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Authors

Gulsrud, Amanda
Lee, Hyon Soo
Hassrick, Elizabeth McGhee
et al.

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It's who you know: Caregiver social networks predict service use among under-resourced children with autism

Amanda Gulsrud[1] 0000-0001-9537-8601
Hyon Soo Lee[1] 0000-0002-5009-619X
Elizabeth McGhee Hassrick[2] 0000-0002-0520-2598
Suzannah Iadarola[3] 0000-0001-6828-8379
Melanie Pellechia[4]
Wendy Shih[1]
Sarah Vejnoska[5] 0000-0002-7915-8702
Elizabeth H Morgan[5] 0000-0002-4379-6091
Samantha Hochheimer[3]
Samantha Crabbe[4]
Jennica Li[5]
Lindsay Hauptman[1]
Fernanda Castellon[1]
Heather Nuske[4]
Consuelo Garcia[1]
Rachel King[3]
Paul Luelmo[1,6] 0000-0003-4607-0146
Kathleen Carley[2]
Tristram Smith[3] 0000-0002-2104-2264
David Mandell[4] 0000-0001-8240-820X
Connie Kasari[1] 0000-0003-2266-170X
Aubyn C Stahmer[5] 0000-0002-1596-9848

[1]University of California, Los Angles Graduate School of Education & Information Studies & Center for Autism Research & Treatment, Department of Psychiatry, UCLA Semel Institute 68-268, Los Angeles, CA 90024
[2]Drexel University, A.J. Drexel Autism Institute, 3020 Market Street | Suite 560. Philadelphia, PA 19104
[3]University of Rochester Medical Center, Division of Developmental and Behavioral Pediatrics & Strong Center for Developmental Disabilities, 265 Crittenden Blvd. Rochester, NY 14642
[4]University of Pennsylvania, Perelman School of Medicine, Center for Mental Health Policy and Services Research, 3535 Market St., Rm. 3100, Philadelphia, PA 19104
[5]University of California, Davis MIND Institute, Departments of Psychiatry, Psychology & Human Development, 2825 50th St, Sacramento, CA 95817
[6]San Diego State University, Department of Special Education, 5500 Campanile Dr. San Diego, CA 92182

Corresponding Author: Dr. Amanda Gulsrud agulsrud@mednet.ucla.edu, 310-825-0575
Permanent Address: UCLA Semel Institute, 760 Westwood Plaza Room 68-237C, Los Angeles 90024

Abstract

Background: Numerous studies have shown that racial/ethnic minority and under-resourced families face barriers that delay timely access to autism services. These barriers include lack of resources and information about autism, financial hardship, mistrust in the service system, cultural and language mismatch, and other factors that have yet to be identified.

Method: The current study aimed to examine additional caregiver and system-level factors that could be associated with early service access using a diverse sample from four study sites (Los Angeles, CA; Philadelphia, PA; Sacramento, CA; and Rochester, NY). Partnering with community agencies that serve traditionally underrepresented groups, the research team recruited 118 caregivers of young children with autism who were low-income, English, Spanish or Korean speaking and had not accessed autism-specific services.

Results: Regression analyses revealed that the total number of services accessed were predicted by caregiver social network size (p=0.011) but not by race, autism knowledge and caregiver agency. Primary language spoken in the home was marginally related to the number of services accessed, with English-speaking participants receiving more services than caregivers whose primary language was not English (p=0.064). Among families receiving at least one service, a marginally significant interaction effect of site and primary language on total services received was observed (p=0.06).

Conclusion: Findings suggest that caregivers’ social network connections are crucial in early service access, and future interventions could target increasing social networks to improve families’ service engagement. More attention for non-English speaking families, especially those living in areas with few supports in their native languages, is needed.

Keywords: Autism spectrum disorder; disparities; services; culture; social networks

Declarations

Availability of data and materials

The datasets generated and/or analyzed during the current study are not publicly available due to the full trial still being underway, but they are available from the corresponding author on reasonable request.

Ethics Statement

All procedures performed involving human subjects were in accordance with the ethical standards of the institutional review board. Informed consent was obtained from all individual participants involved in this study.

Introduction

Timely identification and access to services for children with autism spectrum disorder (ASD) are key to ensure children optimally benefit from intervention services (Boyd et al., 2010; National Research Council, 2001; Kasari et al., 2005; Myers et al., 2007). Participation in early intervention is linked to positive outcomes in cognition, language development, and social relationships (Liptak et al., 2008; Ventola et al. 2006). Unfortunately, minority and under-resourced families experience significant disparities in timely diagnosis and access to services. Children from racial and ethnic minority backgrounds are more likely to be misdiagnosed or to be diagnosed later than children who are White and non-Hispanic, resulting in delays in initiating appropriate care (Angell et al., 2018; Magaña et al., 2017; Mandell et al. 2009). Once diagnosed, racial/ethnic minority children are less likely to access autism-related services (Smith et al., 2020; Thomas et al., 2007), sub-specialty services such as gastroenterology and neurological testing (Broder-Fingert et al., 2013), and school-based services (Locke et al., 2017). Children from economically disadvantaged backgrounds are also diagnosed later and receive fewer evaluations overall than their peers (Fountain et al., 2011; Mazurek et al., 2014; Thomas et al., 2012).

For under-resourced and traditionally disenfranchised groups, common barriers to accessing services once receiving an ASD diagnosis include lack of resources and knowledge about ASD, mistrust of the service system and providers, and cultural and linguistic mismatch with early intervention approaches and providers (Liptak et al., 2008; Mandell et al., 2002; Stahmer et al., 2019). Caregivers emphasize that structural barriers (e.g., work schedule or transportation) impede their ability to meet their child's developmental needs (Stahmer et al., 2019; Pickard et al., 2016) and that they lack information regarding where or how to access services for their children. Parents' knowledge about services mediates the relationship between parent socioeconomic status and ASD service use (Pickard et al., 2016). Despite the important role of parental knowledge in helping their children, caregivers often report that they receive limited guidance post-diagnosis on next steps to accessing services for their child with ASD

(Stahmer et al., 2019; Pickard et al., 2016). In addition, families often cite mistrust in the service system and challenges forming connections with service providers (Burkett et al., 2015; Zeleke et al., 2019). For example, Black parents express distrust in the healthcare system and think that White doctors often misread the needs of their children (Burkett et al., 2015). This distrust is often warranted, as providers tend to dismiss concerns from Black parents and misdiagnose Black children with disruptive behavior disorders (Stahmer et al., 2019; Ennis-Cole et al., 2013).

Language barriers also present a significant challenge to service access for many racial and ethnic minority groups (St Amant et al., 2018; Magaña et al., 2013; Zuckerman et al., 2014). In a qualitative study, Spanish- and Korean-speaking caregivers of children with ASD reported that language barriers were a major obstacle in obtaining their children's ASD diagnosis and services, advocating for their children when service needs were not met, and selecting providers, due to a scarcity of qualified bilingual professionals (Stahmer et al., 2019). Children with ASD from linguistic minority families are less likely to receive services that target core autism symptoms, such as social skills and communication skills (St Amant et al., 2018). Other concerns related to language mismatch for families of children with ASD include difficulties scheduling services and accessing information about services in languages other than English (Zuckerman et al., 2014).

Contrasting these known barriers to service access, a strong network of social relationships can facilitate access to care. Family networks can provide emotional and financial supports, while community and professional network ties can provide service and intervention related expertise and information. For example, people in caregiver networks can share expertise about ASD symptoms, advice about evidence-based interventions for children with ASD or information about the availability and quality of early childhood therapeutic services (Hassrick, 2019; Smith et al., 2012). Community and professional ties can also serve as conduits for sharing valuable information about how to navigate diagnosis and first service access (Young et al., 2019). The resources embedded in networks are called "social capital" (Bourdieu, 1977; Coleman, 1990; Lin, 2001). Much research suggests social capital advantages are unequally distributed across social class. Families with limited resources have less access to social capital outside of the family (Bourdieu, 1977; Lareau, 1989; Lareau & Weininger, 2003). Conversely, caregivers with larger networks that include community and professional members potentially have access to social capital that can help them navigate healthcare systems to secure their child's first services, post diagnosis. Caregivers embedded in smaller social networks with fewer resources, less autism expertise, and less access to information will likely have a harder time accessing diagnostic and service resources (Morgan & Stahmer, 2020).

Similarly, caregiver agency, or the ability to achieve one's goals despite changing or challenging environmental conditions, may help facilitate access to services (Tsushima & Burke, 1999). For caregivers from under-resourced communities, developing and expressing this agency can be more difficult because of the barriers associated with inequalities and institutional racism (Horvat et al., 2003; Skiba et al., 2008). In interviews, underrepresented caregivers of children on the autism spectrum identified lack of collaboration and imbalanced partnerships with their interventionists, (Stahmer et al., 2019; Morgan & Stahmer, 2020; Zeitlin & Curcic, 2014) which may lead to reduced feelings of agency. Thus, the relationship between caregiver agency and service utilization warrants further exploration.

Understanding determinants of disparity in service access is highly relevant, yet far less studied than factors related to timing of diagnosis (Smith et al., 2020). To date studies have largely focused on patterns in service access and use by race, ethnicity, or SES and used large data sets that provide limited information. This study adds to the existing knowledge regarding barriers and facilitators to service access for under-resourced families of children with ASD by including caregiver and system-level features. Specifically, we evaluated how factors such as primary language, autism knowledge, caregiver agency, and social networks were associated with early service access in a sample of families who had not yet accessed autism specific services for their child. We relied on a large and geographically diverse sample of caregivers whose children recently received an autism diagnosis. Increasing knowledge of the determinants of service usage in under-resourced families may help build more effective supports and programs to improve outcomes for children with ASD.

Methods

Setting/Recruitment

Participants were recruited from a larger intervention study across four study sites: Los Angeles, CA (LA); Philadelphia, PA (PHL); Sacramento, CA (SAC); and Rochester, NY (ROC). Together, these sites form the Autism Intervention Research Behavioral Network (AIR-B). AIR-B is a federally funded research network with the goal of improving outcomes for children with ASD and their families who experience income inequalities and represent under-resourced populations. To engage these families, we used community-partnered participatory research (CPPR) methods to include community members in study design, recruitment, outreach and implementation. Research-community partnerships through CPPR can enhance research participation for racial/ethnic minority groups (Iyer et al., 2015; Jones et al. 2013; Khodyakov et al., 2014).

To ensure recruitment of an under-resourced sample, network sites leveraged existing and newly established community partnerships to identify and engage potentially eligible parents. Parent participants were identified by referring pediatricians, school staff, family resource centers, early intervention agencies, homeless shelters, parent support groups or self-referral via recruitment documents. Network sites and community partners distributed flyers during community events as well. Referring providers could elect to distribute recruitment materials (i.e., permission to contact form, recruitment flyer, study overview document) to interested families that may qualify for the study. Interested participants were contacted by research staff to describe the study and screened for eligibility.

Participants

Caregivers were included if: (1) they were an English, Spanish, or Korean speaking primary caregiver of a child with a diagnosis of ASD (selected due to the primary groups and partnerships represented within each site); (2) their child with ASD was age 8 years or younger; (3) their child was not receiving or on a waitlist for ASD specific services; and (4) their household income was at or below 250% of the federal poverty line. Our only exclusion criterion was if the child was in foster care or did not live at home. Confirmation of ASD diagnosis was ascertained through record review, as represented by their primary educational eligibility or with a medical diagnosis from a qualified professional. There was a wide range in the time from diagnosis, ranging from zero to 80 months with an average of 15.85 months (SD=20.62).

Over the 2-year recruitment period, 286 families were screened and 133 families enrolled (32 LA, 26 PHL, 38 SAC, 33 ROC) in the study. Of the 159 excluded from participation, 87 did not meet inclusion criteria, 8 declined to participate and 44 were lost to contact after screening but before the study started. Of the 133 families eligible for the study, 15 families dropped immediately following consent due to loss of contact or deciding not to participate resulting in 118 enrolled families (Figure 1).

Of the 118 participating caregivers, 90% were female (n=106) and 10% were male (n=12). Caregiver's self-reported ethnicity was 36% Hispanic or Latino and 58% Non-Hispanic. Race categories included 37% White, 30% Black/African American and 33% multiracial. The primary languages spoken at home included English (69%), Spanish (23%), Korean (4%), and other (4%). Full demographic details are outlined in Table 1.

Procedures

Caregivers who passed the initial screening were given additional details of the study over the phone and verbally consented to participate. Following the screening call, research staff met with each participant to conduct an in-person consent meeting where study procedures were reviewed again and questions were answered. During this visit, participants completed a demographic form and a set of measures assessing autism knowledge, caregiver agency, current resources and services and additional needs.

Measures

The measures consisted of self-reported surveys and an interview on participants' social network.

Demographics. This 33-item survey includes questions about the participant's race, household income, and primary languages spoken at home.

Caregiver Agency Questionnaire (adapted from Kuhn & Carter, 2006 [Kuhn & Carter, 2006]**).** This 10-item survey asked caregivers to rate how often they engage in certain activities related to promoting child development on a 5-point Likert scale (i.e., 1 = "Never", 5 = "Almost Always"). Answers to the questions were summed to yield a total score (10-50), with higher scores indicating greater levels of caregiver proactivity.

Caregiver Autism Knowledge Questionnaire (adapted from Kuhn & Carter, 2006 [Kuhn & Carter, 2006]**).** This 43-item true/false questionnaire (with an option of responding "Don't Know") measures knowledge of facts about diagnosis, symptoms, treatments, and etiology of autism spectrum disorders and is reported as having good internal consistency (standardized α = 0.79) (Kuhn & Carter, 2006). To reduce burden, we selected 10 questions representative of information provided in the intervention with approval from the survey author. Percent correct of these 10 questions was examined as the unit of analysis for this paper.

Social Dynamics of Intervention (SODI) Network Survey*.* Social network measurement includes the number and type of social connections a person has with others (Wasserman & Faust, 1994). Parent total network size was calculated using an egocentric network survey called the *Social Dynamics of Intervention (SODI) Survey* (adapted from McGhee Hassrick et al., 2018). Each network survey was conducted individually, with the interviewer asking the parent about their network. Network interviews with parents were approximately 5 to 15 minutes in length, depending on the number of people named in the parent's network. Each parent was asked to identify up to five people from home/community and an additional five professionals who helped them with support related to their child's autism. For each name generated, several additional questions were asked that characterize the key identified people in each participant's network. Total network size, the network variable used in the analysis for this paper, is the sum of all key people identified by the parent.

Service and Community Resource Access Form. Caregivers identified current services their child was receiving or attempting to receive (e.g., on a waitlist for a service) in an interview with research staff. In addition to reporting the service type and service provider (i.e., community-based or school-based), caregivers reported on the frequency at which their child is receiving any active services and the status of inactive services. They reported any difficulties experienced while accessing or attempting to access a service (e.g., transportation to appointments).

Analytic Plan

Descriptive statistical analyses were performed on continuous and categorical data. Results are reported as frequencies (percentages) for categorical data and median [IQR] for continuous data. Poisson regression was used to explore the relationship between number of services accessed and primary language spoken in the home, caregiver social network size, caregiver knowledge and agency while controlling for family income, race/ ethnicity and site. In a subgroup of families receiving any service, linear regression was used to determine the relationship between number of services accessed with primary language spoken in the home, caregiver social network size, caregiver knowledge and agency while controlling for family income, race/ ethnicity and site.

Results

Description of Service Usage

At the interview, 23% (n = 26) of families reported that their children were not receiving any kind of services, and 77% (n = 87) reported accessing some kind of non- ASD specific service, either at school or in the community. On average, families reported that their children received about two types of services (*M* = 1.95, *SD* = 1.54). The average number of school services received was 1.34 (*SD* = 1.46). The average number of community services received was .67 (*SD* = 1.11). Eighty-seven families reported receiving any services at all, 23 (26.4%) families received community services only, 50 (57.5%) families received school services only, and 14 (16.1%) families received both community and school services. Among the 64 families receiving any school services, the top three services reported were speech therapy (93%), occupational therapy (72%) and physical therapy (23%). Among the 37 families receiving any community services, the top three received services were speech therapy (78%), occupational therapy (54%) and early intervention (23%). Families could receive more than one type of service; hence, the percentages do not add up to 100%. There were significant differences in distributions of race/ethnicity and English vs Non-English-speaking families among the four sites where White families were more common in SAC (53%) and ROC (52%) and African-American families were more common in PHL (78%). Among all sites, LA had the greatest sample of Hispanic/Latinx families (77%) with non-English (73%) as the primary language. In See Table 2 for a summary of descriptive data on service usage and other measures.

Regression Analyses

Larger peer support network size significantly predicted a higher number of total services received (p=0.011). Primary language, race, autism knowledge, and caregiver agency were not significantly associated with total services received.

Across the entire sample, primary language was marginally associated with the number of services received (p=0.064) where families who spoke English as their primary language reported receiving more services compared to families where English was not their primary language. Additional regression analysis indicated that among families receiving at least one service, there was a marginally statistically significant interaction effect of site and primary language on total services received (p=0.06). Within LA, 73% of the families' primary language was not English; whereas, English was the primary language for a majority of families in all other sites (63%-95%). In SAC, PHL, and ROC, families with English as the primary language received more services compared to families whose primary language was not English. Within LA, non-English speaking families received a greater number of services compared to families who spoke English as their primary language. The results of the regression analyses are presented in Table 3 for the whole sample and Table 4 for participants already accessing services.

Discussion

We enrolled a highly diverse community sample of low-income parents of newly diagnosed children with ASD who had not yet accessed autism specific intervention services and evaluated the predictive value of their social networks and demographic characteristics on their child's initial service access. There were some significant site differences related to the number of services accessed, with children in ROC receiving more services, on average, than children in other sites.

We evaluated the relationship among demographic characteristics and service access in this sample of low-income families. Race and ethnicity were not associated with service access, which diverges from much of the literature on service-related disparities (Magaña et al., 2013; Shattuck et al., 2009). Our sample included exclusively families from low-income households who were very early in the process of seeking services, which stands in contrast from most studies on service access that include a larger income range in their sample. These data are consistent with a recent examination of children with ASD in South Carolina accessing early intensive behavioral intervention through a Medicaid waiver in which race/ethnicity and neighborhood did not predict time to service access (Yingling et al., 2018). It is possible that the interaction of race/ethnicity with income disparities reduces group differences in service access. There may also be differences among families willing to participate in a research study. As suggested by Yingling and colleagues, 2018, there may be other factors that play a greater role in service access than race/ethnicity or income.

One potential area for exploration is the relationship between social support and service access. Social networks provide important information on connectedness to family support, community providers and broader service systems. Larger social network size positively predicted service access for all families. Although provider connections and relationships have been shown to increase ASD-related service access (Mandell et al., 2009; Hassrick, 2019), our findings highlight the critical importance of network connections for parents immediately post-ASD diagnosis and expand upon the limited research on how formally defined social networks influence important service outcomes. While demographics in the context of social networks did not differentially predict service outcomes in this particular sample, it is important to acknowledge that family characteristics such as race, ethnicity, and income may still influence the size of a family's network (Lareau & Weininger, 2003, Hassrick & Schneider, 2009) This paper demonstrates variability in network support among parents. We did not test this particular path (i.e., demographics as predictive of network size/reach, as in turn predictive of service access), and this may be a worthwhile direction for future work.

Primary language did not predict service access. However, at the time of entry into the service system, a unique pattern of language-based disparities in service emerged for families receiving at least one service. Specifically, in LA, non-English speaking families had, on average, more services than English-speaking families, whereas the opposite was true for the remaining three sites (of note, this finding approached but did not reach statistical significance). The overall relationship between being from an English-speaking household and service-access mirrors findings from previous research (Smith et al., 2020; St Amant et al., 2018; Zuckerman et al., 2014). This disparity endured even after controlling for race and household income, which individually are robust predictors of service access (Locke et al., 2017; Mazurek et al., 2014). Our results are not to say that non-English speaking families in LA do not experience challenges; in fact, previous research shows that families with limited English proficiency face significant barriers in all aspects of accessing services, (Stahmer et al., 2019) and families in LA overall had significantly fewer services than the other sites. However, the availability of services provided in languages other than English and large ethnic communities in the LA area (as compared to what is available at other sites) may have facilitated obtaining services. It is important to note the distinct characteristics of the LA site's sample. Among the four sites, LA was the only site where the majority of participants were Hispanic or Latino, included participants whose primary language was not English, and included Korean-speaking participants – none of whom spoke English as their primary language. Language barriers pose a significant challenge to families regardless of the location, but linguistic minorities in areas that do not provide services and supports in their native languages are likely facing additional obstacles.

Parent-reported perspectives on their own agency and ASD knowledge did not significantly predict the number of services received. Caregiver agency is a relatively new construct within the literature, and there are limited previous data on its relationships to other outcomes. Similarly, while knowledge about the service system itself relates to more successful service navigation (McKenzie et al., 2014), as does overall health literacy (Ratzan et al., 2000), there is limited support that condition-specific knowledge influences access in the same way. While our study does not clarify this issue, the null findings suggest that inclusion of service system-level knowledge may be a more illuminating construct to include in the future. We also acknowledge that scores on the knowledge questionnaire were relatively high, such that the majority of responses hovered around 7.33 (out of 10). The limited variability may have hindered our ability to look at the true predictive value of ASD knowledge on service access.

This study included a highly diverse sample with a high proportion of ethnic minority families, usually not represented in autism intervention research. The current findings may differ from previous research regarding service access due to the fact that participants in this study were much more diverse than those in most previous studies and all met low-income criteria. Families from ethnic minority, low-income households, and non-English speaking households likely experience many institutional barriers, which increases the complexity of disentangling and identifying their barriers to service access. We also caution that findings from this sample are not necessarily representative of all families post-diagnosis, as we systematically excluded families that were already receiving high levels of services.

Findings from the current study identify critical stops along a roadmap for engaging under-resourced families in their child's service. Careful consideration of families' social supports, networks, and resources while adopting targeted strategies to improve these supports and networks may be instrumental to improving parents' successful engagement in their child's services. Our findings also highlight that additional strategies are likely needed to ensure successful engagement for families who speak a language other than English.

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Conflicts of interests

The authors declare they have no conflict of interest.

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Table 1

Caregiver Demographics

Family Characteristics: Average (SD)	Total	Sacramento (SAC)	Philadelphia (PHL)	Rochester (ROC)	Los Angeles (LA)	
	n=118	n=32	n=23	n=33	n=30	p-value
Caregiver Age (Years)	34.24 (8.36)	34.56 (8.61)	34.22 (9.39)	32.48 (8.92)	35.83 (6.46)	0.103
Gender: n (%)						0.479
Female	106 (90%)	30 (93.75%)	22 (95.65%)	29 (87.88%)	25 (83.33%)	
Male	12 (10%)	2 (6.25%)	1 (4.35%)	4 (12.12%)	5 (16.67%)	
Ethnicity: n (%)						p<0.001
Hispanic or Latino	43 (36%)	14 (43.75%)	2 (8.7%)	4 (12.12%)	23 (76.67%)	
Not Hispanic or Latino	69 (58%)	17 (53.13%)	19 (82.61%)	26 (78.79%)	7 (23.33%)	
Prefer not to answer	6 (6%)	1 (3.13%)	2 (8.7%)	1 (9.09%)	0 (0%)	
Race: n (%)						p<0.001
African American	35 (30%)	7 (21.88%)	18 (78.26%)	10 (30.3%)	0 (0%)	
White	44 (37%)	17 (53.13%)	4 (17.39%)	17 (51.52%)	6 (20%)	
Other/Multiracial	39 (33%)	8 (25%)	1 (4.35%)	6 (18.18%)	24 (80%)	
English as Primary Language: n (%)						p<0.001
No	37 (31%)	12 (37.5%)	1 (4.35%)	2 (6.06%)	22 (73.33%)	
Yes	81 (69%)	20 (62.5%)	22 (95.65%)	31 (93.94%)	8 (26.67%)	
Income						0.14

$9, 999 or less	23 (20%)	5 (15.63%)	9 (39.13%)	5 (15.15%)	4 (13.79%)	
$10, 000 - 19, 999	30 (26%)	4 (12.5%)	9 (39.13%)	10 (30.3%)	7 (24.14%)	
$20, 000 - 29, 999	20 (17%)	8 (25%)	2 (8.7%)	6 (18.18%)	4 (13.79%)	
$30, 000 - 39, 999	20 (17%)	6 (18.75%)	1 (4.35%)	8 (24.24%)	5 (17.24%)	
$40, 000 - 49, 999	12 (10%)	5 (15.63%)	1 (4.35%)	2 (6.06%)	4 (13.79%)	
>$50, 000	12 (10%)	4 (12.5%)	1 (4.35%)	2 (6.06%)	5 (17.24%)	
Child's Age (Years)	4.14 (1.90)	4.06 (1.9)	4.96 (1.72)	3.33 (1.67)	4.47 (2.01)	0.004
Child's Gender: n (%)						0.025
Female	28 (24%)	2 (6.45%)	9 (39.13%)	9 (27.27%)	8 (26.67%)	
Male	89 (76%)	29 (93.55%)	14 (60.87%)	24 (72.73%)	22 (73.33%)	
Child's Time since Diagnosis (Months)	15.85 (20.62)	13.28 (19)	26.83 (22.03)	5.33 (10.31)	21.93 (24.15)	p<0.001

Table 2

Descriptive Data on Measures

Family Characteristics: Average (SD)	Total n=118	Sacramento (SAC) n=32	Philadelphia (PHL) n=23	Rochester (ROC) n=33	Los Angeles (LA) n=30	p-value
Social Network Support	5.15 (2.41)	6.13 (2.21)	5.04 (2.5)	5 (2)	4.34 (2.73)	0.027
Family	2.90 (1.59)	3.38 (1.56)	2.91 (1.83)	2.61 (1.17)	2.69 (1.77)	0.190
Professional	2.26 (1.47)	2.75 (1.52)	2.13 (1.36)	2.39 (1.32)	1.66 (1.52)	0.032
ASD Stigma	46.52 (7.80)	46.94 (7.74)	46.91 (7.12)	48.06 (7.12)	44.07 (8.81)	0.227
Caregiver Agency	36.36 (6.63)	36.91 (6.32)	34.99 (5.58)	37.09 (7.03)	36.01 (7.34)	0.675
Caregiver ASD Knowledge	7.33 (2.00)	7.09 (2.02)	7.83 (1.19)	7.33 (2.61)	7.2 (1.75)	0.553
Total Services Received	1.96 (1.54)	1.66 (1.21)	2.05 (1.53)	2.58 (1.82)	1.46 (1.33)	0.047
Community Services: n (%)						0.011
0	76 (67%)	17 (53.13%)	15 (68.18%)	23 (69.7%)	21 (80.77%)	
1	20 (18%)	11 (34.38%)	5 (22.73%)	1 (3.03%)	3 (11.54%)	
2+	17 (15%)	4 (12.5%)	2 (9.09%)	9 (27.27%)	2 (7.69%)	
School Services: n (%)						0.008
0	49 (43%)	15 (46.88%)	7 (31.82%)	17 (51.52%)	10 (38.46%)	
1	16 (14%)	8 (25%)	3 (13.64%)	1 (3.03%)	4 (15.38%)	
2	23 (20%)	3 (9.38%)	7 (31.82%)	3 (9.09%)	10 (38.46%)	
3+	25 (23%)	6 (18.75%)	5 (22.73%)	12 (36.36%)	2 (7.69%)	

Table 3

Regression Analysis of the Relationship Between the Number of Services Received and Predictors

Outcome: Total Services Received	Rate Ratio	Confidence Interval 2.50%	97.50%	p-value
Primary Language: English vs Not English	1.154	0.773	1.723	0.483
Race				
African American vs White	0.978	0.682	1.402	0.905
Other/Mixed vs White	1.119	0.733	1.710	0.602
Household Income	1.014	0.921	1.116	0.776
Family/Professional Network Size	1.081	1.018	1.148	0.011
Caregiver Autism Knowledge	1.072	0.988	1.164	0.094
Caregiver Agency	0.990	0.967	1.015	0.434
Site				
PHL vs SAC	1.231	0.767	1.974	0.389
ROC vs SAC	1.625	1.122	2.356	0.010
LA vs SAC	0.919	0.559	1.509	0.737

Table 4

Regression Analysis of the Number of Services Accessed Among Families Already Receiving Services and Predictors

Outcome: Log of Number of Services Accessed (among those with services)	Estimate	SE	t value	p-value
Intercept	0.268	0.390	0.688	0.494
Primary Language: English vs Not English	0.259	0.138	1.879	0.064
Race				
African American vs White	0.145	0.139	1.040	0.302
Other/Mixed vs White	0.097	0.166	0.584	0.561
Family Income	0.010	0.035	0.273	0.786
Caregiver/Professional Network Size	0.057	0.023	2.467	0.016
Caregiver Autism Knowledge	0.003	0.032	0.084	0.933

Caregiver Agency	-0.011	0.009	-1.267	0.209
Site				
PHL vs SAC	0.373	0.171	2.186	0.032
ROC vs SAC	0.553	0.139	3.978	p<0.001
LA vs SAC	0.352	0.186	1.896	0.062

Figure 1. Participant enrollment procedure.