HHS Public Access

Author manuscript

Autism. Author manuscript; available in PMC 2021 February 03.

Published in final edited form as:

Autism. 2021 January ; 25(1): 258–265. doi:10.1177/1362361320953967.

Specialized primary care medical home: A positive impact on continuity of care among autistic adults

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Abstract

While the medical home has proven effective at improving continuity of care among other populations, there is a paucity of literature testing the effectiveness of medical homes in serving the healthcare needs of autistic adults. We conducted a retrospective cohort study to compare the continuity of care of autistic adult patients at a specialized primary care medical home designed to remove barriers to care for autistic adults, called the Center for Autism Services and Transition (CAST), to propensity score matched national samples of autistic adults with private insurance or Medicare. The unadjusted median Bice-Boxerman continuity of care index was 0.6 (IQR=0.4–1.0) for CAST patients, 0.5 (IQR=0.3–1.0) for Medicare beneficiaries, and 0.6 (IQR=0.4–1.0) for privately insured autistic adults. In multivariable models controlling for demographic characteristics, on average, CAST patients had continuity of care indices that were 10% higher than national samples of autistic adult Medicare beneficiaries ($p<0.0001$). Continuity of care among CAST patients did not significantly differ from that of the national sample of privately insured autistic adults ($p=0.08$). Our findings suggest that medical homes, like CAST, may be a promising solution to improve healthcare delivery for the growing population of autistic adults.

Lay Abstract

There is a nationally recognized need for innovative healthcare delivery models to improve care continuity for autistic adults as they age out of pediatric and into adult healthcare systems. One possible model of care delivery is called the "medical home." The medical home is not a residential home, but a system where a patient's healthcare is coordinated through a primary care physician to ensure necessary care is received when and where the patient needs it. We compared the continuity of care among autistic adult patients at a specialized primary care medical home

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Ethical approval:

The Institutional Review Board (IRB) reviewed this study and determined it to be IRB-exempt due to the use of limited datasets (Protocol Number: 2019E0283).

designed to remove barriers to care for autistic adults, called the Center for Autism Services and Transition (CAST), to matched national samples of autistic adults with private insurance or Medicare. Continuity of primary care among CAST patients was significantly better than that of matched national samples of autistic adult Medicare beneficiaries and similar to that of privately insured autistic adults. Our findings suggest that medical homes, like CAST, are a promising solution to improve healthcare delivery for the growing population of autistic adults.

Introduction

Continuity of care, defined as the degree to which an individual's healthcare is concentrated with a single provider, is strongly correlated with many objective and subjective health outcomes. For example, better continuity of care has been linked with significantly lower: healthcare costs, rates of secondary complications, mortality, number hospitalizations, and length of hospitalizations (Hussey et al., 2014;·Van Walraven et al., 2010; Gray et al., 2018). With regard to subjective (patient-reported) outcomes, continuity of care is positively correlated with satisfaction with care provision, perceived quality of care, and confidence in the physicians' recommendations (Saultz & Albedaiwi, 2004). Unfortunately, due to well-documented barriers to accessing and using healthcare services (e.g., Nicolaidis et al., 2015; Saqr et al., 2018; Duker et al., 2019), many autistic individuals experience poor continuity of care during and after the transition from pediatric to adult health systems (Vohra et al., 2014).

Inadequate primary care may reduce autistic adults' access to preventive services (Benevides et al., 2017) and leave common physical and mental health conditions, such as hypertension and depression (Croen et al., 2015), untreated. If not addressed, these conditions can have serious health consequences including cardiovascular disease (Croen et al., 2015), over-reliance on emergency department services (Kalb et al., 2018;·Hand, Boan et al., 2019a) and premature death (Hirvikoski et al., 2016). As such, in the United States there is a nationally-recognized demand for improved healthcare service delivery models that promote continuity of care for autistic individuals across the lifespan (Interagency Autism Coordinating Committee (IACC), 2017).

One model of care delivery that has been linked with better continuity of care in other populations within the United States (US) healthcare system is the primary care medical home (Chaiyachati et al., 2014; Coleman et al., 2010; Timbie et al., 2017; Van Walraven et al., 2010). The primary care medical home is not a residential home, but rather a healthcare delivery model where a patient's healthcare is coordinated through a primary care provider to ensure necessary care is received when and where the patient needs it (Waisman Center, 2008;·Shahidullah et al., 2018). For example, a patient's primary care provider may coordinate with the specialists the patient sees to share relevant clinical information about the patient's care in order to provide more effective, comprehensive care. Primary care medical homes are hallmarked by the following five key features: 1) comprehensive care, which includes a multi-disciplinary team of providers that can meet the large majority of each patients' physical and mental healthcare needs; 2) patient-centered care, which recognizes patients and families as core members of the care team; 3) coordinated care, in

which the medical home coordinates the patient's care across all elements of the broader health care system; 4) accessible services, which may include reduced wait times for urgent needs, enhanced in-person hours, and alternative methods of communication (e.g., via email or telephone); and 5) an emphasis on quality and safety, which may include use of evidence-based medicine and clinical decision-support tools (Agency for Healthcare Research and Quality, n.d.). However, there is a paucity of literature on testing the effectiveness of primary care medical homes in serving the healthcare needs of autistic adults (Rogers & Zeni, 2015).

In this study, we will address this critical gap in the literature by evaluating the extent to which adult healthcare services delivered through a specialized primary care medical home called the Center for Autism Services and Transition (CAST) is associated with better continuity of care among autistic adults. CAST differs from the standard medical home in that patients have an initial intake appointment to identify accommodations necessary for care (Saqr et al., 2018). For example, patients with sensory sensitivities may need to bypass the waiting room, or patients with anxiety may need to watch a high-fidelity video model prior to their formal medical appointment to familiarize themselves with the environment and expectations. Additionally, CAST differs from the standard medical home in that it has designated primary care physicians with extensive experience working with autistic youth and adults.

Methods

Study Design

We conducted a retrospective cohort study to compare the continuity of care of CAST patients to national samples of autistic adults with private insurance or public (Medicare) insurance.

Data Sources

Three independent data sources were used in this study. Medical encounter records of CAST patients were identified by an honest broker process at our Institutional Information Warehouse based on the completion of a CAST intake appointment. Data, including demographic characteristics and indicators of continuity of care, were then extracted from patient medical encounters in our healthcare system that occurred between November 1, 2014- October 31, 2019. In this study, we used de-identified, individual-level healthcare records for outpatient visits to any location or provider within our system.

Data from a national sample of autistic adults with private insurance were obtained from IBM MarketScan Commercial Claims and Encounters Databases for the years 2012–2016. These databases contain individual-level information on approximately 50 million employees, dependents, and retirees annually covered by roughly 350 insurance companies. De-identified individual-level health care records for outpatient visits were used in this analysis.

Last, data from a national sample of autistic adult Medicare beneficiaries were derived from Medicare Standard Analytic Files (SAF). Medicare is a US government program of voluntary medical insurance coverage where beneficiaries receive cost assistance for

medical care. While Medicare is predominately utilized by individuals over the age of 65 years, younger adults can be eligible for and enroll in Medicare if they have a formal disability determination by the Social Security Administration. The SAF used in this study include Limited Data Set information on 100% of Medicare beneficiaries for the years 2013–2017. De-identified beneficiary-level healthcare claims for outpatient encounters were used in this analysis. The Medicare outpatient records used in this study contained medical billing claims from institutional outpatient providers such as hospital outpatient departments, rural health clinics, renal dialysis facilities, outpatient rehabilitation facilities, Federally Qualified Health Centers, and community mental health centers. These outpatient records do not include professional service claims from non-institutional professional providers such as physicians, physician assistants, clinical social workers, or nurse practitioners.

Sample Identification

All individuals included in this analysis met the following eligibility criteria: 1) at least one (Benevides et al., 2019) medical encounter with an autism diagnosis, as defined by International Classification of Diseases, 9th edition (ICD-9) or ICD-10 codes for autistic disorder (299.0x, F84,0), atypical autism (F84.1), Asperger's syndrome (299.8x, F84.5), or pervasive developmental disorder – unspecified (299.9x, F84.9); 2) aged 18–60 years; and 3) records for at least four primary care visits,[a] as this was required for a stable calculation of the primary outcome measure (Christakis et al., 2001). Additionally, some data-source specific criteria were used in sample identification. We excluded all individuals in the MarketScan and Medicare databases who live in the same state as CAST to minimize the likelihood that any CAST patient records were captured in these data sources. We also excluded individuals from the MarketScan data who had any primary care visit with a missing value for provider identification, the unique alphanumeric code assigned to each provider, due to the impact this would have on the calculation of the outcome measure. Medical records from our institution's data Information Warehouse and Medicare SAF had no missing values for provider identification. Figure 1 depicts the sample identification process and sample sizes at each stage for each data source.

Propensity Score Matching.—After eligible individuals were identified from each of the three data sources, we used propensity score matching (1:2:2) to identify subsets of beneficiaries with private insurance and Medicare who were well-balanced with CAST patients on the distribution of baseline characteristics. The following covariates were used for propensity score matching: age in years at first observed visit, sex, rural residence, intellectual disability, duration of observation, number of outpatient visits, and Charlson Comorbidity Index (Quan et al., 2011). Rural residence was defined as living in a non-Metropolitan Statistical Area. Intellectual disability was identified using ICD-9 codes 317–319 and ICD-10 codes F70–F79. Duration of observation was defined as the number of weeks for which an individual's medical records were captured in the data. Matching was performed without replacement using a greedy nearest neighbor strategy, which generally produces the highest quality (Jacovidis et al., 2017) and number of matches (Hand, Hyer et

[a]Defined as outpatient visits with providers classified as general medicine, internal medicine, pediatric, geriatric, family medicine, or preventive care providers.

al., 2019). We confirmed match quality with standardized mean differences on observed variables of <0.1 and graphical displays of propensity score distributions pre and post matching (Stuart, 2010).

Measures

Demographic variables were extracted from the first recorded date of service. The primary independent variable was cohort membership. The primary outcome measure was continuity of primary care, as quantified by the Bice-Boxerman Continuity of Care Index (Bice & Boxerman, 1977). The Bice-Boxerman Continuity of Care Index ranges from 0 to 1, where larger values indicate that a patient's primary care visits are more concentrated with a single provider.

Statistical Analysis

Sample demographic characteristics were summarized descriptively. To maintain confidentiality and compliance with our data use agreements, only categories where frequency counts were ≥10 for all cohorts are shown in the tables. We tested for differences between cohorts on characteristics using Chi-square tests for categorical variables and Kruskal-Wallis tests for continuous variables. We performed a linear regression to compare the continuity of care of CAST patients to that of national samples of autistic adults with Medicare or private health insurance while controlling for age at first observed visit, sex, intellectual disability, number of outpatient visits, and duration (weeks) of observation.

Results

The final matched sample consisted of 192 CAST patients, 384 Medicare beneficiaries, and 384 privately insured beneficiaries. Demographic information about each cohort is shown in Table 1. Most autistic adults included in this analysis were male, did not have an intellectual disability, and lived in non-rural areas. The cohorts were similar on median: age (22 years), Charlson comorbidity indices (Charlson et al., 1987; Quan et al., 2011), number of primary care visits, and weeks observed. All CAST patients were residents of the state of Ohio, which is in the East North Central region of the US. With regard to the national samples, the Southern US was the most common region of residence for those with Medicare (42.2%) or private insurance (30.2%). Figures 2A and 2B depict the state-level distribution of the included beneficiaries from the privately insured and Medicare samples, respectively.

The unadjusted median Bice-Boxerman continuity of care index was 0.6 (IQR=0.4–1.0) for CAST patients, 0.5 (IQR=0.3–1.0) for Medicare beneficiaries, and 0.6 (IQR=0.4–1.0) for privately insured autistic adults. Table 2 provides the results of the regression model comparing the continuity of care of CAST patients to that of national samples of publicly and privately insured autistic adults. After controlling for demographic characteristics, on average, CAST patients had continuity of care indices that were 10% higher than national samples of autistic adult Medicare beneficiaries ($p<0.0001$). CAST patients did not significantly differ from the national sample of privately insured autistic adults in continuity of care ($p=0.08$). Autistic adults with intellectual disabilities had, on average, continuity of care indices 7% lower than that of autistic adults without intellectual disability. There were

no significant differences in continuity of care indices as a function of other demographic characteristics.

Discussion

Continuity of care is strongly associated with many patient outcomes. Evidence demonstrates that autistic individuals have significantly poorer care continuity than the general population (Vohra et al., 2014). As such, there is a critical need to test evidence-informed models of care delivery that may better serve this population's needs. The present study offers a unique contribution to the literature by studying the extent to which receiving medical care through a specialized primary care medical home designed for autistic adults, CAST, was associated with better continuity of care.

Prior research has shown that many US populations have Bice-Boxerman continuity of care indices in the range of 0.3–0.4. For example, adults in New York aged 18+ in New York and children with complex medical needs have average Bice-Boxerman continuity of care indices around 0.3 (Arthur et al., 2018; Kern et al., 2018). Medicare beneficiaries of any age have an average continuity of care index around 0.4 (Johnston et al., 2020) and older adult Medicare beneficiaries have continuity of care indices ranging from 0.3–0.4 depending on the study sample (Romano et al., 2015; Johnston & Hockenberry, 2016). Autistic adults in our sample, however, had continuity of care indices ranging from 0.5, for Medicare beneficiaries, to 0.6 for CAST patients and privately insured autistic adults. The reason for the higher continuity of care indices observed in our sample relative to prior studies is unclear but may be due to differing choices made in study design. For example, our study required at least 4 visits for continuity of care index calculations while others have required only 3 or more visits (Johnston et al., 2020). Additionally, our study controlled for age at first observed visit, sex, intellectual disability, number of outpatient visits, and weeks of observation while other studies controlled for different variables like social risk, medical complexity, and education in calculating adjusted Bice-Boxerman continuity of care indices (Johnston et al., 2020). As such, comparing the continuity of care indices of the samples in this study to prior studies should be done with caution. Regardless, the comparisons between the cohorts within this study are valid and offer a novel contribution to the literature.

Our results revealed that CAST patients had, on average, 10% higher continuity of care relative to national samples of autistic adult Medicare beneficiaries. While we did not examine other health outcomes in the present study, literature from other populations suggests that a 10% improvement in continuity of care can have significant, positive health effects. Specifically, a 10% increase in continuity of care has been linked with significantly lower odds of emergency department visits and medical complications, as well as lower healthcare costs (Hussey et al., 2014). Our results suggest that patient-centered approaches to medical care, like CAST, are beneficial for autistic adults.

Results also revealed that CAST patients had similar continuity of care to national samples of privately insured autistic adults. While our data do not provide reasons for the absence of a significant difference in continuity of care between CAST patients and privately insured autistic adults, we posit that the sample of privately insured autistic adults included in this

study may also receive primary care through medical homes. Research among other populations has demonstrated that those with private health insurance are significantly more likely than those with public insurance (i.e., Medicare or Medicaid) to have access to or receive care through a medical home (Almalki et al., 2018; Le et al., 2019; Zickafoose et al., 2012). In future work, it will be important to conduct prospective studies and/or consider alternative data sources that provide information about medical home status among autistic adults from across the US.

Our study also found that autistic adults with co-occurring intellectual disability have significantly poorer continuity of care than those without. This may be due in part to the high staff turnover rate for programs serving those with intellectual and developmental disabilities (Gerhardt & Lainer, 2011). Alternatively, these findings may suggest that autistic adults with an intellectual disability are less likely to have a centralized place where they receive primary care. These results contribute to a growing body of literature on differences in the healthcare needs and utilization patterns of autistic individuals with and without co-occurring intellectual disability (Benevides et al., 2020; Hand, Boan et al., 2019a, 2019b).

Methodologic Considerations

We acknowledge several limitations to this work. First, there are limitations inherent to the use of medical billing data in research. Our identification of autistic adults was based solely on medical billing records. There are a number of variables for which we could not control that may be important social determinants of health. For example, socioeconomic variables are not contained in routine medical billing data and, while race and ethnicity were present for the CAST and Medicare samples, we did not have this information about our privately insured sample and, as such, could not control for race/ethnicity in our analysis. Another inherent limitation of the data sources used in this study is that medical visits made by CAST patients outside our institution's healthcare system would not be captured in the data received from our data Information Warehouse. As such, we could not determine the extent to which our Information Warehouse data contained complete medical records for CAST patients. Additionally, our analysis assumes accuracy in the provider identification variable in the MarketScan data. This may be problematic, as other studies have suggested that medical groups may bill under a single provider identifier, even if another provider delivered the care (e.g., Dunn & Shapiro, 2015). As a result, our analysis may have overestimated the continuity of care among our privately insured sample.

Second, while it is unlikely that individuals included in the national samples ever received treatment through CAST due to lack of geographical overlap, we cannot know whether they receive care though another medical home. Unfortunately, there are no published studies, to our knowledge, that report the prevalence of medical home utilization among autistic adults in the US from which we could make generalizations about the samples included in this study. However, evidence suggests that medical homes are relatively rare among autistic children (19%) and adolescents with special physical and mental healthcare needs (35%) (Farmer et al., 2014; Park et al., 2011).

Last, there are other important outcomes to consider when evaluating the effectiveness of a primary care medical home, like CAST, beyond continuity of care. In this study, we were

unable to characterize quality of care, satisfaction with care, and whether all of the individuals' healthcare needs were met. However, these are important considerations for future work and necessary for a comprehensive CAST program evaluation.

Conclusion

This study compared the continuity of primary health care among patients at CAST, a specialized primary care medical home designed for autistic adults, relative to US national samples of autistic adults with public or private health insurance. The continuity of primary care among CAST patients was significantly better than that of autistic adult Medicare beneficiaries and similar to that of privately insured autistic adults. Our findings support a specialized, patient-centered, primary care medical home as a promising solution to improve healthcare delivery for the growing population of autistic adults.

Acknowledgements:

We would like to acknowledge the work of Dr. Christopher Hanks, Medical Director of CAST, for establishing this model of care and permitting us to describe this work.

Funding Acknowledgement:

The project described was supported by Award Number Grant 5KL2TR002734–02 from the National Center for Advancing Translational Sciences and Autism Speaks grant number 11761. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Center for Advancing Translational Sciences, the National Institutes of Health, or Autism Speaks.

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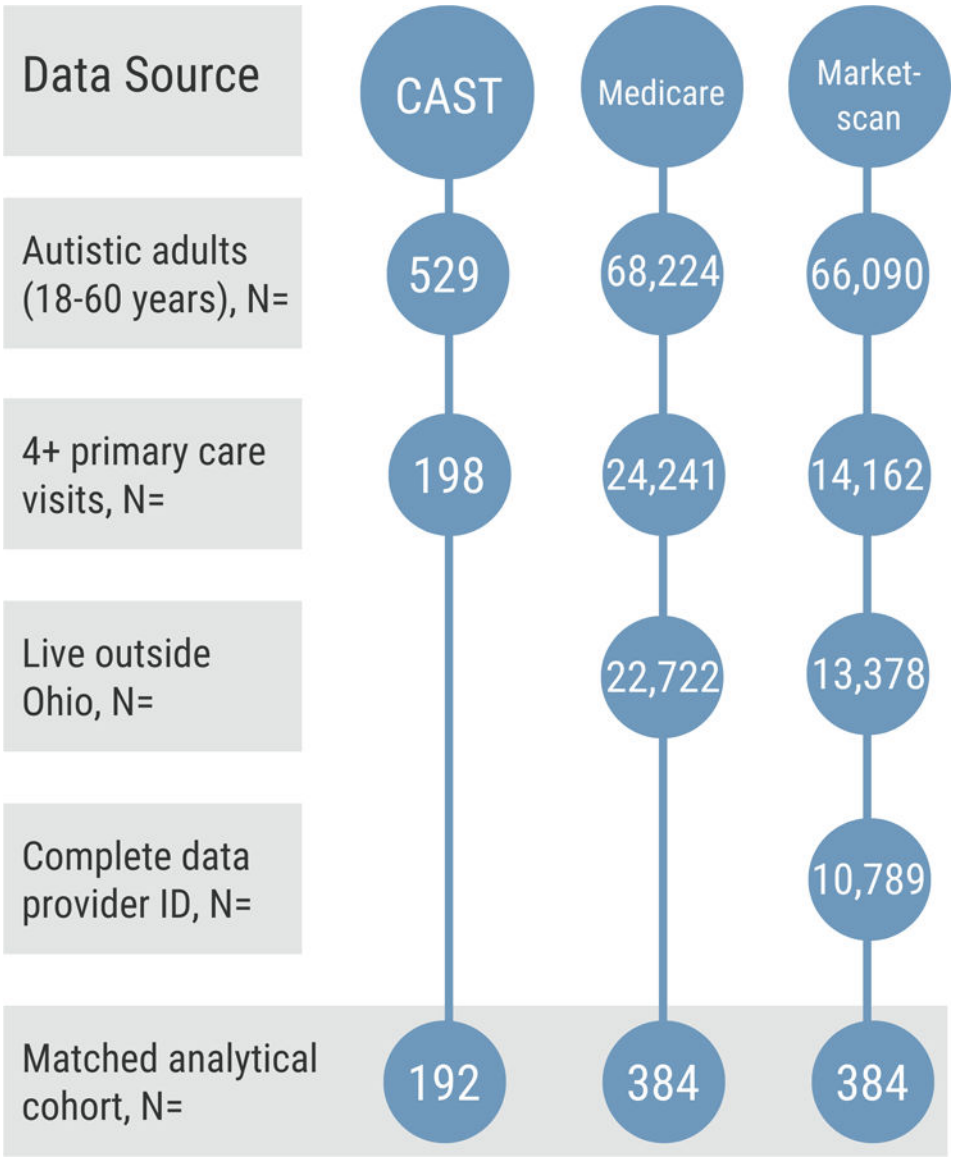

Figure 1.
Sample identification process

Figure 2A: Privately Insured Sample

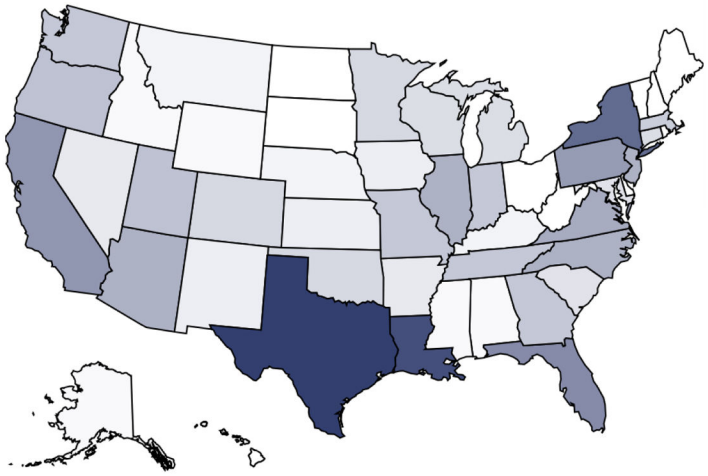

Figure 2B: Medicare Sample

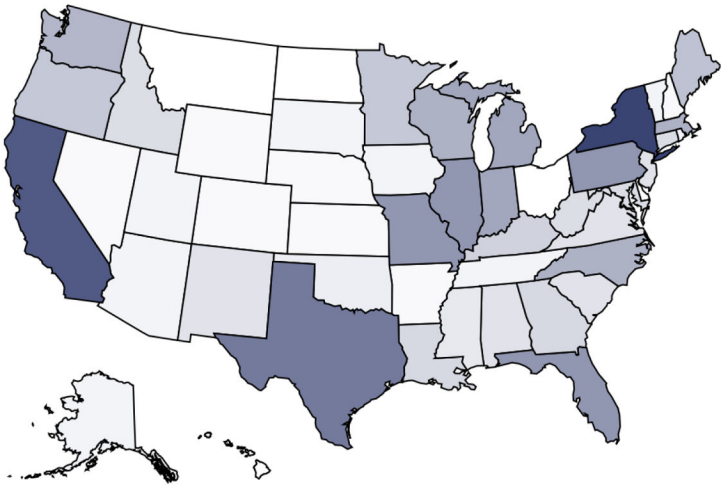

Figure 2A and 2B:

Heat maps displaying the geographic distributions of the privately insured sample (2A) and Medicare sample (2B).

Table 1:

Sample characteristics

Variable	CAST N=192	Medicare N=384	Privately Insured N=384	Total N=960	p-value
Male, N (%)	145 (75.5%)	313 (81.5%)	299 (77.9%)	145 (75.5%)	0.209
Intellectual Disability, N (%)	44 (22.9%)	85 (22.1%)	81 (21.1%)	44 (22.9%)	0.872
Race/Ethnicity, N (%)					0.072[a]
White non-Hispanic	146 (76.0%)	274 (71.4%)		420 (43.8%)	
Black non-Hispanic	27 (14.1%)	56 (14.6%)		83 (8.6%)	
Hispanic, Other, or Unknown	19 (9.9%)	53 (14.1%)	384 (100%)[b]	457 (47.6%)	
US Region, N (%)					<0.001[c]
Northeast		74 (19.3%)	94 (24.5%)	168 (17.6%)	
New England		15 (3.9%)	36 (9.4%)	51 (5.3%)	
Middle Atlantic		59 (15.5%)	58 (15.1%)	117 (12.2%)	
Midwest	192 (100%)	90 (23.4%)	71 (18.5%)	353 (36.9%)	
East North Central	192 (100%)	65 (17.0%)	36 (9.4%)	293 (30.6%)	
West North Central		25 (6.6%)	35 (9.1%)	60 (6.3%)	
South		162 (42.2%)	116 (30.2%)	278 (29.1%)	
South Atlantic		70 (18.4%)	62 (16.2%)	132 (13.8%)	
East South Central		14 (3.7%)	19 (5.0%)	33 (3.5%)	
West South Central		78 (20.5%)	35 (9.1%)	113 (11.8%)	
West		84 (21.9%)	73 (19.0%)	157 (16.4%)	
Mountain		43 (11.3%)	18 (4.7%)	61 (6.4%)	
Pacific		41 (10.8%)	55 (14.4%)	96 (10.0%)	
Rural, N (%)	20 (5.3%)	35 (4.6%)	28 (3.7%)	83 (4.4%)	0.431
Age in Years, Median (IQR)	22 (20, 28)	22 (20, 26)	22 (19, 28)	22 (20, 28)	0.082
Charlson Comorbidity Index, Median (IQR)	0 (0, 0)	0 (0, 0)	0 (0, 0)	0 (0, 0)	0.311
PCP Visits, Median (IQR)	5 (4, 6)	6 (4, 8)	5 (4, 6)	5 (4, 7)	0.509
Weeks Observed, Median (IQR)	153 (95, 198)	168 (96, 229)	154 (84, 217)	156 (91, 218)	0.136

[a] p-value reported here compares only CAST and Medicare samples.

[b] Unknown as race and ethnicity data are not provided in MarketScan databases.

[c] p-value reported here compares only Medicare and privately insured samples.

Table 2:

Comparison of continuity of care among CAST patients to national samples of publicly and privately insured autistic adults

Variable	Estimate	SE	p-value
Cohort			
Medicare	−0.10	0.03	<0.0001
Privately Insured	0.05	0.03	0.08
CAST (reference)	0.00		
Female sex	0.04	0.03	0.15
Age in years	<0.01	<0.01	0.22
Intellectual disability	−0.07	0.02	0.004
Rural, N (%)	0.05	0.04	0.26
Number of PCP Visits	<−0.01	<0.01	0.26
Charlson Comorbidity Index	0.05	0.13	0.67
Weeks Observed	<−0.01	<0.01	0.90

Abbreviations: SE = Standard error; CAST = Center for Autism Services and Transition; PCP = Primary care physician