Defending ‘snake oil’: The preservation of contentious knowledge and practices

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Abstract
How does belief in controversial ideas persist? I study a community of parents and practitioners who contend that autism spectrum disorder is caused by harmful environmental exposures – notably, early childhood vaccinations – and that there are worthwhile alternative or experimental treatments. Despite objections from dominant experts, these actors maintain their disputed ideas. This study identifies a set of strategies that help maintain internal legitimacy. In particular, actors protect internal legitimacy through professional alignment and contrastive boundary work. Professional alignment mobilizes resemblances to conventional counterparts (i.e. mainstream doctors) to defend unorthodox practices. Meanwhile, contrastive boundary-work performances convey the defining values and strengths that actors associate with their knowledge community and concomitantly, the weaknesses they ascribe to competing groups. Through these activities, actors respond to perceived threats and construct a distinct group identity anchored in shared knowledge, ways of knowing and practice.

Keywords
controversy, boundary work, autism spectrum disorder, alternative medicine, vaccine hesitancy

In September 2007, media personality Jenny McCarthy appeared on The Oprah Winfrey Show and Larry King Live just one week apart to promote her new book about the ‘recovery’ of her autistic son. This was a controversial claim, as ‘recovery’ implies having been first injured and then being healed back to former health and functioning. Her narrative

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contradicted the uncertainties related to the etiology and treatment of autism spectrum disorder (henceforth, simply autism). Before millions of viewers, McCarthy associated autism with vaccines and advertised the possibility of reversing the core symptoms with unconventional treatments. Despite numerous peer-reviewed, evidence-based studies proving otherwise (Institute of Medicine, 2011), belief in a vaccine-autism link endures (Reich, 2016), along with related promises of recovery (Silverman, 2011). This case inspires questions about the tenacity of epistemic resistances (Medina, 2013), which in this paper, broadly refers to the collective challenges against dominant knowledge and ways of knowing. How does belief in controversial or disproven ideas persist?

Scientific crises and controversies present opportunities to reveal the structures, processes and mechanisms that constitute knowledge regimes (e.g. Bloor, 1976, 1991; Collins, 1983; Frickel and Gross, 2005; Jasanoff and Kim, 2009). Controversy is especially valuable to studying forces that drive resistances against dominant knowledge (Gauchat, 2008). At a time when there is vocal public distrust in the epistemic authority of experts (Eyal, 2019; Gauchat, 2012; Tom, 2018) – exemplified by vaccine hesitancy (Reich, 2016; Senier, 2008), COVID-19 conspiracy theories (Van Bavel et al., 2020), climate change denial (Jacques and Knox, 2016) and other forms of ‘post-truth politics’ (Collins et al., 2017; Jasanoff and Simmet, 2017; Sismondo, 2017a) – it is critical to better understand the persistence of disproven facts and collective oppositions against dominant knowledge.

Recent attention to the crisis of expertise considers the institutional and political processes that have kindled public distrust overtime. For instance, Eyal (2019) argues that since the second half of the 20th century, the ineluctable entanglement of science/technology and the state in regulatory science has motivated the public to question the biases, credibility and legitimacy of experts (not limited to scientists) (Jasanoff, 2009). Continued research is needed to understand not just the dynamics and emergence of public distrust, but also the social forces that fuel anti-science, anti-expert attitudes and the circulation of claims that have been retracted/disproven. As illustrated by recent outbreaks of preventable diseases associated with increased vaccine refusal (Lo and Hotez, 2017; Phadke et al., 2016; World Health Organization, 2019) and the spread of COVID-19 misinformation (Brennen et al., 2020), the beliefs of a relatively small population can have profound social consequences. Yet, these ideas are difficult to dispel and pushing scientific research can further agitate challengers (Nyhan et al., 2014; Thornock, 2017). Thus, the resiliency of contentious beliefs demands attention.

I investigate how disproven and controversial ideas about autism are maintained within the ‘alternative biomedical movement’. The alternative biomedical movement is predominantly composed of parents and practitioners who challenge mainstream understandings and constructions of autism, arguing that it is fundamentally an immunological condition ‘triggered’ by environmental exposures, most notably and controversially, early childhood vaccines. Members contend that it is possible to reverse damages with experimental and alternative treatment practices that correspond with their theory of causation. Alternative biomedical subscribers uphold a disputed understanding of autism’s causation, characteristics and treatment. From in-depth interviews and ethnographic observations, I investigate how they collectively resist dominant knowledge and withstand invalidation – and effectively, preserve the hope of treating autism.
This study merges the theoretical orientations of science and technology studies (STS) and social movements scholarship to examine epistemic resistance and the tenacity of contentious knowledge – knowledge that challenges authority and orthodoxy. Scholarship on challenges to experts and expertise tends to focus on lay demands for inclusion and equity, and efforts to shift research foci (Benjamin, 2013; Brown and Zavestoski, 2005; Epstein, 1996), which ultimately affirm the legitimacy of medical and scientific expertise. Fewer studies examine movements that seek to oppose the authority of dominant expertise altogether (Markle et al., 1978). Contributing to this area of research, I consider the social mechanisms that perpetuate a more subversive resistance that rejects incumbent expert authority and dominant forms of knowledge. Investigating the alternative biomedical movement, I demonstrate how defense strategies are shaped by actors’ understandings of their own contentiousness and vulnerability. To fortify internal legitimacy, members mobilize two boundary-work strategies: professional alignment and contrastive boundary work. I show that while professional alignment claims conventional forms of qualification, contrastive boundary work highlights the desirable characteristics that set alternative biomedical members apart from (and above) doctors and parents outside their community. From these findings, the resilience of contentious knowledge is buttressed by shared values and identity.

The case: Autism communities and alternative biomedicine

Autism is a developmental disability characterized by atypical social communication and restricted or repetitive behaviors (American Psychiatric Association, 2013). In the United States, some degree of autism is estimated to affect 1 in 54 children (Maenner et al., 2020). The causes are uncertain, but studies find that certain genetic (e.g. Hallmayer et al., 2011) and environmental factors, like maternal age and exposure (Atladóttir et al., 2010; Shelton et al., 2014; Volk et al., 2014), can increase risk. According to the Centers for Disease Control and Prevention (2019), there is no medical treatment or cure for the core symptoms; rather, it is typically managed with an assortment of educational and behavioral interventions (Granpeesheh et al., 2009).

The case of autism is sociologically alluring because of its rapidly growing prevalence, etiological uncertainty, controversies and cultural relevance – a set of features that have created opportunities to advance scholarship on several issues, such as diagnostic influences (Eyal et al., 2010; King and Bearman, 2011; Liu et al., 2010), constructions of risk (Lappé, 2016), health social movements (Chamak, 2008; Orsini and Smith, 2010) and geneticization (Navon and Eyal, 2016). In particular, as I focus here, autism serves as a dynamic case in the study of knowledge production and protection.

Studies on the alternative biomedical movement have explored its emergence, membership and methodologies to illustrate how actors interact with a set of contested beliefs and activities (Eyal et al., 2010; Silverman, 2011). For instance, Decoteau (2017) shows how experiences of racial and national exclusion contribute to Somali refugees’ acceptance of contested theories of autism causation, adapting the term epistemic community to describe this group as ‘united around coherent theories of the etiology of autism, its defining features, and most promising therapies’ (p. 170). Here, epistemic community
approaches knowledge as an organizing force. Yet, when facing criticism and attack, how do members of these communities maintain their controversial beliefs?

In the context of ongoing research and uncertainty, alternative biomedical members stand out in their adamancy that autism is triggered by environmental exposures and that affected children can recover from the damages of toxic exposures (Decoteau, 2017; Eyal et al., 2010; Kirkland, 2012b; Silverman, 2011). Of course, the claim that environmental factors contribute to autism risk is not itself controversial. Explorations of environmental factors and gene-environment interaction are core areas of autism research (Singh, 2016). However, what is controversial is members’ promotion of a vaccine-autism link. Members propose that autism is an immunological issue triggered by a variety of environmental exposures, including vaccines, resulting in various physiological dysfunctions with different behavioral presentations as described in the Diagnostic and Statistical Manual of Mental Disorders. On this issue, the alternative biomedical movement overlaps with the broader vaccine hesitancy movement, but vaccine critics do not necessarily subscribe to alternative biomedical practices. While other scholars (Eyal et al., 2010) and I refer to this community of parents and practitioners as ‘alternative biomedical’, to indicate their discordant relationship with conventional medicine, members usually refer to themselves simply as ‘biomedical’ – or ‘biomed’ for short – because their practices and research are modeled after a biomedical system of rationality (Silverman, 2011). Moreover, as I will develop in the findings, ‘biomedical’ and ‘biomed’ can be seen as part of their larger effort to claim legitimacy by strategically aligning unorthodox practices with science and conventional medicine.

Eyal et al. (2010) point to how distrust and limited confidence in experts have inspired this alternative network of expertise that blurs the boundaries between alternative practice and medical establishment. In 1964, Bernard Rimland disputed the psychogenic theory of causation – that posed autism was caused by unaffectionate ‘refrigerator parents’ (specifically mothers) – and offered a biological explanation. For a time, he was celebrated by the parents he exculpated and respected by medical professionals and researchers, but as he pushed the vaccine-autism hypothesis and alternative interventions (e.g. megavitamins), he lost credibility and fell out of the mainstream (Eyal et al., 2010). Yet he maintained a coterie of parents and professionals who suspected environmental causation. In 1995, Rimland’s Autism Research Institute (ARI) organized the first Defeat Autism Now! (DAN!) conference, which convened parents, practitioners and researchers (Pangborn and Baker, 2005).

DAN! held its last conference in 2011, but the same group of doctors later formed a professional organization, and parent advocacy organizations continued to host similar conferences. A systematic review of English and German language research finds that a range of 28% to 95% (median 54%) of families with autistic children have tried some form of complementary and alternative medicine to help their diagnosed children, with the most popular intervention being special diets and vitamins (Höfer et al., 2017). However, it is unclear how many parents subscribe to a cohesive ‘alternative biomedical’ framework or follow established organizations.

Over the past decade, the social and political context of alternative biomedical practice has shifted toward increased hostility directed from those outside this community. With the resurgence of preventable diseases, this community and other vaccine critics
have experienced public blame and condemnation for undermining herd immunity (Lo and Hotez, 2017). In addition, multiple doctors have been disciplined and gained public attention for prescribing experimental and alternative treatments to children diagnosed with autism (Haelle, 2016; Shelton, 2012). While scholars have considered the strategies alternative biomedical members publicly deploy to defend controversial theories of causation (Decoteau and Underman, 2015; Kirkland, 2012a), less is known about how members engage with these ideas and maintain beliefs within their own communities (Silverman, 2011). In what follows, I illustrate how this community interprets their marginalization and resists outside opposition.

**Contestation and knowledge-based movements**

Calling for continued research on the integration of STS and social movement studies, Hess (2016) emphasizes the need to better understand the modern landscape of increasing scientific complexity and ‘mobilizing publics’ that seek to advance their own research agenda. He argues that neither field has the complete theoretical and conceptual tools to fully address the evolving politics of expertise and innovation; for instance, when examining mobilization, STS often neglects subordinate actors/organizations and social movements neglects epistemic factors. Yet, when these theoretical orientations are merged together, scholars could begin to develop frameworks for analysing the structures and networks of contentious knowledge (Hess, 2016). Such an interdisciplinary approach is critical to investigating the social mechanisms that drive and sustain challenges against dominant epistemic paradigms. STS and social movements scholarship has investigated knowledge-based conflicts and controversies but focus on those that reinforce dominant structures and processes. Fewer studies examine more subversive forms of epistemic resistance that question incumbent authority and expertise.

Some STS scholarship suggests that contentious knowledge is constructed through de-legitimation processes (Collins and Pinch, 1979; Gieryn, 1999) and precluded by disciplinary proscriptions (Frickel et al., 2010; Kempner et al., 2011). These studies tend to examine activities concentrated in intellectual and academic institutions; less is known about how marginal actors engage with controversies (Hara and Sanfilippo, 2016; Reich, 2016). First, when constructed through de-legitimation processes, contentious knowledge is differentiated from dominant and accepted forms of knowledge. For instance, Collins and Pinch (1979) contend that legitimacy is not generated only in constitutive forums of formal scientific activities but also contingent forums where activities such as gossip, fundraising and publicity seeking take place. In these forums, fields like parapsychology are constructed as pseudoscience through institutionalized and informal methods of exclusion. When theories are proclaimed ‘dead’, controversial ideas (like cold fusion) may enjoy a prolonged, ‘undead’ life through continued research, but even still, these ideas and their researchers suffer from a lack of legitimacy within the broader science community (Simon, 1999).

Second, contentious knowledge is communicated through disciplinary proscriptions, which explicitly indicate the types of knowledge researchers cannot or should not produce (Gross, 2007; Knorr-Cetina, 1999). One form is forbidden knowledge – ‘knowledge considered too sensitive, dangerous, or taboo to produce’ (Kempner et al., 2011), such as
research that aims to naturalize social inequalities – which is defined by disciplinary norms and formal regulations. In some cases, dominant actors neutralize contentious knowledge by strategically making space within the dominant paradigm and excluding elements that are unorthodox (Decoteau and Daniel, 2020). By these pathways, contentious knowledge is reified through the activities of dominant groups.

Social movements scholarship approaches knowledge-based contestations as forms of collective action, which challenge authority and normative practices (Arthur, 2009; Frickel and Gross, 2005). Still, existing studies analyse how movements evolve and expand the boundaries of epistemic authority. Frickel and Gross (2005) call for the study of scientific or intellectual movements, which are collective efforts to subvert and redirect inquiry and the production of knowledge. Notably, the model limits contention to the activities of intellectual insiders – specifically, ‘higher-status’ actors; as such, it minimizes the relevancy of marginalized actors who operate outside or on the fringes of scientific and intellectual institutions. Addressing the exclusion of non-elite actors, Arthur (2009) presents a complementary study of new knowledge movements (NKMs), which conceptualizes the emergence of new disciplinary fields as social movements led by ‘political and intellectual outsiders’ – those who experience disenfranchisement within academia (e.g. women, people of color). Even on the margins, NKM actors are still part of an extended network of experts.

Outside of intellectual institutions, lay challenges to epistemic authorities are manifested as health social movements and science activism (Benjamin, 2013; Brown et al., 2004; Epstein, 1996; Frickel et al., 2010). Yet studies on the participation of marginalized actors in practical knowledge production often focus on efforts to sway different institutions of authority (e.g. government, medicine, science) by recruiting expert help. These groups navigate existing systems of power. As consumers of healthcare and science, lay stakeholders mobilize to gain inclusion and direct research agendas. Their collective action often involves partnerships with experts. For example, Epstein’s (1996) work on the AIDS movement demonstrates how activists during the 1980s were able to effectively work with experts in the redesign of clinical trials by leveraging both their situated knowledge and newly acquired biomedical knowledge. Such boundary-crossing partnerships may empower the more marginal or disenfranchised actors, but they continue to affirm the legitimacy of incumbent authority. In contrast, this study focuses on antagonistic, not collaborative, relationships between marginal and dominant epistemic actors.

In this article, I investigate hostility between dominant and competing epistemic paradigms, in the form of outright challenges to the legitimacy of incumbent experts and mainstream knowledge and beliefs. These forms of collective action seek to subvert authority and dominant ways of knowing; they not only question the fundamental frameworks that guide inquiry but also the very institutions entrusted with knowledge production. I ask, how do challengers resist and mobilize against dominant experts and authorities?

**Research design**

This study is part of a larger comparative project that explores autism-related advocacy and knowledge production. The research presented in this article draws from the data
collected on the alternative biomedical movement. Between 2014 and 2016, I conducted an estimated 414 hours of ethnographic observations and semi-structured, in-depth interviews with thirty-one unique participants (Table 1). Participant observations took place at conferences, practitioners’ offices and informal events, such as social gatherings. I conducted interviews with parents of autistic children, practitioners, one researcher and two autistic adults, all of whom were involved in the alternative biomedical community. In addition, I gathered published materials that were either issued or promoted by the sampled organizations and reviewed media coverage on alternative biomedical-related issues.

To sample this population for ethnographic observation, I first selected the most recognized organizations that promote an alternative biomedical perspective. Recognition was determined by media presence and mentions in related literature. I used a theoretical sampling method that aims to capture the key organizations that make up the larger movement, which shares common members, experts and practices (Charmaz, 2014), totaling four organizations. Because this sampling strategy targeted national organizations, this study excludes local and international organizations and online groups. After gaining entry into these organizations, I asked three well-known alternative biomedical doctors for the opportunity to conduct observations at their private practices to understand medical decision-making processes between doctors, patients and patients’ parents. All three agreed to participate.

I recruited interview participants during conferences and through snowballing. Of the thirty-one interviews, this article draws from those with parents and practitioners (Table 2), as they compose the majority of members. In demographics, my sample resembles that of other studies that survey parents who administer alternative treatments to children with autism (Owen-Smith et al., 2015) – such as having relatively high education – and the general population of complementary and alternative medicine users (Laiyemo et al., 2015; Owen-Smith et al., 2015). My sampling strategy attracted participants who are generally more involved in the alternative biomedical community and committed to its framework. Active participation in the alternative biomedical community is costly (i.e. consultation, treatment, conference attendance), thus my sample has an under-representation of lower socioeconomic members.

### Table 1. Collected data.

<table>
<thead>
<tr>
<th>Observations</th>
<th>Multi-day conferences</th>
<th>Practitioners’ offices</th>
<th>Doctor-patient interactions</th>
<th>Organization office</th>
<th>Total (~414 hours)</th>
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<tbody>
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<td>Interviews</td>
<td>Parents of autistic children</td>
<td>18</td>
<td>Practitioners</td>
<td>10</td>
<td>Autistic adults</td>
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<td>Researcher</td>
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*Table 1. Collected data.*
Leaders of the sampled organizations all agreed to disclose the names of their respective organizations. I assigned pseudonyms to observation and interview participants to maintain confidentiality. Because conferences were accessible to the public, I disclose the identities of presenters whose names were published in the program. Throughout this article, to help clarify roles, parent and non-doctor participants are referred to by first names and practitioners by professional title and last names.

### Analysis

Alternative biomedical members’ epistemic resistance to the dominant autism paradigm is a collective challenge against incumbent authority – that is, medical professionals, researchers, public health experts (Snow, 2004). As already discussed, they are contentious because of two main factors – their etiological theory (that implicates early childhood vaccines) and autism treatment protocols, which typically include the reduction of toxic exposures in everyday life, specialized diets, nutritional supplements and a variety of experimental therapies (e.g. anti-fungals or virals, off label use of pharmaceutical drugs, hyperbaric oxygen therapy). Members are sensitive to criticisms and the potential consequences that threaten their pursuit of alternative and experimental autism treatment; at stake is the possibility of achieving neurological typicality.

Their fears are not unfounded. Popular media coverage chastises their vaccine skepticism and medical practices, portraying them as ignorant and negligent. Alternative biomedical practitioners worry about professional jeopardy, as a couple of their prominent peers have faced lawsuits and probation (e.g. Callahan, 2014; Haelle, 2016). Similarly, cautionary stories warn parents about their risk of being charged with medical neglect or
medical child abuse (e.g. Brand-Williams, 2017). Less extreme, parent participants also reported that friends, family and pediatricians are often unsupportive of the unconventional choices they make for their children’s health. Providing unorthodox treatment to a vulnerable population—children, especially children with disabilities—demands reconciliation with social and possible legal consequences. As this case illustrates, styles of defending contentious knowledge are associated with understandings of threat.

One way in which actors protect contentious knowledge is through boundary-work performances. Taylor and Whittier (1992) indicate that boundaries delimit ‘social territories’ by defining the commonalities between in-group members and distinctions from outsiders. In addition to informing activities and interactions with dominant groups, boundaries are critical to generating ‘self-affirming values and structures’ (Taylor and Whittier, 1992), evoking positive identity and connections between members. Strategies reflect knowledge struggles between groups and actors’ understandings of the environment in which they are embedded (Bourdieu, 2004; Bourdieu and Wacquant, 1992; Melucci, 1995).

When applied to constructions of knowledge—particularly, scientific knowledge and expertise—boundaries are instrumental to securing resources and power (Abbott, 1988; Gieryn, 1999; Jasanoff, 1987). For instance, litigations around the teaching of creationism and evolution in public education exemplify struggles to establish epistemic authority, negotiating fundamental differences between science and competing frameworks (Gieryn et al., 1985; Nelkin, 1982). An emphasis on privileged epistemology, however, neglects how challengers mobilize boundary-work strategies to protect subordinate and/or subversive knowledge and ways of knowing. I demonstrate how rhetorical boundary work functions as a method of resistance in vulnerable circumstances—not only a strategy to demarcate epistemological territories and retain power. As I show, boundary-work activities—alignment and contrastive—are at once defensive strategies and articulations of group identity.

First, I focus on one particular event to illustrate the community’s perception of their own contentiousness and how this orients their strategies. Perceived contentiousness articulates members’ understanding of their position within the broader field of autism discourse. Accordingly, from this vantage, members identify vulnerabilities, resources and antagonists. Next, I illustrate parents’ and practitioners’ mobilization of two boundary work strategies: professional alignment and contrastive boundary work. I show how members use professional alignment strategies to claim conventional forms of institutionalized cultural capital. Members marshal professional resemblances to delimit their jurisdiction and defend their qualifications to treat. Contrastive boundary-work strategies, however, distinguish alternative biomedical practitioners and parents as intellectually and morally superior to their conventional counterparts. Although these tactics seem contradictory, they dovetail together to carefully situate alternative biomedical practice as being simultaneously within the general bounds of science but ahead of their time. Responding to perceived conflict, members deploy these two strategies to deflect criticism, strengthen internal legitimacy and define a group identity.

**Perceptions of contentiousness**

Here, I focus on one particular incident that ignited frank discussions among alternative biomedical members about the nature of their contentiousness, which highlight understandings of the external threats and dangers facing their community.
Shortly after I entered the field, on June 19th, 2015, Dr James Jeffrey Bradstreet died in Chimney Rock, North Carolina. He was a well-known and highly respected doctor in the alternative biomedical movement. The details of his sudden and peculiar passing struck a nerve in the community, eliciting candid discussions about how they are seen by others and their relationship to government, medicine and the pharmaceutical industry. Dr Bradstreet had been found in a river with a bullet in his chest, a few days after his office was raided by the federal Food and Drug Administration (FDA) and the Georgia Drugs and Narcotics Agency in investigation of his prescription of Globulin component Macrophage-Activating Factor (GcMAF) injections to autism patients (Miller, 2015). GcMAF injections, a protein extracted from human blood, was rumored to treat a number of conditions, like autism, cancer, dementia and athlete’s foot. A few parent participants had administered it to their autistic children; one mother said that one could purchase it from Bulgaria at $1000 per vial and have it shipped in special packaging to circumvent embargo.

The reported cause of Bradstreet’s death was suicide, but some of his supporters suggested that he was murdered. They linked his death to the recent passing of other practitioners of alternative medicine, to tell a conspiratorial story of serial murders motivated by violent objections to their unconventional practices and research. Many dismissed these conspiracies, but nevertheless the stories circulated and gained attention. When asked if she believes these rumors, Christine, a mother of an autistic teen, initially expressed some doubt, ‘there is a whole movement of people that think he was killed because of the research that he was doing and possibly some exposing that he may have done … I don’t know. It’s like a huge conspiracy theory.’ Shortly after, she confirmed her belief in the floating theory, ‘I can subscribe to the theory that they were targeted. And killed.’ She said that she is not sure who carried out the murders, but offered a hypothesis, ‘I don’t know why. You know, it could be pharmaceutical [industry].’ For parents like Christine, the death of Dr Bradstreet was a reminder of the contentiousness of their medical choices.

That year, a couple of ice sculptures were erected in Bradstreet’s memory and displayed at conferences. On the last day of one conference, practitioners and parents joined hands, forming a large circle, and collectively sang Bill Wither’s ‘Lean on me’ as a tribute to the late doctor. For them, Bradstreet’s death signified an attack on the community as a whole; but in their daily lives, parents also experienced more immediate and frequent criticisms from friends, family and conventional doctors. For instance, in an interview with Grace, a mother of two autistic children, she supposed, ‘probably a lot of them think we’re really crazy, because a lot of people think biomed people are crazy. I think some of them get it.’ Susan, whose daughter recently had been diagnosed with autism, said she does not tell too many people about her stance on vaccines and use of alternative biomedical treatments because many of her friends are pediatricians, pharmacists and lawyers, so it would be too complicated to explain her choices to them. Robyn, who was starting her own practice with a friend and was attending conferences to learn more about alternative biomedical methods, worried that doctors may judge her vaccine choices more harshly because of her training as a nurse practitioner: ‘Being a parent, you know, you can do one thing for your child and you can refuse the vaccines if you want and I’m sure our pediatrician would just shake his head at me because he knows I’m a nurse.
practitioner.’ As many parents saw themselves judged for their choices, practitioners perceived themselves to be in danger.

Among practitioners, the death of their prominent colleague was an extreme but sobering reminder of their professional deviance and its consequences. In an interview, Dr Kavita Maddan, one of Bradstreet’s close colleagues, proposed that the very qualities that brought him success and won him respect within the community simultaneously created enemies. She admitted that the treatments she and her colleagues implement depart from mainstream medicine, but why they are regarded as ‘controversial’ eluded her:

He was a genius, but the downfall there is you’re fighting against a system that really doesn’t want us doing what we’re doing, and I don’t know why that is. You would think that they – people, like my [medical] board, would want somebody in the area that’s helping families and not hurting families with psychotropic drugs that can really hurt kids. But, because they think it’s controversial, and I don’t know why they think it’s controversial. They just create the controversy. It’s because it’s different. It’s not controversial, it’s just different than how they think about health.

Maddan contended that there is nothing intrinsically controversial about the type of treatment she and her colleagues provide, especially when compared to some of the psychotropic drugs prescribed to children; rather, the controversy is constructed by their conventional counterparts.

Dr Bernard Sachwell, a Yale School of Medicine graduate and one of the pioneers of alternative biomedical treatments for autism, shared Maddan’s perspective. During an interview at his home and office in Sag Harbor, New York he bemoaned that the rigidity of the medical profession limits the pursuit of experimentation and methods that do not agree with traditional practice, which he described as being too intertwined with the interests of pharmaceutical companies. Working on the fringes of this professional environment, he expressed his and others’ fear of losing their licenses to practice.

And people are so afraid. Here, I’m maybe – I’m a little afraid of liability. Not that patients [are] going to sue me but that the medical board is going to come knock on my door because somebody dropped a dime on me. But doctors are afraid of doing anything that’s outside their circle.

Bradstreet’s death reinforced and magnified existing ideas about the boundaries and frictions between the alternative biomedical movement and its detractors – mainstream medical professionals, government agencies (e.g. FDA, CPS) and the pharmaceutical industry. In posthumous descriptions, many community members portrayed Bradstreet as a martyr, embodying the community’s fundamental values, purpose and most of all, the realization of its deepest fears; as Dr Maddan said during our interview, ‘[I]t just hits too close to home. What we do is not looked upon well by whatever agencies and, so, none of us want that. So, regardless of whether he was shot or shot himself, whatever happened with the FBI and FDA, that pushed him to that point, it’s our world.’ To her, for someone of his reputation to buckle under the psychological pressures of controversy or the antagonism from government agencies, implied the fragility of most other practitioners.
It was in a context of looming fear that members guarded their beliefs and practices against outside attacks. As I will next illustrate, in response to antagonism and accusations of ‘quackery’, participants mobilized boundary-work strategies to establish internal legitimacy and resist de-legitimation. These strategies also conveyed their sense of intellectual superiority and underdog righteousness. Participants portrayed their community members – parents and practitioners – as possessing these qualities, which joins them together and sets them apart from conventional counterparts.

**Professional alignment**

In the pursuit of autism treatment, alternative biomedical parents and practitioners described a divergence – rather than a complete break – from the dominant paradigm. Pointing to institutional markers, like credentials, education and peer-reviewed publications, they delicately position their practice as simultaneously distinct from and an extension of conventional medicine. Through alignment strategies – by noting congruences – members actively invoked professional similarities to affirm their practitioners’ qualifications to treat and the legitimacy of their practices. Members – practitioners especially – strategically blurred professional boundaries between the alternative and conventional, seeking refuge within the very system they challenge.

As challengers against the incumbent authority, alternative biomedical members cannot expand their boundaries into the domain of conventional medicine. However, through alignment, they claim conventional forms of institutionalized cultural capital and authority (Bourdieu, 2004). Members understand their specialized practitioners as concurrently competing within the broader boundaries of medicine but also outside its conventions, offering a competing epistemic framework that is scientifically valid and advanced. After all, many doctors received a formal medical education and while their interventions are largely experimental, they are loosely guided by published scientific research. In their performances of boundary work, participants noted that their specialized practitioners have the same basic education and credentials as their conventional counterparts – plus additional training to set them apart.

The alternative biomedical movement may be critical of medical orthodoxy, but members use the authority conferred by medical credentials. Parents trust practitioners because of their formal training. During an interview, Trudy, mother to an autistic son, contrasted the credentials of her child’s alternative biomedical practitioners to images of sinister Macbethian witches, ‘[T]his is done by MDs and DOs and doctorates. They’re not like some crazy person back stirring a big caldron of like bubbling stuff to give to our kids or some quack doctor website, you know?’ She argued that the interventions, though unconventional, are prescribed by medical authorities, as opposed to someone who is unqualified or dangerous.

Meanwhile, practitioner participants align with medical professionals to indicate that they possess the same type of authority. For instance, during my observations at Dr Kurt Martinek’s private practice in Irvine, California, a mother came in to receive a vaccine exemption letter and discuss her daughter’s co-morbid condition, Obsessive Compulsive Disorder, which she thinks causes sensitivity to sound and certain fabrics. The mother said she tried ‘modern medicine’, but it did not work. Martinek quickly snapped back to
correct that he, too, practices modern medicine. Although he is one of the most well-known doctors in the community, Dr Martinek was reluctant to label the type of medicine he practices as anything other than regular medicine; in his interview, he said, ‘there’s nothing unique about the biomedical approach. It’s just medicine.’ However, he distinguished his type of practice as ‘good medicine’, defining ‘good’ as spending more time with each patient, which is afforded because he and many of his peers do not accept health insurance. In that statement, he placed himself and peers within and above conventional medicine. Members understand their methodology to be within the logic and rationale of medicine – different but not so different that they are at risk of invalidation.

Practitioner participants argued that they are more, and thus, better educated than conventional doctors. On top of their formal medical training, they have to learn additional sciences, like osteopathy and naturopathy, to understand patients’ physiological dysfunctions and intervention needs. For instance, Dr Ravi Zahin sees himself as having extra education. He is a naturopathic doctor who owns a couple of wellness spas. He works with a general population, which includes autistic children and other pediatric patients with neurodevelopmental conditions. In an interview, he said he originally planned to attend a ‘regular medical school’, but after attending an informational lecture about a program in which ‘you could learn conventional medicine plus this other thing called herbs’, he interviewed and gained admission into a naturopathic medicine program. Zahin said he received the same education as other doctors and more, which was framed as a positive attribute:

[In] comparison to a medical school in Harvard and all these other [institutions] – it’s probably still on their website – but and you see how many class hours you get in pathology, oncology, neurology, and so it was, it was cool to me that I get all of that, plus I get like stuff that I didn’t know, so I just thought it was more education.

Practitioner participants also pointed to their use of peer-reviewed research in medical decision-making, claiming legitimacy associated with published research. During an interview, Dr Travis Drummond, who works mostly with autistic patients in California, emphasized that his experimental methods are informed by research conducted at high-prestige universities and hospitals:

[What makes this my approach or the approach I try to employ – I don’t know if it’s unique, but perhaps, discriminates it from the standard professional …. Again, I’m really looking at the research that has been done on these children …. Let me give you an example. UC Davis, UC San Francisco, Mount Sinai, Einstein have all done work with something called intranasal oxytocin. And I use intranasal oxytocin in my practice as a trial.

Dr Drummond separated himself from ‘the standard professional’, while loosely associating himself with top scientists and claiming that his methods draw from knowledge generated at trusted institutions; he presents his practice as unorthodox but cutting-edge.

These alignment strategies, which work to internally legitimize unconventional practices by conventional measures, suggest that members respect conventional forms of medical and scientific authority and understand themselves as entitled to the same privileges. Furthermore, professional alignment sends a powerful message to parents,
especially when their practitioner is educated in both orthodox and alternative medicine but has made a career with the latter. First, it implies that after surveying the medical landscape, practitioners rationally selected what they believe to be the better way to treat patients. Second, it suggests that practitioners continue to be dually informed by both paradigms in their treatment decision-making. The alignment with the medical mainstream communicates that alternative biomedical practice is well-informed and engages with the orthodox paradigm – as opposed to being insular and ignorant.

Members’ alignment strategies express a complex relationship with conventional medicine and its experts. They perceive themselves as better educated and more knowledgeable than mainstream medical professionals. Yet, by identifying resemblances to conventional counterparts, members demarcate their medical jurisdiction and defend their right to treat autistic children. However, as I illustrate in the next section, to empower their unorthodoxy and neutralize the attacks against them, members point to intellectual and moral strengths that distinguish them from other actors in the field of autism treatment.

Contrastive boundary-work performances

Contrastive boundary-work performances sharpen the unique features that validate alternative biomedicine. This strategy conveys the defining values and culture that members associate with their knowledge community and concomitantly, the weaknesses they ascribe to competing groups. Members celebrate the very qualities that attract outside criticism – namely, an experimental spirit and the maverick trait of ‘thinking outside the box’.

Parents and practitioners typically discover the alternative biomedical movement after feeling disappointed and disenchanted with mainstream medicine. For many interviewed parents, alternative biomedical practice was the last resort, after they judged behavioral and educational therapies to be unsuccessful and/or had poor encounters with their children’s doctors, eventually leading them to lose trust in conventional medical practice all together. Whitney, who has an autistic son, noted that families turn to alternative biomedical practices when they run out of options:

I think there is this silly idea that the research community has, ‘These people are dumb and they’re taken advantaged of and they don’t know what works.’ … I don’t know one mother who didn’t try traditional [therapies] first. I can’t think of one – and you go there after it all fails. For years. You only end up there after it fails.

Similarly, among practitioners who hold medical degrees, at some point they found their toolkits to be inadequate and believed it was necessary to expand their repertoire. Sometimes this realization was driven by patients’ interest and other times it was a personal experience. For instance, before becoming one of the most well-recognized doctors in the alternative biomedical community, Dr Martinek was in general pediatrics. Then, his son was diagnosed with autism. He recalled how his wife had accused him of causing autism with vaccines. He remembered his wife saying something to the effect of,
‘This really sucks. You broke him, now you fix him.’ So I started doing research to find out what … Well, she knew it was after a vaccine called the MMR [measles, mumps, and rubella] that we lost him. … Well, I don’t play games. It’s like, ‘He’s broken, I gotta fix him. This is not going away.’

It was then that he gradually entered into alternative biomedicine. Given many participants’ narratives about their negative encounters with conventional medicine, it is unsurprising that when seeking something different, parents and practitioners value non-conformity.

**Doctors who ‘think outside the box’**

On the last day of a 2014 conference in Dallas, Texas, attendees gathered to see the special guest – the man whose work has significantly influenced their knowledge about autism and its causation, and whose biography is an allegory of their collective struggle. Mark Blaxill, a vocal vaccine skeptic and writer, presented the 2014 Galileo Award – for someone who embodies a heretical and innovative spirit – to Andrew Wakefield, a British physician gastroenterologist, who, in 1998, published a paper controversially suggesting a relationship between autism and the MMR vaccine. This publication was retracted from *The Lancet* in 2010; that same year, he lost his medical license to practice (Park, 2010). At what would seem to be the nadir of his career, Wakefield is elevated to enjoy a life of celebrated infamy within the alternative biomedical community.

Blaxill drew parallels between the brave but tortured lives of Galileo and Wakefield. Galileo is to heliocentrism as Wakefield is to ‘autistic enterocolitis’ (Blaxill, 2008), a condition that describes gastrointestinal disease associated with autism and is discredited by the medical community; Galileo being condemned and placed under house arrest until his death was likened to Wakefield losing his medical license. However, Blaxill asserted that in contrast with Galileo, whom he dismissed of having ‘chickened out’ in the retraction of his theory under coercion, Wakefield did not succumb, making him more morally resolute and admirable. The theatre of the Galileo Award ceremony captures the community’s conscious and proud divergence from mainstream medical and scientific communities that have rejected Wakefield’s research.

Interviews with practitioners also reveal their admiration for unorthodoxy. Describing his peers in Medical Academy of Pediatric Special Needs (MAPS), the professional organization for alternative biomedical practitioners, Dr Martinek said, ‘If they’re involved with MAPS, they’re interested in thinking outside the box.’ In my interview with Dr Dahlia Pagani, a naturopathic doctor, she expressed the same sentiment nearly verbatim, ‘I don’t consider any of these MAPS doctors conventional MDs. They are MDs who are like thinking outside the box.’ When comparing their training to that of their ‘mainstream’ and ‘conventional’ counterparts, practitioners criticized their peers for under-education, rote learning and inflexibility. Practitioners hold degrees in a range of disciplines: medicine, osteopathic medicine, naturopathic medicine, chiropractic medicine, nursing, etc. However, they recognize a paradigmatic difference between themselves (as a collective) and mainstream counterparts.
Participants portrayed conventional doctors as complacent pawns of a flawed medical system. They argued that traditional medical education and training, by their own design, produce staunchly compliant and unimaginative doctors. For instance, Claire, a mother of an autistic son, criticized her son’s former pediatric neurologist of being blindly stubborn in her commitment to traditional practice. Claire recalled how the doctor had noticed her child’s improvement, but attributed all the progress to Applied Behavior Analysis (ABA) therapy (a popular behavioral program for autistic children), denying the efficacy of alternative biomedical interventions:

And so, I told [the pediatric neurologist] about all the traditional therapies he was getting, which he was, and I told her about the biomedical interventions that we had done, and she shook her head ‘no’ and she said ‘I hate to see you waste your money like that.’ And I said to her, ‘You honestly think that a little bit of [Applied Behavior Analysis] therapy at my house has made the impact that you’re seeing right now?’ and she said, ‘Yep. It’s the only thing I know that works.’ And I said, ‘Well then I’m done here.’ … I think because of her medical training she just simply can’t imagine it to be true, and I think that she is also probably not, has not seen a lot of parents at that point.

Claire interpreted this exchange as an indication that the doctor’s training had stunted her from even ‘imagining’ the potential of unorthodox interventions. Subsequently, Claire continued using alternative biomedical practice and stopped seeing this particular pediatric neurologist, ‘And we never went back again and I never paid for that appointment either.’ Robyn, a nurse practitioner by training, similarly observed that conventionally trained doctors are less willing to diverge from their teachings. She characterized them as being less effective and slower to adopt new methods because, for one, they choose to passively wait for scientific evidence, as ‘They’ve done what they know or if research isn’t out about it they won’t teach it and so they’re waiting for that research instead of being proactive and saying, “well, here’s what we see”, or you know, “what’s been tried and what works.”’ Robyn suggested that, by comparison, alternative biomedical practitioners are admirably innovative and experimental.

During her interview, Dr Maddan differentiated the world in which she received her medical training from the world in which she currently practices. She indicated that the conventional standards for ‘good’ doctoring is the ability to memorize information, thus those doctors are ‘not good at thinking outside or freely’, which she equated to ‘brain-washing’. Pointing to a similar sort of rote medical practice in his interview, Dr Darren Jesson described his clinical training as primarily drug dispensation: ‘[I]t sort of feels like a lot of the basic science is thrown out the window, and it felt like we were just matching a pill to a problem.’ Similarly, Dr Gabriel Hernan, the father of an autistic boy, used to be an emergency room doctor, but has since left the profession. At the time of our meeting, he had adopted alternative biomedical methods two years prior to treat his autistic son – not to practice on his own patients. He said that had it not been for his son, he would have dismissed the interventions: ‘I can tell you how I would’ve received it had I not had a child affected with autism, and I would’ve received it as rubbish and pooh-pooh. I would’ve thought it was quackery and wouldn’t have been as open to look at it. Conventional medicine training doesn’t teach us any of this.’ Like most other interviewed
practitioners with an MD, he thought his ‘traditional medical training’ was a good foundation, but ultimately insufficient. Where his medical education left him, Gabriel was picked back up by alternative biomedical methodology.

In contrast to the flaws and rigidity of traditionally trained medical professionals, participants portrayed specialized practitioners as dynamic, innovative pioneers. Fiona, a mother of an autistic adult son, described alternative biomedical practitioners as being more sophisticated and knowledgeable than their conventional counterparts, ‘mainstream basically does not – my experience has been that they really don’t understand a lot of the complicated health issues that go with autism. And the biomed practitioners clearly have protocols and have an understanding of these complex medical challenges that traditional medical practitioners are just in the dark about.’ Like many other interviewed parents, Fiona sought out the innovation and specialized insights offered by alternative biomedical practitioners.

Dr Maddan contrasted her peers’ search for the root of a condition to the shallow assessment done by conventional counterparts, ‘our thinking process is different. We look at the body and we try to figure out where the symptoms are coming from. Whereas, when I was trained from a regular perspective, you look at the symptoms and you make a diagnosis based on the symptoms and some lab testing.’ Furthermore, Maddan argued that conventional doctors lack the inductive reasoning to experimentally translate research (from multiple biological science disciplines) into treatment. She uses the example of joint pain to compare how a ‘regular doctor’ would prescribe anti-inflammatories to treat the symptom, while an alternative biomedical doctor would design a treatment protocol informed by research on possible underlying issues, like fat absorption, Lyme disease, chronic gut infection and omega-3 deficiencies, ‘And there’s no double blind and placebo control studies to prove that what you do is going to help the patient, but there are studies to say that if you have omega-3 issues, then you could have joint problems. But [regular doctors] can’t make that leap.’ Dr Drummond similarly differentiated his work from that of ‘the average doctor’, drawing attention to his application of research, ‘So I have to be able to [show] research and evidence behind my decisions. That’s part of what I do, um, and the other part of it is what makes it different is that I really arduously, to the point of – maybe the point of overkill, put research on the table in front of my parents, everything that I do. The average doctor does not do that, as you already could guess.’

Critical of mainstream medicine, members share pride in being different and non-conforming, often wearing their heresy as a badge of honor. During a 2015 parent-oriented conference in Costa Mesa, California, one doctor proudly admitted that he has been called a ‘charlatan’ and ‘snake oil salesman’, but he has a retort for all those criticisms – ‘Don’t you know? Snake oil has omega-3 fatty acids.’ The audience roared appreciatively with laughter. A snake oil salesman, in this cheeky re-appropriation, suggested an inventive cleverness and the underestimation by others. While there is insufficient scientific evidence to support the efficacy of omega-3 fatty acids for improving autistic behaviors (James et al., 2011), within the movement community, they are commonly prescribed to address multiple issues from hyperactivity to seizures. For instance, at one conference in 2015, another doctor recommended omega-3 from fish oil to improve autistic children’s speech (a year later, he was investigated for medical
Illustrated here, contrastive boundary-work strategies differentiate alternative biomedical practitioners from and elevate them above conventional counterparts.

**Unlike ‘meek’ and ‘lazy’ parents**

Like the practitioners, alternative biomedical parents also pride themselves on ‘thinking outside the box’ but also emphasize how this epistemic framework requires them to be proactive and make sacrifices. In addition to promises of recovery, parents continue to support unorthodox practices because their dedication is interpreted as necessary for good parenting, a message that is reinforced within the community. As previously noted, parent participants understand that friends, family and doctors question their medical choices. Members perform boundary work to set themselves apart from parents who rely on conventional models to understand and treat their autistic children, conveying a group identity defined by parental empowerment, savviness and tenacity.

Among the parents I interviewed and interacted with during observations, many took pride in their community and what membership signified. By reconstructing autism as a recoverable condition, the alternative biomedical framework is instructive. It requires parents’ perseverance and tests their character. For instance, during her interview, Claire emphasized members’ shared priorities and extreme sacrifice, ‘… having a network of people who do not give up on their children, who are willing to put a second mortgage on their house, and not have a social life, and lose family and friends for their child’s health, those are the people I want to know. Those are the people I want to be friends with.’ Certainly, in practice, not all parents can be so devoted, as treatments are time-consuming and costly; participants reported paying varying amounts for specialized treatments and consultations; one claimed that treatments cost between $30,000 and $60,000 a year, another parent said she had to sell a house and accrued $125,000 in credit card debt. While parents’ investments in the pursuit of treatment vary, participants perceived themselves as more dedicated than other parents of autistic children.

Parents’ shared ways of knowing, inclusive of its demands, implies a shared set of valued characteristics. In 2015, at the end of a conference day, I attended an informal dinner with several of the organization leaders and members, all of whom are mothers to autistic children. The women reflected on the siblings’ panel hosted earlier that afternoon, during which the neurologically typical children of the alternative biomedical movement shared their experiences of growing up with an autistic sibling. The women at dinner praised the children’s eloquence and maturity. One mother, Paula, remarked that alternative biomedical parents simply raise better children than do parents outside their community. Another mother interjected to say that they should not be so dismissive of other families, to which Paula clarified that the children of ‘passionate’ parents – like themselves – are particularly special. This inspired a frank conversation comparing their community members to non-alternative biomedical parents of autistic children. Paula said that she knows of families who instrumentally seek out an autism diagnosis to take advantage of the free respite care services. Another asserted that some parents she knows even take pleasure in complaining about their autistic children for attention. From this conversation and many other interactions during conference weekends, participants
depicted themselves as generally superior to parents outside their community in their devotion and resourcefulness.

Fiona, who also works as a disabilities advocate, noticed that fellow alternative biomedical parents – particularly mothers – are highly knowledgeable, networked and capable of providing treatment for their children, even when it comes to something as challenging as injections (the most common are B-12 vitamins).

The moms who pursue biomed have really done their research and done their homework, and they understand – they really understand what’s going on medically for their kids. And, they’re strong networking with other moms. … I think they’re some of the brightest moms I’ve ever met, because they’ve educated themselves, to understand what’s going on with their kids and how to intervene and how to deliver, you know, whatever kind of supplements, including, injections.

Aside from just being well-read, parent participants explained that they have to be assertive when challenging mainstream medicine; as such, implementing unorthodox treatments requires steadfast confidence. For instance, one interviewed mother, Melissa, judged herself as being more tenacious than other parents of autistic children. Recounting her interactions with her son’s pediatrician, she portrayed herself as an uncompromising force, uninhibited by the authority of conventional doctors:

Many of those women hadn’t done all of the reading, so they weren’t as knowledgeable, and I feel like their personality was a little bit more subdued and kind of meek and mild about it. Because they were just overwhelmed themselves and I think they go in there and say, ‘Uh, wondering about that diet ….’ Whereas I am like, ‘We are doing this diet, and this is what I need. Don’t question me.’

Similarly, Whitney said that fighting against mainstream medical professionals requires self-education and conviction. In addition, she noted that some characteristics, such as libertarian attitudes, are cultivated when parents take treatment into their own hands and resist the interference from medical and government authorities. Whitney’s insights on parental resistance are reminiscent of Reich’s (2014) work on neoliberal mothering and vaccine hesitancy; mothers perceive themselves as the true experts on their children’s health and exercise privilege to decide what is best for their individual children, even if it is contrary to expert advice. For cases in which children responded to traditional interventions, Whitney imagined that those parents, in their fortunate circumstance, are not forced to develop these respected traits,

I think biomedical parents have to just read a lot more, go to lectures, talk with other parents. … They are telling me to give [my son] [an antipsychotic medication] and that will solve his [gastro-intestinal] problems, and I’m like, ‘To me that sounds stupid and I’m not going to do that.’ Biomedical parents, I think, have more self-confidence in dealing with the medical community. Because it hasn’t worked for us, versus with more traditional autism it mostly works for them, so… Also, you become much more of a libertarian. Like, with the medical marijuana, ‘Get out of my life!’

Some participants accused other parents of autistic children of being lazy and unwilling to inconvenience themselves for the sake of their child’s recovery. For example, Kelly, a
mother to an autistic boy, opined, ‘I really think they’re lazy. I think that it’s a copout, that doing the diet is hard. It’s easier to drive through the McDonald’s driveway and feed your kids crap all the time, it is.’ In this damning portrayal, those who do not take advantage of these intervention methods are bad and selfish parents – especially those who are aware of but forego these treatment options.

To validate their continuing efforts to recover their children, parents point to the key characteristics and values that connect them to fellow insiders and separate them from outsiders. Parent participants understand their unorthodox treatment strategies as the best form of care for their autistic children, but its access requires intense effort that tests parents’ dedication and implicitly, the love for their child. Struggles to provide treatment present opportunities to demonstrate parental commitment, and concurrently, distinguish parent participants from other parents of autistic children.

Discussion
During a parent-oriented conference in 2015, Jenny McCarthy approached the stage to a roar of cheers and applause. Playing up her famously rambunctious and uncensored persona, she greeted her fans, ‘Welcome to this warrior gang and we are bad motherfuckers!’ Parents embraced this moniker on printed t-shirts and hats. These ‘warriors’ find themselves in a metaphorical battle against autism and the people who question or try to interfere with their unorthodox treatment practices. The tantalizing hope of recovering an autistic child to neurological typicality brings parents and practitioners into the alternative biomedical ‘gang’. Despite accusations of quackery, malpractice and abuse, participants continue to engage within this community. How do they keep faith in alternative biomedicine? How do they defend ideas that are disputed by experts?

The case of the alternative biomedical movement illustrates how actors defend contentious knowledge from within their communities. Members’ strategies are shaped by perceived threats posed by actors who empower the dominant autism epistemic framework, namely researchers, medical professionals, public health experts, government and friends and family. Accordingly, members tout their intellectual and moral superiority relative to their most immediate detractors: conventional doctors and other parents of autistic children. Members maintain contentious knowledge through two strategies: professional alignment and contrastive boundary work. Professional alignment selectively claims traditional forms of credibility to assert the qualification of alternative biomedical practitioners. Contrastive boundary work, however, celebrates the unique characteristics that set alternative biomedical members apart from their conventional counterparts. Here, parents and practitioners take pride in their innovative spirit and way of ‘thinking outside the box’. Members deploy boundary work not necessarily to convince those outside their community, but to generate internal legitimacy. This helps shield and insulate beliefs and practices from outside attack.

These boundary-work strategies simultaneously reveal the texture of a distinct group identity. Parents and practitioners initially came together in the pursuit of autism recovery, but subsequently, their relationship and affinity became partially defined by the repercussions of their unorthodoxy. Alternative biomedical participants demonstrated a sense of social cohesion and membership anchored in shared knowledge, ways of
knowing and practice. The unique dispositions and consequences of subscribing to and engaging with contentious knowledge largely contour the distinctive features of their solidarity, like shared language, narratives and objectives.

The findings of this study also shed new light on a familiar theme in sociological research on autism – the emotional labor of caring for autistic children (Hart, 2014; Lappé, 2014; Navon and Eyal, 2016; Silverman, 2011). In this particular case, especially among parent participants, the cultivation of internal legitimacy is a form of emotional labor. Beyond dedicating time and resources to treatment (like other parents of autistic children), alternative biomedical parents also work to defend the epistemic framework that promises the hope of recovery. Believing in and sustaining contentious knowledge present a unique set of emotional demands.

Actors act on perceptions of conflict to fortify contentious knowledge against attack. However, because epistemic controversies and contestations are pluralistic, further research should consider how the structures that empower them are organized. The case of the alternative biomedical movement might offer insights into the persistence of other scientifically unsupported ideas and unorthodox practices. In recent years, scholars have emphasized the importance of investigating the social forces that sustain post-truth and developing insights into how post-truth movements can be resisted (Collins et al., 2017; Lynch, 2017; Sismondo, 2017b). Today, this research is of great urgency. The COVID-19 pandemic, in particular, has highlighted how the propagation of conspiracy theories and falsehoods is highly consequential. Misinformation about preventative measures (i.e. mask-wearing, staying-in-place, and physical distancing) and untested remedies has endangered public health, undermined disease control efforts, and drowned out credible sources (Bursztyn et al., 2020; Mian and Khan, 2020). Individual-level factors, like education, do not fully account for challenges to the authority of science and medicine (Reich, 2014). Thus, it is important to also approach resistance against experts as collective experiences and group processes.

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