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Understanding Racial and Ethnic Disparities in Autism-Related Service Use Among Medicaid-Enrolled Children

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Abstract

Racial and ethnic disparities in the use of nine common autism-related services among Medicaid-enrolled children with autism spectrum disorder (ASD) were examined, distinguishing between school and other community-based outpatient settings. Using 2012 Medicaid Analytic Extract data, we identified 117,848 continuously enrolled children with ASD. Several racial and ethnic disparities were found, varying by geography. Black, Asian, and Native American/Pacific Islanders received fewer outpatient services compared with white children, but there was no disparity for Latinx children. Black and Asian children received more school-based services than white children. Disparities in case management/care coordination services were largest and present in each minority group. Geographic variation in receipt of services suggests targets for policy intervention to improve access for minorities with ASD.

Keywords

Autism spectrum disorder; Racial and ethnic disparities; Medicaid; School-based services; Outpatient services

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Authors Contribution LB conceived of the study, participated in its design, performed the statistical analysis, and drafted the manuscript; SS participated in the interpretation of the data and helped to draft the manuscript; DM participated in the design of the study, interpretation of the data, and helped to draft the manuscript. All authors read and approved the final manuscript.

Compliance with Ethical Standards

Ethical approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. This project was determined to be exempt by the institutional review board at Northwestern University.

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Conflict of interest The authors declare that they have no conflicts of interest.

Introduction

Racial and ethnic disparities are known to exist in access to timely diagnostic services for autism spectrum disorder (ASD) (Mandell et al. 2002). Studies have also examined disparities in the use of autism-related health and education services (Bilaver and Havlicek 2019; Liptak et al. 2008; Magaña et al. 2012, 2016; Smith et al. 2020) as well as subspecialty services (Broder-Fingert et al. 2013). Limitations in English language proficiency has been found to relate to barriers to service access for the Latinx population (Zuckerman et al. 2017). However, most studies that examine disparities in autism-related service use do not distinguish between clinical factors that may affect service use, such as disorder severity, versus factors that reflect unequal treatment. Understanding the source of differences is an important step towards implementing practice or policy solutions to mitigate racial and ethnic inequities.

The Medicaid program is the single largest payer for autism-related health care services. In addition to paying for care for children categorically eligible due to low income, disability, and being in foster care, Medicaid also pays for school-based services for eligible children in most states (Baller and Barry 2016). However, school and other community-based outpatient clinical services (hereafter outpatient) have different purposes in supporting children with ASD; in many cases both may be indicated. Services delivered at school should be designed to facilitate a “free and appropriate education,” (Education for All Handicapped Children’s Act 1975; Individual with Disabilities Education Act 1997, 1990) while outpatient services should be designed to maximize functioning in a broader range of environments, including home. For example, school-based services may not be granted if a child with autism is performing at grade level, even if their social impairments may affect long-term outcomes such as higher educational attainment, employment, and overall family functioning.

Recent studies of racial disparities in the Medicaid program have focused on services delivered through the home and community-based services (HCBS) waiver program. Although previous research on HCBS programs finds they are associated with reduced racial and ethnic disparities in unmet need for services among children with ASD (LaClair et al. 2019), less is known about the extent of disparities for children insured through Medicaid outside of waiver programs or disparities in school-based Medicaid-funded services. Although families of children with ASD may consider specific school and outpatient services interchangeable, procedures to access services in different settings vary. Furthermore, it is unclear how previous research on disparities among Latino children with ASD in the general population (Magaña et al. 2013; Zuckerman et al. 2013, 2014, 2016) applies to children served in the Medicaid program.

Conceptual Model

This study employs the framework of racial and ethnic disparity put forth in the Institute of Medicine’s (IOM) 2003 report, *Unequal Treatment* (Institute of Medicine 2003), to address gaps in our understanding of disparities in Medicaid-funded autism service use. The IOM framework distinguishes among factors that make up a disparity in health care. Figure 1 presents the framework. Differences between racial groups due to factors reflecting clinical appropriateness, need for service or patient preferences are considered justifiable in the IOM

framework (hereafter “need factors”). Factors stemming from the operation of the health care system, legal and regulatory climates, bias, discrimination, and stereotype are conceptualized as unjustifiable differences between groups (hereafter “non-need factors”). We categorized variables available in our data as need or non-need factors and applied methods so that our estimates of disparity reflected the definition put forth by the IOM.

In this study, we focused on nine services that children with ASD most often use and distinguished between school and outpatient services. Based on previous research (Bilaver and Havlicek 2019; Magaña et al. 2013, 2016; Zuckerman et al. 2017), we hypothesized that Latinx and black children would use fewer autism-related services than white children with ASD. We did not specify a priori hypotheses about disparities for Asian or Native American/Pacific Islander children, nor did we state hypotheses regarding the significance or size of specific contributions to disparities as there is not sufficient literature for these groups to make hypotheses. Instead, we used a decomposition analysis to guide post-hoc analyses.

Methods

Participants

Participants for this study were drawn from secondary data reflecting Medicaid claims. We used three files from the 2012 Medicaid Analytic eXtract (MAX) data in order to construct the study sample and measure outcomes: Other Therapy, Inpatient, and Personal Summary. The Other Therapy file includes many service types, such as physician and allied health care professional services, outpatient and clinic, lab, and home health, among others. The Personal Summary file provides information on months of enrollment and categories of eligibility. We also used data from the National Plan and Provider Enumeration System (NPPES) and the Area Health Resource File (AHRF). The NPPES data were used to categorize the type of provider. By using the taxonomy code and classification variable associated with the national provider ID, we identified Medicaid claims billed by a Local Education Agency (LEA) as a part of Medicaid special-education programs. AHRF data were used as the source for county-level indicators of health care resources.

The sample was drawn from MAX data from all 50 states and the District of Columbia (DC). It included 165,185 children ages 3–17 as of January 1, 2012 with an ASD diagnosis who were enrolled in the Medicaid program for all 12 months of 2012, were not dually enrolled in the Medicare program (as a result of end stage renal disease), and had access to full rather than partial benefits [as a result of dual eligibility or other state-specific restricted benefit plans (i.e. prescription drugs or pregnancy related services only)]. ASD was identified based on criteria used in previous studies: (Burke et al. 2014; Mandell et al. 2010) having at least two claims with an ASD ICD-9 diagnosis (299.0, 299.8, or 299.8) in the OT file within a 6-month period or one claim in the IP file with an ASD diagnosis. Children ages 0–3 were excluded because these children would have been eligible for services through Early Intervention Programs instead of School-based programs, and we were interested in understanding school-based Medicaid claims.

Additional exclusions were made based on data quality and the amount of missing data. Children in three states ($n = 12,033$) were excluded from the analysis. Idaho was excluded

because most children in the Medicaid program did not have access to full benefits. Colorado was excluded because the race/ethnicity variable was missing in the MAX data. New York was excluded because claims in the OT file did not have associated procedure codes and could not be categorized in the same way as other states. Across the other 46 states and the District of Columbia, another 35,064 children were excluded due to missing or unknown race/ethnicity. Multi-racial was not used as a race category in all states; therefore children listed as multiracial were excluded from the analysis. Finally, a small number of observations ($n = 240$) were excluded due to missing values in the independent variables central to our analysis. There were 117,848 children included in the final analytic sample. The number of children with ASD in each state ranged from 174 (Hawai'i) to 7889 (Pennsylvania). Most of these children (92%) had some fee for service (FFS) claims during the year although a much smaller percentage (24%) only had FFS claims.

Procedures

We created dependent variables to reflect nine types of autism-related services that children with ASD typically use outside of a hospital or residential care setting: physical therapy, occupational therapy, speech therapy, mental health/social skills/behavior modification, case management/ care coordination, other 1-on-1 therapy or services, other group therapy or services, personal assistant or school aide, or respite care. Both binary and discrete count measures were created. Binary variables were created to indicate any versus no service use during 2012 (0 or 1). The number of claims for each service was treated as a discrete count variable. We identified all services using the procedure code found in the OT file records. The categorization of procedure codes was based on previous autism services research (Mandell et al. 2012). The study authors reviewed and categorized procedure codes uncategorized in the original typology (categorization available upon request). Supplementary Table E1 presents the top five procedure codes in each service category.

We also identified school-based services by identifying all claims where the national provider ID belonged to a LEA. These claims are assumed to be generated through the administration of school-based Medicaid programs. Although we expected at least 44 states to have claims billed by a LEA based on previous research (Baller and Barry 2016), we found only 27 with claims associated with an ASD diagnosis for our study sample. In addition, California and Maine had very low rates of billing by LEAs for any diagnosis within the study population (6% and 2% of study children with ASD, respectively), and thus were excluded. These exclusions were made in order to prevent bias due to systematic underreporting or variation in local billing practices that would affect the data that we had available in the MAX data. These exclusions left 75,200 children across 25 states for the analysis of school-based services. All services had to have either a primary or secondary diagnosis of ASD on the claim in order to be included in the analysis.

The primary independent variable was a five-level combined race/ethnicity variable. Categories include white (white, non-Latinx), black (African American or black, non-Latinx), Asian (Asian, non-Latinx), Native American/Pacific Islander (American Indian, Alaskan Native, Native Hawaiian, Pacific Islander, non-Latinx), and Latinx. White children served as the reference group in the analysis. The MAX data does not identify children by

any other racial or ethnic groups aside from multi-racial, which was excluded from the analysis.

Need Factors

We included three types of need factors in the analysis: gender (male vs. female), age (categorized as 3–5 years, 6–8 years, 9–11 years, 12–14 years, and 15–17 years), and ASD-related comorbidities. Comorbidities common among children with ASD that could relate to the need for services were identified based on the clinical expertise of the authors and previous literature (Close et al. 2012; Frazier et al. 2014; Werling and Geschwind 2013). Variables were created from the OT and IP files using ICD-9 codes and HEDIS clinical classification software (Healthcare Cost and Utilization Project-HCUP 2014). Specifically we identified children with at least one claim with a diagnosis of intellectual disability, Attention Deficit Hyperactivity Disorder (ADHD), anxiety disorders, mood disorders, developmental delay, disruptive behavior and conduct disorders, schizophrenia and other psychotic disorders, learning disability, speech-language disorder, and sleep disorder. Supplemental Table E2 presents the ICD-9 codes used to define each comorbidity. Because gender and age could be correlated with unobserved severity, we included both variables as need factors in the analysis.

Non-need Factors

Non-need factors in the IOM framework may include any measured system, provider, or individual level factor that has the potential to impact health care delivery or quality. A four-level category of Medicaid program enrollment and a dichotomous indicator of home and community based waiver participation in January 2012 were the only individual-level non-need factor used in the analysis. Categories of Medicaid program enrollment included foster care, disability, low-income, and other. Several county-level non-need factors from the AHRF were used to reflect local health care characteristics. These included a three-level primary care and mental health care health professional shortage areas (no shortage in county, whole county shortage, partial county shortage). The AHRF includes a nine-level urban–rural continuum code for each county in the US. We created a five-level variable to describe both population density and land-use (metro county with population 1 million or more, metro county with 1 million to 250 K, metro county with less than 250 K, urban county with 20 K or more, completely rural or urban county with less than 20 K). Finally, we included the density of general pediatricians and pediatric specialists per 10 K in the child population as an indicator of health care access, a methodology previously described (Mandell et al. 2010, 2012).

Data Analysis

Disparity was measured using a three-step process concordant with the IOM definition which has been used throughout the health services literature (Cook et al. 2010, 2012; McGuire et al. 2006). The process includes (1) model estimation, (2) transformation of the distribution of need factors for racial and ethnic minorities, and (3) prediction. All analyses were performed using Stata 15.1.

Model Estimation

Separate logistic regression models were fit to estimate the log odds of ever receiving each of the autism-related services described above, and negative binomial regression was used to estimate the log of total services. The main specification for each model included race, the need and non-need factors described above, and state fixed effects. In some models state fixed effects could not be included due to problems of perfect prediction and convergence.

Transformation of Distribution of Need Factors

Transformation is the step in the process that creates IOM concordant estimates by adjusting the allowable differences between racial and ethnic groups before predicting the disparity. Transformation was done using the rank-and-replace method (Cook et al. 2010), the method most commonly used to create IOM concordant estimates (Cook et al. 2010, 2012; McGuire et al. 2006). The process involves equalizing the need factors between two groups by ranking observations according to the sum of the predicted value of the need factors and then replacing the prediction of the *n*th-ranked minority child with the *n*th-ranked white child. The process creates a counterfactual in which the need factors of the minority children are equal to that of white children, while non-need factors are allowed to vary.

Prediction

After equalizing the need factor related predictions between minority and white children, predicted service use of the counterfactual population was then calculated for each racial and ethnic group and compared to predicted service use among white children. The difference between minority and white in predicted mean service use is the IOM-concordant measure of disparity. Standard errors for the IOM concordant disparities were calculated using 1000 bootstrapped replicates (Efron 1979).

In post-hoc analyses of our primary logistic model, we used the Fairlie (2005) decomposition method and stratified analyses to examine the contribution of potentially modifiable drivers of disparities. The Fairlie method is an extension of the Oaxaca-Blinder decomposition model (Blinder 1973; Oaxaca 1973) applied to nonlinear binary outcome models. Because a randomly selected white subsample is used to estimate the contributions, the process is repeated with 1,000 randomly selected samples and results averaged. We used the Stata program developed by Ben Jann (2008) and random ordering of variables to address path dependence as described by Fairlie (2017). The choice of variables for the stratified analysis was based on the result of the decomposition. Specifically, we stratified the primary IOM concordant estimates of service use by whether the child lived in a metropolitan county with population over 250 K (large metro) versus other counties (small metro or non-metro). The dichotomous version of the urban–rural continuum code has been described elsewhere and used for policy decisions (Hart et al. 2005).

In addition to the post-hoc analyses informed by the decomposition, several sensitivity analyses were performed to assess our assumptions about sample selection criteria and variable choice. First, we ran our primary analysis on the subset of children with only FFS claims during 2012. Second, we assessed whether our criteria related to having an ASD diagnosis on the service claim was too strict. For example, children with ASD could be

receiving some of the services included in our analysis as a result of comorbid conditions. We ran our primary analysis by include all claims of a particular service type regardless of the diagnosis (primary or secondary) on the claim. Finally, we assessed whether our results were robust to our conceptualization of gender as a need factor. If differences by gender reflect unjustified differential treatment within the health care system, gender should be considered a non-need factor. We tested the robustness of our primary analysis to a different assumption by interacting gender and race as a non-need factor in the analysis.

Results

Descriptive statistics for the study population by race/ethnicity are presented in Table 1. Among Medicaid enrolled children with ASD in the analytic sample, 64% were white, 18% black, 14% Latinx, 2% Asian, and 2% Native American/Pacific Islander. The percentage of children with co-occurring conditions ranged from 34.5% (ADHD) to 3.0% (Schizophrenia and other psychotic disorders) and in many cases varied substantially across race/ethnicity. Most children with ASD were enrolled in Medicaid due to disability (50.7%) and through a waiver program (59.5%), although there was considerable variation by race/ethnicity in some categories. For example, 11.5% of black children were enrolled through foster care compared with 4% of Latinx, 2% of Asian, 7.5% of Native American/Pacific Islander, and 8.1% of white children. Similarly, 51.1% of black children were enrolled in a waiver program compared with 66.3% Latinx, 70.7% of Asian, 68.7% of Native American/Pacific Islander, and 59.7% of white children.

More than 70% of Medicaid enrolled children with ASD in each race/ethnicity group billed at least one autism-related service outside of school (Supplementary Figure E2). The number of service claims outside of school ranged from an average of 24 for black children to 35 for Asian children (Supplementary Figure E3). The percentage of children with school-based services was much lower, and ranged from 21% of Native American/Pacific Islander to 31% of Asian children. The average number of school-based claims ranged from 7 to 10 per year.

Table 2 presents the unadjusted differences and IOM concordant disparities in the percentage of service use. Differences described as disparities are those where the minority children receive fewer services than white children, and this is assumed to represent a disadvantage for the minority child. IOM concordant estimates of outpatient service use revealed disadvantage for black, Asian, and Native American/Pacific Islander children compared with white children. Black children had rates of service use that were 5.2 percentage points lower than white children, while Asian children had rates 2.6 percentage points lower and Native American/Pacific Islander children had rates 3.7 percentage points lower. There were no significant disparities in use of school-based services. In contrast, black and Asian children had a rate of school-based service use that was 5.6 and 4.8 percentage points *higher* than white children respectively.

IOM concordant disparities in specific services varied considerably by type of service and race/ethnicity. The only type of services that consistently found minority disadvantage in the IOM concordant estimate were physical therapy, occupational therapy, and case management/care coordination services where only the latter had statistically significant

disparities in three of four racial groups. Specifically, disparities in case management/care coordination ranged from 1.9 percentage points lower (black) to 8.3 percentage points lower (Asian). IOM concordant disparities were found in the use of 1-on-1 therapy or counselling services, and personal assistant or school aide services in three of the four race/ethnicity groups. Only Native American/Pacific Islander children had a disparity in speech therapy (-3.1%). In contrast, all other minority groups had significantly higher rates of speech therapy compared with white children.

IOM concordant disparities in the number of billed services are presented in Supplementary Table E3. Estimates for black children continue to reveal disadvantage in the number of billed services outside of school [mean -2.1, standard error (SE) 0.4] while there was no significant difference in the number of billed services between Latinx and Native American/Pacific Islander compared with white children. Asian children had significantly more outpatient services billed (mean 7.1, SE 1.5). Only Latinx children had a significant IOM concordant disparity in the average number of school-based services (mean -0.9, SE 0.3). IOM concordant mean numbers of billed case management and care coordination services revealed significant disadvantage in all four minority groups.

Decomposition

Table 3 presents the decomposition of outpatient service disparities for the three groups with significant IOM disparities in our primary logistic model. The coefficient describes the change in the minority white gap due to racial differences in the distribution of the variable and the percentage describes the coefficient as a percent of the minority-white gap. For example, 7.7% of the difference between black and white children in outpatient services use was accounted for by differences in the distribution of urban-rural county of residence. Put another way, if the distribution of urban-rural county of residence classification between black and white children were equalized, the difference in outpatient service use would be 7.7% *smaller*. State fixed effects accounted for the largest percentage of the minority-white gap indicating a significant contribution of unknown state characteristics.

Post-hoc Analysis

Table 4 presents the results of the IOM concordant estimates of service use stratified by large metro vs. small metro or non-metro county classification status. The disparity in outpatient service use for black children was driven largely by children living in large metro counties where the disparity compared to white children was -6.0% compared with a higher percentage of black children using services in small metro or non-metro counties (2.6%). The opposite was true for Native American/Pacific Islander children where only those living outside of large metro counties had a disparity (-7.5%). Although there were no overall disparities in school-based services we did find two significant disparities in the stratified analysis, both among children living in small metro or non-metro counties. Black children living in these areas had rates of school-based service use that were 4.4 percentage points lower than white children, while Latinx children had rates that were 6.8 percentage points lower.

Sensitivity Analyses

Three sensitivity analyses were performed for our main analysis of outpatient services and school-school based services (Supplementary Table E4). Among black and Native American/Pacific Islander children, outpatient disparities remained in estimates that included children with only FFS claims. Latinx children on the other hand had a large disparity (−6.0%) when children with only FFS claims were used to estimate outpatient service use. There were no new disparities in estimates for school based services although most of the differences in service use increased when based on children with only FFS claims.

Analysis 2 examined the impact of relaxing the diagnosis requirement on the service claims such that any claim for that type of service was used to measure disparities. For black–white and Native American/Pacific Islander–white outpatient disparities the size of the disparity decreased but remained statistically significant (−2.8% black–white and −1.7% Native American/Pacific Islander–white, $p < 0.001$). With respect to school-based services, a new Native American/Pacific Islander–white emerged when using claims with any diagnosis (−9.5%). Analysis 3 treated gender as a non-need factor. There were no substantive differences with this assumption.

Discussion

Significant racial and ethnic disparities in autism-related services were found among Medicaid enrolled children with ASD. Black, Asian, and Native American/Pacific Islanders received fewer outpatient, autism-related services compared with white children, but there was no disparity among Latinx children. There were no disparities in school-based services. To our surprise black and Asian children received more services than white children in the school setting. Disparities in case management/care coordination services were largest; there was a significant 8.3, 7.3, and 1.9 percentage point disparity for Asian, Latinx, and black children respectively. In stratified analyses, we found a disparity for black children (6 percentage points) in outpatient services for children living in large metro areas.

Our empirical strategy attempts to identify the origin of differences in received services. While the metro status of the county in which a child lives is associated with disparities, the measured characteristics including those captured in state-level fixed effects do not fully explain the differences we observe. Consistent with the IOM definition, we expect that unmeasured factors such as bias and discrimination, including interpersonal and structural racism, contribute to disparities. Structural racism refers to “the totality of ways in which societies foster racial discrimination through mutually reinforcing systems of housing, education, employment, earnings, benefits, credit, media, health care, and criminal justice” (Bailey et al. 2017). In this study, the downstream effects of structural racism may manifest in a variety of contexts including the school system, the Medicaid program, and the healthcare system. Although we could not identify differences in school billing practices in this study, the racial disparities that we observe could be a downstream consequence of structural racism in housing such that schools in poorer neighborhoods are incentivized to make up revenue gaps by billing Medicaid. In addition to structural barriers that promote

racial disparities in service use, families bring with them the legacy of these experiences that may affect their preferences to pursue services to support their children with ASD.

When compared with white children, black children with ASD were 5.3% less likely to use outpatient autism related services but 5.6% more likely to use school-based services, a result driven by children living in large metro areas. One hypothesis to explain this substitution effect would be easier access and availability of school-based services compared with outpatient services in large metro counties with large concentrations of minority children. Although obtaining an individualized education plan to receive school-based services can be challenging for families (MacLeod et al. 2017; Salembier and Furney 1997), at least the process typically occurs in the building where a child attends school and requires no additional family travel. A second hypothesis is that the school context, including racial composition and fiscal resources, are associated with the propensity to place minority children in special education and possibly bill Medicaid for school-based services. There is a significant body of literature that has documented a higher likelihood of special education placement among minority children (National Research Council 2002; Zhang et al. 2014); however, recent studies have challenged this finding after more fully controlling for socioeconomic correlates, school context, and type of disability (Fish 2019; Morgan et al. 2017; Schussler et al. 2016). It is possible that the pattern of greater service use among black children stems in part from this legacy as well as variation in school-based Medicaid billing practices. Future research should examine the contribution of school context including racial composition and fiscal resources on disparities.

The other racial and ethnic groups in the study had mixed findings. Overall, there were no significant disparities in outpatient or school-based autism-related services among Latinx children; Latinx children were 0.6% more likely to receive outpatient services and just as likely to receive school-based service compared with white children. There were different patterns among Asian and Native American/Pacific Islander children. Asian children were less likely to receive outpatient services (−2.6%) but 4.8% more likely to receive school-based services compared with white children. Native American/Pacific Islander children had a disparity in the likelihood of outpatient services (−3.7%) but were equally likely to receive school-based services compared with white children. Although our overall findings did not support our hypothesis of widespread disparities across outpatient services among Latinx children, we did find disparities in occupational therapy consistent with some prior literature (Bilaver and Havlicek 2019; Harstad et al. 2013; Irvin et al. 2012; Magaña et al. 2016). However, we also found an increased likelihood of speech therapy, mental health/social skills/behavior modification services, and 1 on 1 therapy or counseling services not consistent with previous estimates in the general population (Bilaver and Havlicek 2019; Magaña et al. 2016). Although population-level research on service use among Asian, Native American, and Pacific Islander children with ASD is extremely limited, evidence from California's Department of Developmental Services found greater per-person non-medical spending (including respite and day services) among Asian and "other" race/ethnicity children than Latinx and black children (Leigh et al. 2016). Qualitative studies of Asian immigrant parents of children with ASD reveal the influence of unique cultural, religious, and environmental factors that may influence service utilization (Shorey et al. 2020; Wang and Casillas 2013) as well as the challenges that limited language proficiency

presents when trying to access quality autism-related services (Zuckerman et al. 2014). Our mixed findings for these groups of children suggest a more complex dynamic that requires further study to understand why population average patterns should increase use of some services but not others.

To our knowledge, disparities in case management/care coordination services for children with ASD have not been documented previously. The claims for children with ASD in this category of service consisted largely of both case management and target case management services. Case management refers broadly to services used to support recipients find medical or other services necessary for the treatment of a health condition while targeted case management (TCM) refers to services restricted to a specific groups of recipients (Binder 2008). There is a long history of legislative and regulatory action around the use of case management and TCM in the Medicaid program beginning in 1981. On March 3, 2008, a CMS rule became effective that clarified the use of TCM in both Medicaid waiver and non-waiver programs (Rosenbaum 2008). The rule was expected to reduce federal Medicaid expenditures by \$1.28 billion between fiscal year (FY) 2008 and FY 2012 (Binder 2008). Because TCM refers to specific groups of recipients it is possible that certain racial and ethnic groups are overrepresented, and therefore less likely to receive TCM as a result of the rule change compared with white children. Future research needs to examine the extent to which inequitable use of case management and/or TCM contributes to disparities, as it is critical that all children with ASD have equal access to this important service.

Our findings must be interpreted within the context of a health system which has documented disparities in receiving an ASD diagnosis for racial and ethnic minorities. The Autism and Developmental Disabilities Monitoring (ADDM) Network, a collaboration tracking the number and characteristics of children with ASD across 16 US sites, has reported higher rate of white children identified with ASD than black or Latinx children, although black and white prevalence has equalized in the most recent report. (CDC 2018; Maenner 2020) This discrepancy may mean that minority children have more delays to diagnosis and fewer diagnoses overall and that those with fewer functional limitations are less likely to be diagnosed in racial/ethnic minority children. Our analysis cannot untangle systemic biases in assigning comorbidities, for example the potentially increased likelihood of a black child of receiving a diagnosis of intellectual disability or behavioral problems. It is also possible that these racial discrepancies impact case identification for ASD through diagnostic substitution, and therefore strategies to address racial inequities in diagnoses and supportive services must take a broad approach across developmental disabilities. Standardizing the diagnostic process for school-aged children and assigning appropriate services ought to include ready access to school-based and medically-based multidisciplinary assessment professionals in order to reduce disparities in diagnostic service access and avoid implicit biases.

This reality makes our empirical strategy all the more important. By controlling for comorbid conditions that may be associated with more significant limitations, we attempted to measure disparities after accounted for variation by race/ethnicity in these factors. Higher levels of functioning, however, may not be well distinguished by comorbidities. In our analysis, if the white population included more children with autism and no intellectual

disability, this may explain why these children received fewer in-school services than minority children with ASD, as they may not have qualified for school-based services despite the general autism designation. For example, a child with autism who is at grade level, but who struggles with social nuance and relationships may not qualify for speech therapies in school, versus a child with autism who struggles with simple requesting or answering questions.

The concurrent analysis of school and outpatient services begs a provocative question about how school-based services are financed nationally. Part B of the IDEA covers funding for the education of all children with disabilities. These federal funds are intended to support, for example, children with autism to access education, which in many cases includes creating a behavioral plan and engaging in regular occupational and speech therapy services. However, educational funding is only in small part from the federal government; local school districts fund the majority. Therefore disparities in community resources for education may explain why some schools utilize the family medical insurance to cover education access instead of relying purely on educational funds. In most circumstances, this would have the negative impact of prohibiting families from accessing outpatient therapeutic services due to insurance limits on the quantity of services. Therefore, the observed increased access of school-based services may represent another type of hidden disparity for minority children. A detailed exploration about how special education and related services are financed, specifically autism-related services, would bolster support for children with disabilities in and out of the school system.

There are several limitations related to our analysis. First, claims data do not allow for clinical confirmation of the ASD diagnosis. Based on a previous validation study, the strategy that we employed is associated with a positive predictive value of 87.4% (Burke et al. 2014). Second, although the MAX data reflect a relatively harmonized claims database, quality control in all fields is lacking and led us to exclude some states from the analysis. For example, standard documentation and anomaly reports did not include information about the procedure code anomaly that we encountered in the New York state data. Data quality may also have impacted the categorization of service settings and types. Although we expected 44 states to have school-based Medicaid claims, we only found such claims in 27 states and excluded another two from the analysis based on an unbelievably low percentage of claims. Regarding service type categorization, we used multiple variables to help to identify relevant procedure codes, but we recognize that such a data driven procedure is subject to unmeasurable error. Finally, although the IOM definition includes patient preferences and discrimination, our data lacked specific measures of both. With respect to discrimination, our measured county-level characteristics only address the pathway between racism and discrimination and inadequate healthcare; however, racism can affect health care seeking behavior and thus service utilization for children with ASD through many other pathways not measured in this study (Bailey et al. 2017).

Balancing these limitations are the size and scope of our sample, our ability to examine multiple racial and ethnic groups, and our ability to examine school and outpatient settings in the same sample.

Conclusion

Within the Medicaid program, disparities in autism-related service use exists across all minority racial and ethnic groups although there is significant variation by type of service. School-based services are an important source of services for children with ASD and disparities in outpatient services appear to be ameliorated in school settings. Geographic variation in disparities suggest potential targets for policy intervention to achieve equal access to services.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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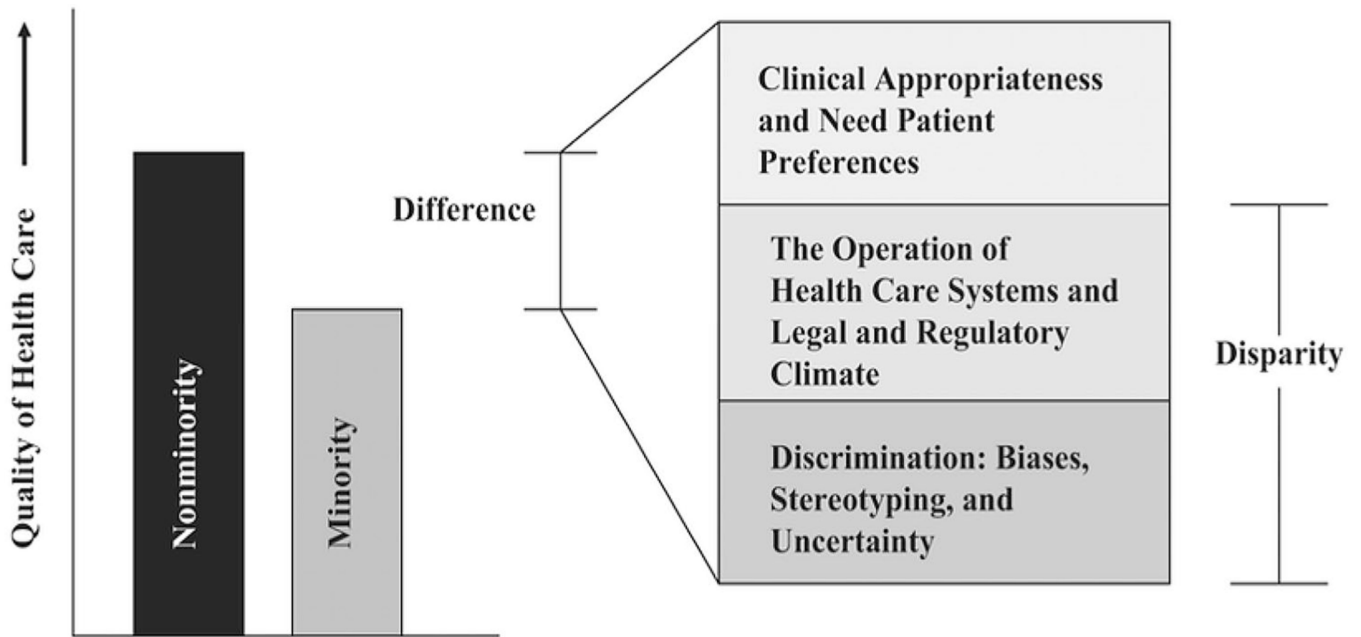


Fig. 1. Differences, disparities, and discrimination: populations with equal access to health care. Source: Institute of Medicine. Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care, 2003

Table 1
Descriptive statistics for Medicaid enrolled children ages 3–17 with ASD in 2012

Variable	Total (n = 117,848)		Black, non-Latinx (n = 20,907)		Latinx (n = 16,966)		Asian, non-Latinx (n = 2154)		Native American/Pacific Islander, non-Latinx (n = 1871)		White, non-Latinx (n = 75,950)	
	n	%	n	%	n	%	n	%	n	%	n	%
Need factors												
Gender												
Male	93,694	79.5	16,511	79.0	13,824	81.5	1720	79.9	1522	81.3	60,117	79.2
Female	24,154	20.5	4396	21.0	3142	18.5	434	20.1	349	18.7	15,833	20.8
Age (as of 1/1/2012)												
3–5	24,231	20.6	4691	22.4	4908	28.9	436	20.2	383	20.5	13,813	18.2
6–8	28,403	24.1	5072	24.3	4583	27.0	575	26.7	452	24.2	17,721	23.3
9–11	26,742	22.7	4542	21.7	3500	20.6	484	22.5	425	22.7	17,791	23.4
12–14	22,217	18.9	3659	17.5	2487	14.7	360	16.7	368	19.7	15,343	20.2
15–17	16,255	13.8	2943	14.1	1488	8.8	299	13.9	243	13.0	11,282	14.9
Comorbidities												
Any ADHD	40,647	34.5	6688	32.0	4709	27.8	337	15.6	639	34.2	28,274	37.2
Any speech-language disorder	26,894	22.8	5516	26.4	5092	30.0	590	27.4	397	21.2	15,299	20.1
Any developmental delay	21,864	18.6	3926	18.8	3354	19.8	490	22.7	318	17.0	13,776	18.1
Any disruptive behavior or conduct disorder	19,189	16.3	3304	15.8	2350	13.9	208	9.7	327	17.5	13,000	17.1
Any intellectual disability	17,456	14.8	3428	16.4	2044	12.0	431	20.0	268	14.3	11,285	14.9
Any anxiety disorder	12,845	10.9	1314	6.3	1395	8.2	124	5.8	229	12.2	9783	12.9
Any mood disorder	18,043	15.3	2589	12.4	1669	9.8	146	6.8	330	17.6	13,309	17.5
Any schizophrenia and other psychotic disorder	3514	3.0	747	3.6	394	2.3	37	1.7	56	3.0	2280	3.0
Any learning disability	5715	4.8	957	4.6	1848	10.9	110	5.1	84	4.5	2716	3.6
Any sleep disorder	3892	3.3	666	3.2	479	2.8	54	2.5	56	3.0	2637	3.5
Non-need factors—patient level												
Medicaid enrollment category												
Foster care	9411	8.0	2406	11.5	678	4.0	43	2.0	140	7.5	6144	8.1

Variable	Total (n = 117,848)		Black, non-Latinx (n = 20,907)		Latinx (n = 16,966)		Asian, non-Latinx (n = 2154)		Native American/Pacific Islander, non-Latinx (n = 1871)		White, non-Latinx (n = 75,950)	
	n	%	n	%	n	%	n	%	n	%	n	%
Disability	59,771	50.7	11,474	54.9	8228	48.5	1220	56.6	1008	53.9	37,841	49.8
Income	45,088	38.3	6644	31.8	7716	45.5	842	39.1	666	35.6	29,220	38.5
Other	3578	3.0	383	1.8	344	2.0	49	2.3	57	3.0	2745	3.6
Enrolled in home and community based waiver												
No	47,736	40.5	10,215	48.9	5711	33.7	632	29.3	585	31.3	30,593	40.3
Yes	70,112	59.5	10,692	51.1	11,255	66.3	1522	70.7	1286	68.7	45,357	59.7
Non-need factors—county level												
Health professional shortage area (primary care)												
None of the county is a shortage area	14,226	12.1	1894	9.1	1033	6.1	230	10.7	67	3.6	11,002	14.5
The whole county is a shortage area	50,229	42.6	9520	45.5	9876	58.2	862	40.0	982	52.5	28,989	38.2
Part of the county is a shortage area	53,393	45.3	9493	45.4	6057	35.7	1062	49.3	822	43.9	35,959	47.3
Health professional shortage area (mental health)												
None of the county is a shortage area	14,617	12.4	2136	10.2	1027	6.1	247	11.5	80	4.3	11,127	14.7
The whole county is a shortage area	47,331	40.2	7528	36.0	7978	47.0	572	26.6	1106	59.1	30,147	39.7
Part of the county is a shortage area	55,900	47.4	11,243	53.8	7961	46.9	1335	62.0	685	36.6	34,676	45.7
Urban-rural continuum code												
Counties in metro areas of 1 million or more	54,130	45.9	12,839	61.4	10,918	64.4	1622	75.3	577	30.8	28,174	37.1
Counties in metro areas of 250 K to 1 million	27,943	23.7	4352	20.8	4009	23.6	354	16.4	425	22.7	18,803	24.8
Counties in metro areas of fewer than 250 K	13,602	11.5	1782	8.5	980	5.8	96	4.5	232	12.4	10,512	13.8
Counties with urban population of 20 K or more	9164	7.8	892	4.3	518	3.1	54	2.5	215	11.5	7485	9.9
Counties with completely rural or urban population of less than 20 K	13,009	11.0	1042	5.0	541	3.2	28	1.3	422	22.6	10,976	14.5
	n	Mean	n	Mean	n	Mean	n	Mean	n	Mean	n	Mean

Variable	Total (n = 117,848)		Black, non-Latinx (n = 20,907)		Latinx (n = 16,966)		Asian, non-Latinx (n = 2154)		Native American/ Pacific Islander, non-Latinx (n= 1871)		White, non-Latinx (n = 75,950)	
	n	%	n	%	n	%	n	%	n	%	n	%
General pediatricians per 10 K child population	117,848	586.7	20,907	812.4	16,966	635.6	2154	862.9	1871	454.6	75,950	509.1
Pediatric specialists per 10 K child population	117,848	180.6	20,907	313.7	16,966	177.1	2154	281.4	1871	106.2	75,950	143.8

All states except Idaho, Colorado, and New York are included in the sample

Table 2 Unadjusted differences and IOM concordant estimates of the percentage of autism-related service use for Medicaid enrolled children ages 3–17 in 2012

Variable	Black/white difference		Latinx/white difference		Asian/white difference		Native American or Pacific Islander/white difference	
	% (se)	p-value	% (se)	p-value	% (se)	p-value	% (se)	p-value
Service type								
Any outpatient service								
Unadjusted difference	-5.2 (0.3)	***	0.8 (0.3)	*	-3.2 (0.9)	***	-3.8 (1.0)	***
IOM concordant estimate	-5.3 (0.3)	***	0.6 (0.3)	*	-2.6 (0.9)	***	-3.7 (1.0)	***
Any school-based service								
Unadjusted difference	7.0 (0.4)	***	2.8 (0.5)	***	8.6 (1.4)	***	-1.5 (1.4)	
IOM concordant estimate	5.6 (0.4)	***	0.5 (0.5)		4.8 (1.2)	***	-1.8 (1.4)	
Any physical therapy								
Unadjusted difference	-0.8 (0.1)	***	0.3 (0.1)	**	0.4 (0.3)		-1.0 (0.2)	
IOM concordant estimate	-1.0 (0.1)	***	-0.2 (0.1)		-0.2 (0.3)		-1.2 (0.3)	***
Any occupational therapy								
Unadjusted difference	-0.5 (0.2)	**	1.5 (0.2)	***	1.3 (0.6)	*	0.1 (0.6)	
IOM concordant estimate	-1.3 (0.2)	***	-0.2 (0.2)		-0.3 (0.5)		-0.2 (0.6)	
Any speech therapy								
Unadjusted difference	6.4 (0.3)	***	7.9 (0.4)	***	12.8 (1.0)	***	-2.6 (0.8)	***
IOM concordant estimate	4.4 (0.3)	***	3.7 (0.3)	***	7.9 (0.8)	***	-3.1 (0.7)	***
Any mental health/social skills/behavior modification								
Unadjusted difference	-2.7 (0.2)	***	1.5 (0.3)	***	1.4 (0.7)	*	0.9 (0.7)	
IOM concordant estimate	-2.5 (0.3)	***	1.1 (0.3)	***	1.6 (0.7)	**	0.7 (0.8)	
Any case management/care coordination								
Unadjusted difference	-2.5 (0.3)	***	-8.8 (0.3)	***	-9.8 (0.8)	***	-2.3 (1.0)	**
IOM concordant estimate	-1.9 (0.4)	**	-7.3 (0.4)	***	-8.3 (0.9)	***	-1.2 (1.0)	
Any 1 on 1 therapy or counseling service								
Unadjusted difference	-4.3 (0.4)	***	2.8 (0.4)	***	-5.0 (1.1)	***	-4.2 (1.2)	***
IOM concordant estimate	-4.0 (0.4)	***	2.0 (0.4)	***	-4.1 (1.1)	***	-4.2 (1.1)	***
Any group therapy/counseling service								
Unadjusted difference	0.2 (0.3)		-0.3 (0.3)		-5.6 (0.7)	***	-1.5 (0.9)	

Variable	Black/white difference		Latinx/white difference		Asian/white difference		Native American or Pacific Islander/white difference	
	% (se)	p-value	% (se)	p-value	% (se)	p-value	% (se)	p-value
IOM concordant estimate	0.9 (0.3)	***	0.2 (0.3)		-4.7 (0.8)	***	-1.5 (0.8)	*
Any personal assistant/school aide								
Unadjusted difference	-3.1 (0.3)	***	-2.2 (0.3)	***	4.2 (0.9)	***	-2.6 (0.8)	***
IOM concordant estimate	-3.3 (0.2)	***	-1.9 (0.3)	***	3.3 (0.8)	***	-2.5 (0.8)	***
Any respite								
Unadjusted difference	-2.4 (0.1)	***	0.2 (0.2)		0.6 (0.5)		0.6 (0.5)	
IOM concordant estimate	-3.9 (0.4)	***	0.3 (0.4)		5.9 (1.5)	***	1.6 (1.1)	

Standard errors are based on 500 bootstrap replicates. All models include race, need and non-need factors, and state fixed effects

p < 0.001

**
p < 0.01

*
p < 0.05

Table 3
Decomposition of significant disparities in outpatient autism-related service use among Medicaid enrolled children

	Black-White gap		Asian-White Gap		Native American/Pacific Islander-White Gap	
	Coefficient	(%)	Coefficient	(%)	Coefficient	(%)
Proportion with outpatient service use						
Minority	0.732		0.753		0.747	
White	0.785		0.785		0.785	
Minority-white gap	0.052		0.032		0.038	
Contributions from racial differences in:						
Need factors	0.000	(0.0%)	0.006	(18.8%) ^{***}	0.001	(2.6%) ^{***}
Non-need factors—patient level						
Medicaid enrollment category	0.000	(0.0%)	0.000	(0.0%)	0.000	(0.0%)
Home and community based waiver	0.000	(0.0%)	-0.001	(-3.1%)	0.000	(0.0%)
State fixed effects	0.014	(26.9%) ^{***}	0.031	(96.9%) ^{***}	-0.019	(-50.0%) ^{***}
Non-need factors—county level						
Health care shortage area (primary care)	0.002	(3.8%) ^{***}	0.000	(0.0%)	0.002	(5.3%) ^{***}
Health care shortage area (mental health)	0.000	(0.0%)	0.000	(0.0%)	0.000	(0.0%)
Urban-rural land use indicators	0.004	(7.7%) ^{***}	0.006	(18.8%) ^{***}	-0.001	(-2.6%) ^{***}
Rate of pediatric providers (per 10 K)	0.001	(1.9%)	0.001	(3.1%)	0.000	(0.0%)
Rate of specialty pediatric providers (per 10 K)	-0.001	(-1.9%)	-0.001	(-3.1%)	0.000	(0.0%)

Standard errors are based on 1000 replicates. All models include race, need and non-need factors, and state fixed effects

^{***} p < 0.001

^{**} p < 0.01

^{*} p < 0.05

Table 4

Post hoc analysis of urban–rural impact on IOM concordant estimates of the percentage of autism-related service use for Medicaid enrolled children ages 3–17 in 2012

Variable	Black/White disparity	Latinx/White disparity	Asian/White difference	Native American or Pacific Islander/White disparity	p-value
Service type	% (se)	% (se)	% (se)	% (se)	p-value
Any outpatient service					
IOM concordant estimate (unstratified model)	-5.3 (0.3) ***	0.6 (0.3) *	-2.6 (0.9) ***	-3.7 (1.0) ***	***
Estimate among children in large metro areas	-6.0 (0.4) ***	1.4 (0.4) ***	-1.1 (0.9) ***	-0.4 (1.4) ***	***
Estimate among children in small metro and non-metro areas	2.6 (0.7) ***	3.9 (0.8) ***	1.6 (2.7) ***	-7.5 (1.5) ***	***
Any school-based service					
IOM concordant estimate (unstratified model)	5.6 (0.4) ***	0.5 (0.5) ***	4.8 (1.2) ***	-1.8 (1.4) ***	***
Estimate among children in large metro areas	6.5 (0.5) ***	0.8 (0.5) ***	3.3 (1.2) ***	-3.0 (2.5) ***	***
Estimate among children in small metro and non-metro areas	-4.4 (0.8) ***	-6.8 (1.2) ***	-5.9 (3.6) ***	-0.7 (1.9) ***	***
Any physical therapy					
IOM concordant estimate (unstratified model)	-1.0 (0.1) ***	-0.2 (0.1) ***	-0.2 (0.3) ***	-1.2 (0.3) ***	***
Estimate among children in large metro areas	-0.9 (0.1) ***	-0.4 (0.1) ***	-0.1 (0.3) ***	-1.0 (0.3) ***	***
Estimate among children in small metro and non-metro areas	-1.1 (0.2) ***	0.6 (0.3) ***	0.1 (1.1) *	-1.1 (0.4) ***	***
Any occupational therapy					
IOM concordant estimate (unstratified model)	-1.3 (0.2) ***	-0.2 (0.2) ***	-0.3 (0.5) ***	-0.2 (0.6) ***	***
Estimate among children in large metro areas	-1.4 (0.2) ***	-0.8 (0.2) ***	-0.7 (0.5) ***	-0.9 (0.8) ***	***
Estimate among children in small metro and non-metro areas	-1.8 (0.4) ***	0.2 (0.5) ***	2.1 (2.0) ***	0.7 (0.9) ***	***
Any speech therapy					
IOM concordant estimate (unstratified model)	4.4 (0.3) ***	3.7 (0.3) ***	7.9 (0.8) ***	-3.1 (0.7) ***	***
Estimate among children in large metro areas	4.5 (0.4) ***	2.7 (0.3) ***	6.0 (0.8) ***	-3.9 (1.1) ***	***
Estimate among children in small metro and non-metro areas	-2.4 (0.5) ***	0.9 (0.7) ***	2.8 (2.6) ***	-1.4 (1.0) ***	***
Any mental health/social skills/behavior modification IOM concordant estimate (unstratified model)	-2.5 (0.3) ***	1.1 (0.3) ***	1.6 (0.7) ***	0.7 (0.8) ***	***
Estimate among children in large metro areas	-2.9 (0.3) ***	0.9 (0.4) ***	0.2 (0.7) **	1.0 (1.2) ***	***

Variable	Black/White disparity	Latinx/White disparity	Asian/White difference	Native American or Pacific Islander/White disparity
Estimate among children in small metro and non-metro areas	-3.5 (0.4) ***	2.1 (0.7) ***	3.9 (2.5) ***	1.0 (1.1)
;Any case management/care coordination				
IOM concordant estimate (unstratified model)	-1.9 (0.4) ***	-7.3 (0.4) ***	-8.3 (0.9) ***	-1.2 (1.0) ***
Estimate among children in large metro areas	-0.2 (0.4)	-5.0 (0.4) ***	-6.5 (0.9) ***	0.2 (1.3)
Estimate among children in small metro and non-metro areas	-0.5 (0.8)	-6.8 (1.0) ***	-9.8 (3.1) ***	-5.8 (1.4) ***
Any 1 on 1 therapy or counseling service				
IOM concordant estimate (unstratified model)	-4.0 (0.4) ***	2.0 (0.4) ***	-4.1 (1.1) ***	-4.2 (1.1) ***
Estimate among children in large metro areas	-4.5 (0.5) ***	2.7 (0.5) ***	-3.8 (1.1) ***	-5.1 (1.5) ***
Estimate among children in small metro and non-metro areas	-2.2 (0.9) **	2.5 (1.2) **	1.6 (3.7)	-3.1 (1.6) *
Any group therapy/counseling service				
IOM concordant estimate (unstratified model)	0.9 (0.3) ***	0.2 (0.3)	-4.7 (0.8) ***	-1.5 (0.8) *
Estimate among children in large metro areas	0.7 (0.4) *	-0.4 (0.4)	-5.0 (0.8) ***	-1.6 (1.3)
Estimate among children in small metro and non-metro areas	-0.4 (0.6)	3.5 (0.9) ***	-6.7 (2.3) ***	-0.9 (1.1)
Any personal assistant/school aide				
IOM concordant estimate (unstratified model)	-3.3 (0.2) ***	-1.9 (0.3) ***	3.3 (0.8) ***	-2.5 (0.8) ***
Estimate among children in large metro areas	-2.9 (0.3) ***	-1.8 (0.3) ***	3.6 (0.9) ***	-0.8 (1.2)
Estimate among children in small metro and non-metro areas	-4.2 (0.6) ***	-2.8 (0.8) ***	-2.0 (2.6)	-4.5 (1.1) ***
Any respite				
IOM concordant estimate (unstratified model)	-3.9 (0.4) ***	0.3 (0.4)	5.9 (1.5) ***	1.6 (1.1)
Estimate among children in small metro and non-metro areas	-3.2 (0.2) ***	-0.7 (0.2) ***	-0.7 (0.5) ***	0.5 (0.8)
Estimate among children in large metro areas	-1.3 (0.3) ***	3.1 (0.7) ***	0.5 (1.6)	1.3 (0.9)

Standard errors are based on 500 bootstrap replicates. The unstratified model include race, need and non-need factors, and state fixed effects. Stratified models exclude the state fixed effects

p < 0.001

**
p < 0.01

*
p < 0.05