J Autism Dev Disord (2016) 46:3729–3738
DOI 10.1007/s10803-016-2913-3

ORIGINAL PAPER

Sociodemographic Disparities in Intervention Service Utilization in Families of Children with Autism Spectrum Disorder

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Abstract This study investigates whether sociodemographic factors are associated with utilization of intervention services for children with autism spectrum disorder (ASD) enrolled in the Childhood Autism Risks from Genetics and the Environment Study. Maternal ethnicity, insurance status, and education for 696 families of children with ASD were available. Children of Black mothers entered intervention earlier compared to White mothers (2 vs. 2.6 years; $p = 0.001$). Having public insurance was associated with receiving <15 h/week of individual services, while having a Bachelor degree was associated with receiving <15 h/week of classroom-based services. These differences suggest that SES may be a factor in utilization of services. Efforts should be made to ensure that interventions offered are culturally and linguistically accessible.

Keywords Autism spectrum disorder · Intervention services · Utilization · Family characteristics

Introduction

Autism spectrum disorder (ASD) is a developmental disorder that is reliably diagnosed in early childhood. ASD is characterized by communication problems, social interaction impairments, and restricted, repetitive patterns of behavior and interests (American Psychiatric Association 2013). In the past 10 years, ASD has become a growing public health topic as the prevalence of children with ASD has increased from 1 in 150 in 2000 to 1 in 68 (Centers for Disease Control and Prevention 2014) just 10 years later. ASD has a heterogeneous etiology, and current research has not yet identified a specific biological treatment for the core symptoms of ASD. At present, the evidence-based treatments for core ASD symptoms in young children supported by research are early intensive behavioral intervention (EIBI) (Remington et al. 2007) programs that are based on the principles of Applied Behavior Analysis (ABA), such as Discrete Trial Teaching (Smith 2001), Pivotal Response Treatment (Smith and Iadarola 2015), the Early Start Denver Model (Dawson et al. 2010; Estes et al. 2015), and others (Schreibman and Stahmer 2014).

Children with ASD who are enrolled earlier in intensive early interventions have better outcomes, which include improved daily living and cognitive skills (Peters-Scheffer et al. 2011; Perry et al. 2011; Dawson et al. 2010). With such promising data to support the effectiveness of early intervention services, it is troubling that an estimated 9 in 10 children with ASD are not fully utilizing behavioral health services even with the existence of the Individuals with Disabilities Education Act (IDEA) (Ruble et al. 2005). IDEA mandates the provision of intervention services to children with disabilities, including both general interventions, such as speech and occupational therapy, as well as autism-specific therapies, such as EIBI and emerging interventions such as Naturalistic

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Electronic Supplementary Material The online version of this article (doi:10.1007/s10803-016-2913-3) contains supplementary material, which is available to authorized users.

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Developmental Behavioral Interventions (Schreibman et al. 2015) and developmental social-pragmatics (Smith and Iadarola 2015). IDEA does not endorse any particular type of intervention or specify the need to provide "optimal" intervention (National Center for Learning Disabilities 2014). These intervention services are governed by Part C of the IDEA for children under 3 years of age and Part B for preschool-aged (3–5 years) children. In order to address the accessibility of intervention services for children with ASD, the utilization patterns of the service system must first be identified. It is important to identify sociodemographic factors and potential barriers for families of children with ASD who are not fully utilizing intervention in order to develop effective strategies for optimizing service utilization.

This study used data collected in the Childhood Autism Risks from Genetics and the Environment (CHARGE) Study (Hertz-Picciotto et al. 2006) to determine if demographic factors are associated with the number of hours of intervention services children with ASD receive and with how early they are enrolled in these services. Our first aim was to evaluate differences in service utilization based on race/ethnicity. We hypothesized that (a) White families would receive the most hours per week of services compared to other races/ethnicities, and (b) White families would start intervention earlier than non-White families. Our second aim was to evaluate differences in services utilization based on the primary language spoken at home. We hypothesized that (a) English speaking families would receive more hours per week of services than non-English speaking families, and (b) English speaking families would start intervention earlier than non-English speaking families. Our third aim evaluated the differences in service utilization based on whether the family had private insurance or public insurance (e.g., Medicaid) to pay for the child's birth, which served as a proxy for income and socioeconomic resources. We hypothesized that (a) families with private insurance would receive more hours per week of services than families with public insurance, and (b) families with private insurance would start intervention earlier than families with public insurance. Our last aim was to evaluate differences in services utilization based on maternal education. We hypothesized that (a) families with higher maternal education would receive more hours per week of services than families with lower maternal education, and (b) families with higher maternal education would start intervention earlier.

Methods

Participants

Participants were a subset of 696 children with ASD and their families from the CHARGE study, an ongoing population-based case-control study whose primary focus is identifying the genetic and environmental contributions to ASD risk. The CHARGE study inclusion criteria were children who: (a) were between the ages of 24 and 60 months, (b) lived with at least one biologic parent, (c) had a parent who speaks English or Spanish, (d) were born in California, and (e) lived in catchment areas of a priori selected Regional Centers in California, which are funded through the State's Department of Developmental Services (DDS) to provide services for individuals with ASD and other developmental delays and cater to both a mix of small urban and rural populations. Although three groups were recruited for the CHARGE study (general population, ASD, other developmental delays), this study focuses on the subset of participating children whose diagnosis of ASD was confirmed by study clinicians. These children were initially identified primarily through lists received from the DDS, as well as through referrals from the Regional Centers, health and service providers, and other studies at the UC Davis MIND Institute. The families of children with ASD who were successfully recruited were more likely to be higher levels of education, more likely to be born in the US, and to have private insurance The CHARGE protocol was approved by the institutional review boards at the University of California in Davis and Los Angeles and the State of California Committee for the Protection of Human Subjects.

Procedures

For this paper, we specifically limited our analysis and description of methods to the subset of children with a confirmed diagnosis of ASD and their families. Participants in our subset were interviewed over the phone by study staff using the Environmental Exposure Questionnaire to collect medical and demographic information. Participants visited the MIND Institute for two study visits that included several diagnostic assessments, such as the Autism Diagnostic Interview-Revised (ADI-R) (Rutter et al. 2005) and the Autism Diagnostic Observation Schedule (ADOS) (Lord et al. 2012). ADI-R and ADOS were used to confirm the presence of ASD. ADOS comparison scores were used to measure the severity of ASD symptoms on a 10-point scale (Lord et al. 2012; Gotham et al. 2009). Also at the study visit, a physician obtained a medical and intervention services and treatment utilization history using the Services and Treatment Interview. Parents also completed the Multiple Language Questionnaire, which was used to quantify the amount of time different languages were spoken at home to determine the primary home language.

Measures

Demographic Data

Mother's race/ethnicity and education were ascertained using the Environmental Exposure Questionnaire, a structured telephone interview with the mother. Information about type of insurance to pay for delivery came from birth files and served as a proxy for income and socioeconomic resources (income is typically reported by <50 % of study participants). We used maternal race/ethnicity because mothers are usually the primary caregivers and most likely the individual to seek services for their child. Race/ethnicity were divided into five groups: (1) White, (2) Hispanic (any race), (3) Asian, (4) Black, and (5) Mixed or other race. Educational attainment was categorized into three groups: (1) high school or less, (2) some college/vocational, and (3) Bachelor degree or higher. Insurance at time of delivery (i.e. insurance available to pay for the child's birth) was categorized into public (government program) and private insurance.

Autism Diagnostic Observation Schedule

The Autism Diagnostic Observation Schedule (ADOS) is a semi-structured, standardized assessment of communication and social interaction skills. The ADOS includes four different modules and the assessment administrator choses the one that best fits the child's expressive language level. It measures Communication, Social Interaction, Play, and Imaginative Use of Materials (Lord et al. 2012). Scoring is then scaled to ADOS comparison scores for symptom severity: Score 1–3 = Minimal symptoms, 4–6 = Mild to Moderate, or 7–10 = Severe (Gotham 2009).

Services and Treatment Interview

This survey was created for the purpose of assessing general usage of any services and treatments and questions were not specific to services and treatments solely for ASD, although our analyses are limited to the ASD subset. Services and treatments could have been attained from multiple sources including government-funded Regional Centers, public school systems, and privately sourced centers. Trained physicians collected information on the types and hours of services received and age of entry into services through any of the previously listed sources. In order to capture the various types of services provided by any of the previously listed sources, we asked about the number of hours received for both individual (i.e. one-on-one; see Table 3 for examples) and classroom-based (i.e. group) services. This distinction also allowed us to investigate if there were socioeconomic or ethnic disparities in service utilization related to service type/format (individual vs. group). We also collected the age of entry into classroom-based programs. Questions included: "What individual and/or group services, related to [CHILD's] developmental or behavioral condition has [CHILD] received at school and/or outside of school?", "When did he or she begin classroom programs?", "How many days per week does child attend school program?", and "How many hours/day does child attend school program?"

Multiple Language Questionnaire

Primary language spoken at home was collected from the Multiple Language Questionnaire, which is a brief questionnaire developed for the CHARGE study to quantify the proportion of time different languages are spoken in the home. For purposes of this analysis, we classified primary home language as English (if spoken ≥50 %) and otherwise, as non-English.

Statistical Analysis

The services received were categorized into either classroom-based programs or individual services (both private and in school) with the expectation that many of the children would have had both types of services. Our predictors of interest were maternal race/ethnicity and educational attainment, primary language spoken at home, and delivery payer. To determine whether these demographic characteristics were associated with the child's age of entry for classroom-based programs, we fitted linear regression models adjusted for ASD symptom severity and child's age at study enrollment. The predictors were modeled individually in separate models and together in one model. β-coefficients and standard errors (SE) were calculated to measure the association between each predictor and the age of entry for classroom-based programs. We conducted log-linear (Poisson) regression models with robust error variances (Zou 2004) to examine whether our predictors were associated with weekly hours of services, with analyses adjusted for ASD symptom severity and child's age at study enrollment. These analyses were performed for both classroom-based and individual services to investigate if socioeconomic and ethnic disparities are present for either type of service. Hours of services per week were divided into three groups: <15, 15–24, and ≥25 (referent). Prevalence ratios (PR) and 95 % confidence intervals (CI) were calculated to measure the association between each group and the referent. All analyses were carried out using SAS version 9.4 (SAS Institute Inc., Cary, NC).

Results

Of the 696 children with ASD, 656 (94 %) children were receiving classroom-based programs and 678 (97 %) children were receiving individual services. Among families of children receiving classroom-based programs and/or individual services, 59 % of mothers were non-Hispanic White, 92 % were primarily English-speaking, 44 % had Bachelor degrees, and 83 % were privately insured at the time the child was born (Table 1). Sociodemographic characteristics were very similar for those receiving classroom-based services, those not receiving classroom-based services, and those receiving individual-based services; those not receiving individual services were less likely to have graduate education and more likely to have vocational training or college without a bachelor's degree. Also, children of Hispanic families were more likely to receive no individual services (32.5 %) than to receive individual services (24.3 %), a trend not seen in any other race/ethnicity group. At the time of participation in the CHARGE study, approximately 74 % of the children receiving classroom-based and/or individual services were 2 to 3 years old (Table 2); 58 % of children in classroom-based programs and 61 % of children receiving individual services exhibited severe ASD symptoms (ADOS comparison score ≥7) (Table 2). Among the most utilized individual services reported were speech therapy, occupational therapy, and behavior modification (Table 3).

Utilization Predictors and Age of Classroom-based Program Entry

Maternal race/ethnicity was significantly associated with age of entry for classroom-based services independent of our other predictors (maternal education, primary language spoken at home, and delivery payer) and after controlling for child's age at study enrollment and ASD symptom severity. Specifically, compared to children of White mothers, children of Black mothers were half a year younger, on average, when they entered services [2 years 7 months (1 month) vs. 2 years ½ month (2 months), $p = 0.001$]. We also found that children whose primary language spoken at home was not English were approximately 3 months older at entry of classroom-based services than children whose primary language was English, which is one-third of a school year behind [2 years 6½ months (½ month) vs. 2 years 4 months (¾ month), $p = 0.06$]. Mother's educational attainment and delivery payer were not associated with age of entry for these services (Table 4).

Utilization Predictors and Hours of Classroom-based Program

Maternal educational attainment was significantly associated with hours of classroom-based intervention services after adjusting for ASD symptom severity and child's age at study enrollment. Children of mothers with some college education or vocational training were 24 % less likely to receive <15 (vs. ≥25) hours of classroom-based services than children of mothers with a Bachelor degree (PR = 0.76,

Table 1 Family characteristics of children receiving and not receiving intervention services, N = 696

Characteristic	Classroom-based programs				Individual services			
	Services (n = 656)		No services (n = 40)		Services (n = 678)		No services (n = 18)	
	n	%	n	%	n	%	n	%
Mother's age at delivery								
<25 years	106	16.2	111	16.4	111	16.4	7	17.5
25–29 years	179	27.3	183	27.0	183	27.0	8	20.0
30–34 years	201	30.6	210	31.0	210	31.0	18	45.0
≥35 years	170	25.9	174	25.7	174	25.7	7	17.5
Mother's race/ethnicity								
White	380	57.9	399	58.9	399	58.9	23	57.5
Hispanic (any race)	161	24.5	165	24.3	165	24.3	13	32.5
Asian	57	8.7	57	8.4	57	8.4	2	5.0
Black	29	4.4	30	4.4	30	4.4	2	5.0
Mixed race	25	3.8	23	3.4	23	3.4	0	0.0
Native American	3	0.5	3	0.4	3	0.4	0	0.0
Pacific Islander	1	0.2	1	0.2	1	0.2	0	0.0
Mother's birth place								
United States	497	76.1	518	76.7	518	76.7	33	82.5
Mexico	53	8.1	54	8.0	54	8.0	2	5.0
Other	103	15.8	103	15.3	103	15.3	5	12.5
Primary language spoken at home								
English	598	91.2	623	91.9	623	91.9	38	95.0
Spanish	34	5.2	35	5.2	35	5.2	2	5.0
Other	8	1.2	6	0.9	6	0.9	0	0.0
Bilingual[1]	16	2.4	14	2.1	14	2.1	0	0.0
Mother's education level								
Less than high school	26	4.0	26	3.8	26	3.8	1	2.5
High school	83	12.7	87	12.9	87	12.9	5	12.5
Some college/ vocational	259	39.5	267	39.4	267	39.4	20	50.0
Bachelor degree	189	28.8	198	29.3	198	29.3	12	30.0
Graduate/professional degree	98	15.0	99	14.6	99	14.6	2	5.0
Marital status								
Married/living together	527	87.4	544	87.7	544	87.7	33	94.3
Single	38	6.3	36	5.8	36	5.8	0	0.0
Separated/divorced	38	6.3	40	6.5	40	6.5	2	5.7
Home owner								
Yes	386	64.1	393	63.5	393	63.5	21	60.0
No	216	35.9	226	36.5	226	36.5	14	40.0
Insurance at time of delivery								
Private insurance	548	83.7	561	82.9	561	82.9	30	75.0
Public insurance	107	16.3	107	16.3	116	17.1	10	25.0

[1] Bilingual if reported two languages spoken with equal frequency (50 % each)

Table 2 Characteristics of children utilizing classroom-based and individual intervention services

Characteristic	Classroom-based programs N = 656		Individual services N = 678	
	N	%	N	%
Child's age at study entry				
2–2.9 years	145	22.1	165	24.3
3–3.9 years	234	35.7	238	35.1
4–5 years	277	42.2	275	40.6
ASD symptom severity[1]				
Severe	382	58.2	413	60.9
Mild to moderate	198	30.2	236	34.8
Minimal	76	11.6	29	4.3
Age at eligibility for services[2]				
<1 years	22	3.6	21	3.5
1–1.9 years	109	17.8	109	18.2
2–2.9 years	243	39.6	236	39.3
3–3.9 years	209	34.0	206	34.3
4–5 years	31	5.0	28	4.7
Services per week				
<10 h	76	14.1	203	32.9
10–14.9 h	114	21.1	54	8.8
15–19.9 h	110	20.4	73	11.8
20–24.9 h	95	17.6	83	13.5
≥25 h	145	26.8	204	33.1

[1] ASD symptom severity was defined using ADOS comparison scores: 1–3 = minimal symptoms, 4–6 = mild to moderate symptoms, 7–10 = severe symptoms. (All children who met study ASD criteria on both ADOS and ADI-R had ADOS comparison scores ≥ 4)

[2] Age at eligibility for classroom based program or special education

95 % CI 0.61, 0.95). However, there were no significant differences in the proportion of children utilizing classroom-based services between 15 and 24 h/week based on maternal education. Maternal race/ethnicity, primary language spoken at home, and delivery payer were not associated with hours of services (Table 5).

Utilization Predictors and Age of Classroom-Based Program Entry among Children Receiving Individual Services

The CHARGE Study did not collect the age at which the child started individual services. For children who receive individual services, their age of entry for classroom-based services was used as age of program entry. Among children receiving both individual and classroom based services, maternal race/ethnicity was associated with the age of entry for classroom-based services after controlling covariates and independent of our other predictors. Compared to children of White mothers, the mean age of entry for classroom-based services was approximately half a year younger for children of Black mothers [2 years, 6 ½ months (1 month) vs. 2 years (2 months), $p = 0.0004$]. Mother's educational attainment, primary language spoken at home, and delivery payer were not associated with age of entry for classroom-based services among children receiving individual services (Table 6).

Table 3 Individual services ever and currently utilized, N = 678

Service	Ever		Current	
	n	%	n	%
Speech therapy	615	92.3	566	85.0
Occupational therapy	491	74.4	439	66.5
Behavior modification[1]	462	69.2	391	58.5
Sensory integration therapy	295	45.3	247	37.9
Respite care/daycare	234	35.7	220	33.6
Social skills training	187	28.6	166	25.4
Social work services	185	28.1	168	25.5
Audiology	169	25.5	25	3.8
Psychologist	140	21.3	46	7.0
Physical therapy	120	18.2	79	12.0
Nutrition	74	11.2	37	5.6
Vision services	53	8.0	22	3.3
Psychiatry	21	3.2	10	1.5
Nursing services	12	1.8	3	0.5
Other services[2]	120	17.9	93	13.8

Percentages (%) may not add up due to missing data

[1] Includes paraprofessional and behavior specialist services

[2] Includes art, music, or equestrian therapy; yoga, swimming, gymnastics

Utilization Predictors and Hours of Individual Services

Delivery payer was significantly associated with hours of individual services after adjusting for ASD symptom severity and child's age at study enrollment in addition to all predictors of interest. Children of mothers who had public insurance (e.g., Medi-Cal) to pay for delivery were 37 % more likely to receive <15 (vs. ≥25) hours of individual services per week than children of mothers who had private insurance (PR = 1.37, 95 % CI 1.14, 1.66). We also observed a marginal association between receiving fewer hours of individual services and primary language spoken at home. Children from families whose primary language was not English were more likely to receive <15 (vs. ≥25) hours of individual services compared to children from English-speaking households (PR = 1.33, 95 % CI 0.99, 1.80). Maternal race/ethnicity and educational attainment were not associated with hours of these services (Table 7).

Table 4 Associations between demographic characteristics and age of entry for classroom-based programs, N = 614

Characteristic	LS mean (Years)[1]	SE	*p*-value
Mother's race/ethnicity			
White [referent]	2.57	0.08	–
Hispanic (any race)	2.52	0.07	0.5777
Asian	2.68	0.11	0.3416
Black	2.04	0.15	0.0005
Mixed or Other race[2]	2.35	0.16	0.1403
Primary language spoken at home			
English [referent]	2.32	0.06	–
Other	2.55	0.12	0.0611
Mother's education level			
High school or less	2.30	0.10	0.1157
Some college/vocational	2.55	0.08	0.1335
Bachelor degree or higher [referent]	2.45	0.08	–
Insurance at time of delivery			
Private insurance [referent]	2.43	0.07	–
Public insurance	2.43	0.09	0.9461

42 of the 656 participants who were receiving intervention services did not report age of entry; data are presented on the 614 participants with age of entry for intervention services

[1] Least squares (LS) means and standard errors (SE) were calculated from linear regression models adjusted for all demographic characteristics in the table in addition to ASD symptom severity and child's age at study enrollment

[2] Other race includes Native American and Pacific Islander categories

Post-Hoc Analysis

Our post-hoc analysis also revealed that there were no obvious differences in ASD symptom severity across maternal race/ethnicity. In addition, we performed analyses with sampling weights to counterbalance underrepresented groups based on demographic characteristics such as education and race/ethnicity. The results of these analyses did not show any noteworthy differences from the results without the weights. We also performed analyses to determine demographic discrepancies in groups with missing vs. non-missing outcome data. We found that missing age of entry into classroom-based services was associated with Hispanic ethnicity and some college or vocational training for both individual services and classroom-based services analysis (11.5 and 6.4 % missing, respectively). Missing hours of services per week was associated with Hispanic ethnicity, non-English primary language households, and public insurance delivery payers for individual services only (17.7 % missing; Supplemental Tables 1, 2).

Discussion

This study aimed to identify sociodemographic characteristics that are associated with the utilization of intervention services, either classroom-based programs or individual services, in families of children with ASD. We examined four family characteristics (mother's race/ethnicity, education, language spoken at home, and insurance type at time of delivery) to determine if these are related to number of hours of classroom-based programs and individual services received per week and the age of the child at the entry into intervention services. Our results suggest that maternal race/ethnicity, language spoken at home, and insurance type at time of delivery are related to disparities in the service utilization for families of children with ASD. Our post-hoc analysis also revealed that there were no obvious differences in ASD symptom severity across maternal race/ethnicity, suggesting that differences in intervention service utilization are not due to disorder severity.

We found that the age of entry for classroom-based intervention services was significantly younger for children of Black mothers than White mothers. A possible explanation for this observation is that because we did not capture age of entry into individual services, children of White mothers may have received individual services at an earlier age and resulted in delayed entry into center-based services. Conversely, this trend might be explained by Black mothers wanting and seeking opportunities to enter their children into classroom-based services sooner in order to allow them to reduce the impact on employment (Folk and Beller 1993). General public childcare trends also show that Black families are more likely to utilize center-based care in comparison to their Hispanic and White counterparts (Radey and Brewster 2007). These trends, although not specifically about families of children with ASD, may be the explanation for why we see children of Black mothers entering classroom-based intervention services earlier than children of White mothers. Another possible explanation of this trend is that children of Black mothers may have received a more general developmental delay or behavioral disorder diagnosis prior to an ASD diagnosis, which is consistent with previous research (Mandell et al. 2007; Fountain et al. 2011; Magana et al. 2013). Another diagnosis at an early age may have allowed them to enter services and treatment earlier.

We also observed that children from families whose primary language spoken at home is not English had a slightly higher mean age of entry for classroom-based services and were more likely to receive fewer hours/week (<15) of individual services compared to English-speaking families. In addition, children of Hispanic families were more likely to

Table 5 Associations between demographic characteristics and hours per week of classroom-based programs, N = 540

Characteristic	<15 h		15–24 h		≥25 h		<15 h		15–24 h	
	n	%	n	%	n	%	PR[1]	95 % CI	PR[1]	95 % CI
Mother's race/ethnicity										
White [referent]	121	38.9	112	36.0	78	25.1	1.00	–	1.00	–
Hispanic (any race)	38	28.4	53	39.6	43	32.1	0.81	0.11, 1.10	0.93	0.73, 1.18
Asian	18	37.5	20	41.7	10	20.8	1.04	0.77, 1.41	1.11	0.82, 1.49
Black	2	8.7	13	56.5	8	34.8	0.34	0.11, 1.10	1.07	0.74, 1.53
Mixed or other race[2]	11	45.8	7	29.2	6	25.0	1.14	0.78, 1.68	0.94	0.57, 1.57
Primary language spoken at home										
English [referent]	175	35.9	183	37.6	129	26.5	1.00	–	1.00	–
Other	15	28.3	22	41.5	16	30.2	0.89	0.61, 1.08	1.03	0.74, 1.43
Mother's educational attainment										
High school or less	33	35.9	34	37.0	25	27.2	0.93	0.71, 1.23	0.94	0.72, 1.23
Some college/vocational	62	29.5	82	39.1	66	31.4	0.76	0.61, 0.95	0.90	0.73, 1.10
Bachelor degree [referent]	95	40.1	88	37.1	54	22.8	1.00	–	1.00	–
Insurance at time of delivery										
Private insurance [referent]	32	34.4	34	36.6	27	29.0	1.00	–	1.00	–
Public insurance	158	35.4	171	38.3	118	26.4	1.06	0.80, 1.41	0.99	0.76, 1.28

116 of the 656 participants who were receiving intervention services did not report hours of services per week; data are presented on the 540 participants with hours of classroom-based intervention services

[1] Prevalence ratios (PR) and 95 % confidence intervals (CI) were estimated using log-linear (Poisson) regression models with robust error variance, adjusted for all demographic characteristics in the table in addition to ASD symptom severity and age at study enrollment; hours of services were categorized into categories with cutoffs based on recommended hours of services, with ≥25 h/week as the referent

[2] Other race includes Native American and Pacific Islander categories

receive no individual services (32.5 %) than to receive individual services (24.3 %), a trend not seen in any other race/ethnicity group. This finding suggests that language may play a role in accessibility of services for families or in their choice of interventions services, which is consistent with other findings that families of non-white or ethnic minorities are less likely to see a case manager or developmental pediatrician (Thomas et al. 2007; Broder-Fingert et al. 2013; Magana et al. 2013). Public agencies must provide information and support in a broad range of languages and dialects that are culturally attuned. This would allow for more individuals to initially access services, as well as help families understand the nature and utility of early intervention options, especially for those families with cultural stigmas regarding developmental disabilities. Many non-English families lack providers fluent in their native language who can help guide them through the steps necessary for receiving a diagnosis of ASD and accessing intervention services.

Although we did not directly collect information on household income, we used insurance type at time of delivery as a proxy for socioeconomic status and examined whether receiving public assistance affected service utilization; we found that the number of hours of individual intervention services was significantly lower for families with public insurance in comparison to families with private insurance. During the years of the study, insurance status was likely not directly related to the provision of services since ASD-specific intervention services were accessible through government-funded Regional Centers in California for both privately and publicly insured families prior to the implementation of autism insurance legislation (SB946) in 2012. However, it has also been found that children with developmental disabilities from homes with lower income and lower education are less likely to access specialized health services, in part because their parents are less aware of the need for, and benefit from, these services (Porterfield and McBride 2007). Low-income families may also have difficulty accessing services because of the additional time often required to bring children to individual therapies that are not home-based, which may result in lost wages or additional transportation costs. In addition, individual intervention services may include private services that parents paid for in addition to the services provided through the Regional Centers or school districts. This result is consistent with past studies that, not surprisingly, found that families whose household income was over $50,000 per year were more likely to use private speech language therapy and private ABA in comparison to families with lower income levels (Thomas et al. 2007; Irvin et al. 2012). These measures of socioeconomic status are likely reflected in the disparities in

Table 6 Associations between demographic characteristics and age of entry (in years) for classroom-based intervention services among children receiving individual services, N = 600

Characteristic	LS mean (years)[1]	SE	*p*-value
Mother's race/ethnicity			
White [referent]	2.55	0.08	–
Hispanic (any race)	2.52	0.07	0.6659
Asian	2.65	0.12	0.3868
Black	2.00	0.16	0.0004
Mixed or Other race[2]	2.27	0.16	0.0729
Primary language spoken at home			
English [referent]	2.31	0.06	–
Other	2.49	0.12	0.1488
Mother's education level			
High school or less	2.27	0.10	0.0926
Some college/vocational	2.50	0.08	0.2884
Bachelor degree or higher [referent]	2.43	0.08	–
Insurance at time of delivery			
Private insurance [referent]	2.41	0.09	0.8400
Public insurance	2.39	0.08	–

78 of the 678 participants who were receiving private intervention services did not report age of entry for classroom-based or special education program; data are presented on the 600 participants with age of entry for intervention services

[1] Least squares (LS) means and standard errors (SE) were calculated from linear regression models adjusted for all demographic characteristics in the table in addition to ASD symptom severity and child's age at study enrollment

[2] Other race includes Native American and Pacific Islander categories

access to individual services and may relate to factors such as maternal employment, program availability, and cultural preferences.

The differences in utilization of intervention services revealed in our study can be addressed in several ways. Increased education about ASD and its treatment should be targeted to families with lower household incomes or who have public insurance to support early diagnosis and intervention use. This may result in increased utilization of services and possibly offset the difference in hours of individual services received per week. There can also be increased culturally sensitive outreach targeted to families of diverse race and ethnicities about classroom-based or group-based intervention services that allow children to learn skills through peer interaction (Nahmias et al. 2014). In addition, it may allow parents periods of respite. Both of these suggestions can be carried out through increased ASD screening and better outreach to community groups such as cultural centers, churches, daycares, and public assistance agencies. Lastly, expanded case management would also benefit those unfamiliar with the system and the types of services that can be provided.

Although the study of disparities in services and treatments was not a primary aim of the CHARGE Study, it was designed with population-based recruitment in order to best capture the ethnic and socioeconomic distribution within our catchment areas. We also ensured a bilingual, bicultural (English–Spanish, Latino) study team for all contacts with participants (recruitment, informed consent, interviews, psychometric evaluations and medical histories). As a result, the CHARGE ASD group is one of the most diverse, relative to other US studies of ASD. Nevertheless, funding did not permit us to include other languages. As a case-control study, the population examined was children who had already received an ASD diagnosis and whose families were proficient in either English or Spanish. These families had already sought help early, and we did not capture families with perhaps the greatest barriers to services and/or whose child was not identified with a disability until he/she entered the school system (kindergarten or later). Other limitations include the possible biases that relate to data collection on the child's age of intervention service entry, hours of services per week, and insurance status. The age of the child when she/he entered services and hours of services that the child received per week were reported by parents but was not further verified. This could have led to errors in recall given that a year or more may have passed between the child entering services and participation in the CHARGE study between the ages of 2 and 5. However, these errors in recall may be random and not specific to any outcome of interest. We collected the insurance status from the birth certificates, which may have differed from insurance at the time of entering intervention services if the families' economic circumstances changed.

In regards to missing data, we found our primary outcomes, age of entry and hours of services per week, were disproportionately missing for families with Hispanic ethnicity, some college or vocational training, non-English primary language households, and public insurance. We acknowledge that these missing data were not random and may have introduced bias in our measures of associations. Although a quarter of the study sample were Hispanic and over 40 % were non-White or Hispanic, our ability to characterize in detail several minority groups was limited by small sample sizes for Pacific Islanders, Native Americans, and mixed race groups. Additionally, despite exceptional diversity relative to most autism studies, non-White and Hispanic groups were underrepresented relative to the State population. In addition, the families who enrolled into CHARGE were more likely to be higher educated, more likely to be born in the US, and to have private insurance in comparison to the families who receive public insurance. However, we conducted a sensitivity analysis using weights to account for differences in enrollment by sociodemographic factors, and our findings were unchanged.

Table 7 Associations between demographic characteristics and hours per week of individual intervention services, N = 616

Characteristic	<15 h		15–24 h		≥25 h		<15 h		15–24 h	
	n	%	n	%	n	%	PR[1]	95% CI	PR[1]	95% CI
Mother's race/ethnicity										
White [referent]	153	41.5	87	23.6	129	35.0	1.00	–	1.00	–
Hispanic (any race)	59	41.3	37	25.9	47	32.9	0.85	0.68, 1.06	1.03	0.75, 1.42
Asian	22	41.5	13	24.5	18	34.0	0.98	0.72, 1.35	0.98	0.63, 1.53
Black	13	46.4	8	28.6	7	25.0	1.10	0.77, 1.56	1.28	0.78, 2.10
Mixed or other race[2]	10	41.7	8	33.3	6	25.0	1.12	0.78, 1.62	1.49	0.93, 2.39
Primary language spoken at home										
English [referent]	234	40.8	143	25.0	196	34.2	1.00	–	1.00	–
Other	23	52.3	10	22.7	11	25.0	1.33	0.99, 1.80	1.22	0.70, 2.13
Mother's educational attainment										
High school or less	40	40.4	22	22.2	37	37.4	0.88	0.67, 1.14	0.75	0.51, 1.11
Some college/vocational	114	46.9	56	23.1	73	30.0	1.12	0.93, 1.34	0.94	0.72, 1.23
Bachelor degree [referent]	102	37.2	75	27.4	97	35.4	1.00	–	1.00	–
Insurance at time of delivery										
Private insurance [referent]	54	55.1	22	22.5	22	22.5	1.00	–	1.00	–
Public insurance	203	39.2	131	25.3	184	35.5	1.37	1.14, 1.66	1.27	0.90, 1.79

62 of the 678 participants who were receiving intervention services did not report hours of services per week; data are presented on the 616 participants with hours of intervention services

[1] Prevalence ratios (PR) and 95% confidence intervals (CI) were estimated using log-linear (Poisson) regression models with robust error variance, adjusted for all demographic characteristics in the table in addition to ASD symptom severity and age at study enrollment; hours of services were categorized into categories with cutoffs based on recommended hours of services, with ≥25 h/week as the referent

[2] Other race includes Native American and Pacific Islander categories

There were also other variables that would have benefited our study but were not collected such as: (1) age of diagnosis of ASD, (2) any prior diagnoses of other related developmental delays that could have led to uses of services and therapies prior to entry to preschool, (3) specific services received in the home versus in the classroom which may include parent management training, (4) age of entry into individual services, (5) Part B versus Part C funding, (6) quality of the services received, (7) family income, and (8) cultural differences such as attitudes and stigma surrounding developmental disabilities. Our study population was also limited to preschool aged children. As a result, the degree to which our results can be generalized to older ages cannot be determined.

Despite these limitations, our participants had an ASD diagnosis confirmed using gold standard instruments administered by reliable clinicians, ensuring a well-defined sample population. Our sample size was large, and sufficiently diverse to identify racial and ethnic differences in service utilization, age at entry and hours per week. Our analysis also revealed no differences in ASD symptom severity across race and ethnicity. Lastly, we conducted a weighted analysis to account for demographically underrepresented groups in the study, which did not alter the results.

Underlying factors such as the ability to advocate for autism-related services for their child and awareness of the potential services may contribute to the barriers that can lead to the underutilization of services. Efforts should be made to help families understand the benefits of early intervention and to ensure that interventions offered are family-centered and culturally/linguistically accessible. In order to ensure that all families of children with ASD have equal access to intervention services, systematic efforts must be made to increase the availability of culturally and linguistically accessible information and improve community advocacy in order to further identify and reduce barriers to full intervention service utilization.

Acknowledgments We thank the Childhood Autism Risks from Genetics and the Environment study participants and staff for their dedication and effort.

Funding This study was funded by the National Institute of Environmental Health Sciences (1R01-ES015359; 2R01-ES015359; 3R01-ES015359; 5R01-ES015359; 1P30-ES023513; 2P01-ES011269), the U.S. Environmental Protection Agency (R-833292; R-829388), the National Institute of Child Health and Human Development (U54-HD079125), National Institutes of Health (UL1-TR000002), and the University of California Davis MIND (Medical Investigations of Neurodevelopmental Disorders) Institute.

Author Contributions CTN conceived of the study, participated in the design and interpretation of the data and drafted the manuscript; PK performed the statistical analysis and helped draft and review the manuscript; RH conceived of the study, participated in the design and coordination and reviewed the manuscript; IH-P conceived of the study, participated in the design and coordination and reviewed the manuscript;

KA conceived of the study, participated in its design and coordination, assisted in interpretation of results, and helped draft and review the manuscript. All authors read and approved the final manuscript.

Compliance with Ethical Standards

Conflict of Interest The authors declare that they have no conflict of interest.

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.

Informed Consent Informed consent was obtained for all individual participants included in the CHARGE study.

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