Journal of Autism and Developmental Disorders (2019) 49:1652–1664
https://doi.org/10.1007/s10803-018-3862-9

ORIGINAL PAPER

Health Disparities among Children with Autism Spectrum Disorders: Analysis of the National Survey of Children's Health 2016

Arun Karpur[1,2] · Angela Lello[1] · Thomas Frazier[1] · Pamela J. Dixon[1] · Andy J. Shih[1]

Abstract

Utilizing the 2016 National Survey of Children's Health, this study illustrates that children with ASD have nearly 4 times higher odds of unmet health care needs compared to children without disabilities, whereas children with other disabilities had nearly 2 times higher odds of unmet health care needs compared to children without disabilities. Applying Andersen's Behavioral Model of health care utilization, this study estimates that enabling factors (e.g., access to health insurance, quality of health insurance, access to family-centered care, family-level stress, exposure to adverse childhood experiences, and parental employment) improved prediction of regression model for unmet health care needs by 150%. Policy and program implications are discussed and a new framework for responding to observed disparities is discussed.

Keywords Autism Spectrum Disorders (ASD) · Health disparities · Andersen's Behavioral Model · Unmet health care needs

Based on the recent surveillance data, 1 in 59 children in the U.S. have Autism Spectrum Disorder (ASD) (Kurzius-Spencer et al. 2018). The updated prevalence represents a 15% increase in prevalence based on the 2012 data. ASD is a neurodevelopmental condition typically diagnosed in childhood and is characterized by social communication deficits, as well as restricted and repetitive behaviors. It is a life-long condition negatively impacting overall development, and is often associated with other developmental and medical conditions such as intellectual disabilities, psychiatric disorders, gastrointestinal disorders, epilepsy, etc. (Frazier et al. 2018; Neumeyer et al. 2018). Children with ASD have higher health care and mental health needs (Deavenport-Saman et al. 2016), higher health care costs (Shea et al. 2018), higher rates of hospitalization, lower quality of life (Arias et al. 2018) and overall experience lower life-expectancy compared to children without ASD (Bishop-Fitzpatrick and Kind 2017; Hirvikoski et al. 2016). Co-occurring medical conditions including epilepsy, and being female are factors highly associated with increased mortality among children with ASD (Hirvikoski et al. 2016). While data on adults with ASD is sparse, the existing evidence indicates higher morbidity and mortality among those with ASD (Turcotte et al. 2016).

Prior research, utilizing secondary data sets, on children's health have described several of the individual, family, and service-related factors impacting healthcare access and utilization for children with ASD (Bethell et al. 2014; Kogan et al. 2008; Zablotsky et al. 2015). While many have utilized frameworks such as the Andersen's Behavioral Model for describing access to care, none have explicitly examined disparities as hypothesized by Andersen (1995). Further, among children with ASD there is also a need for a comprehensive public health strategy to address their development, health and well-being needs. This paper addresses these two gaps in literature through analysis of the National Survey of Children's Health 2016 data and articulates a new framework for policy-making and programs to address unmet health care for individuals with ASD.

✉ Arun Karpur
arun.karpur@autismspeaks.org

[1] Autism Speaks, 1060 State Rd, Princeton, NJ, USA

[2] Data Science and Evaluation Research, Autism Speaks, 1060 State Rd, Princeton, NJ, USA

Andersen's Behavioral Model and its Application to Health Disparities

Ronald Andersen proposed a framework to describe utilization of health services among families in the U.S. in 1960s (Andersen 1995). Andersen's model (as widely known) has been used widely in health services research, as well as by researchers examining disparities in utilization of health services among children, youth and young adults with ASD (Benevides et al. 2016a, b; Parish et al. 2015). Briefly, the model proposes that individuals use health services as a function of their predisposition for service use, presence of enabling factors that creates access to needed services, and their overall needs for such services (Andersen 1995). Typically, the predisposing characteristics include demographic factors such as age and gender, as well as factors indicative of social structure such as race and ethnicity, and health beliefs. In cases of vulnerable populations these could also include factors such a country of birth/migration status, psychological conditions, and any other characteristics representing a "biological imperative" for higher need to utilize health services (Stein et al. 2007). Enabling factors include both individual- and community-level characteristics that enables access to care such as health insurance, income, employment, community-based services, welfare programs etc. The need-based factors include current state of health and well-being.

In operationalizing the model to examine disparities, Andersen indicated that if most variation in health service use is predicted by predisposing factors and need-based factors then likelihood of disparities resulting from systemic factors is low as individuals predisposed by their characteristics and needs are able to access services as needed (Andersen 1995). Whereas if enabling factors predict substantial amount of variation in the patterns of health service use, then the likelihood of health disparities is much more salient. This paper utilizes this framework to examine the extent to which the enabling factors predict access to services for children with ASD.

Predisposing and Need-Based Factors Impacting Health Care Access Among Individuals with ASD

Children with ASD typically have higher prevalence of co-morbid or co-occurring conditions that require frequent medical attention. Bethell et al. (2014), utilizing the 2007 National Survey of Children with Special Health Care Needs, illustrated that nearly two-thirds of children with special healthcare needs (CSHN) with ASD had four or more conditions compared to only 13% among children with special healthcare needs without ASD. Further, nearly all CSHN with ASD required special services, beyond prescription medications to manage their health conditions, compared to 57% of CSHN without ASD (Bethell et al. 2014). Gender-based differences in service utilization have also been demonstrated, where girls with ASD are more likely to utilize a wider range of services compared to boys with ASD. Specifically, adolescent girls and women with ASD are more likely to utilize psychiatric and emergency services compared to boys (Tint et al. 2017). The gender-based difference is likely due to the differences in the type and severity of ASD in girls compared to boys, although differences in severity may be closing with the increase in identification of cognitively-able presentations of ASD in females (Hull et al. 2017). Cultural differences across race/ethnicity and in some instances immigrant status have also found to contribute to variations in patterns of access to healthcare for children with ASD across various race/ethnic categories (Mire et al. 2015). While such differences originating based on innate characteristics of individuals are known, demographic factors are frequently involved in predicting disparities in access to health care services among individuals with ASD (Frazier et al. 2011).

Belonging to racial/ethnic minority as well as to a family with low-income negatively impacts health and well-being of children with ASD. Magana, et al. (2012), illustrated an interaction effect of race/ethnicity and disability on health care quality outcomes. Specifically, non-Hispanic Black families of children with ASD were much more likely to indicate lack of access to personal physician and dissatisfaction with the amount of time physician or health care provider spent in providing care compared to Black families of children with developmental disabilities. The Hispanic families of children with ASD were more like to report that physician did not listen compared to Hispanic families of children with developmental disabilities (Magana et al. 2012). In addition to such disparities emerging out of structural and cultural changes in healthcare system, cultural preferences of families vary across minority and non-minority groups. For example, families of racial/ethnic minorities have been more likely to indicate a greater need for occupational, speech, and physical therapy and lesser need for prescription medications compared to their non-Hispanic White counterparts. A follow-up study by same authors confirmed that the trend of experiencing low-quality services continue to persist across a 5-year study period between 2005 and 2010 (Magana et al. 2015).

Family's socio-economic status impacts access to services for children with ASD. While access to material resources and health insurance enables families to seek needed services, high parental stress resulting from caring for a child with ASD and/or having a sibling with ASD have been associated with lower likelihood of accessing services. Whereas parental perception of developmental delays has motivated families to seek needed services, the need for care manifests in interesting ways for high-income well-educated parents. In a study utilizing national survey data, Sobotka et al. (2016), illustrate that while overall families of children with ASD indicate higher access to care meeting the criteria of a medical home, the high-income non-Hispanic White parents were more likely to indicate dissatisfaction with care coordination services. They further hypothesize that this observed association could be result of increased knowledge and understanding of the condition prompting families to seek additional care requiring more coordination (Sobotka et al. 2016). Further, Benevides et al. (a, b) illustrated that minority families of children with ASD report less need for prescription medications, and mental health services compared to their Caucasian peers. English-speaking minority families expressed more need for occupational, speech, and physical therapy compared to their Caucasian peers (Benevides et al. 2016a, b). The age of individual with ASD was also associated with increasing cost of care and likely to predict increasing disparities in accessing needed services resulting from the financial burden imposed on the family (Turcotte et al. 2016).

Enabling Factors Impacting Health Care Access Among Individuals with ASD

While children with ASD have higher access to health insurance compared to other children with special healthcare needs, their parents are more likely to report poorer quality of health and higher levels of barriers in accessing needed services. Children with ASD without health insurance are more likely to utilize emergency services, mostly for non-urgent visits (Deavenport-Saman et al. 2016). Having access to medical homes—a term utilized to describe team-based, comprehensive primary care approach focused on increasing access, quality, and safety (American Academy of Pediatrics, American Academy of Family Physicians, & American College of Physicians-American Society of Internal Medicine 2002)—has been shown to reduce family financial burden of children with ASD. Specifically, access to family-centered care and care coordination have shown to be associated with lower unmet healthcare needs of children with ASD (Cheak-Zamora and Farmer 2015).

Another enabling factor that has potential to impact unmet health care needs among children with ASD includes exposure to or lack of exposure to Adverse Childhood Experiences (ACE), which include exposure to household abuse (emotional, physical, and sexual), exposure to domestic violence, family separation or parental divorce, mental illness and substance use in household, and household members with criminal justice involvement. Recent studies have indicated higher prevalence of ACE's among children with ASD compared to those without ASD (Berg et al. 2016; Rigles 2017). Kerns et al. (2017) illustrated that prevalence of ACE among children with ASD was moderated by poverty and co-occurring mental health conditions further highlighting the process through which ACE impact health care needs among children with ASD. Additionally, family's financial hardships and lack of employment for parent(s) exacerbates the unmet health care needs for children with ASD leading to observed disparities in health outcomes (Kerns et al. 2017). Parental caregiving stress, need for caring for siblings for child with ASD, and parent's perception of developmental delays also have been shown to predict utilization of services (Karp et al. 2018).

While these research studies inform understanding of factors related to barriers in accessing needed health care services for children with ASD, no studies have specifically tested Andersen's approach to identifying disparities (1995). Specifically, understanding the role of enabling factors as a set of variables provides opportunity to examine gaps in existing programs and policies to help reduce or eliminate health disparities among children with ASD. Therefore, the purpose of this research, is to apply Andersen's model and his proposed approach to identifying disparities in access to health care services among children with ASD in comparison with children without ASD and those without any disabilities using a nationally existing data set. Specifically, the paper examines the hypothesis that enabling factors incrementally improves prediction of regression model predicting unmet health care needs of children with ASD after controlling for the predisposing and need-based factors. Further, the paper focuses on elaborating on a public health strategy in responding to observed disparities in access to needed health care services for children with ASD.

Methods

Data Source

The 2016 National Survey of Children's Health (NSCH2016) data was used for the analysis. The NSCH2016 is a nationally representative sample survey of children's health conducted by the U.S. Census Bureau for the Maternal and Child Health Bureau (MCBH), Health Resources and Services Administration (HRSA). This survey is a redesign and a combination of the prior two separate surveys—the National Survey of Children's Health (NSCH) and the National Survey of Children with Special Health Care Needs (NSCSHCN). The redesigned survey has two questionnaires: (1) a household screener questionnaire to capture demographics and special healthcare needs characteristics, with an oversampling of children with special healthcare needs; and (2) an age-based topical questionnaire (T1 for 0–5 year old, T2 for 6–11 year old, and T3 for 12–17 year old) that combined core elements of the prior years' NSCH and the NSCSHCN to be completed by the responding parent. Using an address-based sampling approach the U.S. Census Bureau recruited 364,150 households to participate in the survey using a combination of web-based and paper-based screener questionnaire. With a 40.7% response rates, 138,009 screener questions were completed, and 67,047 respondents were invited to complete the topical questionnaire. Of total eligible individuals for topical questionnaire, 50,212 completed the topical questionnaire. This formed the overall study sample for the analysis. All the survey responses were weighted and details about survey methodology and statistical weighting as well as missing data and imputation methods can be found at (https://www.census.gov/content/dam/Census/programs-surveys/nsch/tech-documentation/methodology/2016-NSCH-Methodology-Report.pdf).

Comparison Groups

The children of parents responding affirmatively to the question "Has a doctor or other health care provider EVER told you that this child has Autism or Autism Spectrum Disorder (ASD)? Include diagnoses of Asperger's Disorder or Pervasive Developmental Disorder (PDD)" were classified as children with ASD (N = 1254). Additionally, the children classified as not having ASD but with a positive response to the CSHCN screener were classified as children with other disabilities (N = 10,205), and finally, children without ASD and CSHCN were classified as children without disabilities (N = 38,689).

Dependent Variables

This study examined unmet health care needs as a measure to study utilization or the lack of utilization of health care services. The constructs of unmet health care needs and barriers to access have been demonstrated to serve as a reasonable indicator of health care access across research in the U.S. and other countries (Allin et al. 2010; Barham et al. 2017). Further, the unmet health care needs have been demonstrated to predict poorer health in later life (Hargreaves et al. 2015). The NSCH2016 asked two sets of questions for the parent respondents: (a) "DURING THE PAST 12 MONTHS, was there any time when this child needed health care, but it was not received? By health care, we mean medical care as well as other kinds of care like dental care, vision care, and mental health services."; (b) additionally, participants were asked to indicate the reasons their child was not able to get the "needed health services" which included problems resulting from lack of eligibility, lack of availability of services, difficulty in getting appointments, difficulty resulting from transportation, cost of services, or the hours of operation of the clinical services. Children whose parents responded affirmatively to both set of these questions were identified as having unmet health care needs.

Independent Variables

Based on the Andersen's framework—the pre-disposing factors included demographic characteristics (age, gender, race/ethnicity, and neighborhood factors); the need-based factors included evidence of functional limitations, and co-occurring conditions; the enabling factors included access and quality of health insurance, access to family-centered care, problems in paying for medical bills, exposure to adverse childhood experiences, one-parent versus two-parent household, parental stress in care giving, parental employment status, and hardships faced by the family in providing food and housing. A select list of variables is described below as they were recreated from multiple data elements.

Neighborhood index—was created by adding affirmative responses to the features of neighborhood that are associated with improved well-being. These features include availability of side-walk of walking paths, playgrounds or park, recreation center, community center, or boys or girls club, library or bookmobile, and lack of litter or garbage on street or side walk, poorly kept or rundown housing, and presence of signs of vandalism or neighborhood violence.

Parent stress index—was created by adding responses to three questions "In the past month, how often you felt: (a) that this child is much harder to care for than most children his or her age, (b) that this child does things that really bother you a lot, and (c) angry with this child?" Specifically, the Likert scale values for the responses (ranging from 1 for 'Never' to 5 for 'Usually') were added and a percent score was calculated.

Functional limitations—were defined based on the presence of number of parent reported functional problems related to respiratory function, digestive function, physical pain, toothaches, gum bleeds, and decaying cavities.

Co-occurring conditions—were created based on parent-reported responses to other physical and mental health conditions diagnosed by health care providers or educators that are typically associated with ASD (Neumeyer et al. 2018). Three categories were created consisting of 'no co-occurring conditions,' '1–3 co-occurring conditions,' and 'greater than or equal to 4 co-occurring conditions.'

Quality of health insurance—was created based on the extent of coverage an insurance plan provided for the child to get needed services, visit providers as many times needed, and pays for accessing behavioral health services.

Access to family-centered care—was assessed based on responses of parents recounting their experiences over the last 12 months where they felt their health care provider spend enough time with their child, listened carefully to them, showed sensitivity towards family values, provided specific information about their child's health condition, and made them feel like partner in their child's care. The Likert-scaled responses indicating "Usually" and "Always" were rated as affirmative and those with "sometimes" and "never" were rated as negative responses for each of the elements.

Statistical Analysis

Univariate and bivariate analysis examined the relationship between each of the pre-disposing, need-based, and enabling factors with the outcome variable—i.e., unmet health care needs. To evaluate the hypothesis that enabling factors would significantly and incrementally predict disparities in health care, three successive multiple logistic regression models were constructed, each with unmet health care needs as the dependent variable. In the first model, pre-disposing variables were predictors. In the second model, need-based factors were added to first model with pre-disposing variables. In the third model, enabling factors were added to both pre-disposing and need variables. The extent of contribution from variables belonging to enabling factors was assessed by examining changes in the value for Tjur R-square (Tjur 2009).

Tjur R-square has desirable properties compared to other R-square values in logistic regression, as it is not dependent on a particular estimation method and embodies all important properties for an R-square statistic (Kvalseth 1985). Briefly, the Tjur R-square statistic, is called the coefficient of determination denoted by D, and it is calculated as follows. First, a logistic regression model is fit to the data and predicted probabilities for cases and non-cases based on the regression model are output. Then, histograms of the predicted probabilities are calculated for cases and non-cases, and mean value for each of the histograms are computed. The difference in the mean value for cases (π_1) and non-cases (π_0) represents this coefficient of determination, which is equivalent to the R-squared statistic.

$$D = \pi_1 - \pi_0$$

Additional proofs and methods are described in Tjur (2009). This R-squared value indicates the ability of the model to predict cases from non-cases. Examining the percent different in the R-squared value between the consecutive models nesting the parameters provides opportunity to assess the extent of contribution of the parameters in predicting the outcome probabilities. All statistical analyses accounted for the multistage sampling design of the survey and utilized survey weights in estimating population-level values.

Results

Descriptive Analysis

Table 1 illustrates distribution of key characteristics across the three-comparison groups. Overall, 2.5% of children in the survey were classified as having ASD (N = 1253), 20.4% (N = 10,171) were classified as having other disabilities, and 77.1% were classified as having no disabilities (N = 38,551). Children with ASD were more likely to be male and belonged to families with income below 100% of FPL. There were no substantial differences in the distribution of age and race/ethnicity across the three groups. Ninety-three percent of children with ASD had one or more co-occurring conditions compared to about 62% of children with other disabilities. Similarly, children with ASD were more likely to have functional limitations than the other comparison groups. A lower proportion of children with ASD were uninsured (3.5%) compared to children with other disabilities (7.3%), and those without disabilities (8.4%), however a higher proportion of children with ASD indicated having low-quality health insurance compared to the children in the two comparison groups (19.9% vs. 17.3% vs. 10.6%). Further, nearly 16% of children with ASD did not receive family-centered care compared to 11% among children with other disabilities, and 8% among children without disabilities. About one-third of the parents of children with ASD indicated facing difficulties in paying for medical care, compared to about quarter of families of children with other disabilities, and 13% of families of children without disabilities. Higher proportion of children with ASD belonged to single-parent household, were exposed to higher number of childhood adverse experiences, and belonged to families that faced hardships in providing food and shelter over the past year. Nearly one-third of the parents of children with ASD indicated to have been unemployed, compared to about 12% of parents of children with other disabilities, and nearly 3% of parents of children without disabilities. Parents of children with ASD experienced higher level of overall stress, compared to parents of children with other disabilities, and those without disabilities.

Table 2 illustrates frequency distribution and unadjusted odds ratios for unmet health care needs by key variables representing the predisposing, need-based, and enabling factors. Children with ASD had 15 times higher odds of unmet health care needs compared to those without disabilities (OR = 15.0; 95% CI 10.11–22.30), whereas children with other disabilities had about 5 times higher

Table 1 Percentage distribution of key characteristics across the three comparison groups

Characteristics	ASD (N = 1253) (%)	Other disabilities (N = 10,171) (%)	No disabilities (N = 38,551) (%)
Male	79.5	55.3	49.3
Age			
0–11 years	58.2	56.8	68.4
12–14 years	23.8	20.6	15.8
15–17 years	18.0	22.6	15.8
Race			
Non-Hispanic White	52.2	52.8	51.7
Non-Hispanic Black	16.5	16.1	11.9
Hispanic	23.4	21.9	25.1
Others	8.0	9.1	11.4
Poverty			
Below 100% FPL	30.0	25.5	20.9
Cooccurring conditions			
None	6.6	38.1	88.2
1–4 cooccurring conditions	39.5	47.9	11.5
Greater than 4 cooccurring conditions	53.9	14.0	0.3
Functional limitation			
No functional limitation	50.8	45.6	78.0
1–3 functional limitations	45.9	51.8	21.5
Greater than 3 functional limitations	3.4	2.6	0.4
Has no health insurance	3.5	7.3	8.4
Has low-quality health insurance	19.9	17.3	10.6
Does not receive family-centered care	15.8	10.8	7.5
Single-parent household	33.6	32.9	18.7
Exposure to family adverse events			
No exposure to family adverse events	50.9	49.8	69.8
Exposure to 1–3 family adverse events	40.2	40.9	27.3
Exposure to greater than 3 family adverse events	8.9	9.3	2.9
Parent unemployed	29.0	12.3	2.7
Exposure to hardship	45.9	36.8	23.7
Difficulty in paying medical bills	33.8	23.7	13.4

Data source—the National Survey of Children's Health 2016. All proportions were statistically significantly different with p-values < 0.01

odds of unmet health care needs compared to children without disabilities (OR = 4.55; 95% CI 3.43–6.05). Similarly, variables representing other predisposing factors, need-based factors and enabling factors were all statistically significantly associated with unmet health care in bivariate analysis. Additionally, the neighborhood index and parent-stress index (not shown in table) were also statistically significantly related to unmet health care needs such that one unit increase in neighborhood index reduced the odds of unmet health care needs by 14% (OR = 0.86; 95% CI 0.82–0.91) and one unit increase in parent-stress index increased the odds of unmet health care needs by 6% (OR = 1.06; 95% CI 1.05–1.07).

Regression Analysis

Multivariate sequential logistic regression models were built with a set of pre-disposing factors, need-based factors, and enabling factors added in a sequence. The model-based adjusted odds ratios, confidence intervals, and percent changes in the Tjur R-squared value are noted in Table 3. In the final model, children with ASD had four times higher odds of unmet health care needs compared to those without disabilities (OR = 3.76; 95% CI 2.22–6.38), whereas children with other disabilities had two times higher odds of unmet health care needs compared to those without disabilities (OR = 1.56; 95% CI 1.15–2.12) after controlling for predisposing, need-based, and enabling

Table 2 Bivariate analysis of association between predisposing, need-based, and enabling factors with unmet health care needs

	Percent unmet health care needs (%)	Unadjusted odds ratios
ASD	18.8	15.0 (10.11–22.30)
Other disabilities	9.6	4.55 (3.43–6.05)
No disabilities	2.6	–
Male	4.1	0.99 (0.77–1.28)
Female	4.2	–
0–11 years	3.4	1.266 (0.94–1.70)
12–14 years	4.6	2.21 (1.60–3.07)
15–17 years	6.8	–
Non-Hispanic Black	6.3	1.85 (1.13–3.03)
Hispanic	5.5	1.62 (1.12–2.36)
Others	3.1	1.18 (0.81–1.69)
Non-Hispanic White	3.2	–
Foreign born	8.3	2.32 (1.26–4.27)
U. S. born	4.0	–
GE 3 functional limitations	25.3	22.18 (12.16–40.46)
1–3 functional limitations	8.2	4.48 (3.46–5.81)
No functional limitations	2.4	–
GE 4 cooccurring conditions	17.4	16.40 (11.63–23.14)
1–4 cooccurring conditions	4.8	3.88 (2.87–5.25)
No cooccurring conditions	2.1	–
No health insurance	16.2	8.81 (5.35–14.49)
Has health insurance	3.1	–
Low quality health insurance	12.0	6.53 (5.04–8.46)
High quality health insurance	2.5	–
Does not receive family-centered care	17.5	9.16 (6.75—12.42)
Receives family-centered care	2.8	–
Has difficulty in paying medical bills	13.9	9.09 (7.00–11.83)
No difficulty in paying medical bills	1.7	–
One-parent household	7.8	2.60 (1.91–3.52)
Two-parent household	3.3	–
Exposure to more than 3 ACE	17.0	8.34 (5.45–12.77)
Exposure to 1–3 ACE	6.0	2.89 (2.20–3.81)
No exposure to ACE	2.5	–
Unemployed parent	21.5	7.94 (5.97–10.54)
Employed parent	3.3	–
Exposure to hardship	9.7	5.51 (4.24–7.16)
No exposure to hardship	2.2	–

Data source—the National Survey of Children's Health 2016. All the Odds Ratios were statistically significantly different with p-values < 0.01

factors. The associations between the other predisposing, need-based, and enabling factors with the odds of unmet health care needs in the multivariate model were all in the predicted direction, with increasing deprivation associated with higher odds of the outcome. The changes in Tjur R-square value increased by 90% from Model 1 to Model 2 indicating that inclusion of need-based factors in the model with predisposing factors improved the model's ability to correctly predict variations in the outcome variable by 90%. The inclusion of enabling factors further improved the prediction ability of the model by over 150% in the presence of the predisposing and enabling factors. There were similar improvements observed in the c-statistic from Model 1 through Model 3 (0.77, 0.81, and 0.90).

Table 3 Multivariate logistic regression models predicting unmet health care needs for children with ASD, compared with children with other disabilities and those without disability classification

Independent variables	Model 1	Model 2	Model 3
ASD versus no disabilities	16.96 (11.49–25.04)	4.70 (3.09–7.14)	3.76 (2.22–6.38)
Other disabilities versus no disabilities	4.26 (3.16–5.73)	1.80 (1.36–2.39)	1.56 (1.15–2.12)
Female versus male	1.20 (0.92–1.56)	1.27 (0.97–1.67)	1.33 (1.00–1.77)
Age			
12–14 years versus 0–12 years	1.01 (0.74–1.37)	0.93 (0.68–1.25)	0.95 (0.67–1.35)
15–17 years versus 0–12 years	1.72 (1.21–2.44)	1.48 (1.03–2.15)	1.61 (1.11–2.34)
Race			
Non-Hispanic Black versus non-Hispanic White	1.91 (1.15–3.18)	1.99 (1.20–3.32)	1.16 (0.68–1.97)
Hispanic versus non-Hispanic White	1.64 (1.08–2.47)	1.62 (1.08–2.44)	1.07 (0.69–1.64)
Others versus non-Hispanic White	1.33 (0.91–1.93)	1.39 (0.94–2.05)	1.20 (0.77–1.86)
Adverse neighborhood index	0.86 (0.81–0.91)	0.87 (0.83–0.92)	0.93 (0.88–0.98)
Immigrant versus non-immigrant	2.61 (1.33–5.11)	2.42 (1.19–4.95)	2.08 (0.87–4.99)
No health insurance versus health insurance	–	–	3.60 (1.92–6.74)
Low quality health insurance versus high quality health insurance	–	–	2.27 (1.64–3.14)
No family-centered care versus receives family-centered care	–	–	3.45 (2.31–5.14)
Difficulty in paying medical bills	–	–	3.39 (2.43–4.72)
One-parent versus two-parent household	–	–	1.27 (0.87–1.85)
Family adverse events			
1–3 versus none	–	–	1.36 (0.94–1.97)
GE 3 versus none	–	–	1.82 (1.05–3.17)
Parent unemployed versus employed	–	–	1.78 (1.21–2.60)
Hardship versus no hardship	–	–	1.56 (`1.09–2.23)
Parent stress	–	–	1.02 (1.01–1.03)
Functional limitation			
1–3 versus none	–	2.83 (2.12–3.76)	1.89 (1.39–2.57)
GE 3 versus none	–	6.56 (3.01–14.27)	2.95 (1.58–5.52)
Co-occurring conditions			
1–4 versus none	–	2.31 (1.71–3.12)	1.47 (1.07–2.02)
GE 4 versus none	–	5.33 (3.58–7.94)	1.99 (1.20–3.30)
C-statistic	0.77	0.81	0.9
Tjur R-square	0.044	0.084	0.213
%increase in R-square	–	90.9%	153.6%

Data source: the National Survey of Children's Health 2016. Model 1 includes predisposing factors. Model 2 includes both predisposing and need-based factors. Model 3 includes predisposing, need-based, and enabling factors. All estimates are statistically significant with p-value < 0.01, except for the variable "one-parent versus two-parent household in Model 3

Discussion

The enabling factors substantially improved predictive ability of the regression model examining unmet health care needs among children with ASD, in comparison with those for children with other disabilities, and children without disabilities. Based on Andersen's conceptualization of disparities in utilization of health care services, a sizable increase in prediction when adding enabling factors suggests substantial health disparity associated with ASD. Enabling factors are often amenable to program or policy-based interventions and, therefore, the observed disparity in unmet healthcare needs in children with ASD may be bridgeable. The present results suggest that the most important enabling factors to attend to in future policy interventions, based on the magnitude of their association in the logistic regression model include, improving access to health insurance, improving access to family-centered care, reducing family's burden of out-of-pocket spending for medical or therapeutic services, improving coverage of services in health insurance programs, reducing exposure to adverse childhood events, and improving employment and financial situation of parents of children with ASD. Viewed overall, policy and programmatic interventions that are most likely to reduce unmet healthcare needs include approaches that strengthen capacity of health service system and families caring for children with ASD.

Prior research has highlighted similar factors contributing to unmet health care needs among children with ASD, and a limited number of studies have examined comparisons between children with ASD, and those with other disabilities (Bethell et al. 2011, 2014; Kogan et al. 2008; Zablotsky et al. 2015). Though overall children with special health care needs have higher odds of having unmet health care needs compared to children without disabilities, the disparities are much wider for children with ASD compared to children without disabilities as illustrated in this analysis. These disparities persist after controlling for predisposing, enabling, and need-based factors based in nationally representative survey data. While children with special health care needs have higher than usual health care needs, this analysis illustrated that children with ASD are unique in ways of needing more services and are more likely to report higher unmet needs as well as lower quality of life (Markowitz et al. 2016). This finding is even more relevant considering that only 3.5% of parents of children with ASD indicate that they do not have health insurance, compared with about twice as many children with other disabilities and children without disabilities. Having higher unmet health care needs despite having access to health care through health insurance indicates not only higher needs, but also indicates challenges within the health care system in being responsive to the unique needs, as well as family's ability to coordinate care including identifying appropriate services for individual with ASD.

An important consideration is also that receiving family-centered care was predictive of lower odds of unmet health care needs, and no other components of the medical home was independently statistically significantly related to the outcome variable in multivariate models. Medical home model, a composite concept of providing comprehensive, coordinated, and family-centered care championed by the American Academy of Pediatrics (Medical Home Initiatives for Children With Special Needs Project Advisory Committee 2002), has been shown in prior studies to be significantly predict lower unmet health care needs among children with ASD (Farmer et al. 2014). While other components of medical home—such as care coordination, having a personal doctor or nurse, having usual source of care and problems with referrals—are relevant in providing high quality care for children with special health care needs, the relative salience of family-centered care in this analysis illustrates the source of challenge as well as an opportunity to improve quality of care for children with ASD who were least likely to receive such care among the three comparison groups. A systematic review of literature spanning last two decades of research examining factors related to selection of specific treatment choices for children with ASD implicated parent prior experience (i.e., parent stress, beliefs, and perception of child's behavioral problems) as an important driver in accessing specific services (Wilson et al. 2018). Empowering parents and caregivers with necessary information through program and policy tools might be a key strategy to improving access to care and ultimately reduction in unmet health care needs among children and youth with ASD (Call et al. 2015; Casagrande and Ingersoll 2017; Mire et al. 2015; Turcotte et al. 2016).

Child's family environment, indicated by exposure to family adverse events, parental unemployment, exposure to family's hardship in paying for food and housing, and parental stress in caring for the child, independently predicted higher odds of unmet health care needs. All the family-level adverse environmental factors were more prevalent among children with ASD compared to the other two groups. This finding is especially important considering a growing body of research indicating that family-level adverse environmental factors are related to higher severity of symptoms of ASD, including higher level of prevalence of mental health and behavioral problems (Kerns and Lee 2015; Kerns et al. 2017; Rigles 2017). Program and policy solutions that target the entire family as a unit versus only the child with ASD is likely to have positive impacts on overall health and well-being of children with ASD. Currently, efforts are underway through a multi-partner federal initiative to improve transition to adulthood for youth receiving welfare benefits that targets the entire family as a unit and its results are pointing towards encouraging gains in improving overall well-being (Enayati and Karpur 2018; GAO 2016). Similar initiatives need to be explored to address health and development of children with ASD.

The strengths of this research are derived from its application of the Andersen's Behavioral Model framework to a nationally existing data set. Additionally, utilizing the newly collected data from the redesigned National Survey of Children's Health 2016 allows for direct comparison between the parents responding for children with ASD, those with other disabilities, and those without disabilities. It is also noteworthy that research published in the last decade continue to demonstrate wide disparities in accessing needed care for children with ASD and has identified several factors, similar to those from this analysis (Benevides et al. 2016a, b; Berg et al. 2016; Bethell et al. 2011; Bishop-Fitzpatrick and Kind 2017; Chiri and Warfield 2012; Elder et al. 2016). The persistence of disparities should be a matter of public policy concern, especially given the higher health care expenditures for supporting children with ASD as well as poorer health care outcomes for children and their family members.

The public policy response has been: (a) to increase access to needed services through implementing mandates at state-level that require private insurance to cover for cost of services, both diagnostic and therapeutic and,

(b) support access to services through Medicaid Home and Community-Based Wavier (HCBS Waiver) services under the Section 1915 (c) of the Social Security Act. While 48 states have enacted policies that mandate coverage of autism treatments, a recent study has demonstrated no impact or very limited impact of such policy interventions (Barry et al. 2017). Additionally, Parish et al. (2015) also demonstrated that families of children with ASD holding private health insurance were more than five times likely to have substantial out of pocket health expenditures mostly from medications, outpatient services, and dental care. Thus, while these mandates aim to improve coverage of essential services for children with ASD, they are being implemented with varying efficacy to improve access to services (Parish et al. 2015).

Positive impacts of HCBS waiver programs were observed through reduction unmet health care needs and improving employment and quality of life of parents for children with ASD (Leslie et al. 2017). These beneficial impacts vary substantially by waiver characteristics such as the cost limit for services and enrollment limit. The cost limit for services typically impact service access for families of lesser means and the enrollment limit impact access to families who would not be able to qualify through means-test process (Eskow et al. 2015; Ng et al. 2015). Further, many states do not have ASD-specific waiver program, leading to limited benefits from such efforts (Leslie et al. 2017; Velott et al. 2016). Research has shown that lack of targeting poses barriers for children and families seeking needed services.

More recently, the Centers for Medicare and Medicaid Services (CMS) clarified that behavioral interventions for ASD should be covered under the early and periodic screening, diagnosis, and treatment (EPSDT) benefit and moved away from the HCBS Waivers. The specific details of this policy clarification issued by CMS indicates that it would create greater access to needed health care services to Medicaid recipients with ASD. However, in this analysis the type of health insurance coverage did not matter, indicating that having Medicaid or public funded insurance versus private health insurance did not predict substantial variations in unmet health care needs. The contemporary policy-making efforts are mostly influenced by the economics of providing access to care by employers and the government, as well as efforts to ensure equitable distributing public goods, the findings of this analysis point to the need for a renewed approach toward program and policy-making.

A recent framework developed by the Harvard Center on the Developing Child and the Woman and Children's Health Policy Center at Johns Hopkins provide a strong grounding to redirect health care policy and program approaches to improve outcomes for children with ASD (Center on Developing Child 2010; Mistry et al. 2012). This framework, informed by a life-course perspective on health, suggests that policy and programs should aim to build specific caregiver and community-level capacities to build a foundation for healthy childhood that address needs of all children across the areas of responsive care, safe and secure environments, adequate and appropriate nutrition, and health-promotion behaviors. The framework further connects foundations of health to various health outcomes with focus on understanding underlying biological mechanisms. Using this framework to analyze existing polices and programs for children with ASD as well as employing this framework to identify opportunities for public health response is necessary to achieve reduction and ultimately elimination of health disparities among children with ASD.

Limitations

These findings must be considered in the context of some key limitations, mostly emerging from the methods in collecting data for the NSCH2016. Firstly, it is important to note that the ascertainment of groups—ASD, other disability, and no disability, was primarily based on parent-reported information on diagnosis for their children. There is no way to ascertain the accuracy of diagnosis resulting from self-reporting. Based on the recent estimates on Autism prevalence reported by the Centers of Disease Control and Prevention, the prevalence of estimates of Autism from national surveys are always higher than the one reported from the CDC's surveillance program that relies on identification using administrative records in health care and education systems. In the current analysis the prevalence of ASD is 23.8 per 1000 children between the ages 2–17 years, whereas the reported prevalence by CDC among 8-year old nationally was 16.8 per 1000. It is important to note that CDC surveillance data also covers a broader population base, almost 8% of the total U.S. population of 8-year old.

Secondly, the analysis does not represent any causal association resulting from the cross-sectional nature of the dataset. However, it is important to note that enabling factors, identified in this study, while representing social disadvantage need not be causally linked to observed differences in odds of unmet health care needs between the comparison groups insofar as they are amenable to social policy interventions. Health system and family system factors (Greenlee et al. 2018), both amenable to social policy interventions, achieved salience as enabling factors in this analysis. Thirdly, the study was not able to examine state and regional variations due to the study design restrictions for examining such variations.

Conclusion

This study illustrated, using Andersen's Behavioral Model of healthcare utilization, disparities in unmet health care needs among children with ASD, in comparison to those with other disabilities, and those without disabilities in a nationally representative sample survey in the U.S. This study provides direct comparison of disparities, highlighting higher unmet health care needs among children with ASD and suggests to qualifying children with ASD and their families as one of the health disparities population requiring targeted social and health policy intervention. Further, the paper suggests a comprehensive approach to reframing policy and program solutions using the framework developed by the Center on the Developing Child at Harvard University. The reconceptualization of program and policy solutions directed to increase family and community capacities impacting foundations health that consequently impacts biological mechanisms leading to health and well-being provides opportunity not only to evaluate gaps in the current constellation of policies and programs, but also provides opportunity to develop new policies and programs that are responsive the wellbeing needs of children with ASD and their families.

Author Contributions AK conceptualized the study, analyzed data, wrote the manuscript; AL contributed to writing the manuscript; TF conceptualized and contributed to the writing; PD contributed to the writing; AS helped with conceptualization of the study.

Funding No external funding was received for this research.

Compliance with Ethical Standards

Conflict of interest Arun Karpur, Angela Lello, Thomas Frazier, Pamela J. Dixon, and Andy J. Shih declares that they have no conflict of interest.

Research Involving Human Participants and/or Animals This article does not contain any studies with human participants or animals performed by any of the authors.

References

Allin, S., Grignon, M., & Le Grand, J. (2010). Subjective unmet need and utilization of health care services in Canada: What are the equity implications? *Social Science & Medicine, 70*(3), 465–472. https://doi.org/10.1016/j.socscimed.2009.10.027.

American Academy of Pediatrics, American Academy of Family Physicians, & American College of Physicians-American Society of Internal Medicine. (2002). A consensus statement on health care transitions for young adults with special health care needs. *Pediatrics, 110,* 1304–1306.

Andersen, R. (1995). Revisiting the behavioral model and access to medical care: Does it matter? *Journal of Health and Social Behavior, 36*(1), 1–10.

Arias, V. B., Gomez, L. E., Moran, M. L., Alcedo, M. A., Monsalve, A., & Fontanil, Y. (2018). Does quality of life differ for children with autism spectrum disorder and intellectual disability compared to peers without autism? *Journal of Autism and Developmental Disorders, 48*(1), 123–136. https://doi.org/10.1007/s10803-017-3289-8.

Barham, V., Bataineh, H., & Devlin, R. A. (2017). *Unmet health care and health care utilization*. (WORKING PAPER #1716E).

Barry, C. L., Epstein, A. J., Marcus, S. C., Kennedy-Hendricks, A., Candon, M. K., Xie, M., & Mandell, D. S. (2017). Effects of state insurance mandates on health care use and spending for autism spectrum disorder. *Health Affairs (Millwood), 36*(10), 1754–1761. https://doi.org/10.1377/hlthaff.2017.0515.

Benevides, T. W., Carretta, H. J., & Lane, S. J. (2016a). Unmet need for therapy among children with autism spectrum disorder: Results from the 2005–2006 and 2009–2010 National Survey of Children with special health care needs. *Maternal and Child Health Journal, 20*(4), 878–888. https://doi.org/10.1007/s10995-015-1876-x.

Benevides, T. W., Carretta, H. J., & Mandell, D. S. (2016b). Differences in perceived need for medical, therapeutic, and family support services among children with ASD. *Pediatrics, 137*(Suppl 2), S176–S185. https://doi.org/10.1542/peds.2015-2851P.

Berg, K. L., Shiu, C. S., Acharya, K., Stolbach, B. C., & Msall, M. E. (2016). Disparities in adversity among children with autism spectrum disorder: A population-based study. *Developmental Medicine & Child Neurology, 58*(11), 1124–1131. https://doi.org/10.1111/dmcn.13161.

Bethell, C. D., Kogan, M. D., Strickland, B. B., Schor, E. L., Robertson, J., & Newacheck, P. W. (2011). A national and state profile of leading health problems and health care quality for US children: Key insurance disparities and across-state variations. *Acad Pediatrics, 11*(3 Suppl), 22–33. https://doi.org/10.1016/j.acap.2010.08.011.

Bethell, C. D., Lindly, O., Kogan, M., & Zuckerman, K. (2014). Health care quality for children: The position of autism spectrum disorder. In V. Patel, V. Preedy, & C. Martin (Eds.), *Comprehensive guide to autism* (pp. 139–165). New York: Springer

Bishop-Fitzpatrick, L., & Kind, A. J. H. (2017). A scoping review of health disparities in autism spectrum disorder. *Journal of Autism and Developmental Disorders, 47*(11), 3380–3391. https://doi.org/10.1007/s10803-017-3251-9.

Call, N. A., Delfs, C. H., Reavis, A. R., & Mevers, J. L. (2015). Factors influencing treatment decisions by parents for their children with autism spectrum disorder. *Research in Autism Spectrum Disorders, 15–16*, 10–20. https://doi.org/10.1016/j.rasd.2015.04.001.

Casagrande, K. A., & Ingersoll, B. R. (2017). Service delivery outcomes in ASD: Role of parent education, empowerment, and professional partnerships. *Journal of Child and Family Studies, 26*(9), 2386–2395. https://doi.org/10.1007/s10826-017-0759-8.

Center on Developing Child. (2010). *The foundations of lifelong health are Built in early childhood*. Cambridge, MA: Center on Developing Child.

Cheak-Zamora, N. C., & Farmer, J. E. (2015). The impact of the medical home on access to care for children with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 45*(3), 636–644. https://doi.org/10.1007/s10803-014-2218-3.

Chiri, G., & Warfield, M. E. (2012). Unmet need and problems accessing core health care services for children with autism spectrum disorder. *Maternal and Child Health Journal, 16*(5), 1081–1091. https://doi.org/10.1007/s10995-011-0833-6.

Deavenport-Saman, A., Lu, Y., Smith, K., & Yin, L. (2016). Do children with autism overutilize the emergency department? Examining visit urgency and subsequent hospital admissions. *Maternal and Child Health Journal, 20*(2), 306–314. https://doi.org/10.1007/s10995-015-1830-y.

Elder, J. H., Brasher, S., & Alexander, B. (2016). Identifying the barriers to early diagnosis and treatment in underserved individuals with autism spectrum disorders (ASD) and their families: A qualitative study. *Issues in Mental Health Nursing, 37*(6), 412–420. https://doi.org/10.3109/01612840.2016.1153174.

Enayati, H., & Karpur, A. (2018). Impact of participation in school-to-work programs on postsecondary outcomes for youth with disabilities from low-income families. *Journal of Disability Policy Studies*. https://doi.org/10.1177/1044207318789419.

Eskow, K. G., Chasson, G. S., & Summers, J. A. (2015). A cross-sectional cohort study of a large, statewide Medicaid home and community-based services autism waiver program. *Journal of Autism and Developmental Disorders, 45*(3), 626–635. https://doi.org/10.1007/s10803-014-2217-4.

Farmer, J. E., Clark, M. J., Mayfield, W. A., Cheak-Zamora, N., Marvin, A. R., Law, J. K., & Law, P. A. (2014). The relationship between the medical home and unmet needs for children with autism spectrum disorders. *Maternal and Child Health Journal, 18*(3), 672–680. https://doi.org/10.1007/s10995-013-1292-z.

Frazier, T. W., Dawson, G., Murray, D., Shih, A., Sachs, J. S., & Geiger, A. (2018). Brief Report: A survey of autism research priorities across a diverse community of stakeholders. *Journal of Autism and Developmental Disorders*. https://doi.org/10.1007/s10803-018-3642-6.

Frazier, T. W., Shattuck, P. T., Narendorf, S. C., Cooper, B. P., Wagner, M., & Spitznagel, E. L. (2011). Prevalence and correlates of psychotropic medication use in adolescents with an autism spectrum disorder with and without caregiver-reported attention-deficit/hyperactivity disorder. *Journal of Child and Adolescent Psychopharmacology, 21*(6), 571–579. https://doi.org/10.1089/cap.2011.0057.

GAO. (2016). *Youth with autism: Round table views of service needed during the transition into adulthood*. Washington, DC: GAO.

Greenlee, J. L., Winter, M. A., & Diehl, J. J. (2018). Family level processes associated with outcomes for individuals with autism spectrum disorder: A scoping review. *Research in Autism Spectrum Disorders, 53*, 41–52. https://doi.org/10.1016/j.rasd.2018.06.002.

Hargreaves, D. S., Elliott, M. N., Viner, R. M., Richmond, T. K., & Schuster, M. A. (2015). Unmet health care need in US adolescents and adult health outcomes. *Pediatrics, 136*(3), 513–520. https://doi.org/10.1542/peds.2015-0237.

Hirvikoski, T., Mittendorfer-Rutz, E., Boman, M., Larsson, H., Lichtenstein, P., & Bolte, S. (2016). Premature mortality in autism spectrum disorder. *British Journal of Psychiatry, 208*(3), 232–238. https://doi.org/10.1192/bjp.bp.114.160192.

Hull, L., Mandy, W., & Petrides, K. V. (2017). Behavioural and cognitive sex/gender differences in autism spectrum condition and typically developing males and females. *Autism, 21*(6), 706–727. https://doi.org/10.1177/1362361316669087.

Hull, L., Petrides, K. V., Allison, C., Smith, P., Baron-Cohen, S., Lai, M. C., & Mandy, W. (2017). "Putting on My Best Normal": Social camouflaging in adults with autism spectrum conditions. *Journal of Autism and Developmental Disorders, 47*(8), 2519–2534. https://doi.org/10.1007/s10803-017-3166-5.

Karp, E. A., Dudovitz, R., Nelson, B. B., Shih, W., Gulsrud, A., Orlich, F., et al. (2018). Family characteristics and children's receipt of autism services in low-resourced families. *Pediatrics, 141*(s4), S280–S286. https://doi.org/10.1542/peds.2016-4300D.

Kerns, C., & Lee, B. (2015). The relationship between adverse childhood experiences and autism spectrum disorder in an epidemiological sample from the United States. *European Psychiatry*. https://doi.org/10.1016/s0924-9338(15)30585-x.

Kerns, C. M., Newschaffer, C. J., Berkowitz, S., & Lee, B. K. (2017). Brief Report: Examining the association of autism and adverse childhood experiences in the National Survey of Children's Health: The important role of income and co-occurring mental health conditions. *Journal of Autism and Developmental Disorders, 47*(7), 2275–2281. https://doi.org/10.1007/s10803-017-3111-7.

Kogan, M. D., Strickland, B. B., Blumberg, S. J., Singh, G. K., Perrin, J. M., & van Dyck, P. C. (2008). A national profile of the health care experiences and family impact of autism spectrum disorder among children in the United States, 2005–2006. *Pediatrics, 122*(6), e1149–e1158. https://doi.org/10.1542/peds.2008-1057.

Kurzius-Spencer, M., Zahorodny, W., Rosenberg, C. R., White, T., Durkin, M. S., Imm, P., et al. (2018). Prevalence of autism spectrum disorder among children aged 8 years—Autism and developmental disabilities monitoring network, 11 sites, United States, 2014. *Morbidity and Mortality Weekly Report, 67*(6), 1–23.

Kvalseth, T. O. (1985). Cautionary note about R2. *The American Statistician, 39*(4), 279–285.

Leslie, D. L., Iskandarani, K., Dick, A. W., Mandell, D. S., Yu, H., Velott, D., et al. (2017). The effects of medicaid home and community-based services waivers on unmet needs among children with autism spectrum disorder. *Medical Care, 55*(1), 57–63. https://doi.org/10.1097/MLR.0000000000000621.

Leslie, D. L., Iskandarani, K., Velott, D. L., Stein, B. D., Mandell, D. S., Agbese, E., & Dick, A. W. (2017). Medicaid waivers targeting children with autism spectrum disorder reduce the need for parents to stop working. *Health Affairs (Millwood), 36*(2), 282–288. https://doi.org/10.1377/hlthaff.2016.1136.

Magana, S., Parish, S. L., Rose, R. A., Timberlake, M., & Swaine, J. G. (2012). Racial and ethnic disparities in quality of health care among children with autism and other developmental disabilities. *Journal of Intellectual and Developmental Disability, 50*(4), 287–299. https://doi.org/10.1352/1934-9556-50.4.287.

Magana, S., Parish, S. L., & Son, E. (2015). Have racial and ethnic disparities in the quality of health care relationships changed for children with developmental disabilities and ASD? *American Journal on Intellectual and Developmental Disabilities, 120*(6), 504–513. https://doi.org/10.1352/1944-7558-120.6.504.

Markowitz, L. A., Reyes, C., Embacher, R. A., Speer, L. L., Roizen, N., & Frazier, T. W. (2016). Development and psychometric evaluation of a psychosocial quality-of-life questionnaire for individuals with autism and related developmental disorders. *Autism, 20*(7), 832–844. https://doi.org/10.1177/1362361315611382.

Medical Home Initiatives for Children With Special Needs Project Advisory Committee. (2002). The medical home. *Pediatrics, 10*(1), 184–186.

Mire, S. S., Gealy, W., Kubiszyn, T., Burridge, A. B., & Goin-Kochel, R. P. (2015). Parent perceptions about autism spectrum disorder influence treatment choices. *Focus on Autism and Other Developmental Disabilities, 32*(4), 305–318. https://doi.org/10.1177/1088357615610547.

Mistry, K. B., Minkovitz, C. S., Riley, A. W., Johnson, S. B., Grason, H. A., Dubay, L. C., & Guyer, B. (2012). A new framework for childhood health promotion: The role of policies and programs in building capacity and foundations of early childhood health. *American Journal of Public Health, 102*(9), 1688–1696. https://doi.org/10.2105/AJPH.2012.

Neumeyer, A. M., Anixt, J., Chan, J., Perrin, J., Murray, D., Coury, D. L., et al. (2018). Identifying associations among co-occurring medical conditions in children with autism spectrum disorders. *Academic Pediatrics*. https://doi.org/10.1016/j.acap.2018.06.014.

Ng, T., Stone, J., & Harrington, C. (2015). Medicaid home and community-based services: How consumer access is restricted by state policies. *Journal of Aging & Social Policy, 27*(1), 21–46. https://doi.org/10.1080/08959420.2015.969078.

Parish, S. L., Thomas, K. C., Williams, C. S., & Crossman, M. K. (2015). Autism and families' financial burden: The association with health insurance coverage. *American Journal on Intellectual and Developmental Disabilities, 120*(2), 166–175. https://doi.org/10.1352/1944-7558-120.2.166.

Rigles, B. (2017). The relationship between adverse childhood events, resiliency and health among children with autism. *Journal of Autism and Developmental Disorders, 47*(1), 187–202. https://doi.org/10.1007/s10803-016-2905-3.

Shea, L. L., Xie, M., Turcotte, P., Marcus, S., Field, R., Newschaffer, C., & Mandell, D. (2018). Brief Report: Service use and associated expenditures among adolescents with autism spectrum disorder transitioning to adulthood. *Journal of Autism and Developmental Disorders*. https://doi.org/10.1007/s10803-018-3563-4.

Sobotka, S. A., Francis, A., & Vander, P., & Booth, K. (2016). Associations of family characteristics with perceptions of care among parents of children with autism. *Child: Care, Health and Development, 42*(1), 135–140. https://doi.org/10.1111/cch.12290.

Stein, J. A., Andersen, R., & Gelberg, L. (2007). Applying the Gelberg-Andersen behavioral model for vulnerable populations to health services utilization in homeless women. *Journal of Health Psychology, 12*(5), 791–804. https://doi.org/10.1177/1359105307080612.

Tint, A., Weiss, J. A., & Lunsky, Y. (2017). Identifying the clinical needs and patterns of health service use of adolescent girls and women with autism spectrum disorder. *Autism Research, 10*(9), 1558–1566. https://doi.org/10.1002/aur.1806.

Tjur, T. (2009). Coefficients of determination in logistic regression models—A new proposal: The coefficient of discrimination. *The American Statistician, 63*(4), 366–372.

Turcotte, P., Mathew, M., Shea, L. L., Brusilovskiy, E., & Nonnemacher, S. L. (2016). Service needs across the lifespan for individuals with autism. *Journal of Autism and Developmental Disorders, 46*(7), 2480–2489. https://doi.org/10.1007/s10803-016-2787-4.

Velott, D. L., Agbese, E., Mandell, D., Stein, B. D., Dick, A. W., Yu, H., & Leslie, D. L. (2016). Medicaid 1915(c) Home- and Community-Based Services waivers for children with autism spectrum disorder. *Autism, 20*(4), 473–482. https://doi.org/10.1177/1362361315590806.

Wilson, M., Hamilton, D., Whelan, T., & Pilkington, P. (2018). A systematic review of factors related to parents' treatment decisions for their children with autism spectrum disorders. *Research in Autism Spectrum Disorders, 48*, 17–35. https://doi.org/10.1016/j.rasd.2018.01.004.

Zablotsky, B., Pringle, B. A., Colpe, L. J., Kogan, M. D., Rice, C., & Blumberg, S. J. (2015). Service and treatment use among children diagnosed with autism spectrum disorders. *Journal of Developmental and Behavioral Pediatrics, 36*(2), 98–105. https://doi.org/10.1097/DBP.0000000000000127.