Published in final edited form as:

J Dev Behav Pediatr. 2015 April ; 36(3): 146–157. doi:10.1097/DBP.0000000000000136.

Parent Health Beliefs, Social Determinants of Health, and Child Health Services Utilization among US School-Age Children with Autism

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Abstract

Objective—Substantial variation exists in ASD care by race, ethnicity, and socioeconomic status; however, the role of parent health beliefs in this variation is poorly understood. Study goals were to (1) examine variation in parent beliefs about ASD prognosis and treatment according to social determinants of health (SDH) and (2) assess whether this variation was associated with variable health services utilization, among 1420 children with special health care needs (CSHCN) having autism spectrum disorder (ASD).

Methods—We used linked data from the 2011 Survey of Pathways to Diagnosis and Treatment and the 2009/10 National Survey of Children with Special Health Care Needs. Bivariate and multivariate analyses assessed variation in parent beliefs according to race/ethnicity, household income, and parent educational attainment. Further analyses assessed whether variation in beliefs was associated with use of psychotropic medication, traditional therapy, or complementary/alternative therapy for ASD.

Results—Parents of lower educational attainment or who had lower income were more likely to think that their child's condition was a mystery. Near-poor families were less likely to feel they had the power to change the child's condition. Parents of minority children were more likely than white children to view their child's condition as temporary. However, these differences in beliefs only had modest associations with variation in use of the health services analyzed.

Conclusions—Some SDH-related variation exists in health beliefs among parents of children with ASD, but these differences may not be the main factors accounting for ASD health care disparities.

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The authors have no financial relationships or conflicts of interest to disclose.

Keywords

autism spectrum disorder; health services; health beliefs; healthcare disparities; social determinants of health

INTRODUCTION

Autism spectrum disorders (ASDs) are a class of chronic neurodevelopmental conditions associated with atypical social interaction and communication, and restricted and repetitive patterns of interests and activity.[1] ASDs are common, affecting up to 1 in 68 children in the United States.[2] The optimal type and amount of treatment for ASD is unknown, and children vary widely in the type and amount of ASD-related health services they receive.[3] Some patterns of service utilization (e.g. use of intensive behavioral interventions in early childhood) are generally favored by health care and educational providers since they have been shown to result in some improvements in functioning, though the literature is limited by methodological concerns.[4,5] Use of other services, such as complementary and alternative therapies and psychotropic medication for ASD, is more controversial, both among families and health care providers.[6] Furthermore, different conceptualizations of ASD may bring into question the desirability of treatments to eliminate its characteristic features.[7]

Prior research has demonstrated that some of the variability in ASD-related health services utilization relates to social determinants of health (SDH), such as race/ethnicity, parent income, and parent education.[8] For instance, poor and minority children with ASD have difficulties accessing therapy services,[9–11] and use less medical specialty care than non-poor white children.[12] In addition, poor and minority children face numerous barriers to ASD diagnosis.[9,13,14]

Reasons for SDH-related variation in ASD health services use are poorly understood. Some investigators have hypothesized that differences in ASD health services use may be due to racial/ethnic and socio-economic variation in parent beliefs.[15,16] For instance, if poor or minority parents view ASDs as temporary conditions, they might be less likely to engage in long-term therapy that does not show immediate improvement in child behavior. Likewise, if poor or minority parents believe it is not possible to change a child’s ASD symptoms, they may be less likely to engage mental health professionals in therapy or pharmacological treatments. Theories about the importance of parent beliefs are supported by evidence suggesting that minority parents have differing views on normative childhood development,[17] as well as the utility of mental health care.[18–20] Additionally, studies have found minority parents to be skeptical of the benefits of pharmacological treatment for mental health problems,[21] and are more likely to perceive mental health care as ineffective.[22]

However, it is also possible that SDH-related variation in use of ASD services is not related to parent beliefs and instead reflects primarily issues of healthcare access and quality. Such disparities are known to be quite problematic in communities of lower socio-economic status in general, [23] and may be a particular issue for poor and minority parents and children with ASD. [24,25] For instance, compared to white children with ASD, black children are less likely to experience family-centered care.[26] Children with ASD whose families are poor, black, Hispanic, or have low parent education are less likely to have a doctor that spends enough time with them, and parents who are poor or have low education are less likely to feel that the doctor listened to their concerns.[24] Since such qualities are likely desired by most families, these disparities may relate more to health care access and quality rather than parent beliefs and healthcare preferences per se.

Given that many basic questions regarding ASD treatment, prognosis, and time-course are still unclear, even to the scientific community,[27] it is understandable that parents vary widely in their beliefs about ASD. Likewise, given that health services utilization is similarly quite variable, understanding which parent beliefs lead to utilization of which services may be important in developing strategies to reducing undesirable ASD health care disparities.[16] Even if the optimum set of beliefs or services use is unclear, if parents' beliefs prove to be important, interventions might be developed to accommodate these beliefs into existing treatment paradigms or adjust current treatments to better suit family preferences. On the other hand, if parent beliefs play only a minor role in ASD health care disparities, interventions to reduce ASD health care disparities might better focus on provider or health care system factors.

To better clarify the relationship between health disparities, health beliefs, and health care services utilization for ASD, this project undertook a secondary analysis of national survey data about children with ASD. Primary research questions were: (1) Do parent beliefs about developmental problems associated with ASD differ by race/ethnicity, household income and parent educational attainment? (2) Do these differences in beliefs correlate with differential health services utilization and health care quality?

METHODS

Data source

We drew data from the 2011 Survey of Pathways to Diagnosis and Services (herein called Pathways Survey) and the 2009–10 National Survey of Children with Special Health Care Needs (NS-CSHCN). Both surveys are nationally-representative, parent-reported surveys of health care quality for children with special health care needs (CSHCN), [28] which the Maternal Child Health Bureau defines as those who "have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related service of a type or amount beyond that required by children generally."[29]

While the NS-CSHCN contains data on children with many conditions, the Pathways Survey contains data only on children with diagnoses of ASD, intellectual disability (ID), and/or developmental delay (DD). The Pathways survey is a follow-back to the 2009/10 National Survey of CSHCN (NS-CSHCN). Parents or guardians who completed the NS-CSHCN, who reported that their child was ever diagnosed with ASD, ID, and/or DD, and whose child was age 6–17 in 2011, were re-contacted to participate in the Pathways Survey. 71% were successfully re-contacted; 87% of those contacted agreed to participate.[30] In the survey, a parent or guardian (herein called "parent") was interviewed about one randomly-selected child per household. Pathways data files can be linked to 2009/10 NS-CSHCN files in order to obtain a more comprehensive portrait of a child's health and health care. However, while the NS-CSHCN was administered in multiple languages, Pathways was only administered in English, so the linked sample only includes English-speakers.

Sample

This analysis only assessed the health care experiences and beliefs of parents of CSHCN who were reported to currently have ASD in both the NS-CSHCN and the Pathways survey. The NS-CSHCN assessed the presence of ASD using the items, "Has a doctor or other health care provider *ever* told you that your child had autism, Asperger's disorder, pervasive developmental disorder, or other autism spectrum disorder?" and "Does your child *currently* have autism or an autism spectrum disorder?"[31] Parents who said "yes" to either item were then re-contacted for the Pathways survey, where they were again to confirm that their child had "autism, Asperger's disorder, pervasive developmental disorder, or other autism spectrum disorder" currently. Given this study's research questions, parents of children with only intellectual disability and/or developmental delay, or past (but not current) ASD diagnoses were excluded from this analysis (n = 2098).

Measures

Parent beliefs—The Pathways Survey contains multiple items assessing parent health beliefs, adapted from the Illness-Perception Questionnaire, Revised for Autism (IPQ-RA; Al Anbar, 2010), a validated scale assessing health beliefs among parents of children with ASD.[32] However, since children in the Pathways survey could have multiple developmental diagnoses, items did not ask about beliefs pertaining to autism specifically. Items instead asked about beliefs regarding the child's "learning and developmental conditions." Of the parent belief items available in the survey, we chose four according to the following criteria: (1) that we expected the beliefs to vary by SDH, based on prior research and (2) that we expected to have strong relationships with health services utilization, based on prior research. Of the available items, we chose one from each of four IPQ-RA sub-scales: *acute vs. chronic timeline* ("Condition is lifelong rather than temporary"), *treatment control* ("Condition can be prevented or decreased with treatment"), *illness coherence* ("condition is a mystery to me"), and *personal control* ("I have the power to change [CHILD's] condition"). Parents rated each item on a 4-point Likert scale (Definitely Agree, Somewhat Agree, Somewhat Disagree, Definitely Disagree). We constructed a dichotomous variable for each item according to the central tendency (mean and median) of its distribution to maximize power, which resulted in dichotomizing each item at agree/disagree except for "condition is likely to be lifelong rather than temporary", as the central tendency indicated dichotomizing at definitely agree vs. agree. Cronbach's alpha for the selected items compared to the sub-scale from which they were derived, ranged from 0.62 – 0.73 in the original Al Anbar study.[32]

Health Services Utilization—We selected three items to assess health services utilization, based on a review of prior research about racial/ethnic variation in autism and other child health services use.[10,11,21,24,33]

The first item assessed psychotropic medication use, which has been shown in prior research to vary by race/ethnicity and other SDH.[21,34] We defined this as whether the child was taking any psychotropic medication "to meet his/her developmental needs" currently on a regular basis. The survey asked parents a series of questions about medication use in the following categories: stimulants, anti-depressants, anti-anxiety medications or mood stabilizers, anti-seizure medications, anti-psychotic medications, and sleep medications. Examples of common medication names were provided. If a child was taking any one of these medication categories currently and on a regular basis, then we coded him/her as receiving psychotropic medications.

We assessed one measure of conventional treatment for ASD, which has also been shown to vary by race/ethnicity and socio-economic status[10,11]: whether the child was using "Behavioral intervention or modification services to meet his/her developmental needs" at least once per week currently. Specific examples, including "discrete trail training and other methods of applied behavioral analysis (ABA)" were provided for parents who needed more information.

Finally we assessed one measure of complementary/alternative medicine (CAM) use, which has previously been shown to vary by race/ethnicity in ASD.[35] CAM use was defined as yes/no response to whether the child currently uses "any type of alternative health care or treatment to meet his/her developmental needs." Numerous examples of CAM were provided, including "acupuncture, chiropractic care, relaxation therapies, and herbal supplements."

SDH—Our primary measures of SDH included child race/ethnicity, household income, and parent educational attainment. Race/ethnicity was assessed in the 2009–10 NS-CSHCN only. Multiple responses were permitted. Responses were coded as Hispanic, white non-Hispanic, black non-Hispanic, and other/multi-racial non-Hispanic. Due to the limitations of the linked data file, all Hispanic children (and children of other race/ethnicities as well) had parents who were English speaking. Children for whom race/ethnicity was missing were excluded from further analyses (n = 11).

Parent educational attainment was obtained from the NS-CSHCN via parent responses to the item, "What is the highest grade or year of school you have completed?" Responses were defined as the highest level of education of any parent currently living with child, categorized as high school graduate or less versus more than high school.

Household income was obtained from the NS-CSHCN using a composite of multiple items. Responses were defined in terms of percent of the Federal Poverty Level [FPL], which in 2010 was $22,050 for a family of four, and classified as 0–99% FPL, 100–199% FPL, 200–399% FPL, and ≥400% FPL. Missing values for both parent educational attainment and household income are multiply imputed by the National Center for Health Statistics.[31]

Other socio-demographic characteristics and functional limitations status—We included other socio-demographic characteristics in multivariable models to control for confounding. Selected factors were included because of known associations with ASD prevalence or service utilization,[36–38] and included child age, gender, U.S. census region, insurance type, and family structure (single mother, 2-parent biological or adopted, and other family structure). We also adjusted for functional limitations status in all models, since this might vary by race/ethnicity or poverty status.[39] Functional limitations was assessed as the yes/no response to the CSHCN Screener item, “Is your child limited or prevented in any way in his/her ability to do the things most children of the same age do” due to a “medical, behavioral, or other health condition?”

Statistical Analyses

We used descriptive statistics to describe the socio-demographic characteristics of the sample (Table 1), and we used weighted chi-square tests to compute whether parent health beliefs and child health services utilization varied by the primary SDH variables of interest, as well as by the other socio-demographic characteristics used in models (Table 2). We then assessed how parent beliefs varied according to SDH by fitting a multivariable logistic regression model, adjusting for all other socio-demographic factors (Table 3). To assess how having certain beliefs was associated with health services utilization, we performed chi-square tests and fit multivariable logistic regression models (Table 4). In multivariable models, each health services utilization variable (e.g. use of psychotropic medications, use of behavioral interventions, etc.) was regressed on each belief variable and all other socio-demographic factors. Finally, we fitted nested or hierarchical multivariable logistic regression models (Table 5) to assess how health services utilization was associated with social determinants of health, after adjusting for other socio-demographic differences, and then after adjusting for both socio-demographic differences and health beliefs. Specifically, we regressed each health services utilization indicator first on the SDH and other sociodemographic variables (block 1) and then on the SDH, other sociodemographic and parent belief variables (block 2).[40]

Analyses were performed in the SPSS 22.0 Complex Samples module (Armonk, NY) and Stata 13.1 (College Station, TX). Survey weights were applied in all analyses to account for the Pathways survey’s complex sampling design.

RESULTS

Sample

Of the 1420 children, a majority were white non-Hispanic (66.2%) and lived at >200% of FPL (62.6%). 76.6% had parents with greater than a high school education (Table 1).

Variation in Parent Beliefs

A majority (70.8%) of parents of children with ASD “definitely” believed that their child’s learning or developmental problem was lifelong rather than temporary. Likewise, 81.5% or parents agreed or definitely agreed that their child’s condition could be prevented or decreased with treatment. 44.5% agreed or definitely agreed that the child’s condition was a mystery, and 44.8% agreed or definitely agreed that they had the power to change the child’s condition (Table 2).

Bivariate and multivariate SDH associations with parent beliefs are shown in tables 2 and 3, respectively. Hispanic and Black non-Hispanic children were less likely than white children to have parents who believed that their developmental condition was life-long, on both bivariate and multivariable analysis. On bivariate analysis, all non-white children were more likely than white children to have parents who believed their condition was a mystery, but this association did not persist in multivariable analysis.

In terms of household income, there was a linear trend in beliefs that the child’s condition was a mystery, with highest rates of this belief in families with the lowest income. On bivariate analysis, this difference only reached statistical significance ($P < .05$) in the lowest income category (0–99% FPL); a similar trend was observed on multivariable analysis although it did not reach statistical significance in any group. Additionally, near-poor families were least likely to believe that their child’s condition could be prevented or decreased with treatment, and were also least likely to believe that they had the power to change the child’s condition on both bivariate and multivariable analysis.

Higher parental education was associated with more prevalent beliefs that the child’s condition could be prevented or decreased with treatment on bivariate analysis, and less prevalent beliefs that the child’s condition is a mystery on both bivariate and multivariate analysis.

Association of Beliefs with Health Services Utilization

After adjusting for the primary SDH variables of interest and other sociodemographic factors, we found that parents who believed that their child’s condition was lifelong rather than temporary were more likely to have a child who is using one or more psychotropic medications currently. Parents who believed that ASD was a mystery were less likely to have a child who was using a behavioral intervention or modification at least once per week (Table 4).

Variation in Health Services Utilization According to SDH

Bivariate analyses showed less psychotropic medication use in black non-Hispanic and Hispanic children, as well as other non-Hispanic children compared to white children; however, the finding was only significant for Black children on multivariable analysis (Table 5). There was a trend toward higher use of psychotropic medications among families of lower income, although findings did not reach statistical significance. A trend in lower rates of behavioral intervention or modification was found among children of non-white race/ethnicity, which was significant only in other non-Hispanic children on multivariable analysis (Table 5).

Associations of Beliefs with SDH-associated Variation in Health Services Utilization

When we added health beliefs to regression models testing the association of socio-demographic factors and health services utilization, there were only minor changes to the adjusted odds ratio estimates and no changes to the significance of findings. For instance, the adjusted odds ratio estimating the association between Black race and use of psychotropic medications changed only slightly after adding the beliefs to the model (0.41 to

0.43) and remained significant. Likewise, the odds ratio estimating the association of other race with use of a behavioral intervention or modification at least once per week (0.37) did not change.

DISCUSSION

Our first research question in this investigation was whether parent beliefs about developmental problems associated with ASD varied by SDH such as child race/ethnicity, household income and parent educational attainment. This analysis found a pattern of differences in beliefs according to SDH. In general, parents of lower educational attainment and who were poor had beliefs that were consistent with lower agency in the child's condition. For instance, poor families were more likely to think ASD was a mystery and near-poor families were less likely to feel they had the power to change the child's condition. Less-educated parents were more likely to hold both of these beliefs. Parents of minority children were also more likely to view their child's condition as temporary.

Though these findings have not previously been reported for ASD, they are consistent with related research. For instance, the finding that minority parents were more likely to consider their child's condition as temporary is consistent with Yeh et al's research showing that minority parents are less likely to endorse conventional biospychosocial beliefs about the cause of children's mental health problems.[41] Likewise, Flores et al have highlighted the concept of *fatalismo*, or the belief that an individual can do little to alter fate,[42] as potentially important in Hispanic populations. Our findings suggest that these concepts may play a role in beliefs about ASD.

Of note, while many providers may believe that ASD is usually life-long but that its symptoms may be modifiable by treatment, it is unclear whether some parents' holding of differing beliefs is helpful or harmful, or what this variation in beliefs even means. For instance, some parents' disagreement with statements about the efficacy of treatment or their power to change the child's condition may be related to a belief that ASD is an inherent part of their child's identity therefore not something that they feel is necessary to change.[43] Likewise, some parents' stated belief that their child's health condition is temporary may signal endorsement of a belief in the efficacy of ASD treatment rather than a reluctance to engage in long-term treatments. Likewise, since the efficacy of ASD treatment is enormously variable from child-to-child,[5] parents may vary in beliefs based primarily on their child's individual experiences, whereas providers may conceive of ASD treatment efficacy on more of a population level. More detailed investigation of parents' reasons for holding particular beliefs is necessary before firm conclusions can be drawn regarding these beliefs' importance to families.

Our second research question addressed whether SDH-related differences in beliefs correlate with differential health services utilization. Overall, we found that some SDH factors were associated with variation in health services utilization; however, parent beliefs contributed only somewhat to this variation. For instance, we found that Black non-Hispanic children were less likely to use psychotropic medication for ASD than were white non-Hispanic children, which is consistent with prior research about use of psychopharmacology in minority families.[21,34] We also found other non-Hispanic children were less likely to be using behavioral therapy at least once weekly, a finding consistent with other research showing lower rates of intensive therapy in minority children.[10]

When we added health beliefs to our regression models, there were only minor changes in the point estimates for SDH factors and no change to the significance of findings. This result implies that, while health beliefs are associated with health services utilization, it is likely that most of the SDH-related variation in health outcomes for underserved children relate to other factors. Prior research about access to care in disadvantaged children,[23,44] would suggest that differences in health care delivery may explain some of this variation. For instance, lower use of psychotropic medication among Black children could reflect racial differences in physician prescribing decisions rather than family preferences. Similarly, the trend we found toward increased use of psychotropic medication among families of lower income could result from increased medication prescription among families that lack access to behavioral therapy. It is also possible that variation in service utilization exists due to SDH-related differences in beliefs that we did not investigate. Finally, since the value of some kinds of ASD health services is still under debate, it is unclear whether this variation is beneficial or disadvantageous to minority children.

This study’s results should be interpreted with caution due to significant methodological limitations. First, the parent beliefs we studied were about the child’s “learning and developmental conditions” rather than about ASD per se. As a result, some parents could have answered these questions about multiple conditions, or primarily about other developmental conditions the child might have (e.g. ADHD or ID/DD). Additionally, parents’ beliefs may be volatile over time, which could not be captured in this cross-sectional survey. As previously noted, we were limited to the beliefs that were assessed in the survey, and likewise did not have the opportunity to ask parents why they held particular beliefs or whether they felt these beliefs impacted their treatment decisions. Similarly, parents’ beliefs may depend more strongly on factors the survey did not assess, such as media exposure and usage, social networks, or health literacy.

Characteristics of the study sample may also limit generalizability. Notably, most of the subjects were non-poor white non-Hispanics, which may have limited power to detect small differences among underserved groups. Furthermore, all of the Hispanics in the study were English speaking, which may have biased ethnic differences toward the null. Likewise, our assessment of SDH was limited by variables available in the survey, and we assessed child race instead of parent race because the two were highly correlated.

We had to choose our health services use variables from a larger number of possible variables. In doing so, we chose variables that were likely to vary by SDH based on prior research. However, it is possible that other variation exists in this dataset that we did not identify.

There are different statistical approaches that could have been taken to assess how health beliefs covary with SDH. We assessed the effects of health beliefs jointly by adding all of them to the model at the same time; however, the beliefs could have been added singly, or studied as interaction terms. All though we investigated these latter approaches, we ultimately decided not to employ them since they would vastly increase the number of outcomes and thus inflate the chance of Type 1 error. However, Type 1 error may have still been a factor in this study since multiple outcomes were investigated. Type 2 error may have also played a role since some of the survey items could be underpowered.

Despite these limitations, the study findings should be important for providers and policymakers. The findings suggest that providers should pay attention to differences in parent beliefs since substantial variability exists overall, and some beliefs have predictable associations with SDH. For instance, in their conversations with racial/ethnic minority families, providers might want to take into account that some minority families may not share their mental model of the permanency of ASD or of its susceptibility to treatment. Eliciting information about parental beliefs might help providers and parents approach ASD treatment options with greater attention to shared decision-making.[45]

On the other hand, the findings also signal to providers that they should be hesitant to attribute the majority of ASD health care disparities to “cultural factors” or different preferences among poor, minority or less-educated families, since most of the variation in outcomes we found was not attributable to parental beliefs. As such, this analysis underscores ongoing calls for reduction in disparities for ASD health care access and quality. [16] As has been found in prior reports[24] ASD health care disparities are widespread and present on a national level. While parent factors may play a role, truly reducing such disparities may require more comprehensive system-level interventions.

Acknowledgments

Funding information: This project was funded by the Medical Research Foundation of Oregon. The Principal Investigator’s effort was funded by #1K23MH095828 from the National Institute of Mental Health (NIH).

The authors acknowledge Christina Bethell, PhD MPH MBA and Julie Robertson, MSW MPH, for assistance with assembling the dataset and data analysis support.

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Table 1

Sample Characteristics

	Unweighted n	Overall Percent of Sample
Race/Ethnicity		
White, Non-Hispanic	1056	66.2%
Hispanic	118	13.0%
Black, Non-Hispanic	89	10.7%
Other Race, Non-Hispanic	145	10.1%
Household Income		
0%–99% FPL	198	16.9%
100%–199% FPL	277	20.5%
200%–399% FPL	475	32.7%
≥400% FPL	470	29.9%
Parent Educational Attainment		
High school or less	200	23.4%
More than High school	1220	76.6%
Age		
6–8 years	279	20.9%
9–11 years	443	33.7%
12–14 years	395	25.6%
15–17 years	303	19.7%
Gender		
Female	264	17.9%
Male	1155	82.1%
Health Insurance Type		
Public Insurance Only	366	32.1%
Private Insurance or Both Public and Private Insurance	982	67.9%
Region		
Northeast	277	21.4%
Midwest	338	24.5%
South	388	33.8%
West	417	20.3%
Functional Limitations		
No	515	35.4%
Yes	905	64.6%
Family Structure		
2 parent biological/adopted	953	60.5%

	Unweighted n	Overall Percent of Sample
Single mother	236	22.6%
Other	221	16.9%

Abbreviations: FPL, Federal Poverty Level

Table 2

Bivariate Statistics of Factors Associated with Parental Beliefs about Child’s Condition among CSHCN+ASD Age 6–17 years

	Percent in each demographic category holding belief†				Percent in each catergory receving health service		
	Definitely agree condition is likely to be lifelong rather than temporary	**Agree Condition can be prevented or decreased with treatment**	**Agree Child’s condition is a mystery to parent**	**Agree Parent has the power to change child’s condition**	**≥1 or more psychotropic medication type(s) used currently on a regular basis**	**Current use of behavioral intervention or modification at least once per week**	**Current use of complementary/ alternative health care**
Overalll Percentage of Sample‡	70.8%**	81.5%**	44.5%*	44.8%*	52.9%	28.9%**	17.3%**
Race/Ethnicity							
White, Non-Hispanic	75.5%**	80.2%	39.5%**	43.3%	55.7%	33.0%**	17.4%
Hispanic	54.8%*	87.7%	55.5%	46.1%	46.2%	20.2%	17.7%
Black, Non-Hispanic	56.4%*	79.6%	50.6%	51.7%	45.4%	24.8%	20.8%
Other Race, Non-Hispanic	75.1%	82.8%	54.4%	48.1%	52.8%	19.0%	13.7%
Household Income							
0%–99% FPL	69.8%	80.8%	56.7%*	42.2%	59.1%	26.5%	15.8%
100%–199% FPL	72.3%	70.8%**	46.6%	34.6%*	55.9%	29.5%	18.2%
200%–399% FPL	72.8%	84.4%	41.6%	47.9%	51.7%	32.3%	15.8%
≥400% FPL	68.1%	86.1%	39.3%	50.0%	48.6%	26.0%	19.2%
Parent Educational Attainment							
High school or less	73.3%	72.5%	61.2%	44.5%	61.4%	28.3%	12.1%
More than High school	70.2%	84.2%**	39.5%**	44.9%	50.3%	29.1%	18.9%
Age							
6–8 years	50.5%**	86.1%	51.4%	53.9%*	37.8%**	35.2%	17.7%
9–11 years	69.2%	86.8%*	48.6%	51.5%*	55.9%	30.1%	15.5%
12–14 years	79.2%*	76.8%	35.4%*	35.3%*	52.0%	27.0%	15.6%
15–17 years	84.5%**	73.6%*	41.8%	36.2%	65.4%**	22.7%	22.4%

	Percent in each demographic category holding belief[†]				Percent in each catergory receving health service		
	Definitely agree condition is likely to be lifelong rather than temporary	**Agree Condition can be prevented or decreased with treatment**	**Agree Child’s condition is a mystery to parent**	**Agree Parent has the power to change child’s condition**	**≥1 or more psychotropic medication type(s) used currently on a regular basis**	**Current use of behavioral intervention or modification at least once per week**	**Current use of complementary/ alternative health care**
Gender							
Female	72.5%	75.6%	40.9%	43.2%	51.1%	31.2%	22.1%
Male	70.4%	82.8%	45.3%	45.2%	53.2%	28.4%	16.3%
Health Insurance Type							
Public Insurance Only	72.8%	74.9%	47.4%	41.3%	53.5%	32.4%	18.7%
Private Insurance or Both	70.5%	85.0%**	41.6%	46.2%	52.0%	28.2%	16.8%
Region							
Northeast	73.2%	82.0%	41.6%	45.4%	53.1%	38.9%*	13.8%
Midwest	77.2%	76.1%	42.5%	41.6%	55.2%	30.1%	21.2%
South	67.7%	83.1%	48.8%	48.7%	57.4%	22.3%*	12.6%*
West	65.5%	84.8%	42.8%	41.7%	42.5%*	27.7%	24.3%
Funcional Limitations							
No	59.6%	84.8%	46.3%	48.9%	47.3%	21.3%	14.4%
Yes	77.0%**	79.7%	43.5%	42.6%	55.8%	33.2%**	18.9%
Family Structure							
2 parent biological/adopted	69.8%	82.1%	42.3%	46.5%	47.7%*	29.4%	17.7%
Single mother	74.8%	83.1%	43.0%	40.5%	60.2%	30.7%	20.4%
Other	68.3%	76.2%	55.8%*	43.4%	60.1%	25.5%	12.8%

[‡] Weighted to represent the non-institutionalized population of CSHCN+ASD age 6–17 years in the United States.

[†] Parental belief items were dichotmoized according to the central tendency of CSHCN+ASD responses on each item’s 4-point likert type scale.

[*] p<.05, compared to all other categories

[**] p<.01 compared to all other categories

Table 3

Adjusted Odds Ratios† and 95% CIs for Factors Associated with Parental Beliefs about Child's Condition Among US CSHCN+ASD Age 6–17 years

	Definitely agree condition is likely to be lifelong rather than temporary	**Agree problem can be prevented or decreased with treatment**	**Agree child's condition is a mystery to parent**	**Agree parent has the power to change child's condition**
	AOR (95% CI)	**AOR (95% CI)**	**AOR (95% CI)**	**AOR (95% CI)**
Race/Ethnicity				
Hispanic	0.40 (0.21 – 0.76)	1.18 (0.56 – 2.48)	1.61 (0.83 – 3.14)	0.74 (0.38 – 1.45)
Black, Non-Hispanic	0.41 (0.19 – 0.89)	.82 (0.36 – 1.89)	1.38 (0.66 – 2.89)	1.48 (0.69 – 3.20)
Other, Race Non-Hispanic	1.06 (0.49 – 2.29)	1.00 (0.48 – 2.11)	1.70 (0.93 – 3.11)	1.21 (0.61 – 2.37)
White, Non-Hispanic	1.00	1.00	1.00	1.00
Household Income				
0%–99% FPL	1.00 (0.44 – 2.27)	0.80 (0.35 – 1.84)	1.81 (0.84 – 3.92)	0.53 (0.25 – 1.13)
100%–199% FPL	0.80 (0.39 – 1.62)	0.47 (0.24 – 0.92)	1.21 (0.65 – 2.26)	0.39 (0.20 – 0.73)
200%–399% FPL	1.09 (0.65 – 1.83)	0.89 (0.49 – 1.63)	1.02 (0.64 – 1.64)	0.84 (0.52 – 1.35)
≥400% FPL	1.00	1.00	1.00	1.00
Household Educational Level				
High school or less	1.15 (0.58 – 2.29)	0.62 (0.32 – 1.17)	2.07 (1.18 – 3.61)	1.05 (0.57 – 1.93)
>High school	1.00	1.00	1.00	1.00
Age				
6–8 years	0.17 (0.09 – 0.32)	2.61 (1.31 – 5.20)	1.48 (0.81 – 2.70)	2.22 (1.25 – 3.96)
9–11 years	0.44 (0.23 – 0.82)	2.41 (1.28 – 4.55)	1.14 (0.67 – 1.94)	2.00 (1.16 – 3.43)
12–14 years	0.64 (0.32 – 1.26)	1.19 (0.63 – 2.24)	0.78 (0.44 – 1.38)	0.95 (0.54 – 1.67)
15–17 years	1.00	1.00	1.00	1.00
Gender				
Male	0.84 (0.51 – 1.41)	1.45 (0.83 – 2.52)	1.35 (0.84 – 2.15)	1.03 (0.64 – 1.65)
Female	1.00	1.00	1.00	1.00
Health Insurance Type				
Public Insurance Only	1.06 (0.55 – 2.04)	0.76 (0.43 – 1.34)	0.77 (0.45 – 1.32)	1.17 (0.67 – 2.04)
Private Insurance or Both Public and Private Insurance	1.00	1.00	1.00	1.00
Region				
Northeast	1.46 (0.76 – 2.80)	0.96 (0.48 – 1.92)	0.89 (0.50 – 1.60)	1.17 (0.64 – 2.13)
Midwest	1.74 (0.96 – 3.16)	0.82 (0.43 – 1.57)	0.89 (0.51 – 1.55)	1.10 (0.62 – 1.97)
South	1.05 (0.59 – 1.87)	1.18 (0.62 – 2.24)	1.00 (0.57 – 1.74)	1.19 (0.67 – 2.11)
West	1.00	1.00	1.00	1.00
Funcional Limitations				

	Definitely agree condition is likely to be lifelong rather than temporary	**Agree problem can be prevented or decreased with treatment**	**Agree child's condition is a mystery to parent**	**Agree parent has the power to change child's condition**
	AOR (95% CI)	**AOR (95% CI)**	**AOR (95% CI)**	**AOR (95% CI)**
Yes	2.83 (1.83 – 4.38)	0.79 (0.49 – 1.28)	0.82 (0.55 – 1.24)	0.89 (0.59 – 1.34)
No	1.00	1.00	1.00	1.00
Family Structure				
Single Mother	1.32 (0.69 – 2.54)	1.50 (0.76 – 2.97)	0.72 (0.40 – 1.29)	0.94 (0.55 – 1.62)
Other Family Structure	1.01 (0.56 – 1.81)	0.88 (0.44 – 1.75)	1.56 (0.90 – 2.69)	0.87 (0.50 – 1.49)
2 Biological or Adoptive Parent	1.00	1.00	1.00	1.00

Abbreviations: AOR, Adjusted Odds Ratio; CI, Confidence Interval

[†] All models were adjusted for child age, gender, region, insurance type, household income level, race/ethnicity, family structure, and highest level of parental education.

Table 4

Association of Parent Beliefs with Child Health Services Utilization and Child Health Care Quality.

	≥1 or more psychotropic medication type(s) used currently on a regular basis			Current use of behavioral intervention or modification at least once per week			Current use of complementary/alternative health care		
	Percent with belief using service[‡]	**Chi-square p**	**AOR (95% CI)[†] of service use for those with versus without belief**	**Percent with belief using service[‡]**	**Chi- square p**	**AOR (95% CI)[†] of service use for those with versus without belief**	**Percent with belief using service[‡]**	**Chi-square p**	**AOR (95% CI)[†] of service use for those with versus without belief**
Condition likely to be lifelong rather than temporary									
Definitely Agree	58.1%	p =.003	1.89 (1.21 – 2.94)	30.4%	p =.173	1.42 (0.87 – 2.29)	17.7%	p =.879	1.03 (0.59 – 1.78)
< Definitely Agree	41.9%		1.00	23.9%		1.00	17.1%		1.00
Problem can be prevented or decreased with treatment									
Agree	53.9%	p =.363	1.44 (0.88 – 2.34)	29.6%	p =.516	1.38 (0.77 – 2.46)	17.4%	p =.969	0.91 (0.49 – 1.66)
Disagree	48.5%		1.00	25.9%		1.00	17.6%		1.00
Child's condition is a mystery to the parent									
Agree	54.0%	p =.674	1.08 (0.73 – 1.60)	23.7%	p =.026	0.66 (0.43 – 1.00)	17.8%	p =.863	1.09 (0.67 – 1.77)
Disagree	51.9%		1.00	33.1%		1.00	17.2%		1.00
Parent has power to change condition									
Agree	48.5%	p =.095	0.71 (0.47 – 1.07)	31.1%	p =.352	1.19 (0.77 – 1.84)	20.2%	p =.143	1.44 (0.88 – 2.33)
Disagree	56.8%		1.00	27.0%		1.00	15.1%		1.00

[†] All models were adjusted for child age, gender, region, insurance type, household income level, race/ethnicity, family structure, and highest level of parental education. Separate models were created for each health services utilization variable/health belief combination.

[‡] Weighted to represent the non-institutionalized population of CSHCN+ASD age 6–17 years in the United States.

Abbreviations: AOR, adjusted odds ratio; CI, confidence interval

Table 5

Adjusted ORs and 95% CIs for Factors Associated with Health Services Utilization Among CSHCN+ASD Age 6–17 years

	Health Care Service Utilization					
	AOR (95% CI): Current use of ≥ 1 psychotropic medications		**AOR (95% CI): Current use of a behavioral intervention or modification at least once per week**		**AOR (95% CI): Current use of complimentary and alternative medicine**	
Model	**SDH**†	**SDH + Beliefs**†	**SDH**†	**SDH + Beliefs**†	**SDH**†	**SDH + Beliefs**†
Race/Ethnicity						
Hispanic	0.67 (0.35 – 1.27)	0.68 (0.35 – 1.33)	0.51 (0.25 – 1.06)	0.57 (0.27 – 1.17)	1.13 (0.52 – 2.45)	1.13 (0.56 – 2.30)
Black, Non-Hispanic	0.41 (0.18 – 0.92)	0.43 (0.19 – 0.98)	0.58 (0.25 – 1.35)	0.63 (0.27 – 1.47)	1.59 (0.69 – 3.68)	1.49 (0.62 – 3.58)
Other, Race Non-Hispanic	0.87 (0.44 – 1.71)	0.87 (0.45 – 1.66)	0.37 (0.17 – 0.79)	0.37 (0.17 – 0.82)	0.71 (0.32 – 1.58)	0.66 (0.29 – 1.53)
White, Non-Hispanic	1.00	1.00	1.00	1.00	1.00	1.00
Household Income						
0%–99% FPL	1.32 (0.54 –3.21)	1.29 (0.52 – 3.21)	0.94 (0.40 – 2.24)	0.98 (0.41 – 2.37)	0.60 (0.21 – 1.70)	0.60 (0.20 – 1.81)
100%–199% FPL	1.12 (0.60–2.11)	1.13 (0.60 – 2.15)	1.06 (0.54 – 2.09)	1.17 (0.61 – 2.23)	0.80 (0.39 – 1.65)	0.85 (0.40 – 1.80)
200%–399% FPL	0.95 (0.60 – 1.52)	0.94 (0.59 – 1.51)	1.44 (0.87 – 2.40)	1.45 (0.87 – 2.42)	0.77 (0.44 – 1.36)	0.78 (0.44 – 1.38)
≥400% FPL	1.00	1.00	1.00	1.00	1.00	1.00
Household Educational Level						
High school or less	1.40 (0.77 – 2.54)	1.41 (0.76 – 2.62)	0.99 (0.52 – 1.90)	1.07 (0.55 – 2.05)	0.60 (0.28 – 1.28)	0.56 (0.26 – 1.23)
More than high school	1.00	1.00	1.00	1.00	1.00	1.00

Abbreviations: ASD, autism spectrum disorder; CI, Confidence interval; CI, confidence interval; OR, Odds ratio; SDH, social determinants of health.

† Social Determinants of Health (SDH) Model was adjusted for child age, gender, region, insurance type, household income level, race/ethnicity, family structure, functional limitations Combined Socal Determinants and Parent Belief Model (SDH+Beliefs) was adjusted for child age, gender, region, insurance type, household income level, race/ethnicity, family structure, functional limitations and highest level of parental education as well as parent beliefs on whether the condition is likely to be lifelong rather than temporary, whether the problem can be prevented or decreased with treatment, if the condition is a mystery to the parent and whether the parent feels they have the power to change the child's condition.