting (Kingdon 1997), or issue or problem definition (Baumgartner and Jones 1993; Cobb and Elder 1972; Tarry 2001), few who are involved in public policies and programs would argue that there is only one way to define an issue or that issue definition is irrelevant to the rest of the policy process, up to and including implementation. However, there is often a consensus within a cultural context that there are “correct” ways to define an issue (Baumgartner and Jones 1993). As governance becomes a more international concern and administration a more consciously comparative exercise, international issue definition processes become relevant to both domestic governance and public policy in a global context (Kamat 2003; Mishra 1999).

In this paper, the case of the ongoing issue definition for autism and related disorders

Though autism’s cause remains a mystery, one of the more contested theories has been that at least part of the autism baby boom is a result of the use of thimerosal, a mercury-based preservative, in vaccines given to children under the age of two.

This rise in the incidence of autism has called attention to the fundamental epidemiological concern of causality. Though autism’s cause remains a mystery (Fombonne 2003; Szatmari 2003), one of the more contested theories is that at least part of the autism boom is a result of the use of thimerosal, a mercury-based preservative, in vaccines given to children under the age of two (Burton and Waxman 2003; Fisk 2002; Lathe and Le Page 2003; Madsen, Hviid, and Vestergaard 2003). This proposition and the related scientific evidence appear to have been differentially addressed by nations. The central questions of this

study are as follows: (1) To what degree has issue definition in this case been nationally specific? (2) To the degree that issue definition has differed among nations, how have the construction and management of scientific evidence been politicized in different sociocultural contexts? (3) What roles are government agencies expected to play in the administration of responses to the unfolding of scientific evidence?

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Comparative Issue Definition

Public policy, when in written form, is most often expressed in heavily negotiated documents (Hill 2003). The formulation of public policy often involves some level of compromise between competing interests. Before interests compete, however, they first must be determined and delineated in ways that represent the “most salient concerns of previously legitimized political forces” (Cobb and Elder 1972, 10). A given force’s level of success at defining an issue is connected to its ability to achieve desired policy outcomes (Baumgartner and Jones 1993; Tarry 2001). Issue definition includes the competitive construction of defining aspects of the issue, such as causal explanations, stakeholders, policy images, policy myths, and the assignment of blame, as political problems tend to require villains (Tarry 2001). As a result, issue definition influences the administrative behavior of agencies within a given policy arena.

The engines of democracy require energy to run. Much democratic energy stems from discontent, thus stimulating the mobilization of resources. Because issue definition structures competition around a social concern, it is a manifestation of the power that fuels the rest of the policy process, including the implementation and administration of programs. According to Tarry, “Raw political power, whether it comes from financial resources, membership, or political connections, is seemingly less important than the way in which an issue is defined and how the policy debate is structured” (2001, 571). The way in which an issue is defined determines the constraints of discussion, but also, as Ringquist and Clark explain,

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How an issue is defined ... determines the policy subsystem within which policy decisions are made. The policy subsystem in turn helps to determine which participants have access to policy decisions, and the relative power of those participants. Moreover, redefining an existing policy issue can radically alter or even demolish policy subsystems, instigate significant changes in the magnitude and distribution of budgetary resources devoted to the policy and precipitate substantial changes in legislation. (2002, 357–58)

These elements of issue definition shape the possibilities for and limitations of the implementation of programs for issue stakeholders. Furthermore, these elements tend to be connected with the way in which administrators think about programs because they are issue stakeholders who are deeply involved in ongoing conversations with the policy subsystem.

The articulation of national influence within the context of globalization is a prevailing concern of the modern era. The preponderance of discourse surrounds the traditional axes of national influence: combat and commerce (Kaplan 2002; Naim 2002; Hoffman 2002). Nevertheless, the expression of national power in other aspects of the human condition is also of concern (Mulcahy 2002; Hedley 1998). Democratic governance is a learned activity. Best practices are shared across national borders, especially when professionals or administrators are directly involved in the construction and delivery of publicly provided services. Therefore, the differentiated definition of social issues is an intriguing expression of national influence.

Disability policy offers a fruitful arena from which to draw informative cases of modern issue definition in social policy. Because of improvements in modern medicine, revised diagnosis standards, increased efforts to educate the general public, environmental pollution, increased life expectancy, and warfare, more people are disabled in most societies than at any other time in modern history (Smart 2001). Perhaps more importantly, however, during recent decades, the disability policy arena has been recast as a rights-based arena (Jeon and Haider-Markel 2001). This international change is in tension with the construction of

a disability definition that has traditionally varied significantly among cultures, with differing social requirements and conceptions of human ability (Reinders 2000). Issue (re)definition in the disability policy arena is inspiring programmatic changes resulting from the punctuated equilibrium that recreated disability policy and programs as predominantly civil or human rights–based. Cases drawn from the disability policy arena are therefore sufficiently malleable and bounded enough to offer lessons with potentially generalizable insights into the international comparison of the administration of issue (re)definition.

Methodology

This paper examines how the potential role of the mercury-based preservative thimerosal in the recorded growth in autism incidence has been defined as a public issue in Australia, Canada, the United Kingdom, and the United States. This sample of countries was selected for two reasons. First, in the examination of issue definition, it is helpful to compare countries with a common language and relatively similar systems of government. Second, these countries are a somewhat representative sample of the disability policy arena, in which it is being recast as a rights-based issue.

This study employs a methodology similar to the one used by Baumgartner and Jones (1993) in their study *Agendas and Instability in American Politics* and in their ongoing Policy Agendas Project. The basics of the method have been previously replicated (see, e.g., Jeon and Haider-Markel 2001). According to Baumgartner and Jones, in the study of issue definition,

We use media indicators to note the degree to which an issue is on the broad public agenda and to assess the tone of elite understanding at a given time. We use a variety of governmental and other sources to trace the rise and fall of the same issue on the agendas of a number of institutional venues of policymaking. (1993, 50)

In order to accommodate the comparative focus of this study, we have modified the methodology to include more analysis of the full text of sources. This was both possible and necessary because of the relatively short and volatile history of the autism and mercury issue.

First, government sources were collected using searches of legislative hearings, committee hearings, legislative requests for written answers, and bills from the federal level of government. The federal-level repositories were searched for references to thimerosal, its alternative spellings (thiomersal, thimerosol), and its brand name, Merthiolate. The legislative information was catalogued by date, primary topic, and venue. It was then reviewed for the definition of the public problem, the positions taken by players, the stakeholders involved in the process, and policy proposals made in the course of the legislative conversation. Representative quotations were also recorded. This information was systematically catalogued, coded, and compared across the countries in the study.

To collect the sample of newspaper articles, searches of leading newspaper Web sites and repositories for newspaper articles were conducted using the keyword “thimerosal” and its variants. This single keyword was used to generate the media sample because of the large amount of autism coverage and because the preservative itself is the lightning rod around which the issue can be defined in all countries, regardless of their extant disability policy infrastructure or system of public health. The American spelling, thimerosal, was

increasingly seen in British documents as time passed and as more references to American practices were made.

Next, the sample of newspaper articles generated through this search was refined. Some snowball sampling was used to ensure a more broad-based capture of discourse. Articles that did not address the specific topic of autism and mercury were removed from the sample (e.g., articles advertising opportunities to receive flu shots that listed thimerosal as an allergen). As might be expected given the sheer number of media outlets, more than three times as many articles were found in the United States than in any of the other countries. Table 1 shows the number, date range, modal, and median dates of the articles (listed by month, date, and year).

The timing of the articles suggests that the issue is slightly more mature in the United States than in the other countries in the study. Also, because the issue is not settled in any of the countries, articles are still being generated on the issue. However, the press coverage does not seem to have taken off in Australia as much as in the other countries (especially given the relatively early median date of the articles). Finally, the late median date in Canadian press coverage suggests that the issue may be heating up. One interesting aspect of the Canadian media coverage is that the majority of recent articles discuss or respond to a study released by the University of Rochester involving brain cells and mercury that was absent from the press in the United States and the United Kingdom, at least in the short term.

Each title was coded for indicators of issue definition and for the presence of research and evidence. The coding scheme is described in table 2.

The position of an issue on the public agenda depends on the degree to which it has been defined as an urgent concern in public discourse (Kingdon 1997). Therefore, two categories focused on the urgency of concern, and two others related to the public management of scientific evidence. These first two categories (urgency of concern and causal link) required subjective interpretation associated with a scale (compared to the yes/no coding of a binomial category) because coders were required to judge the intent rather than just the presence of references to the issue. Therefore, each title was coded by three

Table 1 Media Sources

Nation	Number of articles	First Mention	Final Mention	Modal date(s)	Median date
Australia	12	4/18/2001	2/9/2004	11/27/02 (2 articles)	6/14/02
Canada	75	3/2/2000	2/15/2004	2/6/04	1/1/04
United States	256	7/8/1999	2/16/2004	11/13/03 (13 articles)	3/5/03
United Kingdom	70	1/5/2001	2/6/2004	6/19/03 (3 articles)	5/15/03

Table 2 Title Coding Scheme

Indicator	Coding scheme
Urgency of concern	5 Emergency (action must be taken immediately) 4 Urgent concern (action must be taken soon) 3 Moderate concern (action is needed, attention must be given immediately) 2 Concern (action is possibly needed, attention must be given soon) 1 Mild Concern (attention should be given sometime) 0 Not a concern
Causal link	0 No comment on link between autism and mercury in vaccines 1 States link exists 2 Suggests link could exist 3 Suggests link does not exist 4 States link does not exist 5 Balanced—refers to link but does not take sides
Government action	0 Does not mention government activities or officials 1 Mentions government activities or officials
Federal agency	0 Does not mention a federal agency 1 Mentions a federal agency
Executive branch	0 Does not mention the executive branch of government 1 Mentions the executive branch
Legislative branch	0 Does not mention the legislative branch or specific members 1 Mentions the legislative branch or specific members
Courts	0 Does not mention courts or judicial activity 1 Mentions courts or judicial activity
Subnational government	0 Does not mention state, provincial, regional or local activity 1 Mentions state, provincial, regional or local activity
Elections	0 Does not mention candidates or elections 1 Mentions candidate or elections
Interest groups	0 Does not mention specific, organized interest groups 1 Mentions specific, organized, interest groups
Experts	0 Does not mention expert or researcher 1 Mentions an expert or researcher
Study	0 Does not mention a study, research, or report 1 Mentions a study, research, or report

individuals with graduate training in political science or public affairs. Coders were given detailed instructions, did not discuss the coding process with one another, and did not know the date or country of origin of the titles. The other categories were coded by the authors.

The full text of a subset of articles was also coded. The subset was based on availability and designed to be representative of the full sample of articles. In coding the media articles, the date of publication, journalist, outlet, article length, references to other nations, presence of specific scientific evidence, quotes from believers, quotes from nonbelievers, definition of causal link, the articulation of blame, and any mention of other countries were recorded.

Results

Legislative Material

The goal of examining information generated by the legislative branch of government is to analyze the presence of an issue on the agendas of the institutional venues of policy making. Thimerosal appeared on the national legislative agendas of Canada (first found in February 2003), the United Kingdom (first found in March 2000), and the United States (first found in August 1999). At the federal level at least, the issue appeared most often on the institutional agendas of the United States and the United Kingdom. The

majority of the appearances were in the later years, with the number approximately doubling each year.

A search of federal congressional hearings in the United States between 1998 and 2004 for the word “thimerosal” returned 49 hits. The testimony included activity in the House Government Reform Committee, the House Judiciary Committee, the Senate Governmental Affairs Committee, and the Senate Health, Education, Labor, and Pension Committee. The hearings took place between August 1999 and October 2003. The majority of the testimony was given before the House Committee on Government Reform, whose chair, Representative Dan Burton (R-IN), has a grandchild with autism. There was also a rider to a homeland security bill that specifically limited mechanisms by which families could sue vaccine manufacturers for the use of thimerosal; this measure was subsequently repealed. In addition, several states—including Iowa, Missouri, Nebraska, Oregon, and Texas—passed or considered bills designed to restrict or eliminate the use of thimerosal in vaccines as early as 2001.

The topic of the committee hearings was not always specifically thimerosal or autism. For example, on September 26, 2002, the House Committee on Government Reform held a hearing on the overmedication of hyperactive children. During this hearing, thimerosal was first brought up by Burton approximately

halfway through the hearing. Burton discussed having educated doctors who could inform members of Congress about the presence of mercury in vaccines. According to Burton, he told the doctor, “Thimerosal contains mercury. [It] has never been properly tested since 1929. It was tested in 27 people who all were dying from meningitis. All of them died. And so they say that the mercury didn’t cause it.” The discussion went on to define the issue as a lack of accurate information in the medical community and a too-slow removal of vaccines containing thimerosal. Similarly, on April 8, 2003, thimerosal was discussed by the House Judiciary Committee, which described the challenge of handling an expanding caseload of individuals making claims under the Vaccine Injury Compensation Program (there was a reported fourfold increase in these claims in fiscal year 2002).

Other hearings focused specifically on thimerosal and vaccines. For example, on June 12, 2002, the Senate Committee on Governmental Affairs held a hearing on the causes of vaccine shortages. A subsequent hearing before the Senate Health, Education, Labor, and Pensions Committee focused on shortages of childhood vaccines. At this hearing, the issue was presented as one in which vaccine makers were being forced out of the market as a result of thimerosal restrictions. Just one week later, on June 19, 2002, the House Government Reform Subcommittee held a hearing on the status of research into vaccine safety and autism. The issue at this hearing was defined as a trial of vaccines as the cause of an epidemic in autism. In December 2002, Burton defined the issue by saying, “We have an epidemic on our hands—and we can’t just stick our heads in the sand. We have an epidemic and nobody knows what’s causing it. What troubles me most is that there doesn’t seem to be a great sense of urgency to get to the bottom of this.” In November 2002 and October 2003, the same committee also held hearings on the use of mercury in dental amalgams. During this hearing, concerns about neurological damage as a result of mercury exposure were more widely discussed.

Altogether, 20 separate references to thimerosal were found in the activity of the legislatures in the United Kingdom. The issue was also discussed in the Scottish Parliament. For the most part, discussion was in the form of requests for written answers submitted to the record by members of the House of Commons and the House of Lords and subsequent answers to the questions. The earliest question found was specific to the amount of thimerosal in vaccines, although the topics expanded somewhat over subsequent years. Some testimony accompanied the written questions, such as the account by Lord Hodgson of Astley Abbots before the House of Lords, in which he made reference to the experiences of his son with attention deficit and hyperactivity disorder.

On February 5, 2003, Lord Hodgson spoke on plans to reduce attention deficit disorder and related conditions. Thimerosal was discussed as a potential contributor to the recorded increases in neurological differences in children. Lord Hodgson discussed answers that he had received to written questions from Lord Hunt of King’s Heath as “less than full-hearted” and not accurately representing the state of scientific evidence. For example, he pointed out that the answer, which cited the U.S. Institute of Medicine’s null findings—which neither proved nor disproved the hypothetical link—was not definitive evidence proving the safety of thimerosal. Lord Hodgson was also careful to point out that, “I must make it clear that this is not an attack on immunisation. Immunisation is an important part of child healthcare. But it is a question of what goes into the vaccines. Thimerosal is not an essential part of a vaccine; its function is as a preservative.”

Thimerosal made one appearance in the Canadian federal legislative discourse during the 35th to 37th federal parliaments (1996–2003). Evidence was presented to the Standing Committee on Health in February 2003. During this session, “the high incidence of autism and concerns about thimerosal or mercury used in vaccines” was discussed as one of a series of concerns about wellness and children. However, thimerosal was neither the topic nor the central concern of the hearing.

Discussion of thimerosal was not found at the national level of the Australian government. Given the limited yet diverse media coverage found in Australia, thimerosal does not seem to have become an issue on either the systemic or institutional agendas in Australia.

Media Information

The titles of 413 articles were coded. The full texts of a subsample of 226 articles were also coded for additional issue-related content. As shown in table 3, the indicators suggest that each nation has uniquely defined the position of thimerosal in vaccines on the policy system and institutional policy agendas. In Australia, the limited evidence suggests that government action has occurred in the legislative branch. The two interests mentioned are broadly cast as a “minority group” in one case and “drug company” in the other.

Canada had the highest frequency of references to both experts or researchers and studies or evidence. Canadian article titles were four times more likely to mention researchers or experts than titles from the United States and twice as likely to mention researchers or experts as those from the United Kingdom. This suggests that in Canada, the issue has been defined as a technical and, to some degree, scientific one.

Table 3 Percentage of Article Titles Mentioning Issue Definition Indicators

Indicator	Australia	Canada	United Kingdom	United States
Government action	16.67	4	8.57	27.63
Federal agency	0	0	4.29	17.12
Executive branch	0	1.37	1.43	1.98
Legislative branch	16.67	1.37	2.86	18.62
Courts	0	17.8	0	20.72
Subnational government	0	4	0	3.56
Elections	0	0	0	4.36
Interest groups	16.67	13.70	10	16.53
Experts/researchers	0	27.4	10	7.39
Study/evidence	0	23.29	2.86	17.12

Canadian titles mentioned government action the least often of any nation in the study. When titles did mention governmental action, it was generally by subnational governments. However, the titles mentioned interest groups or court action relatively frequently (second to the United States) and interest groups about as often as the other nations in the study. This suggests that the issue position on the institutional agenda in Canada has been defined largely in the realm of experts and as an issue of personal injury.

The results in the United Kingdom were generally in the middle range in terms of the frequency with which indicators were mentioned. When articles mentioned governmental action, they were more likely to reference a component of the governmental bureaucracy than either the executive or legislative branch. Interestingly, courts or related action were not mentioned in any titles from the United Kingdom. Interest groups and researchers or experts were mentioned slightly less often than in the United States or Canada. Finally, scientific evidence and studies were mentioned much less frequently than in the other countries.

There were many more articles in the sample from the United States than from the other countries. It is perhaps not surprising, then, that it was only in the titles from the United States that all indicators were mentioned. The thimerosal issue is slightly more mature in the United States than in the other countries. As a result, governmental action surrounding policy implementation was mentioned in more than a quarter of the titles from the American papers. The United States was also the only country for which references to elections were found in the titles, indicating that in the United States, the issue is considered worthy of some attention during campaigns. As in the other countries, the executive branch of government was mentioned far less frequently than the legislative branch and, in the American case, than the courts. Subnational levels of government were mentioned far less often than the federal level. The increased attention did not, however, imply a greater presence of interest groups in the titles.

In addition to these policy indicators, each title was coded for the tone of the title. Two indicators were used for tone: the urgency of the concern presented and the characterization of the causal link between thimerosal in vaccines and autism in children. Because these indicators are more subjective, the titles were coded by three independent coders. The interrater reliability was far from perfect. On the first pass for the urgency of concern, the three reviewers assigned the same score to only 9 percent of the titles. However, the scores assigned were almost always within one point of each other on the five-point scale (the exception to this rule was in the concern link, for which one coder felt that titles suggesting a call to stop action in progress was an urgent concern, whereas the other two interpreted this set of titles as a mild concern). Because the scores were very close to one another, average scores were used. The coders' scores were more strongly correlated on the causal link scale, for which 43 percent of the titles were assigned the exact same value by all three coders. The judgment on which there was great difference was whether the mention of a lawsuit without further commentary in the title suggested a balanced position.

The urgency of concern was found to be different in each nation. The average score for the Australian titles was 0.79, with a standard of deviation of 1.03. The average score for the titles from the United Kingdom was 0.99, with a standard of deviation of 1.21. The average score for Canadian titles was 1.09, with a standard of deviation of 1.27. The average score for titles from the United States was 1.89, with a standard deviation of 1.33. None of these scores was shown to be statistically significantly different, and in general, the titles suggested that the issue was not an emergency or of urgent concern. However, it is interesting to note that in the United States, where the issue is most mature, the urgency of concern is highest, and in Australia, where the issue has yet to truly find a place on the public agenda, the urgency of concern was the lowest.

The causal link taxonomy was not a scale. Score frequencies rather than averages were used for the analysis of this variable. The frequencies (expressed as percentages) of each link score are shown in table 4. In

Table 4 Frequency of Link Scores

Link Score	Frequency Percentage			
	Australia	Canada	United Kingdom	United States
0=No comment	63.3	42.1	43.3	51
1=States link exists	6.7	11.3	11.1	4.6
2=Suggests link could exist	10	19	28.2	21.6
3=Suggests link does not exist	6.7	12.7	4.9	7.7
4=States link does not exist	0	5.4	1.9	8.1
5=Balanced—refers to link but takes no position	13.3	9.5	10.7	7.2

the analysis of agenda setting, media sources were examined for “the degree to which an issue is on the broad public agenda and to assess the tone of elite understanding at a given time” (Baumgartner and Jones 1993, 50). In each country, close to half the titles made no reference to the link between thimerosal in vaccines and autism, and another 10 referred to the link but did not take a position on it. However, titles that took a position tended to state or suggest that a link between thimerosal in vaccines and autism existed. This was especially true in the United Kingdom, where nearly 40 percent of the titles suggested or stated such a link.

The full texts of the representative sample of 226 articles were also reviewed and coded. The binomial content variables, for which the full texts were coded, included the discussion of scientific evidence, the mention of other countries, the presence of quotations from those who believe a causal link exists, the presence of quotations from those who do not believe a causal link exists, and the discussion of parents’ or children’s rights. In each case, a value of 1 was assigned if the reference existed and 0 if it did not. The length (in words), article focus, characterization of the causal link, definition of the problem, and assignment of blame (if any) were also noted for each article.

The percentage of articles coded for full text, in which the variables coded as binomials were mentioned, is displayed in table 5. Australia is excluded because of the limited number of articles.

The failure to reference other countries might be considered an indicator of independent issue definition. It is perhaps not surprising that articles from the United States were far less likely to cite other coun-

tries. When the articles did include references to other countries, it was exclusively references to studies that contributed evidence disproving the link between thimerosal in vaccines and autism. Policy decisions or activities from other countries were never mentioned in the American papers. Canadian articles very frequently cited the United States, particularly studies done in the United States, but also less frequently making reference to specific policy decisions or administrative actions. Canadian articles were more likely to include quotations from stakeholders on both sides of the issue than the articles from other countries.

Articles from the United Kingdom referenced American studies and policy decisions, as well as studies conducted in the European Union. Furthermore, only articles from the United Kingdom addressed the general question of why that nation was behind other countries. Articles from the United Kingdom were far more likely to characterize the problem as a governmental failure and to place the blame on government inaction. In the texts of the Canadian articles, the blame was not placed on individuals or administrative actions, but more often was characterized as either a fear of the unknown, the spread of misinformation, or the lack of clear scientific evidence. The characterization of the problem and the placement of blame was most diffuse in articles from the United States, in which actors such as lawyers, drug companies, activist parents, the Republican Party, or administrators of public programs were all blamed at one time or another. The public problem was most often characterized as bad politics (particularly with the Homeland Security Act rider), a failure to weigh risks accordingly, an undue slowness in the removal of thimerosal, or hysteria on the part of parents or the general public.

Table 5 Percentage of Articles with Content Variables

Content Variable	Percentage of Articles		
	Canada	United Kingdom	United States
Scientific evidence	83	41	43
Other countries	92	74	22
Parents’ or children’s rights	0	10	4
Quotations from causal link believers	79	53	51
Quotations from causal link nonbelievers	83	63	39

Discussion

The potential connection between the use of thimerosal in vaccines and the rise in the incidence of autism has been differentially defined as a social policy issue in (at least) three of the countries examined in this study. It does not appear that enough public attention has occurred in Australia for the issue to reach the public agenda at either the systemic (public concerns) or the institutional (formal government agendas) level. In Canada, the issue appears to have been defined on the systemic level rather than the institutional level, making the reaction to the issue definition a nearly exclusive administrative challenge. That is, the issue was more a general concern in the context of the implementation of existing policy than an issue to be addressed by immediate legislative action or new policy. Nevertheless, federal agencies were mentioned least often in the titles of Canadian articles (and most often in titles from the U.S. press). This likely reflects the fact that the administration of health care has become more of a provincial responsibility in the past decade, suggesting that this particular issue is not defined as a disability policy issue in Canada (i.e., civil rights based).

Issue definition in the United Kingdom has focused on government action, particularly on the perception of some stakeholders that the issue is moving slowly in the United Kingdom compared to other countries in the European Union and the United States. Articles from the United Kingdom tended to characterize U.S. action as more definitive than was perceived in the United States. For example, in October 2002, the *Times* of London reported, "In the U.S., large payments are being made to children damaged by thiomersal, the mercury preservative used in the U.S. (though not in the UK) version of the MMR [measles, mumps, and rubella] vaccine. More than \$1 billion has been paid out under the National Vaccine Injury Compensation Programme, established in 1986 by U.S. Drug Companies and the government" (Cavendish 2002). This system of "vaccine courts"—for purposes of awarding compensation for vaccine-related injury—was portrayed as either insufficient (by believers in the link) or relatively inconsequential (by nonbelievers) in American discourse. The *Times* reported in May 2003, "The anti-Thimerosal chorus has reached such a crescendo that some predict that it will become a key issue in the 2004 presidential campaign" (Ayles 2003). The *Scotsman* also reported in January 2003, "In the U.S., it is a huge storm involving congressmen, medics, some £30 billion in lawsuits and a cover-up that has left Washington mystified. But in the

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UK, the storm has yet to break" (Nelson 2003). No indigenous references to the issue characterized it as anywhere near as important or urgent.

The way in which the issue has been defined speaks to the public management of scientific evidence, particularly in the administration of programs and implementation of policy. At the time of this discourse, the available scientific evidence regarding the hypothetical link between thimerosal and

autism was inconclusive (Burton and Waxman 2003; Fisk 2002; Lathe and Le Page 2003; Madsen, Hviid, and Vestergaard 2003). One response to this inconclusive evidence has been an effort on the part of those who do not believe the evidence supports a causal link to recharacterize the issue as an opposition to vaccinating children at all. For example, in December 2002, *USA Today* reported that "a core group of American parents is convinced that the vaccines given to babies today play a role in the development of autism and a host of other ills. Mainstream medical experts, backed by reams of scientific studies, say that vaccines are generally safe and that they protect children from deadly diseases with few, if any, negative side effects" (Manning 2002).

Articles from other countries have also discussed the issue in terms of a choice about whether to vaccinate and a failure on the part of some parents to effectively weigh risks. For example, the *Glasgow Herald* reported on May 21, 2003:

The World Health Organisation's Global Advisory Committee on Vaccine Safety has concluded that there is no evidence of toxicity in infants, children, or adults exposed to thiomersal (containing ethyl mercury) in vaccines. Accordingly, advice from the WHO makes clear that the risk of death and complications from vaccine-preventable diseases is real, compared with the theoretical risk of side effects of thiomersal. The childhood immunisation program reflects this balance. (Fraser 2003)

An October 2002 *Maclean's* article quoted the chair of the Canadian Pediatric Society's Infectious Diseases and Immunization Committee with an even dimmer view of how those who believe the link weigh risks: "If you are worried about something that is roughly the equivalent of Elvis showing up on your doorstep, as opposed to the real risk of disease ... then I get upset" (Hawaleshka 2002). This definition has persisted despite ardent statements on the part of many who believe in the possibility of a link and still favor

vaccination in general. In fact, the vast majority of vaccines throughout the countries in the study are available without thimerosal.

The interpretation of null findings is also an intriguing aspect of the public management of scientific evidence. In October 2001, the Institute of Medicine of the United States published a report discussing the available scientific evidence on the causal relationship between thimerosal and autism. The report had a null finding—the hypothesis could neither be proved nor disproved. It went on to state that the connection was “biologically plausible.” The interpretation of this phrase differed not only by stakeholders (it was emphasized by believers and ignored by disbelievers) but also by country. Articles from the United Kingdom tended to present biological plausibility as more conclusive. Excerpts from editorial articles written by public health professionals in the United Kingdom and parents in the United States stated that the biological plausibility was a reason to take thimerosal out of vaccines in United Kingdom and a foolish reason for having removed the preservative in the United States.

One uniquely American take on the issue was the issue of homeland security. A rider, mysteriously added to a homeland security bill at the last minute, redefined ingredients in a vaccine’s product-license application or product label as part of the vaccine, thus requiring families to first seek damages through the National Vaccine Injury Compensation Program (Frisk 2002). Because of the short statute of limitations authorized under the program, many families would not be able to seek damages at all. As one article from the *Las Vegas Review-Journal* in October 2003 described it, “The logic, apparently, is that America needs her vaccine manufacturers to respond to the supposed threat of bio-terrorism, so anything that protects vaccine manufacturers from the inconvenience of being sued ... helps fight terrorism” (Suprynowicz 2003). The article goes on to point out that vaccines used for biological warfare cannot contain thimerosal because they contain live viruses. The *Wall Street Journal* also reported on December 29, 2003, “For any parent, there are few more traumatic diagnoses than that a child suffers from autism. But the increasing attention to that affliction is having the unintended consequence of limiting vaccines for all children.” The link between homeland security and thimerosal was highlighted as a point of origin of the issue’s place on the systemic agenda of many stakeholders.

Conclusion

In 1997, Bruce Willis starred in the film *Mercury Rising*, in which a young boy is pursued by unscrupulous government agents bent on keeping him from revealing secrets unwittingly unmasked by his autistic brain. The real-life story of mercury and autism is a

less formulaic and not so clean-cut battle between good and evil. The messier real-life story, however, presents an opportunity for comparative issue definition and suggests that the issue is occurring with similarities among countries but not without clearly nationalistic characteristics. Nevertheless, the fact that the United States was mentioned more often in the discourse of other nations, whereas the experiences of Australia, Great Britain, and Canada were rarely mentioned in American public discourse, may be interpreted as cultural favoritism. Decisions about scientific evidence made by the National Institutes of Health and the U.S. Food and Drug Administration were cited particularly often in the British press.

As Cobb and Elder pointed out decades ago, the effect of government policies and programs is rooted in the agenda-building process surrounding a particular issue (Cobb and Elder 1972, 26). One element of this management of scientific evidence is the presence of the issue on the systemic (i.e., broad social context) with regard to the formal institutional agendas of governing bodies (Cobb and Elder 1972, 14). Especially when an issue is found more predominantly on the systemic agenda, the construction and management of scientific evidence is a key aspect of the implementation of disability policy. This is particularly true of policies that blend program goals focused on service delivery with a philosophical orientation toward the civil or human rights of individuals and families. The issue of thimerosal in vaccines has not been successfully defined as a disability policy issue on the institutional agendas of the countries examined in this study. As a result, the management of responses to the unfolding scientific evidence have remained a predominantly administrative concern, especially in Canada, where the issue has been discussed as most scientifically contested. The management of unfolding scientific evidence is a growing function of modern public administration because of our increased access to information and the unavoidable period of scientific uncertainty between preliminary, intriguing studies and general agreement on more conclusive evidence. The study of this public management of unfolding scientific evidence and its role in the construction of knowledge around a given issue is a promising area for further study.

Though it is always a mistake to overestimate the generalizability or theoretical relevance of a single case, in the study of issue definition, “valuable lessons can be learned about the interaction of various strategies and techniques used to frame or define issues by conducting a thorough and theoretically driven case study” (Tarry 2001, 573). One lesson suggested by this study relates to the nature of policy arenas in democratic systems. As an emerging area of public policy, disability policy is most often understood as being fundamentally connected to individual civil or

human rights. This focus is widely considered a defining element of modern thinking about disability, distinguishing it from older, more paternalistic thinking about disability, which was largely confined to the medical model (Smart 2001; Stroman 2003). Unlike other areas of disability policy, the issue of mercury and autism was very rarely constructed or discussed as a rights-based issue in any of the discourse of the countries in this study. This suggests that the definition of an issue not only tends to reflect national character but also that the definition of new issues may have significant independence from the trend in a given policy arena under some circumstances, such as the administration of programs or policies affecting the population at large, as is the case with childhood vaccination. The examination of the relationship between prevailing philosophies in policy arenas and the definition of new issues is a potentially interesting question for future research.

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