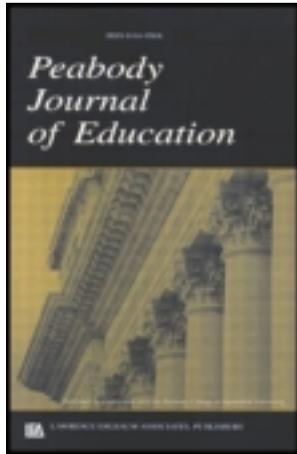


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Autism Advocacy: A Network Striving for Equity

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In this exploratory case study, we examine the rise of autism on the policy agenda and the new generation of autism advocacy. We focus especially on interconnections between the rhetoric about autism in the media and the emergence and political effectiveness of Autism Speaks, the nation's largest autism advocacy group. We portray how influential social actors frame the story of autism and how they have secured policy victories for youth with autism and their families. Whether issue framing affects policy by motivating network collaboration, or whether collaboration affects how social actors frame issues to affect policy is of fundamental concern in our preliminary analyses. We conclude by discussing implications for new research on the framing of the issue and network development.

INTRODUCTION

As a core public value, equity is central in understanding special education in contemporary society. This was not always the case, however. Historically, children with disabilities were stigmatized and left to make it on their own or fail in school, and those with more significant disabilities were altogether excluded from public schools (Biklen, Ferguson, & Ford, 1989). The 1970s era of social reforms, however, put an end to de jure segregation in the education of persons with disabilities. Following the 1970 passage of the Occupational Safety and Health Act and the Vocational Rehabilitation Act of 1973, a monumental federal law passed in 1975, one that guaranteed free and appropriate public education for all children, regardless of the type or degree of their disability (Scotch, 2001). The new law, PL 94-142 (renamed to Individuals with Disabilities Education Act in 1990) grew out of litigation. The legislative language was largely based on two cases, *Mills v. Board of Education* (1972) and *Pennsylvania Association of Retarded Citizens v. Commonwealth of Pennsylvania* (1972). The idea was to push states to enact special education legislation through litigation. Once the Supreme Court ruled in a school finance case in *San Antonio v. Rodriguez* (1973) that the U.S. Constitution did not establish a right to public education, but that education was a matter left to the states, the disability advocates switched their strategy and began to appeal to Congress. They were concerned about the new

precedent, should one of the 27 special education cases rendered or pending across states in 1973 be appealed to the Supreme Court (Melnick, 1995). The enacted law established strong procedural rights for students with disabilities and ensured the involvement of parents in their child's educational program development (Ong-Dean, 2009). The law also guaranteed parents the right to appeal decisions made by school districts in front of an impartial hearing officer, and, if necessary, to appeal that decision through the federal court system if their child did not receive services guaranteed under the law. One could thus argue that student-centered parent advocacy in special education is rooted in the legislative language of a social reform era that expanded the rights of individuals as well as the obligations of society on behalf of people with special needs (Ong-Dean, 2009). There remains some question, however, as to whether equity-based reforms have played out equitably among groups that advocate on behalf of persons with disabilities. This study begins to shed light on this question.

Parents are no longer isolated and on their own in the endeavor to humanize care and services for children with disabilities. Drawing from what is unique about a deeply personal motivation for political activism, parents have organized effectively, under the law, on behalf of various special needs populations. Political activism stemming from such deep personal experience such as having a child with a disability is characterized by high stakes, emotion, and a sense of urgency as new research or public policy can have a direct impact on the person's and family's well-being (Jennings, 1999). Hereafter we refer to such activism as "pain-loss" advocacy.¹ In recent years parents and advocates for children with autism have formed well-networked and resourced advocacy organizations. This cause has sparked a veritable explosion in public concern and is the subject of a great deal of attention regarding autism advocates' outsized success at influencing individuals in the media and in state and federal policymaking circles (Itkonen, 2009).

In this exploratory case study, we bring a new lens to the discussion of special needs groups by focusing on an advocacy organization, Autism Speaks. We targeted autism due to the centrality of the condition on the political agenda. In recent years, there has been a sharp spike in the incidence of autism. For example, the Centers for Disease Control and Prevention (CDC) released a study in 2012 estimating that 1 in 88 children have autism today, the prevalence of which has nearly doubled since 2007. In boys the condition is especially pronounced at 1 in 54 (CDC, 2008). Although evidence for environmental causes is anecdotal, alleged culprits—including heavy metals, pesticides, or childhood vaccines—are under extensive investigation as potential causal agents. Many parents have blamed a mercury-based substance in childhood vaccinations, thimerosal, as the cause for autism. Even though the medical community has produced no evidence to verify this assertion (Grinker, 2007; Madsen et al., 2002; Miller & Reynolds, 2009), in just one year, 2005, parents filed more than 4,800 lawsuits pushing for state and federal legislation to ban thimerosal from vaccinations (Harris & O'Connor, 2005).

Litigation as a policy strategy requires time and resources. Although individual parents may not have the necessary resources, advocacy organizations sometimes "shop" for cases and solicit

¹Previous studies have emphasized how commitments in pain-loss activism differ from conventional political participation, including collective action motivated by an accident (McCarthy & Wolfson, 1996), AIDS (Donovan, 2001), breast cancer (Altman, 1996), disability (Johnson, 1999), or bodily harm due to intentional human action (Sprungen, 1998). We use the term *pain-loss advocacy* for conceptual consistency with the literature on activism stemming from a personal experience, and by no means imply that raising a child with autism is characterized by actual physical pain.

parents to file class action suits (Itkonen, 2009; Melnick, 1995). These pain-loss advocacy organizations and influential social actors have the necessary resources to pursue litigation. Some research suggests that privileged parents are more successful at affecting both their child's education and public policy than are those lacking resources (Ong-Dean, 2009). Yet a growing numbers of families with autism, across social class boundaries and racial/ethnic groups, have become increasingly vocal and visible in the policy arena because autism advocacy organizations are spurring collective action (Itkonen, 2009).

Rather than focusing on how class or race affects autism advocacy, we set our sights on rhetoric and how the media is framing the autism movement.² Specifically, we focus on the interconnections between the rhetoric about autism in the media and the emergence and political effectiveness of pain-loss organizations such as Autism Speaks, the nation's largest autism advocacy group. We also portray how influential social actors—many of whom are affiliated with Autism Speaks—frame the story of autism and secure policy victories on behalf of families with autism. Whether issue framing affects policy by motivating social network collaboration or, alternatively, whether pain-loss collaboration affects how social actors frame the issues to affect policy is a particular interest in our preliminary analyses. Acknowledging limits to the scope of our data, our research cannot infer the kinds of precise predictions we might expect from truly randomized controlled experiments; however, we are able to suggest future frameworks for additional research. We conclude by discussing the implications for new research on the ways in which advocates frame their issues and develop networks.

METHODS

Our research had two phases, beginning with mapping the evolving construction of autism.³ Much of our data in this phase of inquiry consisted of historical documents, including seminal works on autism, which we analyzed using critical reading techniques (e.g., Bettelheim, 1967; Grinker, 2007; Kanner, 1943; Rimland, 1964). We also analyzed versions of the *Diagnostic and Statistical Manual of Mental Disorders (DSM)* on the initial inclusion of autism as a psychiatric disorder and monitored changes over time in the formal clinical definition of autism (American Psychiatric Association, 2000).⁴ As part of mapping the “landscape” of autism interests, we analyzed the *New York Times* as a major print media source that targets a broad public audience. We documented the actual number of *New York Times* articles on autism over a 30-year span, from 1981 to 2010, using the *New York Times* historical database.⁵ We reviewed more than 600 articles from the *New York Times* referencing autism. We did not review editorials or commentary, as these reflect individual views and opinions that might skew our analysis of media representation. To examine

²By “framing” we mean the discourse by which the news media promote narratives to define policy problems. Framing the parameters for how autism will be discussed and how it will *not* be discussed is important because people tend to think in terms of frames and metaphors. Once the framework is accepted into public discourse then “everything you say is common sense” (Lakoff, 2004, p. 115).

³By construction we refer to the way in which autism is being framed by advocates and the media. Edelman (1988) would use the term *social reality* of autism, as opposed to the clinical definition.

⁴*DSM* is the main handbook on psychiatric disorders, initially published in 1952, and is used to diagnose mental and behavioral disorders. *DSM-5* is scheduled to be published in spring 2013 and proposes changes in the diagnosis of autism (Autism Speaks, n.d.-a).

⁵Each article was read to eliminate hits that were position announcements for teaching, clinical work, or administration.

Congressional attention, we used the search capabilities of LexisNexis Academic to identify the number of advocates who testified before Congress during hearings on autism.

We then proceeded to study Autism Speaks as a case study. We chose this organization because it was formed recently, in 2005, and subsequently merged with Cure Autism Now, thus forming the largest advocacy organization for autism both nationally and internationally in just 7 years. We were particularly interested in whether and how issue framing (“the story of autism” according to Autism Speaks) impacted the way in which resourced networks of people joined together to affect changes in autism policy. We were also interested in whether and how people who are well resourced and highly networked can affect how social actors frame autism in order to secure policy victories. In search of framing strategies, we performed content analysis of Autism Speaks’ website and used Congressional hearings to identify not just the frequency of testimony but who had testified and what they had to say. Content or textual analysis methodology treats the content of the sources examined as data, and therefore these data are not cited in the Reference section.

To identify policy victories we used the search capabilities of LexisNexis Academic. Network analysis and the systematic consideration of “who knows whom” consisted of multiple online data sources. First, we utilized a free social network search engine, Muckety.com, to identify individuals who were affiliated with the organization using the search word *Autism Speaks*.⁶ We entered each of the names in the initial and subsequent maps to continue the search on a “snowball” principle, and ended up with a dense network of people and businesses affiliated with Autism Speaks. We then used Google to search for particular individuals we had identified as being linked to the network, and found further connections linking the entertainment industry and Autism Speaks. Finally, we analyzed the composition of the Board of Directors, standing committees, and task forces from the organization’s home page. We shared data and cross-checked codes, and worked on generating alternative interpretations of our findings to support the validity of our interpretations.

FINDINGS: THE CASE OF AUTISM SPEAKS

Autism was initially crudely associated with the notion of a genuine lack of maternal warmth, and chilling labels such as “the refrigerator mom” leveled the blame for autism on ostensibly disconnected mothers (Laidler, 2004). Leo Kanner first introduced the idea in the 1940s. Bernard Rimland challenged this theory in his 1964 book titled *Infantile Autism: The Syndrome and its Implication for a Neural Theory of Behavior*. The book argued that autism was *not* a disorder caused by poor mothering. Rimland saw autism as a biomedical disorder and, after his son’s diagnosis at age 2 in 1958, advocated for early behavioral interventions.

The birth of child psychiatry after World War II was another development that helped change how psychiatrists and doctors diagnosed and defined autism (Grinker, 2007). Psychiatry’s initial emphasis on psychoanalysis identified autism as a disorder of self or the mother. As scientists began to use medical knowledge to study children’s behavior, however, autism became understood

⁶The site uses interactive maps (Adobe Flash) to show networks among people, businesses, and organizations. Influence is measured by actual relationships in the number of direct and once-removed relationships. Social media is not included in reporting networks or influence. For the influence index, the program factors in the importance of first-degree relations, weighing the person’s title. The Muckety database focuses primarily on U.S. business, government, politics, and entertainment.

as a neurological and biological disorder. The Autism Society of America, founded in 1965 by parents (Bernard Rimland, Ruth Sullivan, and others), was the first interest organization for autism, suggesting how parent groups have often been the drivers—not passengers—in special education politics. It started as a support organization advocating for services for families (Autism Society, n.d.).

As applied research began to indicate that autism was a disability involving the social unresponsiveness of the child, a more positive reframing of autism as a disability began to emerge in public discourse. Autism was subsequently added as an eligibility category to IDEA in the 1990 reauthorization, thus increasing the legitimacy of the condition. Based substantially on the power of empirical diagnoses, autism had thus moved from a negatively framed condition attributable to disaffected mothers to a positive one, based on evolving knowledge of science and human development. Still, advocates had relatively low levels of social capital due, in part, to a lack of strategic connections with well-resourced individuals and groups in entertainment, industry, and politics. Autism interests were still lacking a national political voice.

In the 2000s, a new generation of advocacy groups formed around the cause of autism. Cure Autism Now was established in 2003 by the producer of the 1997 American action-thriller film *Air Force One*, Jonathan Shestack, himself a father of a child with autism. Cure Autism Now utilized celebrity connections and media campaigns to advocate for the cause. Two years later, Robert Wright, CEO of NBC Network, and his wife, Suzanne, founded Autism Speaks. Wright also had a personal stake in advocacy—he is a grandparent of a child with autism. Both of these policy entrepreneurs were motivated by a deep personal connection to autism. In an interview with the *Today* show, Robert Wright (2005) stated in emotional terms: “My wife, Suzanne, likens [autism] to a kidnapping, as if someone has taken away the life [our grandson] was meant to live. We all want nothing more than to have him back where he belongs, restored to his family.” In 2006 these two organizations merged, enabling entertainment power-brokers and star-power personalities to foment a cause célèbre on behalf of families and children with autism.

Autism Speaks has conducted large-scale public awareness campaigns to shape the story of autism. To drive the point home, autism advocates now use the term *national health epidemic*, through media campaigns such as “every 20 minutes a child is diagnosed with autism” and “one in every 88 children has autism.” Such framing has partly shaped the rhetorical construction of autism that has evolved from the blame assigned to mothers (1940s on), to a disability (mid-1980s and 1990s), to today’s discourse, which describes autism as a condition that is aggressively on the move and from which no family is immune. Figure 1 depicts the increasing attention in *New York Times* articles and Congressional testimony to illustrate the increasing policy attention the condition has garnered over time. Whereas from 1981 to 1985, there were approximately 50 *New York Times* articles focused on autism, from 2006 to 2010 the *New York Times* published more than 600 articles. Similarly, whereas from 1981 to 1985 no one was invited to testify before Congress (and there were no hearings on autism issues), from 2001 to 2005 more than 80 advocates testified in hearings related to autism.

We next examine the network development and social capital of Autism Speaks. By “social capital,” we mean the capacity of individuals to gain access to scarce resources, including money and political influence, by virtue of their membership in groups and participation in broader structures of society (Bourdieu, 1986; Coleman, 1988). Autism Speaks has effectively leveraged the financial and political strength of its star-studded membership, drawing especially upon extensive ties to the entertainment industry in order to lobby Congress on a regular basis

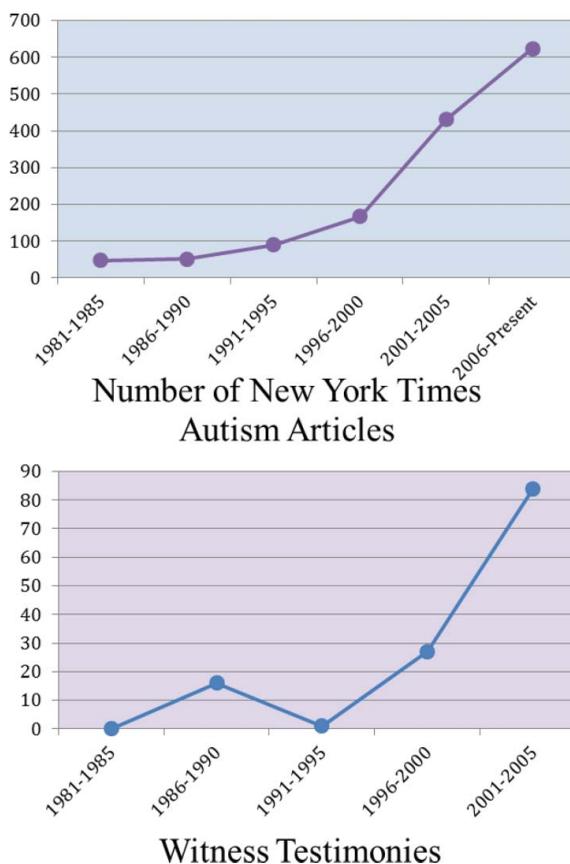


FIGURE 1 The increase of policy attention to autism in the *New York Times* and Congressional testimony. (Color figure available online).

(OpenSecrets.org, n.d.). As another example of networks, Robert Wright is connected to NASCAR through his previous post as a vice chairman of the General Electric Company. NASCAR supports and sponsors autism and also displays information about autism at its competitions. Wright also serves on the boards of the RAND Corporation, Polo Ralph Lauren, and Mission Product, LLC. From this position, Wright has been effective in drawing on the legitimacy of science and the allure of fashion and haute couture to press the case for autism advocacy.

The executive board for Autism Speaks consists of more than 20 members: business executives, medical doctors, media executives, artists, and attorneys.⁷ In addition, the organization has various steering committees and advisory boards, ranging from a scientific advisory board (which reviews research proposals) to an innovative technology advisory board. The organization maintains a prolific fund-raising capacity, which in turn facilitates extraordinary access to key political

⁷Often advocacy groups' boards of directors are elected from the ranks. Autism Speaks instead has a broad-based membership on its board (Autism Speaks, n.d.-b).

insiders. In the 5-year period between 2007 and 2011, Autism Speaks spent nearly \$2.6 million lobbying the federal government. Yet money alone may not be enough to motivate policy action. Social capital and well-positioned political “insiders” must also advocate the cause.

One such Washington insider is Autism Speaks’ senior lobbyist Craig Snyder, who served as the Chief of Staff to former U.S. Senator Arlen Specter (D-PA).⁸ Snyder also served as the Deputy Campaign Chairman for Senator Specter’s 1996 candidacy for the GOP Presidential nomination. Snyder founded the Ikon lobbying firm and has more than 30 years of experience in public affairs and political communication. Snyder’s presence gives Autism Speaks an insider lobbyist who has direct access to federally elected officials and who knows the ways in which the House and Senate operate. Insider knowledge and connections increase the group’s political effectiveness via uncommon access to elected officials and Washington power brokers who know the tricks of the trade in policy making. Coincidentally, sometimes insider political knowledge and entertainment star power can be found under the same roof. Snyder’s wife, NiCole Robinson, is an actress who at one time starred as Margaret (assistant to the White House chief of staff) in the Emmy Award–winning *The West Wing* NBC serial drama.

It thus comes as no surprise that the organization has become astute at placing celebrities front-and-center in its public awareness campaigns. Some of the most well-known figures in television have applied their front-stage talents in the realm of policy making, often testifying within the chamber of Congress. For example, Bradley Whitford (who played Deputy White House chief of staff Josh Lyman in *The West Wing*) testified on behalf of autism alongside with Robert Wright in the 2007 Congressional appropriation hearings (Autism Speaks, 2007). Over time, Autism Speaks has grown skilled at using entertainment industry connections in pursuit of policy goals.

In short, a new way of framing autism and a new set of powerful social connection (e.g., media, board of directors) seem to have contributed to the highly advantaged positioning of autism. Clearly Autism Speaks has capitalized on “bonding” social ties that link similar people and organizations together along some common dimension—in this case emotionally vested pain-loss activism on behalf of families of children with autism. Yet the organization has also developed “bridging” ties that span a cleavage that typically separates disparate individuals and organizations apart from one another. In so doing, Autism Speaks has gained useful access to an extraordinarily wide variety of resources and information as well as valuable political influence. Our findings corroborate a wide range of interdisciplinary research about the value that inheres in social capital—namely, the availability and usefulness of money, information, and political influence depends significantly on social processes and proximal *and* distal social connections that are often hidden from view (Coleman, 1988; Putnam, 2000; Ream, 2005).

We now turn to examine some of the notable policy victories Autism Speaks has achieved. The organization lobbied heavily to enact a law that focused solely on concerns surrounding autism (e.g., funding for research). President George W. Bush signed the Combat Autism Act (P.L. 109–416) in 2006, making it the first federal law to focus on only one subpopulation within the population of people with disabilities.⁹ This law was reauthorized in 2011

⁸Senator Specter was a longtime Republican in the U.S. Senate until 2009, when he switched party affiliation and joined the Democrats in Congress. In 2010, Specter was defeated in the Democratic primary and was replaced in 2011 by current Senator Pat Toomey.

⁹Federal special education laws, Section 504 of the Rehabilitation Act, and Children’s Health Act of 2000 target groups with a variety of diagnosed conditions.

(H.R. 2005). In addition, Autism Speaks has, in only 7 years, expanded its reach by having offices in Los Angeles, New York City, Canada, and the United Kingdom. The organization also recently began working in the country of Qatar to support the establishment of a center for students with autism and other disabilities. In 2008, the United Nations declared an annual international autism awareness day. The symbolic color for autism awareness is blue, and several buildings across the world, including the Sydney Opera House, were lit in blue on April 2. Recently, Autism Speaks partially funded a study in South Korea on the prevalence of autism and is now working with the CDC to implement a study of community screening in the United States. The Congressional Autism Caucus further suggests that autism remains a policy focal point, implying that elected officials see it as in their own best interests to act on the concerns of this particularly influential and broadly networked constituency. The caucus has more than 180 members of Congress from more than 40 states. It was formed and co-chaired during the 107th Congress by Representatives Mike Doyle (D-PA) and Chris Smith (R-NJ).

A present policy interest for Autism Speaks involves the scheduled publication of *DSM-5* in Spring 2013. The new definition of autism proposed by the American Psychiatric Association would eliminate the previously separate categories of Asperger's Syndrome and Pervasive Developmental Disorder and include them under a single category of Autism Spectrum Disorder. Diagnosis would be altered as well. Presently, a person can qualify for a diagnosis by exhibiting at least six of 12 behaviors that include deficits in social interaction or communication, and repetitive behaviors. In the proposed diagnosis, the person would have to exhibit three deficits in social communication and at least two in repetitive behaviors. Autism Speaks has issued a policy paper stating that the organization is extremely concerned about the more cognitively capable individuals who may not receive a diagnosis and subsequent social or medical services under the new diagnostic definition (Autism Speaks, 2012).

DISCUSSION

A policy-related concern regarding autism is the reported frequency with which it occurs, which has financial implications for school districts. Although advocates frame autism as a national health epidemic, some scholars argue that because autism was added to the special education law in 1990 after mental disorders were described more precisely, cases previously unnoted or misdiagnosed began to be counted (Grinker, 2007). For example, in the 1992–1993 Annual Report to Congress, states indicated an increase of autism incidences by 23% (Grinker, 2007). Grinker (2007) argued that the prevalence per se did not increase but that a new eligibility category and subsequent reporting guidelines explained the increase of children previously not reported. A related argument is that the diagnosis process for autism has improved over the years and that including conditions such as Asperger's Syndrome has increased the population eligible for special education. Yet some advocates warn that regardless of the formal technical definition of autism, its spread among the population amounts to no less than a national health epidemic. Rather than being distracted by diagnostics, these parent advocates are calling for a laserlike focus on a cure for autism now.

Although we do not have data to argue why autism is on the rise, our results suggest that the way in which a condition is framed can change over time, making it more favorable in the

eyes of the public.¹⁰ Although our data do not permit causal associations, we do suggest that the extraordinarily well-connected network of individuals affiliated with Autism Speaks may have influenced public image and public policy. We propose that reframing autism from a disability to a health epidemic—an example of a frame extension (Snow, Rochford, Worden, & Benford, 1986)—has broadened the network connections from education and psychology to the fields of psychiatry, medicine, and even stem cell research.

To understand the passion with which Autism Speaks has launched its national and international policy agendas and well-resourced networks, one has to understand the unique properties of parent advocacy. Jennings (1999) proposed that political activism resulting from an emotionally vested, deep personal experience is qualitatively different from political participation stimulated by other causes. A distinguishing feature involves the *stakes*, which are high for the involved individual because public policies have a direct impact on the person's and family's physical and emotional well-being. A second unique aspect consists of the *incentives* (Jennings, 1999; Lichterman, 1995). Although any collective action ultimately seeks to gain concrete policy outcomes, participants in pain-loss movements become politically active, in part, because they value self-realization, emphasize personal fulfillment of needs, and develop a personalized sense of public commitment (Lichterman, 1995). Pain-loss induced activism is also motivated by the support from and bonding with others who share a similar experience, and such movements often originate as local support networks (e.g., Altman, 1996). Having a child with a disability brings parent groups into the political arena with a highly personal, passionate agenda (Itkonen, 2009). As one scholar and a father of a child with autism put it:

I am not a religious person, but there is something profoundly meaningful, if not spiritual, about being the father of a child with autism that has pushed me to consider lofty, abstract principles of life like truth, beauty, and goodness. (Grinker, 2007, p. 24)

Another scholar explained parent advocacy with similar passionate properties:

These are super parents. If they are not there being vigilant, every day looking at every piece of new research, something might be missed—they hold out hope that there is something that can make things better. For parents, this [advocacy] goes to the core of who they are. It is deeply personal for these parents, they really draw the line in the sand. To understand the depth of passion with which parent advocacy occurs, one has to understand the situations in these families. (Itkonen, 2009, p. 109)

Understanding parent advocacy as pain-loss motivated activism has implications for education policy and politics. Parents of children with autism are concerned with autism in general and their own child in particular, not the needs of the school system. This may result in their unwillingness to compromise, if faced with a dilemma of selecting benefits for their own child or those for the entire system (Ong-Dean, 2009). For example, the 1997 reauthorization of IDEA extended over two Congresses as parent advocates and school officials disagreed on the discipline provisions for students with disabilities. At one point parent advocates organized a massive call-in to Capitol Hill, which resulted in the phone and fax lines being jammed for days (Egnor, 2003).

¹⁰Schneider and Ingram (1993, 1997) proposed a model in which populations were depicted based on their power and image, affecting the subsequent policy design targeted for those populations. The authors placed people with disabilities in the quadrant of low power but positive image.

If one is to conceptualize autism advocacy as pain-loss induced activism, it is then similar to other such motivations, such as advocacy for children with leukemia, diabetes, bodily injury, or cancer, where a highly personal experience is the cause for becoming politically active. The uniqueness of Autism Speaks, however, is in its ability to link a variety of well-resourced individuals into a powerful network. In some sense one could argue that the advocacy organization is managed as a company, with high-profile individuals in charge of various highly specified functions. Having an experienced and well-connected CEO also clearly brings in cultural, social, and economic capital that other parent groups may not enjoy.

Finally, it is necessary to point out some limitations of our study. First, Muckety is a site and thus not a research-validated network program (e.g., UCINET version 6.0). Second, we deliberately picked our case study organization and thus cannot make comparisons or generalizations to other parent groups. Our study explored changes in autism construction over time, establishment of a new advocacy organization, and the development of resourced networks to affect autism policy.

CONCLUSION

Our findings contribute to the literature on well-resourced parents making effective claims about their children's education and rehabilitation needs (Ong-Dean, 2009). By extending the unit of analysis from a family and school level to a focus at the organizational level, we portray how influential social actors frame the story of autism and secure policy victories for families of youth with autism. Whether issue framing affects policy by motivating network collaboration, or whether pain-loss collaboration affects how social actors frame the issues in an effort to affect policy is the subject of concern in our preliminary analyses. Future research should systematically examine population construction, networks, and resource development across a variety of students with special and other needs. Doing so will allow researchers to pursue causal associations across those variables, thus aiding in the analysis of *why* and *how* some parent groups are able to mobilize successfully and become politically effective, whereas others are not.

AUTHOR BIOS

Tiina Itkonen is an associate professor at California State University, Channel Islands. Her research focuses on the role of interest groups in education and special education policy.

Robert Ream joined the UC Riverside Graduate School of Education faculty in 2004 after completing postdoctoral fellowships at Princeton University and the RAND Corporation. He uses social capital theory and mixed-methods research techniques to explore the often overlooked relational dynamics that impact educational inequity.

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