

# Policy Awareness, Financial Hardship, and Work Impact: Correlates of Negative Experiences With Health Care Providers and Health Care Insurers Among Caregivers of Children With Autism Spectrum Disorder

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## Abstract

Individuals with disabilities often report difficulty interacting with health care professionals. Addressing this challenge requires greater understanding of factors that exacerbate the odds of negative interactions between health care providers and patients with disabilities. Drawing on the qualitative research describing the features of such incidents, we use logistic regression to explore two dimensions of this dynamic: negative experiences with health care providers (e.g., doctors, specialists) and negative experiences with health insurance carriers (e.g., for profit or non-profit health insurance organizations). Using a non-probability sample of American families who have a child with autism spectrum disorder (ASD), we find that negative experiences with health care providers are associated with the family's income level, as well as changes in parental labor force participation. The odds of a negative interaction with the insurance carrier are intensified when the family experiences financial difficulties and when they have a negative experience with the health care provider. Finally, families who are aware of laws and policies regarding ASD also report increased odds of negative experiences with their insurance carrier but not their health care provider. Policy implications of our findings are discussed.

## Keywords

health care, children, autism spectrum disorder, awareness

Not long ago, health care providers rarely interacted with children with autism spectrum disorder (ASD<sup>1</sup>; American Psychiatric Association, 2013; Grinkler, 2007). Until the last decade or so, some family physicians reported never having a patient with ASD. This situation has changed (Lantos, 2007). Although a vigorous debate continues as to whether or not the prevalence of ASD has genuinely risen, the rate at which children are diagnosed with ASD has grown substantially in the last 20 years (Saracino, Noseworthy, Steiman, Reisinger, & Fombonne, 2010). Whereas ASD was once expected to affect about 1 in every 10,000 children, in the post-millennial world, ASD occurs in somewhere between 1 in 500 children (Fombonne, 2009) to 1 in 68 children (Centers for Disease Control and Prevention, 2014). Having a health care practice not including a patient with ASD is becoming increasingly unusual.

Even so, health care infrastructures incompletely include individuals with ASD. Many individuals with disabilities, including those with neurological differences, report unusual difficulty accessing services (e.g., Chiri & Warfield, 2012;

Warfield & Gulley, 2006) and interacting with health care professionals (Callahan & Cooper, 2006; Smith, 2008). Part of these difficulties arose from a history of expansive social discrimination against individuals with disabilities including often unnecessary institutionalization. Disability activists have at times attributed social exclusion of individuals with disabilities to the “medical model” of disability (Shakespeare, 2008). This characterization is connected to both historical and ongoing experiences of individuals with disabilities in their interactions with members of the medical community.

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However, it also ignores more positive experiences and productive relationships. Use of the phrase “medical model” as a derogatory term can create both the impression and actual existence of hostility toward all health care providers.

Regardless of the motivation for alienation, creating more effective health care policy and practice for persons with ASD requires a better understanding of factors increasing the likelihood of a negative interaction between those working in the health care system and individuals with disabilities. This article explores the factors affecting the negative experiences of families with children who have ASD, their health care providers, and their health care insurers.

We focus on health care providers and health care insurers separately because many parents are seeking services for their child with ASD in a private health care market, where they are tasked with working with their child’s physician or other direct-service providers to obtain services that will assist the child as well as interacting with the insurance carrier to ensure that the services recommended by the pediatrician will be covered by the family’s health plan. As such, we define “health care providers” as medically trained personnel who provide direct-service medical care to patients with ASD (e.g., doctors, nurses, occupational therapists, etc.). These providers are distinct from the individuals working in health insurance companies, who disburse funds to said patients (and their families) to cover the costs of these services (hereafter referred to as “health insurance carriers”).

The intensity of parents’ experiences with these policy subsystems may result in conflict or other challenging interactions as they negotiate caring for a child with ASD. While several analyses have carefully studied how parents of children with ASD are treated by individuals working in the health care system (Gray, 1993; Hutton & Caron, 2005; Ryan & Cole, 2008) and how they engage treatment options offered by their health care providers (Valentine, 2010), the role of a critical player in care for persons with ASD—the health insurance carrier—is largely absent from scholarly study of parent care for children with ASD. This distinction is not a minor one. In private health care settings, providers may advocate parents to pursue one ASD treatment approach for which their health care insurer refuses to provide financial coverage. As such, we investigate whether the factors associated with a negative health care experience among families caring for a child with ASD are unique to each entity. In our study, we answer three primary research questions:

**Research Question 1:** What, if any, are the correlates of negative experiences between caregivers of a child with ASD and their health care providers?

**Research Question 2:** What, if any, are the correlates of negative experiences between caregivers of a child with ASD and their health insurance carriers?

**Research Question 3:** Do they overlap? These analyses will shed light on potential changes to practice and to

health care policy, which could result in improved interactions between individuals with disabilities and health care systems.

## Background

### *Providing Care for Individuals With ASD*

Patients with ASD can present unusual challenges for health care providers (Gurney, McPheeters, & Davis, 2006; Meyers & Johnson, 2007). The highly variable nature of this neurological difference among individuals can challenge physicians’ abilities to make an accurate diagnosis of the condition. In addition, prognoses for children diagnosed with ASD are also unreliable (Matson & Smith, 2008). In the past, the vast majority of children diagnosed with ASD became adults who, if not institutionalized, were almost certainly dependent on their families of origin and social welfare programs (Gray, 1993, 1994). However, public policies and discriminatory social attitudes contributed heavily to these outcomes. While observed and expected improvement in overall outcomes for children with ASD is desirable, managing such uncertainty can complicate relationships between health care providers, health care insurers, and their families.

Furthermore, scientific questions surrounding ASD have become increasingly politically divisive in recent decades (Murray, 2012). Partially owing to suspicion of a causal relationship between childhood vaccines and ASD and increased dependence on the Internet for medical information, opportunities for spread of mistrust between caregivers and health care providers have expanded (Baker, 2008; Offit, 2010; Parikh, 2008). In addition, untested (or less than thoroughly proven) interventions for ASD are increasingly prevalent and popular, creating an additional challenge for health care providers to help patients and their family members evaluate the potential benefits of treatment options given scientific uncertainty.

### *Disability and Health Care*

Aside from these diagnostic challenges, the nature of professional training in the health care field can also serve as a source of strain for patients with ASD and their families (Carbone et al., 2013; Liptak et al., 2006; Rhoades, Scarpa, & Salley, 2007). Health care education generally focuses on deviance from norms. In other words, an important aspect of learning to practice medicine is exposure to human atypicalities (Shapiro, 2008). Both issue stakeholders and disability studies scholars have expressed concern that this mode of medical education, while certainly efficient and effective from the standpoint of student exposure to human variability, overemphasizes deficits even when conditions are not associated with declining functionality (Baker, 2011; Leiter, 2007). A result of this overemphasis on deficits can be the so-called medical model of disability wherein the essence of

the individual becomes defined exclusively in terms of their disability (Murray, 2012).

This model of disability is unfavorably contrasted with the social construction model employed in disability studies literature. Scholars using the social model of disability frame the challenges associated with it as predominantly resulting from discriminatory social infrastructures. Although real-world proponents of the medical model are virtually absent from modern Western democracies (Shakespeare, 2008), disability scholars and activists continue to express concern that particularly within the health care community there exists a subconscious tendency to revert to such essentialist thinking about disability (Baker, 2011; Grinkler, 2007).

### *The Parent as Case Manager for a Child With ASD*

Children are increasingly diagnosed with ASD during early childhood, rather than later in life (Hutton & Caron, 2005; Ryan & Cole, 2008). During this stage of life, they are dependent upon parents for all of their care; this is particularly so for children who have ASD (Bayat, 2007; Gray, 1994, 2002). Parents find themselves as a critical source of support and advocacy for the child's treatment, yet they may have little to no formal knowledge or education of the complexities inherent in this neurological condition (Tomes, 2007; Valentine, 2010). This lack of knowledge is very stressful for parents who often feel disempowered by the health care systems they must rely on to assist their child or children with ASD (Hutton & Caron, 2005; Ryan & Cole, 2008; Valentine, 2010).

Prior research has shown that some of these parents report negative health experiences, expressing feelings of shock and disbelief at their abrupt treatment by clinical staff (Hutton & Caron, 2005; Todd & Jones, 2003). These negative experiences appear to be heightened by parents' difficulties accessing services for their child (Hutton & Caron, 2005). Some parents report feeling so upset and disempowered that they become an activist for children with disabilities (Ryan & Cole, 2008). Social activism is one way in which parents have empowered themselves as stakeholders in the care for their children with ASD, which has led to improved care. For example, the Disability Rights Movement, which began in the United States during the 1970s, was a very influential force in eliminating the practice of institutionalization of individuals with ASD (Ward & Meyer, 1999). Social activism was also responsible for integrating individuals with disabilities into the American public school system (Leiter, 2004a). Both these examples illustrate the power of social activism to change disability policy among publicly funded institutions in the United States.

Parents—especially mothers—play a vital role in that activism because they are often case managers of their child's care for ASD (Baker & Drapela, 2010; Hutton & Caron, 2005; Leiter, 2004b; Ryan & Cole, 2008; Todd & Jones,

2003). Because the American health care system is largely privatized, case management activities usually involve coordinating the child's needs with *both* the health care provider and the health insurance carrier. These two entities sometimes have diverse interests in the management of patient care, with the former being geared toward treatment and the latter toward assessing coverage and rationing availability of treatment services. As such, we consider them separately in our study of negative health experiences among families caring for a child or children with ASD. To date, research in this area has been based on qualitative methods that explored parents' perceptions, coping, and activism responses around their child or children's ASD (Gray, 1993; Hutton & Caron, 2005; Ryan & Cole, 2008; Todd & Jones, 2003; Valentine, 2010). In this study, we build upon that literature by examining quantitatively how individual family characteristics, experiences with and awareness of services for children with ASD, and parental labor force participation are associated with the odds of negative experiences with health care providers and health care insurers among families caring for children with ASD.

We explore four areas of family life that may be associated with negative experiences among parents caring for a child with ASD, their health care providers, and/or their health insurance carriers: (a) household/family characteristics, (b) family awareness of laws and/or policies regarding ASD, (c) the family's type of health care coverage, and (d) parental work issues. While the correlates of conflict with health care systems may be infinite, we focus our attentions on these four areas because of their relevance to the ASD literature.

### *Correlates of Negative Experiences: Family Characteristics, Policy Awareness, Health Care, and Parental Work Indicators*

*Household/family characteristics.* Parents' accessing health care services for their children can be complicated, particularly if they are parenting more than one child with ASD (Kuhn & Carter, 2010) or balancing the needs of a child with ASD with those of a neurotypical sibling or siblings (Chiri & Warfield, 2012; Gray, 2002). Due to the presence of these stressful conditions in their lives, we would expect that the greater the number of children in the family, the greater the odds of having a negative experience with the child's health care provider and/or the family's health care insurer. Families who have more than one member affected by ASD may also exhibit greater levels of conflict with health care providers and/or health care insurers, due to the stress of coordinating for multiple-affected individuals. In addition, families who live in either outlying suburban areas or rural areas may encounter difficulty in commuting to treatment sites for their child or children with ASD (Gray, 1994; Hutton & Caron, 2005). These challenges could enhance the odds of having a

negative experience with either the doctor, if the physician(s) are not willing to have flexible schedules to accommodate the rural families' additional commuting time; or the health care insurer, due to insurer's unwillingness to pay for out-of-plan services that may be closer to the family's rural community. Finally, there is some evidence to suggest that individuals in upper-income families are more likely to challenge physicians during the course of office consultations with them (e.g., Haug & Lavin, 1981, 1983), and there is evidence that they are more willing to file malpractice lawsuits than lower-income families (e.g., Mullis, 1995). As such, we expect household income to be positively associated with having a negative experience with health care providers and/or health care insurers.

**Awareness of autism-related policies and programs.** Policies and programs focusing on the interests of individuals with disabilities and their families generally seek to create conditions that enhance their participation in society (Dalton, 2008; Offit, 2010). They also serve to raise parents' awareness of the kinds of services their child or children with ASD should be receiving (Ryan & Cole, 2008). Furthermore, such political engagement contributes to a rights-based understanding of disability typically involving a sense of outrage when individuals with disability receive disparate treatment (Leiter, 2004a). Such consciousness-raising efforts may increase the odds of parental conflict with a health care provider and/or a health insurance carrier, if the health care organization does not offer services for ASD patients or restricts health care services for children with ASD to only the most severely affected.

**Health care coverage.** Parents can encounter difficulties when accessing health care services for their children with disabilities (Warfield & Gulley, 2006). Parents of children with ASD tend to have higher rates of unmet health care needs than either the general population of children in the United States (Strickland, Jones, Ghandour, Kogan, & Newacheck, 2011) or families caring for children with other types of disabilities (Chiri & Warfield, 2012; Kogan et al., 2008; Vohra, Madhavan, Sambamoorthi, & St. Peter, 2013). Families caring for a child (or children) with ASD also report lower rates of satisfaction with their pediatrician, relative to families caring for children with other types of disabilities (Liptak et al., 2006). Some families qualify for Medicaid, a publicly funded health care program, and still other families go without health care altogether because they have no access to the private market through their employer and do not qualify for publicly funded health care (Chiri & Warfield, 2012). Because health care services in the United States are frequently delivered to families through private or not-for-profit corporations, insurance carriers may refuse services to a patient with ASD because it is believed to be not cost-effective for the health care organization.

Covered access to clinicians who can treat a child with ASD often depends upon referral from the child's

pediatrician. A child's primary care physician may not be convinced of the possibility of a neurological difference in the patient, and therefore may fail, or even directly refuse to refer them for assessments by specialists (Carbone et al., 2013; Gray, 1994). While such a circumstance may be linked to greater odds of a negative experience with a child's health care provider for families carrying either type of health insurance, families with Medicaid may be at a higher relative risk for two reasons: (a) The demand for such services far exceeds the capacity of the public health care system to aid all who need it, and thus the doctor is a gatekeeper for access to publicly funded services; and (b) obtaining services on the private market is not usually an option for families on Medicaid (e.g., Ghandour, Hirai, Blumberg, Strickland, & Kogan, 2014). Thus, the odds of having a negative health experience with the child's health care provider(s) are expected to be greater for families with Medicaid.

**Parental work issues.** Finally, we considered whether parents made changes to their work lives, due to a child (or children's) ASD (e.g., Baker & Drapela, 2010; Gordon, Rosenman, & Cuskelly, 2007; Stoner & Stoner, 2014), and if that change affects their chances of having negative experiences with their child's doctor and/or the family's health insurance carrier. These changes in family work may indirectly affect health care experiences among families caring for children with ASD if financial burdens result from a parent's changed (or reduced) work schedules.

These four areas of family life form the bases of our exploratory analyses that will answer the aforementioned research questions.

## Method

Data for this analysis were collected using a survey titled "Autism, Health Care, and Public Policy: Experiences of Families with Health Care Systems." We used a cross-sectional study design and disseminated our survey in Washington and Oregon between the months of October 2006 and May 2007. The survey was modeled after the "Participation and Activities Limitation Survey" created by Statistics Canada (Statistics Canada, 2006). Versions of the survey have previously been used to examine the experiences of families with children with ASD in Missouri and British Columbia (e.g., Baker, 2009; Baker & Drapela, 2010; Baker & Keiser, 2008; Baker & Meers, 2005; Sharpe & Baker, 2007). The survey consists of 58 questions posed in a variety of forms, including close-ended, multiple choice, Likert-type scale, and open-ended questions that address seven areas: demographics and socioeconomic characteristics; family history with ASD; education, treatment, and interventions; ASD awareness and information; experiences with health care providers; access to health care; and general impressions of the health care system. The survey is designed to take approximately 45 min to complete.

Prevalence figures for ASD have varied considerably over the years, with Centers for Disease Control surveillance studies estimating its expression anywhere from 1 child per 150 children aged 8 or below (Centers for Disease Control and Prevention, 2007) to 1 in 88 children (Centers for Disease Control and Prevention, 2012), and, most recently, to 1 in 68 children (Centers for Disease Control and Prevention, 2014). While the factors associated with the increasing prevalence are a combination of increased ASD awareness and broadened diagnostic criteria (see Saracino et al., 2010), even the highest prevalence rate above would be cost-prohibitive for using probability sampling methods (e.g., to obtain a sample of 100 would have required a sample of at least 8,800 families).

Importantly, we chose a convenience sampling strategy because it allowed us direct access to families caring for children with ASD. Even if we had the funds for a large-scale probability sample, we were still not assured of finding enough families caring for a child with ASD who were willing to answer our survey questions about their negative experiences with providers and insurers. For example, families caring for children with special needs who are receiving services through a “medical home” arrangement—where the health care provider coordinates general and specialty medical care and ensures that services are delivered on a routine basis—may not have negative experiences with either the provider or the insurer, but may have ended up in a large-scale probability sample (e.g., Strickland et al., 2011). Using a convenience sampling strategy allows us the most cost-efficient way to find a sample that has recent experience with the kinds of health care experiences that are the focus of study.

Local leaders in the area of ASD were identified using a comprehensive list of all ASD-oriented groups in Washington and Oregon, and through reviewing articles in the local press and records of appearances at local stakeholders meetings. Leaders in these organizations publicized the study by posting advertising flyers around their offices and announcing the study at their regular meetings. They also publicized an Internet link that potential respondents could use to read about the study and answer the survey. No additional efforts were undertaken by the researchers to recruit members of underrepresented groups.

All respondents completed the survey online (although paper copies were available, no one elected to complete paper copies). Caregivers were asked to provide their informed consent to participate, and instructions indicated that they could refuse to answer any question without penalty. Respondents were allowed to complete the survey only once, though they were allowed multiple visits to the site to complete the instrument. Respondents with more than one child with ASD were asked to complete the survey from the perspective of their experiences with their child who was first diagnosed with ASD (as opposed to the oldest child with ASD since often an older sibling is diagnosed later than a

younger one if the younger child exhibits more behaviors associated with ASD). The website recorded 563 visits, yielding 326 surveys. Of those 326 surveys, 215 contained complete data for the variables used in the study. As such, we are using 66% of the completed forms in our analyses.<sup>2</sup>

## Variables

**Dependent variables.** Survey respondents were asked whether or not they, or their child, had ever had a negative experience with the child’s health care provider, operationally defined as a doctor, nurse, occupational therapist, or other direct-service care provider. Survey respondents were also asked whether they had a negative experience with their health insurance carrier, which we have operationalized as the guarantor of the child’s health care services. Both questions specifically asked the respondent to consider these negative experiences as a result of their child or children’s ASD. Both items on the survey had dichotomous response categories, requiring the respondent to answer “yes” or “no.”

**Predictor variables.** As previously mentioned, negative health experiences may be associated with both personal and household/family characteristics of parents caring for a child or children with ASD. Four categories of factors related to interactions with health care providers and insurers identified in the literature were included in the study: household/family characteristics, the respondent’s awareness of policies and services for ASD, health care coverage (access to health care insurance), and parental work issues associated with ASD.

In terms of family characteristics, we asked respondents to list the number of children who were currently living in the home with them, whether or not they lived in a rural area (1 = *yes*, 0 = *otherwise*), whether their child with ASD was male or female (1 = *male*), and whether there were other persons in the family with ASD (1 = *no one*, 0 = *otherwise*). We measured total family income for 2005 ordinarily, with the following categories: US\$20,000 or less; between US\$20,001 and US\$60,000; US\$60,001- US\$90,000; and US\$90,001- US\$160,000. Thus, a one-unit increase for this variable will represent a potentially substantial increase in annual household income (from US\$20,000 or less to US\$60,000).

We measured two dimensions of policy awareness: whether the respondent currently felt that the family had an unmet need for ASD services (1 = *yes*, 0 = *otherwise*) and whether they were aware of public policies and laws related to ASD. We originally scaled this variable in an ordinal fashion (1 = *no awareness* to 4 = *total awareness*), but it was so highly skewed that we dichotomized it, collapsing the “very aware, aware, somewhat aware” categories into “awareness” and 0 = *all else*.

Access to medical care was measured in two ways: whether or not the family paid for their child (or children’s) medical care with Medicaid or whether they used private

insurance. We did not ask our respondents whether they used both types of insurance; our measure represents the predominant method of payment for health care used by the family. We asked our respondents whether they used their own personal funds to provide services for their child (or children) with ASD, but due to a high level of missing data for this question, we dropped this measure from our analyses. To be consistent with the literature on health care and ASD, we used a dichotomous measure for medical care through publicly funded insurance (Medicaid: 1 = *yes*, 0 = *all other*). The reference category for these individuals are those using private insurance; thus, we can still measure the effects of private and public insurance on conflicts with health care providers and health insurance companies.

We asked families about any changes they had taken in their work lives, due to their child (or children's) ASD. Specifically, we asked respondents whether they had experienced financial problems during the past year, due to their child's ASD (1 = *yes*, 0 = *no, not sure*); whether they had not taken a job, due to their child's ASD (1 = *yes*, 0 = *no*); whether they had not taken a promotion, due to their child's ASD (1 = *yes*, 0 = *no*); and whether they had chosen to work fewer hours, due to their child's ASD (1 = *yes*, 0 = *no*). These questions are consistent with the types of indicators used to measure the financial burdens associated with providing health care to a child (or children) with ASD, per the National Survey of Children With Special Health Care Needs (NS-CSHCN; for example, Ghandour et al., 2014; Kogan et al., 2008).

### Analytical Approach

Logistic regression was employed to model the odds of families having a negative experience with either their health care provider or their health insurance carrier. In logistic regression, the primary analytical goal is to predict the odds of a dichotomous outcome, controlling for a set of conditions (covariates). Logistic regression allows for modeling of how factors are either positively or negatively related to the odds of a negative health experience attributed by the parent or primary caregiver to the child's ASD, while controlling for other covariates. Effect sizes are expressed in odds ratios (ORs), or the ratio of the odds of a negative experience of one level of a covariate to the odds of a negative experience of another level of the covariate. The predictor variables were entered into our logistic regression models in thematic groups. Household characteristics were the first set of variables, followed by policies and services for ASD, then Medicaid use, and parent work variables. Our use of collinearity diagnostics did not indicate the presence of multicollinearity among our independent variables. Results are discussed in terms of their odds on the respondents' reporting negative experiences with the child's doctor and/or the family's insurance carrier.

## Results

### Descriptive Statistics

As shown in Table 1, more than half of our sample reported having a negative experience during the past year with their child's health care provider, due to the child's ASD (58%), and more than two thirds of respondents had a negative experience with their health insurance carrier, due to the child's ASD (69%; Table 1).

These differing percentages are consistent with our argument that families who are caring for a child (or children) with ASD make conceptual distinctions between their child's health care provider and their health insurance carrier. Moreover, a greater proportion of the families in the sample had a negative health care experience with their insurer, relative to their direct-service health care provider (i.e., doctor).

Nineteen percent (19%) of the families in our sample report living in a rural area, a proportion that is very similar to the 2010 U.S. Census figure of 19.3% (U.S. Census Bureau, 2010a). The average number of children among households in our sample is 1.82 (Table 1), a number slightly less than the national average of 1.88 for the closest census year to 2006 (see U.S. Census Bureau, 2010b). Eighty-two percent (82%) of respondents self-report that their answers to our survey questions were specifically about their sons. The male preponderance of ASD-affected individuals in this sample is consistent with the gender prevalence of this neurological difference in general population surveillance studies (Centers for Disease Control and Prevention, 2012). Almost two thirds of the respondents in our survey indicated that they did not have anyone else in the family with ASD (Table 1), a percentage that is slightly lower than a multi-state study of children with special health care needs asking a comparable question (77%; see Warfield & Gulley, 2006). The sample's average annual household income value was between US\$60,001 and US\$90,000 per year (or the third category of our four income groups). This broad range encompasses household incomes that are higher than the median household income for the United States in 2006—US\$48,851 (Webster & Bishaw, 2007).

The majority of our respondents described themselves as well aware of the policies and services for ASD (86%), and 75% of them stated that they had an unmet service need related to ASD (Table 1). These percentages are a bit higher than the percentages derived from multi-state surveys of parents who have children with special health care needs. Unmet needs in these studies range from 4% (Chiri & Warfield, 2012) to 12% (Warfield & Gulley, 2006). One possible reason for these discrepancies entails the recruitment strategy for our study. We used a convenience sampling strategy where we contacted local leaders in the ASD outreach and advocacy community in Washington and Oregon who publicized our study to persons who were caring for a child with autism. This strategy may be one reason why the prevalence

**Table 1.** Household Characteristics, Policy and Service Awareness, Health Insurance, and Parental Work Issues of Families With a Child With ASD: Descriptive Statistics ( $N = 215$ ).

|  | Proportion of families<br>responding "yes" | <i>M</i> |
|--|--|----------|
| Outcome variables  |  |          |
| Negative experience with child's health care provider, due to child's autism | .58  |          |
| Negative experience with health insurance carrier, due to child's autism     | .69  |          |
| Predictor variables  |  |          |
| Household characteristics  |  |          |
| No. of children in the household   |  | 1.82     |
| Rural residence  | .19  |          |
| Total household income   |  | 2.8      |
| Male child   | .82  |          |
| Other persons in the family with autism                                      | .65  |          |
| Autism policies and services awareness                                       |  |          |
| Services for autism needed, but not received                                 | .75  |          |
| Aware of laws, policies, re: Autism  | .86  |          |
| Health insurance   |  |          |
| Medicaid for family health care  | .27  |          |
| Parental work issues   |  |          |
| Financial problems in last year, due to autism                               | .57  |          |
| Not taken a job, due to child's autism                                       | .58  |          |
| Not taken a promotion, due to child's autism                                 | .23  |          |
| Changed jobs, due to child's autism  | .19  |          |
| Worked fewer hours, due to child's autism                                    | .53  |          |

Note. ASD = autism spectrum disorder.

of unmet health care needs for a child with ASD is higher in our sample than in studies of health care needs for children with disabilities using larger samples collected with probability sampling designs.

Twenty-seven percent (27%) of the families in our sample are using Medicaid exclusively for their health insurance carrier, a proportion that is slightly higher than the national rate of 21% (Table 1; Kaiser Family Foundation, n.d.). Given that families in our sample who are carrying private insurance serve as the reference category for insurance type, there will be ample opportunities for us to explore whether the odds of a negative experience with the health care provider versus the health care insurer will be distinct for those using Medicaid, versus those using private insurance.

Parental work issues affected several of the families in our sample (Table 1). Fifty-eight percent (58%) of respondents indicated that they had not taken a job, due to their child's ASD; 57% noted that they had encountered financial problems, due to their child's ASD; and 53% of families reported that someone in the family had worked fewer hours, due to their child's ASD. Around one quarter of the sample (23%) had not taken a promotion, due to the child's ASD, and another 19% had changed jobs for the same reason (Table 1). Corresponding items from the 2005 to 2006 round of the NS-CSHCN showed that 57% of a multi-state sample of families with children with ASD reduced or stopped working, due to the child's condition. Financial

problems were experienced by 40% of this sample (Kogan et al., 2008).

Recall from our earlier discussion that we will explore these correlates of conflict between families and the health care system separately for health care providers and health care insurance companies. We focus on these entities separately because many parents are seeking services for their child with ASD in a private health care market, where they are tasked with working with their child's pediatrician to obtain services that will assist the child, as well as interacting with the insurance carrier to ensure that the services recommended by the pediatrician will be covered by the family's health plan.

### *Negative Experiences With the Child's Health Care Provider*

We used logistic regression to estimate the odds of having a negative experience with the child's health care provider on the 13 covariates (Table 2). In all, 4 of the 13 predictor variables significantly affected the odds of a family having a negative experience with the child's doctor, due to the child's ASD: rural residence, household income, not taking a job due to the child's ASD, and not taking a promotion due to the child's ASD. These four variables have positive coefficients, meaning that they significantly increased the odds of having conflict with a health care provider.

**Table 2.** Factors Affecting Parent's Negative Experiences With a Child's Health Care Provider, Due to the Child's ASD (N = 215).

|   | B       | OR   |
|---|---------|------|
| Intercept                                 | -2.10*  |      |
| Number of children                        | -0.08   | 0.92 |
| Rural residence                           | 0.84*   | 2.31 |
| Household income                          | 0.55*   | 1.73 |
| Male child                                | -0.02   | 0.98 |
| Other persons with autism in family       | -0.09   | 0.92 |
| Autism services needed, but not received? | 0.43    | 1.54 |
| Aware of laws/policies for autism?        | 0.24    | 1.27 |
| Currently on Medicaid                     | 0.33    | 1.40 |
| Financial problems due to autism          | -0.14   | 0.87 |
| Not taken a job, due to autism            | 0.76*   | 2.13 |
| Not taken a promotion, due to autism      | 0.89*   | 2.43 |
| Changed jobs, due to autism               | 0.35    | 1.42 |
| Worked fewer hours, due to autism         | -0.51   | 0.60 |
| -2 LOGL                                   | 262.36  |      |
| Model $\chi^2$                            | 29.97** |      |
| Nagelkerke $R^2$                          | .18     |      |

Note. ASD = autism spectrum disorder; OR = odds ratio.

\* $p < .05$ . \*\* $p < .01$ .

Living in a rural area more than doubles the odds of conflict with a direct-service health care provider, all else being equal (Table 2; OR = 2.31,  $p < .05$ ), a finding that is in the direction we expected. A one-unit increase in the family's income level (i.e., moving to the next group in our grouped income variable) increases the odds of having a negative experience with the child's doctor by more than 70%, all other factors held constant (Table 2; OR = 1.73,  $p < .05$ ).

Our finding that persons from higher-income households had significantly greater odds of having a negative health care experience is consistent with our hypothesis that upper-level income individuals would be more likely to challenge doctors than lower-income individuals (e.g., Haug & Lavin, 1983).

Parental work issues also affected the odds of conflict with a child's health care provider. If a parent did not take a job, due to the child's ASD, the odds of conflict with a health care provider doubles (Table 2; OR = 2.13,  $p < .05$ ), all else being equal. If a parent did not take a promotion, due to the child's ASD, the odds of conflict more than doubled (Table 2; OR = 2.43,  $p < .05$ ). These items are consistent with an interpretation of family financial strains created by ASD; however, three other variables that also measured financial strains were not statistically significant (e.g., financial problems, parent changed jobs, and parent worked fewer hours—all due to child's ASD). Rather, it may be the case that these two questions are measuring some dimension of parent frustration at being either unemployed or underemployed, and it is having impact on the interactions with the child's health care provider (although we do not have those measures in our data).

The coefficients for families' levels of awareness of laws and policies regarding ASD and the families' unmet needs

for ASD were both positive, meaning that they increased the odds of having a negative health experience with their children's health care provider. These findings were consistent with our earlier-stated predictions; however, these coefficients were not statistically significant. These two results—the latter in particular—were somewhat surprising, given that families with children who have ASD experience high levels of unmet needs for health care (Chiri & Warfield, 2012; Kogan et al., 2008). Similarly, respondents who were on Medicaid had a higher odds of a negative health experience with the child's provider (OR = 1.40), but this coefficient failed to reach statistical significance as well. Despite these non-significant predictor variables, the model in Table 2 explains 18% of the variance in the odds of having a negative health care experience with the child's health care provider (Nagelkerke  $R^2 = .18$ ,  $\chi^2 = 29.97$ ,  $p < .01$ ).

### Negative Experiences With the Child's Health Insurance Carrier

We also used logistic regression to estimate the odds of having a negative experience with the child's health insurance carrier on the 13 covariates (Table 3). Only 3 of the 13 predictor variables significantly affected the odds of having a negative experience with the family's health insurance carrier: being aware of laws and policies regarding ASD; experiencing financial problems, due to the child's ASD; and having a negative experience with the child's health care provider (also due to the child's ASD).

If a respondent self-reported that he or she had an awareness of laws and policies regarding ASD, his or her odds of experiencing a negative experience with the health care

**Table 3.** Factors Affecting Parent's Negative Experiences With the Health Insurance Carrier, Due to the Child's ASD ( $N = 215$ ).

|  | B        | OR   |
|--|----------|------|
| Intercept                                      | -2.48    |      |
| Number of children                             | -0.06    | 0.95 |
| Rural residence                                | -0.88    | 0.42 |
| Household income                               | 0.24     | 1.27 |
| Male child                                     | 0.08     | 1.08 |
| Other persons with autism in family            | 0.23     | 1.26 |
| Autism services needed, but not received?      | 0.76     | 2.14 |
| Aware of laws/policies for autism?             | 1.24**   | 3.46 |
| Currently on Medicaid                          | -0.45    | 0.63 |
| Financial problems due to autism               | 1.43***  | 4.19 |
| Not taken a job, due to autism                 | -0.50    | 0.61 |
| Not taken a promotion, due to autism           | 0.73     | 2.07 |
| Changed jobs, due to autism                    | 0.08     | 1.09 |
| Worked fewer hours due to autism               | 0.44     | 1.56 |
| Negative experience with health care provider? | 0.73*    | 2.08 |
| -2 LOGL  | 212.46   |      |
| Model $\chi^2$                                 | 54.32*** |      |
| Nagelkerke $R^2$                               | .31      |      |

Note. ASD = autism spectrum disorder; OR = odds ratio.

\* $p < .05$ . \*\* $p < .01$ . \*\*\* $p < .001$ .

insurer was almost three and one half times greater than persons who did not report such an awareness, all other factors held constant (Table 3; OR = 3.46,  $p < .001$ ). Such awareness was associated with increased tensions between the respondents and their insurance carriers, net of the type of insurance the families were using at the time they completed the survey. (Recall that "Medicare" is dichotomized to include persons with all other types of insurance as the reference category—thus, families who are carrying insurance of any kind are represented in the regression equation.) As previously mentioned, financial problems were also a factor that significantly increased odds of a negative experience with the child's health care insurer (Table 3). Families reporting that they had encountered financial problems due to their child's ASD had four times higher odds of a negative experience with their health insurance carrier than those families who did not have financial problems, all else being equal (OR = 4.19,  $p < .001$ ). These findings are consistent with the expectation that parents' difficulty gaining access to services for their child with ASD would negatively affect their relationship with the child's insurance carrier. Finally, families who indicated that they had had a negative experience in the past year with the child's health care provider doubled their odds of having a negative experience with their health care insurer, relative to those families who did not have a negative experience (Table 3; OR = 2.08,  $p < .05$ ). This model explained nearly one third of the variance in the dependent variable (Nagelkerke  $R^2 = .31$ ,  $\chi^2 = 54.32$ ,  $p < .001$ ).

While these results are consistent with some of the expectations we articulated earlier in this study, there were some

predictor variables that did not significantly affect the odds of our respondents' reporting a negative experience with their health care insurer. Household income did not significantly affect having a negative health care experience with the carrier, which was a bit surprising, as prior research has documented that upper-income individuals are more likely to challenge decision-making in medical organizations (e.g., Haug & Lavin, 1983; Mullis, 1995). Having an unmet need for ASD services did not reach statistical significance (although the coefficient was in the expected direction), which was also of note, due to the fact that unmet need for services is a challenge faced by families who are caring for a child (or children) with ASD (Chiri & Warfield, 2012; Strickland et al., 2011). Our findings suggest that unmet need is not a critical factor in having a negative experience with the health insurer—rather, it is the knowledge of policies and laws regarding ASD that is a driving factor in families' chances of reporting a negative experience with their health insurance organization.

## Discussion

In this study, we investigated three research questions:

**Research Question 1:** What, if any, are the correlates of negative experiences between caregivers of a child with ASD and their health care providers?

**Research Question 2:** What, if any, are the correlates of negative experiences between caregivers of a child with ASD and their health insurance companies?

**Research Question 3:** Do they overlap?

The results of our research answer the third question most clearly: Distinct factors significantly affect the odds of having a negative experience with the health care provider versus the odds of having a negative experience with the health care insurer. Thus, one conclusion of our study is that families who are caring for their child (or children) with ASD make conceptual distinctions between the two entities when they are identifying challenges associated with providing services for them.

This finding is a significant contribution to the ASD literature. Many studies of negative health experiences among these families focus either on parents' interactions with direct-service health care providers, such as doctors and nurses (Hutton & Caron, 2005; Ryan & Cole, 2008; Todd & Jones, 2003; Valentine, 2010) or highlight families' challenges to receive services for their affected children by using medical surveillance approaches to document their unmet needs (Chiri & Warfield, 2012; Ghandour et al., 2014; Kogan et al., 2008; Warfield & Gulley, 2006). Our research suggests that both the direct-service health care providers and the fiscal guarantor of health care services (health care insurers) figure into negative experiences among families caring for a child (or children) with ASD, but in different ways.

Factors that increased the odds of the family having a negative health care experience with the child's doctor, due to the child's ASD, were rural residence, household income, the respondent's not taking a job due to factors attributed to the child's ASD, and whether a family member had not taken a promotion as a result of having a child with ASD. Respondents living in rural residences expressed increased odds of a negative experience with their health care provider. While we did not ask our respondents to report how many miles they must drive to access services for their child with ASD, patients in rural areas consistently report driving distance as a barrier to accessing regular medical care visits (Arcury et al., 2005). As such, our finding is consistent with conflict that may arise between a health care provider and a rural family who may have difficulty keeping weekly appointments for ASD services such as occupational therapy, applied behavior analysis (ABA) therapy, and other interventions.

Household income also significantly increased the odds that a family would have a negative experience with the health care provider, with higher-income households having greater odds of a negative experience than lower-income households. This was the case, even after controlling for any financial difficulties the family may have experienced, due to the child's ASD. It is entirely possible that the negative experience reported by higher socioeconomic households is consistent with other research studies finding a link between higher-income individuals and questioning a physician's authority. Specifically, Haug and Levin (1981, 1983) found that persons who have higher incomes are more likely than lower-income persons to raise questions with a doctor about their medical advice and request greater discussions

of medical issues with their doctor. While their effects are indirect, through increased health knowledge, our income variable has a direct effect on negative interactions with the provider. Similarly, Mullis' (1995) research indicates that higher-income persons have a greater propensity to file malpractice lawsuits than lower-income persons. While we did not measure these types of dynamics with health care providers, our finding is consistent with an interpretation of higher-income households potentially being more willing to articulate their negative experiences with a health care provider, relative to lower-income households.

Families who altered their work habits due to their child's ASD also experienced increased odds of a negative experience with the health care provider, relative to families who did not make these choices. Specifically, persons who either did not take a job or who did not take a promotion, ostensibly to accommodate the needs of their child or children with ASD, doubled their odds of a negative experience with the child's health care provider. While these variables are consistent with an interpretation of the financial impact of caring for a child with ASD, they remained statistically significant even after household income was held constant in our regression models. It is entirely possible that their link to a negative experience with a child's health care provider may be due to their frustration or sense of loss regarding their altered career trajectory (Gordon et al., 2007; Stoner & Stoner, 2014). It may also be the case that the parent with the altered career trajectory has gained both practical and medical knowledge about ASD, thus increasing their willingness to question medical authorities about their child's care (Gray, 1994; Ryan & Cole, 2008). We do not have the necessary measures to isolate these intervening effects; thus, we leave them for future research.

Factors that increased the odds of having a negative experience with the health care insurer were the respondent's awareness of laws and policies regarding ASD, experiencing financial problems, due to the child's ASD, and having a negative experience with the child's doctor in the past year. Families who reported having financial problems in the past year due to their child's ASD had a fourfold increase in the odds of a negative experience with their health care insurer, relative to families who did not experience money problems. This finding was in the expected direction and consistent with the literature on the financial hardships of caring for a child with ASD (Ghandour et al., 2014; Kogan et al., 2008). The fact that this variable significantly affected the odds of a negative experience with the health insurance carrier but did not affect the odds of a negative experience with the health care provider suggests that families are aware of which of these two entities makes the fiscal decision about access to health care resources for ASD. Families who had a negative experience with their child's health care provider also had double the odds of having a negative experience with their health insurance carrier, relative to families who did not have a negative experience. Thus, altered work habits, rural

residence, and household income have indirect effects on negative experiences with health insurance carriers, via their direct effects on negative experiences with health care providers.

Respondents who said they were aware of laws and policies for ASD had triple the odds of having a negative health experience with their health insurance carrier, relative to those who did not have such awareness, a finding consistent with the notion that when individuals educate themselves about options that are available to them, they are more likely to critically evaluate their current situation than if they were not aware of such options (e.g., Todd & Jones, 2003). Because parents of children with ASD often find themselves in the position of being both caregiver and case manager for the services their child needs, they act as an intermediary among pediatricians, specialists, and health insurance carriers. Such pervasive engagement in social infrastructures may lead to politicization of stakeholders, producing a potentially quite positive effect for society at large—vibrantly engaged discourse in a democratic context. However, as this study suggests, it might also be associated with increased potential for negative experiences with social infrastructures upon which the stakeholder depends.

The study is not without its limitations. Foremost among them is our use of a non-probability sampling design. While this approach gave us an opportunity to model relationships among a much larger sample of families than had been done to date (Gray, 1994; Hutton & Caron, 2005; Ryan & Cole, 2008; Todd & Jones, 2003; Valentine, 2010), our findings have limited generalizability due to our convenience sampling strategy. Second, because our data are cross-sectional rather than longitudinal, we can only interpret the relationships among our variables as associations. We cannot identify the causal mechanisms affecting negative experiences between caregivers of a child with autism, their health care providers, and their health care insurers. Thus, while we were able to identify distinct direct effects of our predictor variables on the odds of negative experiences with health care providers and health care insurers, we did not have the measures to investigate the intervening mechanisms that might explain these direct effects. Future studies on families' negative experiences with health care insurers should use longitudinal data to more closely investigate the link between their awareness of laws and policies for ASD, their level of engagement in activism, and conflict between the insurers and the insured, for example. Finally, the results of our study may have varied among members of different racial and ethnic groups, as access to health care in general varies significantly by race and social class (Arcury et al., 2005). We were not able to assess these effects due to very limited data on the race and ethnicity of our respondents.

Despite these caveats, our study underscores the need for researchers in ASD policy to consider ground-level health practitioners as distinct conceptual entities from health care bureaucracies. This is critically important for scholars whose

research populations are located in countries with a robust private market for health care services, as is the case in the United States. This is also an important distinction in the study of health care in the United States, as the country enters into a period of transition during the implementation of the Patient Protection and Affordable Care Act (Public Law 111-148), passed by Congress in 2010.

In seeking services for a child with ASD, many parents learn about their child's disability and learn to work with the diagnosis (Valentine, 2010). In doing so, they work to become aware of the resources inside and outside what is being offered to them that can help their child. Such an awareness is gained through parents' educating themselves about the ASD diagnosis and understanding what services may best fit with the child's presenting behaviors. This knowledge is usually obtained through a combination of information from the health care provider, Internet research, and books on ASD and its related conditions: for example, Kranowitz & Miller's (2005) *The Out-of-Sync Child*, Simone's (2010) *Aspergirls*, or Norall's (2009) *Quirky, Yes—Hopeless, No*.

In addition, parents may also embark upon learning how to negotiate their health care plan to maximize the services for which the child is eligible, or get the health care provider to pay for services once their out-of-pocket deductibles for services have been reached. Such tasks may contribute to parents' greater awareness of the impact of health care policy on the lives of citizens. However, as is described in Paul Offit's *Autism's False Prophets: Bad Science, Risky Medicine, and the Search for a Cure*, not all awareness is created equal. Ideally, experts working with children who have ASD and the parents of those children come together to promote policy interventions designed to improve their lives rather than being associated with more negative interactions. The results of this research suggest that alleviating these families' negative experiences will have distinct paths for the health care provider versus the health insurance carrier. Perhaps building positive interactions will have distinct paths as well.

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### Notes

1. We refer to the neurological condition of autism as "autism spectrum disorder" (ASD), per the revisions to the *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.; *DSM-5*; American Psychiatric Association [APA], 2013).
2. We do not consider this a traditional response rate because we are not able to calculate the total number of individuals who

came into contact with our survey outreach materials as the denominator for the rate. While we used Internet solicitations as well as flyers and word-of-mouth advertising by local stakeholders, the only opportunities to participate in the survey we quantified were those persons who visited the website.

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