



## “We were on our own”: Mothers' experiences navigating the fragmented system of professional care for autism

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### ABSTRACT

Autism is a developmental disorder that emerges in early childhood. Treatments for autism span a wide variety of professionals and paraprofessionals in the medical and educational realms. This article draws on data from a survey of 620 parents of autistic children, including 385 written narratives, to examine the experiences of mothers as they engage with this fragmented system of professional care for children with autism. Findings suggest that engagement with treatments sent families into a complex and confusing universe of diagnosis and treatment. The fragmentation of autism's professional jurisdiction between the medical and educational systems meant that mothers struggled to find comprehensive professional care that met the standards recommended by leading medical research organizations. Many mothers found it necessary to reduce their workforce participation in order to obtain and maintain their children's treatment regimes, a phenomenon that transcended social class. However, the consequences of reducing work had differential impacts on families. While married and high socioeconomic status mothers were more insulated from the potential negative effects of losing one partner's income, single and low SES mothers experienced greater precarity. These findings connect the structure and arrangement of professional jurisdictions to the experiences of parents, suggesting ways that the fragmentation of professional care for autism can have negative impacts for women, single mothers, and low SES families.

Sociologists of occupations and work have documented ways in which the system of American healthcare professionals has become less centralized and more fragmented over the course of the past several decades. Between increased medical specialization (McKinlay and Marceau, 2008; Weisz, 2005) and the explosion of paraprofessionals (Hoff et al., 2017; McKinlay and Marceau, 2002), medical jurisdictions of both individual practitioners and medical specialties have shrunk and the knowledge, skills, authority, and responsibility contained within them have become increasingly dispersed. The sociological literature on professions has focused extensively on the effects of these changes on medical professionals themselves (Abbott, 1988; McKinlay and Marceau, 2002; Menchik and Jin, 2014; Hoff et al., 2017), but researchers have paid less attention to the ways in which this fragmentation of professions affects healthcare consumers.

Here, I examine how the arrangement of professionals affects consumers and determines the nature and consequences of that consumption through the case of parents of children with autism, a neuro-developmental disorder with onset in early childhood that affects an estimated 1 in 68 American children (Centers for Disease Control, 2016). Although autism is primarily seen as a medical disorder and is typically diagnosed by a physician (Eyal et al., 2010), treatment does not fall neatly along professional boundaries. Rather, treatment is split

between the medical and educational realms, within which a large number of professionals and paraprofessionals further divide tasks (Leiter, 2005).

I locate this study within the larger literature on parents of children with disabilities (Green et al., 2017), which has documented that parents often struggle to acquire support from medical and educational professionals (Blum, 2015; McKeever and Miller, 2004; Todd and Jones, 2003). It has also shown that many parents feel that they must reduce their workforce participation in order to successfully navigate their children's healthcare needs (Litt, 2004; Rogers and Hogan, 2003; Scott, 2010). However, current work has not connected parents' struggles to obtain services, nor their decisions to leave the workplace, to the structure and arrangement of the professions providing care for children with disabilities.

Drawing on data from a survey of 620 parents of autistic children, 385 of whom opted to write detailed narratives about their children's life story, I address this gap in the literature by explicitly connecting the fragmented system of professional care for autism to the disruption of parents' workplace participation. As I show, parents felt a moral imperative to enroll children in intensive programs of medically-approved treatment at an early age. However, the fragmentation of autism treatment across different professional realms made it difficult and time

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consuming to navigate treatment and obtain services. Many parents in this study, especially mothers, found that they had to reduce or otherwise alter their workforce participation in order to make the time necessary to navigate services and coordinate between providers. This phenomenon transcended social class, although the consequences of leaving work had a more negative effects on lower SES families.

My findings connect sociological studies of medical professional jurisdictions to studies of family care workers by showing that the structure of healthcare delivery can have important consequences for patients and their families. In combining these two literature, I situate the process of health care consumption and its family-level consequences within the structural and historically-informed trajectory of professions and professionals. The fragmentation of professional care may have the unintended consequence of reinforcing women's inequality by increasing the burden of unpaid care work that brings them out of the paid workforce. It may also reinforce disadvantage among families already living on limited resources by forcing them to choose between financial stability and the well-being of their children. These potentially cumulative outcomes, both gendered and socioeconomic, are obfuscated without the linking of patient and family narratives and the professional context in which they are created.

## 1. Family caregivers, medical professional jurisdictions, and autism

### 1.1. Gender, socioeconomic status, and family caregivers

A large literature on gender, work, and the family documents the experiences of family caregivers, individuals who provide support for sick, elderly, and disabled family members (Hogan, 2012; Leiter et al., 2004; Levitsky, 2014; Ong-Dean, 2009). Family caregivers engage in direct forms of care work, like managing medical technologies and administering medications and therapies, as well as more indirect forms of care, like advocating for services and coordinating providers (Litt, 2004). These duties typically fall to women, in part because of social norms that suggest women are “naturally” better suited to caregiving than men (Blum, 2015; Levitsky, 2014; Scott, 2010). These norms are undergirded by structural inequalities, such as men's typically higher salaries, which make it “economically rational” for men to invest more effort in paid work compared to their lower-paid female counterparts (England, 2010; Petersen and Morgan, 1995).

While some scholars document the ways caregivers benefit from providing care to sick or disabled family members (Green, 2007), many others find that acting as family caregivers can have negative consequences, particularly for women. For example, caregiving can restrict women's ability to participate in the paid workforce (Levitsky, 2014; Rogers and Hogan, 2003). Women who leave the workforce, even temporarily, can lose out on earnings, promotions, and pensions (Budig and England, 2001; Hogan et al., 2005). They may become more financially dependent on marital partners, which can give them less negotiating power in marriages and make it more difficult to leave marriages that turn bad (England 1989). Therefore, having a sick family member may exacerbate gender inequalities by creating extra unpaid care work that women have to reduce their paid work to manage.

Socioeconomic (SES) status shapes women's ability to adjust to the financial strain that may come from reducing work to care for a sick family member. While married and wealthier women may have stronger social safety nets that allow them to afford decreased salaries with minimal consequences, single and poor women may be less able to manage absences from paid work (Litt, 2004; Lukemeyer et al., 2000; Scott, 2010). At the same time, SES may influence the extent to which women become actively involved in family members' healthcare. While low SES women may be more likely to have sick family members (Hayward et al., 2000), higher SES women may have greater cultural health capital (Shim, 2010) that enables them to engage in sophisticated research related to loved ones' health and steer the direction of their

medical treatment (Gengler, 2014).

When explaining the burdens placed on family caregivers, scholars of gender and the family typically point to the inadequacies of public assistance programs (Litt, 2004; Lukemeyer et al., 2000), the inflexibility of the paid workforce when it comes to family medical leave (Gornick and Meyers, 2005), and the lack of remuneration for informal care work (Glazer, 1988; Levitsky, 2014). The limitations of policies like the 1993 Family Medical Leave Act (FMLA), the 1996 Personal Responsibility and Work Opportunity Reconciliation Act (PRWO), and 1997 Temporary Assistance to Needy Families (TANF) have made it difficult for women to balance employment with care work while simultaneously demanding that they achieve this balance. However, these studies focus on the social supports available to caregivers once they reduce work rather than problematizing the ways that the fragmented healthcare delivery system can create the need for extra care in the first place. Researchers who do focus on the structure of the healthcare delivery system have shown that economic pressure to discharge patients from hospitals “quicker and sicker” devolve responsibility onto unpaid family members in order to save money (Donelan et al., 2002; Light, 2001). However, these scholars do not consider the ways that the *arrangement* of the professionals within the healthcare delivery system might shape the experiences of family caregivers.

### 1.2. The professional jurisdiction of childhood disabilities

Scholarship from medical sociology points to ways that the structure and arrangement of the healthcare delivery system might be vitally important to understanding the experiences of patients and their families. Changes in healthcare in the past several decades have led to a system that is less centralized and more fragmented than in the past. Professional “jurisdictions,” the areas of work over which professions compete (Abbott, 1988), have shrunk in medicine due to specialization (McKinlay and Marceau, 2008; Weisz, 2005). Further, the rise and expansion of paraprofessions, which include physical, occupational, and speech therapists, chiropractors, and other non-physician clinicians, have further fragmented medicine's jurisdiction (Hoff et al., 2017; McKinlay and Marceau, 2002). These actors, whose interests and ethics are not always well-aligned with those of physicians, also compete for and often win control over aspects of medical care. The implication is that patients now must see a larger number and kind of healthcare workers to get comprehensive care than they would have in the past. However, work in this field has rarely connected the structure of the healthcare delivery system to the experiences of family caregivers in navigating diagnosis and treatment for children with disabilities.

The jurisdiction of childhood disabilities is especially complex because it is divided between the medical and educational systems (Leiter, 2005). This division is in large part the result of the Individuals with Disabilities Education Act (IDEA), a federal law passed in 1975 aimed at community integration for children with disabilities, many of whom had previously been cared for in custodial institutions away from their families. IDEA requires public schools to provide appropriate education for children with disabilities, including special education services, and classrooms that resemble those of non-disabled students (EACHA, 1975). Amendments to this law have established that children below school age who are diagnosed with disabilities are entitled to services through state-run Early Intervention programs, which aim to minimize special educational needs before children enter public schools (IDEA, 1997).

Parents of disabled children fought for the passage of IDEA and its amendments, seeing these changes as essential to children's integration into community and family life (Leiter, 2004; Ong-Dean, 2009). Yet, with its passage, IDEA effectively split the jurisdiction of childhood disabilities in two, meaning that parents have to coordinate between professionals in both the educational and medical systems in order to obtain comprehensive care for their children. Today, many children with disabilities receive diagnoses, prescriptions, referrals, and

therapies from doctors and medical paraprofessionals while also receiving referrals and therapies from special educators and paraprofessionals attached to schools and early intervention programs (Leiter, 2005). Further, children typically need medical diagnoses to receive educational services, meaning that these disabilities have become both medical and educational problems. In this paper, I will argue that this bifurcation of the jurisdiction of childhood disabilities has created more work for parents. My analysis reveals the unintended negative consequences of this new system.

### 1.3. The case of autism

The professional arrangements and caregiver demands of autism are like those of many other childhood disabilities whose diagnosis, treatment, and care are divided between the medical and educational realms following IDEA. In this sense, the experiences of parents of autistic children can speak to those of parents of disabled children more broadly. Autism is unique in some ways, however. It constitutes an “invisible disability,” a class of social, emotional, and behavioral disorders for which rates of diagnosis have been rising in recent decades (Blum, 2015). Invisible disabilities generally lack physical markers that would make their presence obvious to onlookers. Autism is also different from other invisible childhood disorders in that there is no single pharmaceutical treatment that can comprehensively alleviate symptoms, as Ritalin and similar drugs have done for ADHD (Eyal et al., 2010). In the absence of such drugs, ameliorative therapies, including speech therapy, occupational therapy, physical therapy, behavioral modification therapy, play therapy, and many others, are generally seen as the most effective way to rehabilitate an autistic child. Children with autism are typically engaged in more therapies than children with other invisible disorders, with the average autistic child participating in six forms of therapy (Green et al., 2006). In this sense, autism's jurisdiction may be particularly fragmented compared with that of other childhood disabilities.

Eyal et al. (2010) support this point in their detailed account of changes to autism's professional jurisdiction after deinstitutionalization in the 1970s. They describe a “great, silent revolution” taking place in the early 1970s in which the jurisdiction of children's developmental disabilities was “extracted” from child psychiatry and invaded by a variety of paraprofessionals, including psychologists, speech therapists, occupational therapists, behavior modification therapists, special educators, and others, who could benefit in terms of money and prestige from occupying this jurisdiction (Eyal et al., 2010, page 125). Parents often endorsed these new actors, preferring their methods to those of psychiatrists who recommended extreme measures for the treatment of autism-like symptoms, including electro-convulsive therapy, and tended to adhere to parental neglect as an etiology. In particular, “refrigerator mothers” (e.g. emotionally cold) were said to cause their children's autism through a lack of maternal warmth (Kanner, 1943; Bettelheim, 1967).

These peculiarities make autism a useful case for investigating how the fragmentation of a professional jurisdiction influences family caregivers. This article connects the sociological literature on gender and care work to the literature on jurisdictional structures, two literature which are not usually in conversation. The experiences of mothers of autistic children show how the fragmentation of professional care for autism creates extra care work for mothers and how the ability to manage extra care work may differ by SES.

## 2. Data and methods

This article draws on data collected through an IRB-approved survey of parents of autistic children living in the United States conducted between September 2010 and April 2011. I distributed the survey by contacting over one hundred websites, blogs, and mailing lists associated with autism and parents of children with autism and

**Table 1**  
Descriptive statistics.

	Full Sample	Narrative Writers	Parents who Altered Work
N	620	385	85
% Women	93.3	95.8	98.8
% White	90.3	89.9	92.9
% Bachelor's Degree or More	69.5	73.2	71.1
Median Parent Age	43	42	42
Parent Age Range	23 to 72	25 to 64	28 to 62
Median Child Age	10	10	10
Child Age Range	2 to 51	3 to 30	3 to 30
Median Number of Children	2	2	2

asking them to share the survey with their online community. 620 parents completed the survey, answering close-ended questions about themselves, their children, their engagement with physicians and paraprofessionals, and their sources of information about autism, and their pathways to diagnosis. Of the 620 parents who answered the survey, 385 chose to answer an additional open-ended question inviting them to tell “the whole story” of their experience with autism, from first noticing a problem, to obtaining a diagnosis, to the choices they have made for their child since diagnosis. These narratives are the main focus of this study. While I draw descriptive statistics from the broader pool of 620 survey respondents, survey questions were mostly focused on the process of obtaining an autism *diagnosis*. For example, questions asked how many doctors children had seen prior to diagnosis and how much time elapsed between the first suspicion of autism and official diagnosis. Responses to closed-ended survey questions, therefore, do not shed light on parents' experiences navigating autism *treatment*. Despite the fact that survey questions focused on the moments leading up to diagnosis, narrative writers focused a great deal of their story on treatment, the focus of this paper.

Table 1 displays demographic information about the total population of parent respondents, the subgroup of parents who wrote narratives, and the subset of those narrative writers who reported altering their workforce participation as a result of their child's autism. These subgroups were demographically similar to the survey population, with the notable exception of gender. Women were overrepresented in the sample as a whole (92.8% of respondents were mothers), and to a greater degree among the group of narrative writers (95.8%). Women also made up the majority of respondents who reported altering their workforce participation because of their children's autism (98.8%) Participants in this study reflect other findings that show that mothers take on a disproportionate amount of the labor associated with raising children with disabilities (Litt, 2004; Rogers and Hogan, 2003; Scott, 2010). The parents who participated in my study are more highly educated and more white than the general population, but may reflect the population of parents of autistic children more generally, as autism diagnoses are more prevalent among the socially advantaged (King and Bearman, 2011).

### 2.1. Data analysis

Analysis of written narratives involved iterative inductive and deductive processes, based in abductive analysis (Timmermans and Tavory, 2014). An initial round of open coding generated a series of potential hypotheses and a second more focused round of coding systematically explored each narrative for the hypotheses developed during open coding and allowed for their elaboration (Saldaña, 2016). After this second round of coding, I conducted a preliminary analysis of codes in order to identify and elucidate major patterns occurring in the data. Of the 385 women who wrote narratives, roughly half (174) reported decreasing workforce participation at some point in their child's

life, while only two of 16 male respondents reported decreasing work. Of these parents who reduced or otherwise altered their workforce participation, 85 individuals, 84 women and one man, explicitly connected their decisions to reduce workforce participation to their child's autism. Due to this absence of stories of men leaving work, I chose to focus my analysis on the experiences of mothers. In a third round of coding, I focused specifically on the experiences of mothers who left the workforce, cut back hours, or switched jobs because of having an autistic child. In order to protect individuals' privacy, all names used in this paper are pseudonyms.

### 3. Findings

The vast majority of parents in this sample viewed autism as a medical disorder caused by genetics (40%), gene-environment interaction (39%), or vaccines (15%). In accordance with this interpretation, nearly every parent in the sample expressed support for the kinds of treatments endorsed by the medical establishment and sought care for their children therein. While the treatments employed by parents of autistic children are notoriously broad in range (Green et al., 2006), most of the parents in my sample reported enrolling their children in some combination of “ameliorative therapies,” a term I borrow from Eyal et al. (2010) to describe the wide variety of educational, behavioral, and developmental therapies that are typically available through public school systems, state early intervention agencies, and private agencies. These therapies include occupational and speech therapies, music and play therapies, and autism-specific therapies, like Applied Behavioral Analysis (ABA). Although these modes of therapy differ in their specific approach to treatment, they share a conceptualization of autism as a medical disorder whose symptoms can improve through regular, and often intensive, work with a trained therapist. These ameliorative therapies are described as the most effective treatments for autism by medical research organizations, such as the National Institute of Neurological Disorders and Stroke (2017) and the National Research Council (2001), and autism advocacy organizations, such as Autism Speaks (2010).

In accepting the medically recommended approach to treating autism, parents encountered a problem: obtaining and maintaining the ameliorative therapies prescribed by the medical establishment could be challenging. This challenge often pulled parents, and especially mothers, out of the workplace, as I will now show. While parents of young children reduce workforce participation for many reasons (including childbirth), in 85 narratives, parents' decisions to reduce workforce participation were specifically related to their autistic child's healthcare needs. Of these 85 parents, 43 (50.5%) quit work entirely; 16 (18.8%) cut back their hours at work; 15 (17.6%) switched to more flexible jobs or ones that were autism-related; 7 (8.2%) did not go back to work as planned after a period of time off; 3 (3.5%) were fired because of taking too much time off for childcare; and 1 (1.2%) chose not to accept a higher paying job that would require moving out of state.

How did parents explain their decisions to reduce work? About half of the subsample of parents who altered work because of their child's autism (48) described in detail the particular aspects of raising a child with autism that demanded adjustments to their employment. I divide their explanations into two broad, non-mutually exclusive descriptive categories: *decentralized services* and *mismatch between scientific recommendations and available services*, which I describe in sections 3.1 and 3.2. The divisions between service providers may allow them to shift responsibility onto others, permitting them to deny responsibility for individual children, a topic I cover in section 3.3. An analysis of differences in experience by SES in section 3.4 reveals that mothers from all class backgrounds found it necessary to reduce work, but that single and low-income mothers experienced greater precarity as a result of these decisions.

#### 3.1. Decentralized services

The 28 mothers who reported reducing work because of decentralized services wrote about the need to coordinate between the various groups, institutions, and individuals who cared for their children. Dana was one of these mothers; although she lived in a top-ten city for autism services and resources, according to Autism Speaks (2011), a major science and advocacy organization, she was astonished at how complicated it was to access services. “As a social worker,” she writes, “I know how to locate and navigate systems. However I had never done it to this extent...I found that there is absolutely no coordination or collaboration amongst systems.” Even with her expert knowledge about navigating social services and living in a city with ample resources, Dana struggled to obtain and manage services for her daughter. She ended up leaving her job: “I stayed home to oversee Samantha's programs and get her where she needed to be all over town.”

Other mothers told similar stories. Lisa left her job as a kindergarten teacher to start “24/7 therapy” and homeschooling. In her narrative, she expressed frustration with her doctor's lack of knowledge about autism treatment: “I wasn't told how to deal with this, just that it was autism... [Our doctor] didn't know the battle plan. After I got home and researched [autism], I phoned him back to ask what to do. The response was to put Timmy in therapy or something. No referrals. No suggestions.” Louise, who had an Associate's degree, wrote, “I've had to stay home in order for her to get the treatments [my daughter Chloe] needs. I'm not certain how parents who work are able to keep up with all the treatments.” Alice, a high school graduate, described similar dismay: “With multiple therapy appointments, doctors' appointments for everything and then some... it's *very* work intensive” (emphasis original). These stories underline how autism's fragmented jurisdiction caused parents to struggle with obtaining and maintaining their children's services. Finding that there was “no collaboration among systems,” they themselves had to coordinate care for their children, a task that could be “very work intensive.” Their stories indicate a link between the structure of autism's professional jurisdiction and the experiences of families in raising their children.

One of the main themes among mothers who wrote about leaving work due to decentralized services was the time it took to transport children between appointments with different professionals. Dana's comment above about leaving work to take her daughter Samantha “all over town” is revealing of how the professional and physical decentralization of children's services could demand mothers' time. Some mothers reported having to travel long distances to take their children to different appointments, which could add hours of extra work to their lives every week. Janine, a graduate-educated mother, traveled forty miles a day to take her son to therapy appointments. Similarly, Amanda, a college graduate, “cut [her] work hours down to almost nothing” to drive her son fifty miles to speech therapy, occupational therapy, play therapy, and music therapy four times a week in the nearest city. Even in the best of situations, committing to therapy could require sacrifices. Sarah, a married 43-year-old professional with a post-graduate degree living in a large West Coast city, described her son's preschool as “really wonderful” because they allowed his therapists to be present at school all day. Yet she still reported having to cut back some work hours so she could drive him to speech and occupational therapy a few times a week. For these mothers, navigating the bifurcated jurisdictions of autism treatment made it impossible to maintain fulltime paid work.

#### 3.2. Mismatch between scientific recommendations and available services

Twenty mothers reported reduced work because they were unable to find a satisfactory quality and/or quantity of care for their autistic child within the medical and educational systems. Mothers often found that state- or federally-funded services fell short of the amount of the minimum of 25 h of therapy per week recommended by the National

Research Council (2001), the organization whose standards are used by the National Institutes of Health and U.S. Department of Education. Other research advocates 40 h per week of therapy (Dawson and Burner, 2011). Many parents in my sample attempted to adhere to the 25–40 h standards, seeing compliance with scientific recommendations as imperative to their children's well-being. Yet, they struggled to achieve this goal. Eleanor, a college graduate, summarized this sentiment in her narrative:

I think the decision to have me quit work/school to stay home with him was the best thing that we could offer Thomas. No one else loves our son as much as we do, nor would they devote as much time to working with him. The public school system is a joke and many insurance companies prevent access to the specialists that could be of assistance....The additional one-on-one time gave us extra time to listen to what he needed/wanted and to better explain what is required by others.

Her narrative exemplifies a common parental statement in this research: the services available to children through public schools and those covered by health insurance were not sufficient for their child's needs. The only way to obtain a fully adequate program of treatment was to do it oneself. And for parents attempting to meet the 25–40 h per week therapy recommendation, this could leave little time for fulltime paid employment.

Other mothers wrote about quitting work to provide services for their children while waiting for an official autism diagnosis, a necessary precondition to receiving state-provided services. Medical research suggests that children with autism benefit from early intervention with ameliorative therapies (Zwaigenbaum et al., 2015). The National Research Council (2001) recommends that children begin intensive therapy at age two. Narratives indicated that parents who took this survey were aware of these standards, but that obtaining a diagnosis that would allow them to meet them could be difficult. Parents in this study waited an average of two years between first suspecting autism and obtaining an official diagnosis, a time period that typically spanned ages two through four for their child. Parents offered several explanations for this delay, most of which had to do with barriers in the medical system. Many parents encountered long wait lists for qualified diagnosticians. They often met resistance from doctors, some of whom wanted to “wait and see” how the child developed before giving a diagnosis or who denied that the child was experiencing autism symptoms altogether.

Ineligible for state-run Early Intervention programs or public school services, parents waiting for diagnoses could either pay out-of-pocket for private therapists or learn to administer therapies themselves, a practice that autism professionals refer to as “co-therapy.” While some parents who opted for the former option *increased* their paid workload in order to afford therapy, many parents who conducted co-therapy *reduced* their workforce participation. Emily, a college graduate, discusses the impact co-therapy had on her workforce participation:

I am so glad that we started [therapy] immediately and did not wait for the state or school district to do it for us. We would have lost more than 7 valuable months and may never have gotten a 35–40 hour a week program... I was able to make Taylor's autism my full time job without a significant loss in wages. I hate to think how hard this would have been otherwise.

Emily's story shows that her decision to reduce her workforce participation was driven by the long wait for publicly provided services. For her, obtaining adequate services would have been difficult if she had not reduced her work to make Taylor her full time job. At the point of completing the survey narrative, she expressed her commitment to co-therapy, as she felt that state-sponsored services would never have been comparable to what she was able to provide for Taylor at home. Emily's story, however, was somewhat unusual because this decision did not come with negative financial consequences, as it did for many

other mothers.

### 3.3. Denying responsibility

The decentralization of autism services gave providers the opportunity to deny responsibility for treatment: they could claim that care for an autistic child fell onto a different institution. Parents reported feeling that they were being batted back and forth between the medical and educational realms, told by each that the care they sought was the responsibility of the other. This made the placement of responsibility for care complicated and confusing: parents struggled to determine who was ultimately responsible for their child's treatment. Not knowing where to turn for help was a common theme in narratives. Parents from all SES backgrounds described being denied help by doctors, schools, and others. Some mothers, unwilling to take “no” for an answer, engaged in “battles” with school districts in order to obtain required services they felt the district had a mandate to provide. Acting as their children's legal advocates could become a fulltime occupation, pulling mothers' away from paid employment. A few mothers wrote that they quit or reduced work in order to fill this role. Barbara, who had a graduate degree, states, “I had to give up my job entirely in order to manage the lawsuit against the Board of Ed [ucation] for reimbursement.” Jane describes a similar experience:

When Liam was diagnosed, I decided that my number one obligation was being mom to my three sons. My number two obligation is to serve as Ian's advocate. I became educated on the law. I even went back to get my Master's degree in special education, specializing in students with autism. I want to be knowledgeable in the best way to teach students with autism so that I can speak about it at Liam's IEP meetings and be treated with respect because of my specialty. I believe that this helps Ian receive the services that he is entitled to in the school system.

Jane's pursuit of graduate education was not aimed at improving her desirability or compensation in the workforce; rather, she used it as a tool to secure resources from her son Liam's school. This career move would most likely have been unnecessary if the public school system readily accepted responsibility for providing special education services to children with autism. Jane's story reveals ways that socioeconomic privilege can benefit children: Jane was able to afford a career shift that allowed her to focus more attention on advocating for Liam. She credits leaving work to earn a Master's in special education with the provision of services for Liam through the public school system.

Single and low SES mothers had a harder time navigating services when the service providers denied responsibility. Heidi, whose son Tanner had major behavioral problems, described some of the challenges of fighting to obtain autism services as a single mother who could not afford to leave work to pursue autism advocacy-relevant education:

Some mornings Tanner would be so out of sorts and stressed out that he would begin hitting and attacking me or his sisters. I took him to the Children's Hospital Emergency room to see what sort of support my family could get. They often just told me that there was nothing they could do. It was affecting my ability to keep a job and support my family because I was unable to get to work on time.

At the same time as the medical system denied Heidi help with Tanner, the school system refused to give Tanner the services that might help him, labeling him with behavioral problems rather than a disability. Much of Heidi's 2500 word narrative – one of the longer ones in my sample – was dedicated to describing her battle to obtain services for Tanner with a school district that did not believe caring for this child fell within its jurisdiction. “Tanner's school refused to acknowledge that their program did not address Tanner's classroom needs and was only traumatizing him...They began expelling him from school and requiring that he go through an apology process before being allowed

back in. He refused.” Heidi lost her job because neither the healthcare system nor the school district would provide comprehensive care for Tanner, the consequences of which I will discuss in greater detail in the next section.

### 3.4. SES, family structure, and precarity

For the participants in my study, the feeling that they had a moral imperative to enroll their autistic child in intensive programs of therapy transcended expected social class differences in childrearing styles (Lareau, 2003): nearly all parents sought various therapies, often fighting to obtain the desired amounts and types of services, sometimes at great personal sacrifice. Even in this fairly privileged sample of mothers, study participants often wrote about facing economic hardship as a result of leaving work. In two-parent families, losing one partner's income often meant living more frugally. Married mothers wrote that they were “thankful,” “fortunate,” or “privileged” to have husbands whose income could support their decision to decrease workforce participation to focus on their autistic child. Georgia, a married, college-educated mother, wrote that the best decision she made for her daughter Franny was leaving the workforce for five years to help navigate Franny's treatment. “I regret it personally because it really hurt my professional career,” she says. “But it was the only right thing to do. We are privileged that my husband's income by itself could support the family.” Amber, also a married, college-educated mother, echoed Georgia: “Thankfully, my spouse supported me 100% and has provided financially for our family and made it possible for me to help our son be where and who he is today.”

Although mothers across social classes complained of the financial stress caused by losing income, higher-SES families tended to report less severe adjustments to their decreased family income than lower-SES families. Higher-SES families generally found that their budgets were tighter, but they were still able to pay for the necessities of life and did not have to make major sacrifices. Adjusting to loss of income was more difficult for low SES and single mothers, who did not have the option of relying on a partner's income to support their family. The impact of altering workforce participation in a one-income household created precarious situations. Joyce, a single mother with a high school education, describes sacrificing health insurance for flexible work hours:

The only job I could find that would let me off when Teddy needs care is low paying with no insurance but I make just enough that I do not qualify for any real assistance. Teddy does receive Medicaid and some SSI, but if I find a better job then I will not be able to afford insurance for him. At the moment my other two children and I do not have insurance. Friends go away when you have children with a disability. We do not have family close by because if I move I cannot be sure I will be able to support my family.

Because Joyce was unable to find a job that would provide medical benefits and allow her to take time off for her autistic son, she and her other two children lived without insurance, an arrangement that left the family vulnerable to the possibility of financial disaster should an emergency arise.

Heidi's story presents a more extreme example of the precarity of being the single parent of an autistic child. Heidi became a single mother when Tanner was five years old. After a long battle with Tanner's school, she was able to obtain a trial run with in-school services. After Tanner had a major outburst, however, the district decided to provide him with instruction at home. Heidi had to stay home for Tanner to receive services, making it impossible to work. She writes, “Without a job, I couldn't pay for a place to live. We ended up in a homeless shelter.” Heidi's experiences highlight the precarity of raising a child with autism as a single mother on a limited income. Although Heidi's story is extreme in terms of the stories represented in my sample, it is illustrative of the difficulties that less privileged families can face in navigating autism treatment.

## 4. Conclusion

Engagement with medical interpretations of autism can send families on a journey through a complex system of diagnosis and treatment. In order to adhere to medical recommendations encouraging early and intensive therapy for autistic children, the parents in my sample had to coordinate and negotiate among the multiple actors and institutions who span autism's professional jurisdiction. Navigating these fragmented systems demanded a great deal of time and effort from parents, especially mothers, who generally took on a greater share of family caregiving duties. Many mothers attributed their decisions to reduce their workforce participation to the fragmentation of the healthcare delivery system, a phenomenon that transcended SES. The consequences of reducing work had differential impacts on families: Married and highly educated parents were more insulated from the potential negative effects of losing one parent's income; single and low SES parents, however, experienced greater precariousness.

The experiences of parents within the fragmented medical world of autism treatment demonstrate how the structure of the healthcare delivery system has unintended consequences for patients and their families. This finding contributes to the sociological studies of gender, work, and the family, which have demonstrated that that having a child with a disability can pull mothers out of the workforce (Litt, 2004; Rogers and Hogan, 2003; Scott, 2010), but that typically associate their difficulties with the inflexibilities of the paid workforce (Gornick and Meyers, 2005) or the inadequacies of federal- and state-level social welfare programs (Glazer, 1988; Levitsky, 2014; Litt, 2004). Instead, this study points to the ways that the fragmentation of medical professional jurisdictions can generate extra care work that may cause primary family caregivers – usually mothers – to reduce their workforce participation. That is not to say that the inflexible paid workforce and inadequate social welfare did not play a role in mothers' decisions to reduce paid work or their shape experiences after making these decisions. In fact, the stories of low-SES and unmarried mothers like Heidi and Joyce, who encountered extreme financial precariousness after altering their workforce participation to accommodate their children's needs, provide strong support for improvements to policies like FMLA and TANF that would help family caregivers remain financially stable when reducing workforce participation in response to navigating treatment options. Rather, I argue that many of the extra care work duties that caused mothers to leave work were *generated by* the way that the professional jurisdiction of autism treatment is split between medicine and public education, and their associated professionals and paraprofessionals. Policies aimed at improving the lives of family caregivers should therefore take the structure of the healthcare delivery system into account.

This study suggests that sociologists working on medical professions and the healthcare delivery system should pay greater attention to the consequences of changes in the arrangement of professions for patients and their families. These sociological subfields tend to focus more on how professional changes affect professionals themselves (Abbott, 1988; McKinlay and Marceau, 2002). When scholars do consider how changes in the healthcare delivery system affect patients, they typically focus on the ways in which economic constraints under managed care have “devolved” labor onto medical “consumers” (Donelan et al., 2002; Light, 2001). However, the professions literature demonstrates that changes occur in the healthcare delivery system for reasons unrelated to economic constraints. Changes in the professional jurisdiction of autism treatment have to do with inter- and intra-professional battles for power as well as parents' own advocacy for services that would enable their children's integration into communities and family life (Eyal et al., 2010; Leiter, 2005). These changes may come with the unintended consequence of extra burdens for families. Research on families of children with disabilities have shown that parents often struggle to acquire support from medical and educational professionals (Blum, 2015; Green et al., 2017; McKeever and Miller, 2004; Todd and Jones,

2003), but has not explored the various ways that the arrangement of professional care can create confusion and difficulty in this process. My research reveals the importance of putting this literature into communication with the literature on professions in order to situate the family-level consequences of disability within the structural and historically informed trajectory of professions and professionals.

There are several limitations to this study. First, collecting data through websites and blogs may have drawn a sample of parents who are more likely to be highly educated and white than the general population. Sociological research indicates that parents from these backgrounds might be more actively involved in their children's healthcare (Gengler, 2014) and in their education and extra-education activities more broadly (Lareau, 2003). As a result, higher SES parents might be more likely than lower SES parents to engage with autism therapies in a way that pulls them out of the workforce. Further, my sample likely overestimates the extent to which parents of autistic children leave the workforce. Parents who reduced their workforce participation may be more likely to take the time to participate in the online autism community and therefore to encounter and respond to this survey. They may also have been taken more time to write detailed narratives. Additionally, online autism communities may attract a particular kind of parent – namely those who search for and engage in every available therapeutic option – meaning that the experiences of parents in my sample may not be representative of parents with children with autism more broadly.

Second, although parents of autistic children share some commonalities with parents of children with other disabilities, it is not clear to what extent my findings might be applicable outside of this particular case. Comparative research suggests that parents of autistic children spend more time providing care for their children at home than those of children with other invisible disorders (Romley et al., 2016), but further research is needed in order to understand the extent to which these differences are related to the structure and arrangement of professional services. Finally, while this article describes pathways of autism parenting that emerge out of a medical interpretation of autism, I am unable to speak to whether these pathways are more or less labor-intensive for parents who espouse or encounter a different approach to autism. It is possible that alternate interpretations may require more time and effort from parents because the symptoms that make it challenging for children to fit into schools and communities are not ameliorated by therapies. I posit that this would be most likely in the case of children with low-functioning and/or severe autism who are also most likely to receive a timely medical diagnosis. For high-functioning and/or mild autism, the engagement with medical treatments may itself be a cause of extra care work that causes parents to leave the workplace. However, the fact that the parents in my sample left work *after* diagnosis rather than *prior* to diagnosis suggests that engagement with medical treatments itself generated extra work. Future research on this topic should compare the experiences of parents who avoided medical approaches to autism to those who did not in order to provide further evidence for this idea.

Despite these limitations, this study highlights the importance of the structure and arrangement of professional jurisdictions to the experiences of parents raising children with autism. The bifurcation of autism's jurisdiction between medical and educational professionals creates a situation that pulls many mothers out of the workforce, a phenomenon that has the potential to reinforce gender and socioeconomic inequalities.

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