

SERVICE USE IN ADULTS WITH AUTISM SPECTRUM DISORDERS IN RURAL AND
URBAN COMMUNITIES: A GEOGRAPHICAL INFORMATION SYSTEM APPROACH

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ABSTRACT

Kelsie Ann Adkisson: Service Use In Adults With Autism Spectrum Disorders In Rural And Urban Communities: A Geographical Information System Approach
(Under the direction of Mark R. Klinger)

There is little research on the services adults with Autism Spectrum Disorders (ASD) use, satisfaction with these services, and barriers to receiving services. Population density may affect service use outcomes. This study aimed to examine service use outcomes and the effect of population density using a Geographical Information Systems (GIS) approach, in adults with ASD diagnosed by the TEACCH Autism program as children. Caregiver surveys from 91 participants were collected and questions about the types of services, barriers to services, and satisfaction with services were analyzed for relations with population density. Results showed that individuals with higher childhood IQ scores were less likely to utilize services, and that living in rural communities decreased service use for all adults studied. Rehabilitation counselors can serve as a resource for increasing knowledge about available services in the communities they serve and advocate for services and community support in more rural areas.

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CHAPTER 1: PURPOSE

Research on children with Autism Spectrum Disorder (ASD) has increased in the past 20 years. However, little research exists on adults with ASD. Adults with ASD have a unique set of barriers that affect employment outcomes, independent living outcomes, and participation in the community. While funding from Medicaid and Medicare allows many individuals with disabilities to benefit from services, including vocational supports, mental health counseling, therapy, and case management, little is known about what services are used by adults with ASD and if they are satisfied with these services. Additionally, individuals living in rural communities, as opposed to highly populated communities, may have fewer services available or accessible to utilize. The purpose of this study is to report on the service outcomes of adults with ASD, including satisfaction with services, barriers to service use, and how population density affects service use.

ASD is a developmental disability caused by differences in brain development. The disorder is characterized by two main categories of symptoms: 1) deficits in social communication and social interactions, and 2) restricted, repetitive patterns of behavior, activities, and interests (American Psychiatric Association [APA], 2013). ASD serves as an umbrella term for a number of disorders that were once diagnosed separately including autistic disorder, pervasive developmental disorder not otherwise specified (PDD-NOS), and Asperger disorder (Centers for Disease Control and Prevention [CDC], 2014). As of March 2014, 1 in 68

(1.5%) children have ASD, a significant increase since 2000 when the rate of diagnosis of ASD was 1 in 150 (0.7%) children (CDC, 2014). The CDC also reported that ASD affects males almost five times more often than females, reporting prevalence rates of 1 in 42 males, and 1 in 189 females. The trend of increasing prevalence in ASD has been associated with many different factors. Matson and Kozlowski (2010) examined theories of increasing prevalence of this disorder since Leo Kanner first discovered it in 1943. The diagnostic criterion for ASD has changed in the past 70 years, with the age of a valid diagnosis decreasing to include early childhood as young as 15 months (Croen, Grether, Hoogstrate, & Selvin, 2002; Williams, Mellis, & Peat, 2005; Leonard et al., 2010). Assessment of ASD has varied in the past. Changes in diagnostic instruments have created more systematic ways of diagnosing ASD, increasing prevalence rates (Posserud, Lundervold, Lie, & Gillberg, 2009). ASD has also become more apparent in the media, which has increased awareness in parents and clinicians. Parents may have their children assessed when they previously would not have done so because of a new awareness of the symptoms of the disorder. Finally, diagnostic criteria for autism has changed with the publishing of the DSM-5, removing Rhett's Disorder, and combining the remaining autism diagnoses into one umbrella term, now known as ASD (APA, 2013). Now the general concept of ASD includes Asperger Syndrome, often termed as the "mildest" form of ASD causing higher functioning individuals to be given an ASD diagnosis who otherwise may not have received a diagnosis in the past (Fombonne, 2009).

Individuals with ASD present symptoms in different ways that can range from mild to severe. Research is limited on how symptoms present across the lifespan. One study reported that with treatment, over 90% of individuals demonstrated an increase in social ability between childhood and adolescence (Mazurek, Kanne, & Miles, 2012). Another study found that

adolescents and adults with ASD showed a greater prevalence of impairments in nonverbal communication and social reciprocity (Shattuck et al., 2006). This shows how symptoms vary along the spectrum and across the lifespan. In addition to autism symptoms, individuals with ASD often exhibit maladaptive behaviors including aggression, self-injurious behavior, and stereotypies (i.e., body rocking, self-caressing, etc.). Hartley, Sikora, and McCoy (2008) found that one-third of children with ASD showed clinically significant maladaptive behaviors that interfered with intervention and were distressing to caregivers. Both autism symptoms and maladaptive behaviors have negative effects on functional outcomes. For example, Eaves and Ho (2007) and Renty and Roeyers (2006) reported that worse functional outcomes in quality of life were related to more severe autism symptoms. Shattuck et al. (2006) found that having better verbal skills in childhood was predictive of better prognoses for social communication and interaction in young adulthood. Additionally, individuals with ASD who had maladaptive behavior problems were found to be more likely to be in day rehabilitation programs, not employment, and were less functionally independent (Taylor & Seltzer, 2011). However, maladaptive behaviors and autism symptoms may improve with behavioral intervention and visual supports (Rogers & Vismara, 2008; Rao & Gagie, 2006). These interventions are often available during childhood through both school and clinical services. Services are available in adulthood, but are typically less accessible, as they require more coordination and funding to access.

In addition to autism symptoms and maladaptive behaviors, many individuals with ASD have a comorbid intellectual disability (ID). Rates of co-occurring ID and ASD vary. The CDC (2014) reported 31% of children with ASD had an ID (IQ less than 70), whereas Matson & Shoemaker (2009) reported 50-70% of individuals with ASD have an ID (IQ less than 70),

though this higher rate may be reflective of the earlier times when these individuals were diagnosed. Presence of an ID affects behavior and support needed in individuals with ASD. Lower IQ in ASD correlates with increased severity of autism behaviors and maladaptive behaviors, and individuals with lower IQ have been found to be less likely to grow out of these behaviors, resulting in poor employment and independent living outcomes (Matson & Shoemaker, 2009). Although lower IQ has a negative impact on autism-related behaviors, individuals with average or above average intellectual functioning often have poor outcomes as well. In a study on employment and post-secondary educational activities for young adults with ASD, it was found that adults without an ID were three times more likely to be involved in no daytime activities or employment compared to adults with ASD and ID (Taylor & Seltzer, 2011). Renty and Roeyers (2006) found similar findings in high-functioning adults with ASD (IQ above 70). These adults were more likely to have poor outcomes related to quality of life including employment, living arrangements, and social implications. Matson and Shoemaker (2009) noted that as IQ increased in children with ASD there was limited improvement in social and daily living skills. The disparity in outcomes between individuals with ASD that are high-functioning and those with an intellectual disability may be due to a lack of services available to adults with high-functioning ASD. Independent living, employment, and interpersonal skills services currently available may better fit the needs of individuals with both ASD and ID, however, little is known about services utilized in adults from both of these groups.

Individuals with ASD also have an increased risk for developing a comorbid psychiatric disability. Prevalence of ASD and psychiatric disability have been reported in individuals with ASD to be as high as 64%, the most common psychiatric disorders being anxiety, attention deficit disorder, and major depressive disorder (Taylor, Smith, & Mailick, 2013). Kim, Szatmari,

Bryson, Streiner, and Wilson (2000) reported that depression and anxiety in children with high-functioning autism and Asperger syndrome were more common than in the general community of children of the same age. Affective disorders such as depression, bipolar disorder, and anxiety may be more common in higher-functioning adults with ASD due to greater insight into their social deficits and greater sensitivity to social stigma and discrimination (Tsakanikos et al., 2006). Individuals with ASD often have a difficult time accepting change and may be more prone to anxiety because of this difficulty. Psychiatric disorders can cause clinically significant impairments to daily functioning in individuals without another disability. An adult with ASD and a comorbid psychiatric disability may have an especially difficult time adjusting to treatment and show higher suicide rates than the general population, negatively affecting the ability to stay employed or integrated in the community (Wing, 2000). Psychological services, such as counseling and medication management, may be utilized to help manage psychiatric symptoms, but little is known about how often services are used.

In addition to social and daily living skills, employment is an area that individuals with ASD have especially poor outcomes. Rates of employment in adults with ASD are low with 25% to 50% of adults participating in any type of paid employment (Hendricks, 2009). Employment rates for adults with ASD are lower than other disabilities. Shattuck et al. (2012) used data from the National Longitudinal Transition Study 2 and found that only 53% of young adults with ASD have had at least one job since high school as compared to 62% of individuals with ID, and 80% of individuals with Learning Disabilities (LD), Emotional Disturbance (ED), or Severe Language Impairment (SLI). When young adults with ASD were employed, they were less likely to work full time, held fewer jobs, and earned lower wages in these jobs than individuals with LD, ED, and SLI (Roux et al., 2013).

Adults with ASD face many challenges with attaining and retaining employment. Holwerda, van der Klink, Groothoff, and Brouwer (2012) conducted a systematic literature review on factors that hinder work for individuals with ASD. They reported eight main factors that cause poor employment outcomes: severity of the disorder, co-morbidity of a psychiatric disorder, gender (with females having poorer outcomes), lower speech and language abilities, the presence of maladaptive behavior, social impairments and poor social skills, lack of work drive, and prior institutionalization. Adults with ASD have difficulties with tasks important to successful work including executive functioning, task execution, acclimating to new job routines, problem solving, and organization. These individuals often require structured schedules and routines. Employers are often unaware of these needs or do not know how to provide adaptations to help the individual. Adults with ASD often report high levels of anxiety and depressive disorders, which may cause significant impairment to daily functioning, including work duties (Kim et al., 2000).

Employment services often address the challenges adults with ASD face in gaining and maintaining employment. Hendricks (2009) outlined several strategies to improve employment for adults with ASD. On-the-job support services and programs that specifically target the needs of individuals with ASD led to improved employment outcomes and are cost effective as compared to programs generalized to all disability populations. This same strategy was seen in a study on transition services for students with ASD. Wehman et al. (2013) compared employment outcomes of high school students in the Project SEARCH plus ASD Supports program to students using their Individualized Education Program (IEP) as outlined. The Project SEARCH plus ASD supports program provided on-site job coaching, use of applied behavior analysis (ABA), and intensive training on ASD for staff. The study reported 88% of the group in the

Project SEARCH plus ASD Supports program received competitive employment after graduation compared to 6% of the control group (Wehman et al., 2013). Other strategies identified by Hendricks (2009) included appropriate job placement, education for supervisors and co-workers about ASD, work place modifications, and long-term support. Supported employment, a model placing individuals in integrated work settings using on-the-job supports, is another successful service that improves employment outcomes for adults with ASD. Adults with ASD using VR services had a higher successful closure rate when using supported employment (75%) as opposed to those starting straight into competitive employment (58%) (Schaller & Yang, 2005). Lawer, Brusilovskiy, Salzer, and Mandell (2009) reported that inclusion of on-the-job supports that are often found in supported employment were related to a higher likelihood of employment in the community for adults with ASD. Employment services that address the individual needs of adults with ASD lead to better employment outcomes. However, there is not much known about the availability of these services and satisfaction from consumers.

Service Use

Therapeutic and diagnostic services in childhood have been the focus of research and treatment for individuals with ASD. In early childhood, families reported using services like occupational therapy (OT), physical therapy (PT), speech therapy, and diagnostic/assessment services (Cidav, Mandell and Shea, 2012). Most services children with ASD use are provided in schools, with speech therapy and occupational therapy being the most used in schools (White, Scahill, Klin, Koenig & Volkmar, 2007). Use of these services decrease with age, and outpatient services such as case management, medication management, day treatment, personal care, and respite care increase with age (Cidav et al., 2012). Ruble, Heflinger, Renfrew and Saunders

(2005) support these findings, by reporting that as children's age increased, use of case management, medication management, and crisis services increased. As individuals with ASD enter high school, they are more likely to use mental health services. Narendorf, Shattuck and Sterzing (2011) reported that 46% of adolescents with ASD in high school used mental health services in the past year and nearly half (49%) had received these services in school. Children with ASD appeared to use more services while in elementary school, peaking in 5th grade (87% using services) and decreasing as they entered secondary school (White et al., 2007). Research seems to support that as children with ASD grow older, the types of services they use change, but the need for services does not (Cidav, Mandell, & Shea, 2012; Narendorf, Shattuck & Sterzing, 2011).

Little research exists on the types of services used and satisfaction associated with services use in adults with ASD. One study by Shattuck, Wagner, Narendorf, Sterzing, and Hensley (2011) reported that young adults, ages 19-23, used fewer services than they did in high school, with 39% of youth receiving no services after graduation. Most young adults reported receiving case management services (42%), mental health services (35%), medical services (24%), and speech therapy (9%). Further research is needed on the types of services adults with ASD utilize in middle adulthood. Additionally, overall satisfaction with services used by adults is missing from the literature. Of the families with children with ASD that use services, satisfaction with services is mixed. Overall 19-20% of families are dissatisfied with the services their children are receiving, and 63% reporting they are somewhat satisfied (Thomas, Morrissey, & McLaurin, 2006; Montes, Halterman, & Magyar, 2009). Only 18% of families reported being very satisfied with the services their children were receiving, while 27% of families were using a service they did not find useful (Thomas, Morrissey, & McLaurin, 2006). Reasons for

dissatisfaction with services included difficulty using school and community services, lack of available services, and lack of trained physicians and professionals in the area (Murphy & Ruble, 2012; Montes, Halterman, & Magyar, 2009). It is unknown if these reasons for dissatisfaction continue into adulthood, but is likely as they suggest accessing community services is a driving factor in dissatisfaction.

To help adults with ASD achieve better outcomes and quality of life in their community, services have been made available largely through Medicaid and Medicare funded agencies. However, service use in individuals with ASD is less than what is expected compared to current ASD diagnosis prevalence rates. In families using Medicaid, service use was 10% of what was expected (Ruble, Heflinger, Renfrew & Saunders, 2005). Lack of service use may be due accessibility to these services. Families living in rural communities report significantly more difficulty accessing trained physicians and professionals in their area compared to families in urban communities (Murphy & Ruble, 2012). Children in rural communities are also diagnosed at a later age than those living in urban communities, further suggesting a lack of accessibility to services in rural communities prevents service use (Mandell, Novak, & Zubritsky, 2005). Employment services, such as Vocational Rehabilitation (VR) agencies, tend to have more resources in urban communities than rural communities. The average money reportedly spent in 2014 on purchasing vocational services for urban clients was higher than for rural clients, indicating employment services are more available in higher population dense areas (Ipsen & Swicegood, 2014). Urban clients were more likely to receive diagnosis, treatment, job placement assistance, and transportation services than rural clients, which are services that benefit adults with ASD in gaining and maintaining employment (Ipsen & Swicegood, 2014; Hendricks, 2009). Further, Ipsen and Swicegood (2014) reported that rural case closures had a lower percentage of

closures with employment in integrated settings compared to urban case closures. As integrated, competitive employment in the community has become the standard of a successful employment outcome, this finding further points to the need for research on how service use differs between rural and urban communities. One way to incorporate the impact of population density on employment and service use in research is using geographic information systems (GIS).

Geographic Information Systems

The study of geographic features and social sciences has become more prevalent due to the creation of GIS. GIS is defined as “an integrated collection of computer software and data used to view and manage information about geographic places, analyze spatial relationships, and model spatial processes” (Brown, 2013). Computer-generated maps are created using a specific coordinate system, unit of measurement and map projection to display data using spatial information of latitude and longitude coordinates, or street location. Specific data features are grouped together to create a layer of a map. For example, one layer with all the streets in North Carolina can be created, while another layer may feature all the restaurants in North Carolina. Geospatial data layers of different features can be acquired through manual data entry, or through pre-generated data files found on government, private company, academic institution, and nonprofit websites (Folger, 2011). Data layers can then be overlaid, creating a unique ability to analyze different features and give the user a visual representation of the data (Folger, 2011). Proximity analyses and spatial analyses are some of the geospatial calculations GIS can compute. Proximity analyses are used to determine relationships between distances features. Users can create buffers, or rings, around a specific feature to show areas of influence. For example, a user might create a buffer ring one mile around a health and fitness club and use the buffer to see how many members live within the buffer. Spatial clustering is a tool used to group together related

attributes and can be used to show relationships between different features, such as analyzing features of locations with high crime.

Geographical software has been used in medical research, scientific research, land management, transportation, criminology, and many other types of research. More recently, a GIS approach has been used in mental health and community integration research. Leslie et al. (2005) used GIS to objectively measure features of the environment that influence adults' physical activity. Other uses include looking at the proximity of community features that may predict substance use, and the relationship of proximity to outcomes of individuals with severe mental illness (Mason, Cheung, & Walker, 2009; Metraux, Brusilovskiy, Prvu-Bettger, Wong, & Salzer, 2012). GIS has also been used to create an individual's activity space to measure one's spatial presence in the community, and analyzed with community integration outcomes (Chan, Helfrich, Hursh, Rogers, & Gopal, 2014; Zenk et al., 2011).

Creating and analyzing population density maps using GIS provides a unique way of analyzing outcome data. Using population data from the U.S. Census, a data layer is created by grouping areas into tracts of 4,000 people per tract. In GIS, a population density map can be created allowing the user to measure density for a specific tract and then spatially join other outcome data occurring in the same geographic area. GIS thereby provides a visual representation of what outcomes are occurring where, and potential environmental or contextual factors impacting these outcomes. Many studies have used the population density feature of GIS to examine effects on outcomes. Vine, Buys, and Aird (2012) explored the effects of high and low-density neighborhoods in urban communities on older individuals. Pearce, Witten, and Bartie (2006) also examined rural and urban neighborhoods as they affected the health status of residents in New Zealand. Another study examined health care utilization among residents of

rural North Carolina counties, concluding an inequality in rural health care utilization (Arcury, et al., 2005). While there are a growing number of studies using population density and other geospatial analyses, there is still a lack of studies comparing functional and behavioral outcomes in urban and rural communities, and further, a lack of studies on adults with ASD and their interactions with their communities, including services used.

The Present Study

The purpose of this study is to report on service use in adults with ASD in North Carolina and analyze how population density affects service use using a GIS approach. The types of services utilized by adults with ASD have only been reported once in young adults (Shattuck et al., 2011). Little is known about the types of services used beyond young adulthood, satisfaction with services, and barriers to service use in the growing population of adults with ASD. As much of the research suggests, service use factors may be related to the population density of the communities adults with ASD live in (Murphy & Ruble, 2012; Mandell, Novak, & Zubritsky, 2005; Ipsen & Swicegood, 2014). GIS provides a unique method of analyzing spatial relationships and modeling spatial processes, while providing a visual representation of data. As use of a GIS approach in health care and community mental health related to neighborhoods and population density becomes more widely used, the use of GIS in analyzing service utilization will grow. The current study will use GIS mapping to present a visual view of population density for adults with ASD living in North Carolina and report the types of services adults with ASD use, their satisfaction with services, barriers to using services, and the relationship between these service use and population density.

The present study is part of a longitudinal study of adults diagnosed with ASD as a child at TEACCH clinics in North Carolina from 1970-1999. The aims of the larger study were to 1) conduct a survey to assess long-term adult outcomes for individuals with ASD, 2) identify predictors of adult outcomes in individuals with ASD, and 3) examine the association between childhood functioning and adult outcomes. Caregivers of adults with ASD who were diagnosed by the TEACCH Autism Program between 1970 and 1999 were recruited for this study. Caregivers completed surveys that included many measures. For this study, questions from the TEACCH Autism in Adulthood Survey relating to employment, use of services, and current living situation will be used.

Research Questions

1. What services are adults with ASD utilizing, what barriers are they reporting to service use, how satisfied are they with the services they are receiving, and what services do they report needing?
2. How does population density affect service utilization, barriers to accessing services, and satisfaction with services?
3. If population density affects service use outcomes, for whom does it affect?

CHAPTER 2: METHODS

Participants

Data were originally collected from 284 caregivers of adults (21-54 years old) with ASD who were diagnosed during childhood by the University of North Carolina TEACCH Autism Program between 1970-1999. All adults had a confirmed diagnosis of ASD, and had a completed survey by a caregiver. Only adults with ASD currently living in North Carolina were included in the current study. Data from 193 caregivers were excluded because the adult currently lived outside of the state of North Carolina or an exact address could not be found. Participants were 91 caregivers of adults with ASD who were diagnosed during childhood by the University of North Carolina TEACCH Autism Program between 1970-1999. A statistical power analysis was conducted and determined that with 91 participants the study has 91% power to detect a medium correlation of $r = .3$.

Measures

TEACCH Adulthood Survey. Data from the TEACCH Adulthood Survey were used. The survey included 88 questions assessing demographic information (ethnicity, socioeconomic status), current developmental level (current language and independent living skills), educational background (high school and college experiences), residential setting (currently and during the past two years), employment and income history (currently and during the past two years), social and recreational activities (past year), current medication use, and service delivery usage

(currently and in the past two years). Specific questions the survey were analyzed in the present study.

Participants completed seven questions measuring services used. Participants marked each service used in the last two years. Services included: 1) Help in finding a job, 2) Training in job skills or vocational education, other than from an employer, 3) Job coaching, 4) Financial aid, like paying for college classes or training, 5) Educational assistance or tutoring (e.g., managing money, cooking,) not including instruction from family members or friends, 6) Psychological or mental health services or counseling, 7) Social work services, 8) Physical therapy, and 9) Assistive technology services or devices (e.g., special calculator, reading machine, or augmentative & alternative communication device (AAC)), 10) Transportation assistance because of disability, 11) Medical services for diagnosis or evaluation related to his/her disability, 12) Speech or language therapy, or communication services, 13) Audiology services for hearing problem, 14) Respite care, 15) Housing assistance or residential services or help with a supervised living arrangement (e.g., a group home), 16) Personal assistant/or in-the-home aid, and 17) Nursing care.

Participants' satisfaction with services was measured across a single item: "Overall, how satisfied have you been with all services he/she has received?" Satisfaction was measured on a 7-point scale from Very dissatisfied (1) to Very satisfied (7).

Barriers to service use was measured across seven areas. Participants reported each barrier to service use in the past 12 months in the areas of: 1) Cost of services, 2) Services not available or too far away, 3) Poor service quality, 4) Language problems (include sign language

or interpreter), 5) Transportation, 6) Adult is not eligible for the service, and 7) Not sure where to find services needed.

Participant address. Using the TEACCH survey, participants marked where the adult with ASD lived to confirm the individual's address. Answer choices were 1) Independently (alone), 2) Independently (with spouse or roommate), 3) Supervised housing, 4) With parent(s), 5) With another relative/guardian other than a spouse or parent, 6) Community group home, 7) Intermediate Care Facility for Individuals with Mental Retardation/Intellectual Disability (ICF-MR/IDD home), 8) "Family Care" home, 9) Correctional facility, 10) Transient, homeless, on the street, in their car, 11) Other, or 12) Don't know. Addresses from caregivers were matched with those reporting living at home. Specific group home and ICF-MR/IDD homes were reported on the survey. The remaining addresses were collected through follow-up phone calls to participants. Using ArcGIS software, each adult address was plotted as a data layer using x, y, coordinates onto a pre-generated county map of North Carolina data layer retrieved from the NC Map database (see Figure 1).

Population density. Point population density was collected for each participant address. Point population density by square mile was calculated by using a pre-generated 2010 Census tract data map (retrieved from www.census.gov). Census tracts generally have a population size between 1,200 and 8,000 people, with the optimal size of 4,000 people. Tracts of different square miles were created using the GIS population density function (see Figure 2 and 3). Using the information function on GIS, the point population density was measured and recorded for each address in North Carolina.

Procedure

Data were collected from caregivers of adults with ASD from the longitudinal study. Participants were recruited using the TEACCH Autism program database and archived records. In total, 1710 addresses of individuals diagnosed at a TEACCH center were collected. Letters were sent to each address. Of the 1710, correct phone numbers were found for 799 individuals. Contact was made with 529 caregivers, in whom 408 were enrolled to participate in the study. A total of 316 surveys were completed, 284 filled out by caregivers, 32 filled out by adults with ASD. Only caregiver surveys were used for this study. Addresses for adults with ASD were collected for 173 participants. Of the 173 addresses, 70 were not located in North Carolina and were excluded from the study. For 12 of the remaining participants, exact addresses could not be determined and were also excluded from the study. Answers from 91 caregiver surveys were coded and entered into SPSS.

CHAPTER 3: RESULTS

Participants

A descriptive analysis of demographic information including age, race, sex, and co-occurring disorders was completed. Participants ranged in age from 21 to 54 years old ($M=34$, $SD=7$), with 80% Male, and 20% female. A majority of participants identified as White (74%), the remainder identifying as Black or African-American (25%), American Indian or Alaska Native (2%), and Asian (1%). All participants had a confirmed diagnosis of ASD, with 51% having a co-occurring ID. Other co-occurring disorders reported included Epilepsy and/or seizures (24%), Anxiety (24%), Learning Disability (22%), Attention Deficit Disorder (20%), Depression (10%), other PD (7%), and Fragile X Syndrome (1%).

Living Situation

A descriptive analysis of living situation was completed. A majority of participants reported currently living with a relative or guardian (75%), in an ICF or Institution (13%), in supervised housing (7%), in a group home or in the community (4%), with only one individual living independently (1%). Participants lived across the state in both rural and urban areas, covering 31 different counties. Fifty-six percent of the population lived in rural areas (<1000 people per square mile); the remaining 44% lived in urban areas ($>$ or $=$ 1000 people per square mile) (U.S. Department of Commerce, Census Bureau [U.S. Census], 2010). A Pearson correlation found that older individuals were more likely to live in rural communities ($r(90) = -$

.21, $p=.04$) (see Figure 4). Mother's highest level of education was positively correlated with population density ($r(90) = .23, p=.03$) (see Figure 5). No other factors were significantly related to population density including childhood IQ, CARS score, childhood Vineland score, Waisman score, SRS score, Quality of Life, or conversational skills.

Service Use Outcomes

A descriptive analysis of service use data was completed by calculating frequencies of services used in the past two years, frequencies of reported barriers to service use and means and standard deviation of service satisfaction. Participants reported using 17 different kinds of services in the past two years (see Table 1). The most frequently used services reported included Medical services for diagnosis or evaluation (43%), Transportation assistance (33%), Social work services (32%), Psychological or mental health services or counseling (31%), Instruction or help with independent living skills (30%), Job Coaching (29%), and Help in finding a job, training in job skills, or vocational education (28%). Total number of services received by each individual ranged from zero services to 11 services received ($M=3.3, SD=2.8$) (see Figure 6). As can be seen from the Figure 6, the most common number of services used was 0 with approximately 21% of individuals receiving no services over the past 2 years. Overall, a majority of caregivers reported being somewhat satisfied, satisfied, or very satisfied with the services being received (61%). The remaining caregivers reported being somewhat dissatisfied, dissatisfied, or very dissatisfied with services being received (19%) or neutral about services received (19%).

While many services were utilized, over half of caregivers believed additional services were needed (57%). Of those reporting need for additional services, 75% stated they attempted to

access these services, and only 21% were on a waiting list for the services. A majority of participants reported experiencing no barriers or only one barrier to getting services (69%), with one individual reporting experiencing six barriers (1.1%). Specific barriers to service use were also reported, with almost a third reporting they were not sure where to find the services participants needed (33%). Other barriers included individuals not being eligible for services (24%), services not available or too far away (24%), cost of services (14%), poor service quality (12%), lack of transportation (11%), and language problems (including sign language or interpreter) (6%).

Population Density and Service Use Interactions

A Pearson correlation found that population density alone was not correlated with number of services received ($r(90) = .20, p = .06$), number of barriers encounters ($r(90) = .11, p = .31$) or satisfaction with services ($r(90) = .03, p = .80$). It was noted that twelve participants reported living in an ICF or institutional setting. Individuals that live in this type of setting are usually provided 24-hour care and do not have much control over the kinds of services they receive. They also do not have control over what population density they live in, as a majority of ICFs or institutions identified were located in rural areas of the state. Therefore, these individuals were dropped from these correlational analyses. The correlation became significant when all participants except those living in an ICF or institution setting (13%) were included ($r(67) = .31, p = .01$). It was also noted that a vast majority of participants were living with a parent or a guardian (75%), and upon further investigation, there was nearly an equal distribution between living in urban (56%) and rural communities (44%). When looking at just these participants, there was also significant positive correlation between number of services received and population density ($r(67) = .32, p = .01$).

Number of Services Received and Population Density. Next, a series of regression analyses were performed to determine any other factors affecting population density and number of services received. These ANCOVAs examined the effects of population density, number of services utilized in the past two years, and other data collected from the survey. One significant interaction was found. The amount of unpaid supervision a participant received daily had a significant interaction with population density that affected the number of services received ($f = 2.65, p = .03$). No significant interactions were found when looking at population density and number of services utilized interacting with childhood IQ, communication level, receiving government benefits, amount of money spent on care, childhood IQ, CARS score, childhood Vineland score, Waisman score, SRS score, Quality of Life, employment status, areas of independent living skills training needed, or paid supervision.

While there were no other significant interactions with population density, there were interesting findings between certain factors and number of services used. Childhood IQ negatively correlated with number of services used, with lower IQ scores using more services ($r(90) = -.35, p = .00$) (see Figure 7). This finding was also significant when looking at only participants living with a parent or a guardian ($r(67) = -.342, p = .01$) (see Figure 8). Communication level (rated from doesn't communicate at all, a lot of trouble communicating, a little trouble communicating, or no trouble communicating) had a positive significant correlation with number of services received ($r(90) = .29, p = .01$), with a stronger correlation for those living at home ($r(67) = .39, p = .00$). Other significant correlations with number of services received, but no significant interaction with population density include a negative correlation with the amount of money spent on the participant in the last 12 months ($r(90) = -.210, p = .05$), and a positive correlation with areas of instruction the participant needed help in ($r(90) = .453, p = .00$).

Number of Barriers Encountered. Since no significant relation was found between barriers to service use and population density ($r(90) = .11, p=.301$), a series of regression analyses were performed to determine any significant interactions between certain factors and population density in predicting the number of barriers individuals encounter when accessing services. No significant interactions were found when looking at population density and number of barriers to use interacting with childhood IQ, communication level, receiving government benefits, amount of money spent on care, childhood IQ, CARS score, childhood Vineland score, Waisman score, SRS score, Quality of Life, employment status, areas of independent living skills training needed, or paid or unpaid supervision. While there were no interaction effects found, one factor was found to significantly predict barriers with service use. Household income for the past 12 months was negatively related to number of barriers encountered for those living with a parent or guardian ($r(67) = -.263, p=.04$).

Satisfaction with Services. No significant relation was found between satisfaction with services and population density ($r(90) = .03, p=.80$). A series of regression analyses were performed to determine any significant interactions between certain factors and population density to affect satisfaction with services. No significant interactions were found when looking at population density and satisfaction with services interacting with childhood IQ, communication level, receiving government benefits, amount of money spent on care, childhood IQ, CARS score, childhood Vineland score, Waisman score, SRS score, Quality of Life, employment status, areas of independent living skills training needed, or paid or unpaid supervision.

CHAPTER 4: DISCUSSION

The present data provide important insight into the services used by adults with ASD. Ninety-one adults with ASD ages 20-54, living across North Carolina provided responses to questions about their services being utilized, barriers to services, satisfaction with services, and how population density affected those outcomes. The sample was representative of North Carolina racial census information (sample 74% White, 25% Black or African American compared to NC 69% White, 22% Black or African American) (U.S. Census, 2010). Sex of participants was similar to ASD prevalence statistics (5 males to every 1 female), with the sample being 4 males to every 1 female (CDC, 2014). Almost half of adults in this study reported having a co-occurring diagnosis of ID, similar to CDC (2014) findings (54%).

Participants reported using 17 different services in the past two years with the most frequent services used being medical services, transportation assistance, social work services, psychological or mental health services or counseling, instruction or help with independent living skills, job coaching, and services related to finding and keeping a job. These findings are similar to Shattuck et al.'s (2011) findings regarding service use after high school in young adults with ASD, with case management services, mental health services, and medical services, being the most used services for this population. As individuals get older, types of services used are likely to change due to many services ending once exiting high school. Services used in adulthood may also differ than in childhood due to different areas of need as the individual ages. Services revolving around common adult themes such as employment, independent living skills

(cooking, cleaning, money management, etc.), and transportation were commonly used whereas services such as speech therapy, PT, and OT were infrequently used, though these services are commonly used with children with ASD. Many adults in this study reported accessing mental health or social work services, which are also not common in childhood. Many psychiatric disorder symptoms including those reported by participants in this study (anxiety, depression, other mental disorders) onset during early adulthood (Kessler et al., 2007). An increase in mental health services from childhood to adulthood is then expected, especially because as high as 64% of individuals with ASD have psychiatric disorders that requires treatment (Taylor, Smith, & Mailick, 2013).

A range of barriers to accessing services was experienced. The most common barriers experienced included not knowing where to find services, being ineligible for services, and services not being available in their areas or being too far away. These barriers are similar to barriers reported by caregivers of children with ASD (Murphy & Ruble, 2012; Montes, Halterman, & Magyar, 2009). While previous research showed that families living in rural communities reported significantly more difficulty accessing trained professionals than families living in urban areas, the current study did not replicate these findings as barriers to service use was not significantly correlated to population density (Murphy & Ruble, 2012). The mean number of barriers experienced was also lower than expected ($M=1.2$), especially given that 57% of caregivers stated they believed the adult with ASD needed more services than they were currently receiving.

Surprisingly, population density did not correlate with any service use outcomes when analyzing the entire population. However, when removing individuals living in ICFs or institutional settings, results showed that individuals living in urban communities received

significantly more services than those living in rural areas. ICFs and institutions serve individuals with more severe disabilities and the ICF or Institution typically determines which and how many services an individual receives, leaving little opportunity for population density to affect these services (Krauss, Seltzer, & Jacobson, 2005). Eight participants were living at the same ICF in a rural community in NC, which also likely affected the outcome of these analyses. Results on only those living in other settings match previous research showing that families living in rural areas access fewer services than those in urban areas and that this may be due to accessibility to trained professionals in rural areas (Murphy & Ruble, 2012). More densely populated areas have more people to provide services and more options for individuals to choose from, whereas less densely populated communities typically have fewer services available, limiting the number of people served. A significant positive correlation was also found for just individuals living with a parent or guardian (n=68). This is an important finding, because adults with ASD are more likely to live with a parent or guardian, than other disability groups (Anderson, Shattuck, Cooper, Roux, & Wagner, 2014). While analyses found that individuals in rural communities received fewer services, number of barriers to service use was not significantly correlated with population density. Additionally, satisfaction with services received was not correlated with population density. It appears that individuals living in either community are encountering similar barriers to utilizing services and are equally happy with the services that they do receive.

One of the strongest relations found in this study was the relation between childhood IQ score and number of services used. Adults with ASD who had lower full-scale IQ scores as a child used significantly more services than those with higher IQ scores. Service use for individuals with greater intellectual difficulties may be higher due an increased need for

supervision, as well as the visibility of their disability. Individuals with ASD and average or above average IQ do often have less visible symptoms, but still have poor employment and social outcomes (Lee & Carter, 2012; Taylor & Seltzer, 2011). Due to perceived competence, these individuals may not receive services vital to adult outcomes, including employment and case management services. In addition to visibility of disability, there may be more services available for individuals with ID. Services such as one-on-one support staff, job coaching, and day programs teaching daily living skills are widely available and utilized for individuals with ID (Bigby & Knox, 2009). This study supports these previous findings, as amount of supervision (paid or unpaid) increases as IQ decreases. Strategies such as behavioral plans and the use of reinforcement techniques, proven to be effective with individuals with ID, are not suitable for individuals without ID (Thompson et al., 2009). Additionally, the present study found that population density had the same effect on both IQ groups (those with IQs below 70 and above 70), with service use increasing as population density increased. However, individuals living in rural areas received fewer services overall, providing further support for the argument that less services are available in rural communities, especially those with higher IQ scores. The lack of service use in adults with ASD with higher IQ scores, but continual poor adult outcomes, suggests that additional services are needed for this specific population, especially in rural communities.

Limitations

Results from this study should be interpreted with caution due to several limitations. The study only analyzed individuals currently living in the state of North Carolina. While there was a similar distribution in population density looking at those living in urban and rural communities, North Carolina ranks as the 17th most population dense state in the United States making it,

overall, a quite urban state (U. S. Census, 2010). This may have an effect on service use outcomes for individuals with ASD. This study is also limited in generalizability due to the unique ASD focused services offered in North Carolina. Eric Schopler founded the TEACCH Autism program in 1972, providing clinical services including diagnostic evaluations, support groups for families and individuals with ASD, and treatment through the structured teaching approach (Mesibov and Shea, 2010). The TEACCH Autism program was the first statewide program that specifically targeted ASD and continues to serve as a program model for organizations across the world. Many families of children and adults with ASD have reported that they moved to NC to access these services, also providing an explanation for a higher rate of ASD prevalence in North Carolina. The prevalence of ASD in North Carolina is 1 in 58 compared to the national prevalence rate of 1 in 68 (North Carolina Autism and Developmental Disabilities Monitoring Network [NCADDM], 2010; CDC, 2014). While no relations were found between distance to a TEACCH center and service use outcomes, adults in North Carolina may be accessing more services, finding less barriers, and be more satisfied with their services because of the high quality ASD programs in the state. In a study on older neurotypical individuals and service use, older adults that learned about services from a formal source (professional organizations that serve older adults) were more likely to use these services (Silverstein, 1984). This may generalize to adults and caregivers of individuals with ASD, with TEACCH and other high quality service providers in NC serving as formal sources. Because all of the participants in this study were evaluated at TEACCH as children, they may have been likely to learn about other services available in North Carolina, giving them more reasons to stay. Therefore, service use outcomes may look differently in North Carolina than they do in other states.

Another limitation to the generalizability of this study is that the sample studied was largely individuals in middle adulthood (M = 35 years) diagnosed before 2000 and may not reflect the services received by younger adults with ASD. All individuals included in this study were diagnosed with ASD as a child. Diagnostic criteria and assessment has changed in the past 40 years, resulting in an increased prevalence rate in ASD (CDC, 2014). Individuals diagnosed in 1970s, 1980s, and early 1990s may show more severe ASD symptoms and be more likely to have an accompanying ID, as seen by a prevalence rate of 50-70% of individuals with both ASD and ID (APA, 2013; Matson and Shoemaker, 2009). Due to increased awareness and change in diagnostic criteria, more individuals are being diagnosed with ASD without ID (also known as high-functioning ASD or Asperger's syndrome) especially in adulthood (APA, 2013; Fombonne, 2009). Most recently, the CDC (2014) reported only 35% of individuals with ASD have an ID. The present study had a 50.5% prevalence rate of ID, closely matching Shoemaker and Matson's (2009) findings. Therefore, individuals in the present study may be different from the service outcomes seen for the upcoming generation of individuals with ASD. Individuals diagnosed as children now, may use different services than those as children in the past 40 years. However, the present findings are still applicable, as the sample represents adults with ASD currently and the services they need. These adults will continue to need similar services for the next several decades. The present findings also suggest that individuals without an ID are still receiving fewer services, especially living in rural areas, which can be generalized to individuals diagnosed with ASD as children and adults currently.

Recommendations for Future Research

Further research is needed on service utilization of adults with ASD. As previously discussed, the present study examined individuals living in North Carolina. While North

Carolina provides diverse population density communities, it is important to test how these findings generalize to other states. States with both more rural and more urban states should be studied, especially those with fewer services individualized for adults with ASD. Future research should continue to gather data on the types of services adults used and needed, especially the individuals exiting high school and beginning adulthood. There is currently only one study that has looked at this population (Shattuck et al., 2011). Continued research is needed to determine how services can be more effective and determine predictors of successful outcomes, as related to service utilization.

Implications for Rehabilitation Counseling

The findings from this study provide several implications for practice for rehabilitation counselors. First, rehabilitation counselors should work to increase awareness of available services in the communities they serve. One of the biggest barriers reported to service use in this study was that adults and families did not know where to find services. Rehabilitation counselors can support adults with ASD and their families by being familiar with the variety of services their community provides and sharing this information with consumers. Counselors should also be knowledgeable of the cost of different services and familiar with resources to financially aid with receiving these services. Government benefits including SSI and SSDI can be confusing and challenging for families and adults with ASD to navigate. Rehabilitation counselors can serve as a valuable resource to aid in applying for government benefits, especially for individuals leaving high school. Starting to look at services and government benefits while still in high school can aid in the transition process and lead to overall better outcomes. Some benefits, such as Medicaid waivers, have long waitlists. The earlier an individual can on the waitlist, the earlier they can

start receiving services and increase the chances for better outcomes, including employment and community integration outcomes.

As this study showed, individuals living in rural communities utilize less services and experience barriers to service use relating to location, with services reported being too far away or not knowing where to find services. In both urban and rural communities, rehabilitation counselors work in various organizations including vocational rehabilitation services, hospitals, and mental health settings. Because of the availability of rehabilitation counselors in rural communities, these professionals can be pivotal for improving services for adults with ASD, with proper training and education. Rehabilitation counselors should receive training specific to working with adults with ASD both with and without a co-occurring ID. Trainings specific to ASD should include an overview of ASD and its prevalence, learning styles and executive functioning of an adult with ASD, challenges unique to adults with ASD especially while looking for a job, developing independent living skills, and socializing, and different interventions and techniques for working with adults with ASD that are evidence-based (Swiezy, Stuart, & Korzekwa, 2008). Adults with ASD have different challenges and learning styles than other disability populations seen by rehabilitation counselors. By giving rehabilitation counselors an increased awareness and understanding of ASD, they can modify and improve services already being provided to consumers and advocate for more evidence-based services and community involvement in rural areas.

Rehabilitation counselors can serve as advocates for adults with ASD living in rural areas, where fewer services are being used. Because rural communities may not have the funding or personnel to provide the same services as those offered in urban areas, it is especially important for rehabilitation counselors to promote services for individuals with ASD in rural

settings. Counselors can increase awareness of what ASD is and how it affects the outcomes of individuals in the community. By increasing awareness in the community, other members may be more likely to get involved and work towards providing supports for adults with ASD. Rehabilitation counselors can also teach adults with ASD important self-advocacy skills to improve overall outcomes despite a lack of services available in the community. Self-advocacy skills frequently lead to better employment outcomes, especially when learned early in high school (Test, Fowler, Wood, Brewer, and Eddy, 2005). Self-advocacy skills include knowledge of self, knowledge of rights, effective communication, and leadership (Test et al., 2005). These are skills rehabilitation counselors can teach in most settings. Through a combination of self-advocacy from adults with ASD and advocacy from the rehabilitation counselor, changes may occur in rural communities to provide more services or to provide more natural supports. While creating services may not be cost-effective for certain communities, advocacy can increase natural supports in its place. Members of the community may be more willing to take on a supportive role in offering transportation, hiring individuals with ASD, or making community events more inclusive. When natural supports are in place, the need for services may ultimately decrease.

The current study provided evidence for the lack of services available for individuals with ASD without an ID. While research shows that adults with ASD with higher childhood IQ scores experienced poor employment outcomes and were more likely to participate in no daily activities after high school, there may be limited services available for these individuals (Taylor and Seltzer, 2011; Renty and Roeyers, 2009). Rehabilitation counselors should strive to research best practices for working with these individuals with ASD and be active in developing supports for these individuals, especially in rural communities. Lee and Carter (2012) suggest that

outcomes for adults with ASD without ID are poor due to four factors: 1) Adults may not be eligible to receive formal services and supports due to perception of reduced need, 2) Educational programs emphasize academic achievement and general education for adolescents as opposed to career development and work experiences, 3) Adults face challenges related to socializing with others that may interfere with keeping a job, and 4) Interventions are focused on post-secondary education as opposed to preparation for the workforce, unlike other disability populations. Rehabilitation counselors can address several of these factors, by being involved with the individual while they are still in high school. By starting early, rehabilitation counselors can provide supplemental instruction on employment skills, in addition to what schools are already doing. While post-secondary education should still be encouraged, adolescents can also plan for entering the workforce with a rehabilitation counselor by setting goals, completing work experiences while in high school, and developing job placement skills including interviewing skills and writing resumes.

Conclusion

There is a growing population of adults with ASD, but little research on service utilization and needs in this population. Adults with ASD may experience barriers in finding and maintaining employment, developing relationships, and learning independent living skills, all major milestones accomplished in adulthood. Services need to be created to specifically fit the needs of adults with ASD both with and without ID. Rural communities, especially, need more services and resources to serve these adults and their families. By advocating for services and increasing awareness about the unique challenges individuals with ASD face as they grow older, rehabilitation counselors can help communities provide natural supports for adults with ASD and strive to provide cost-effective, evidence-based services.

FIGURES

FIGURE 1, GIS Map of Participants Living in NC

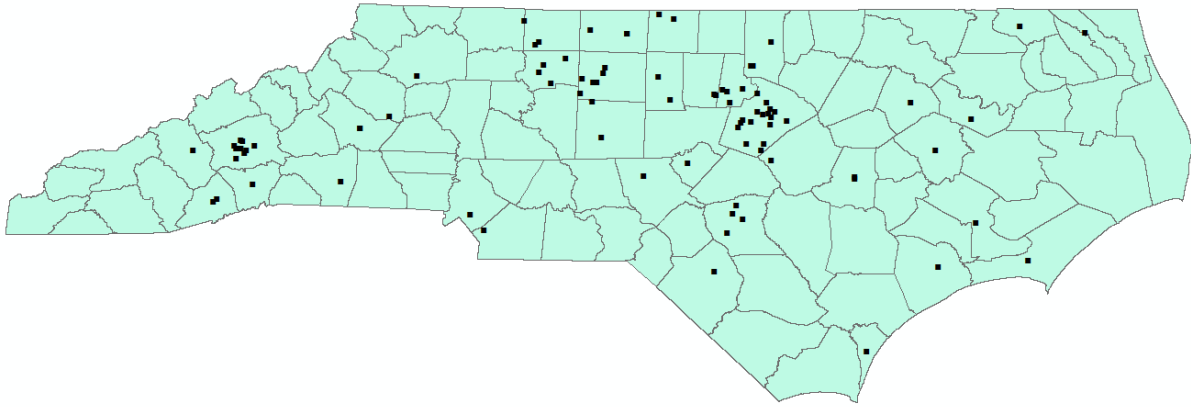


FIGURE 2, GIS Population Density Map of Participants

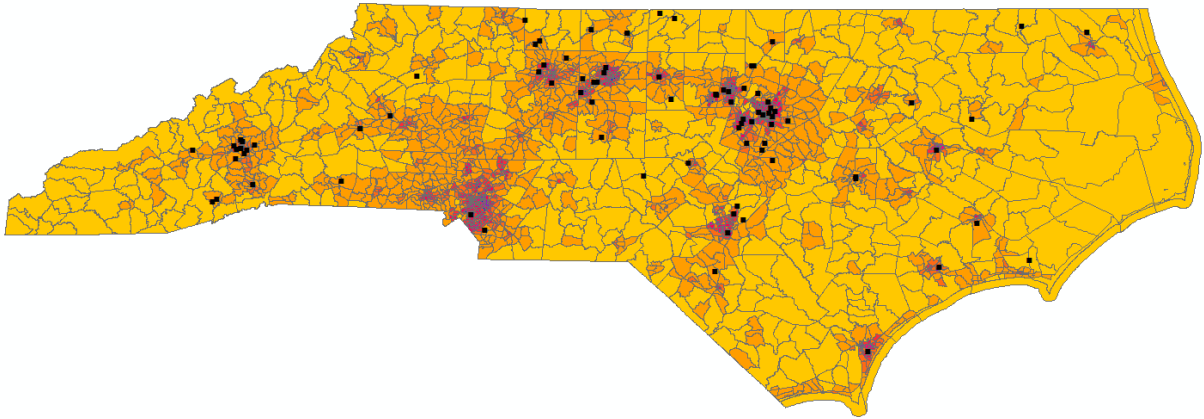


FIGURE 3, GIS Population Density Map zoomed in to Orange, Durham, and Wake Counties

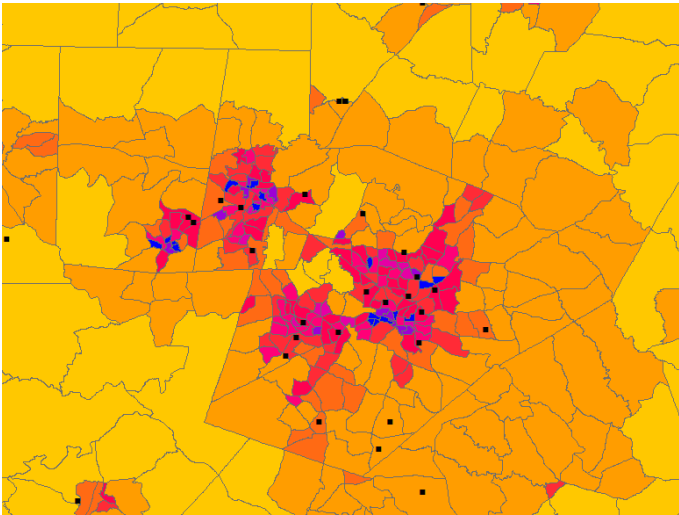


FIGURE 4, Graph of Correlation between Population Density and Age of Adult

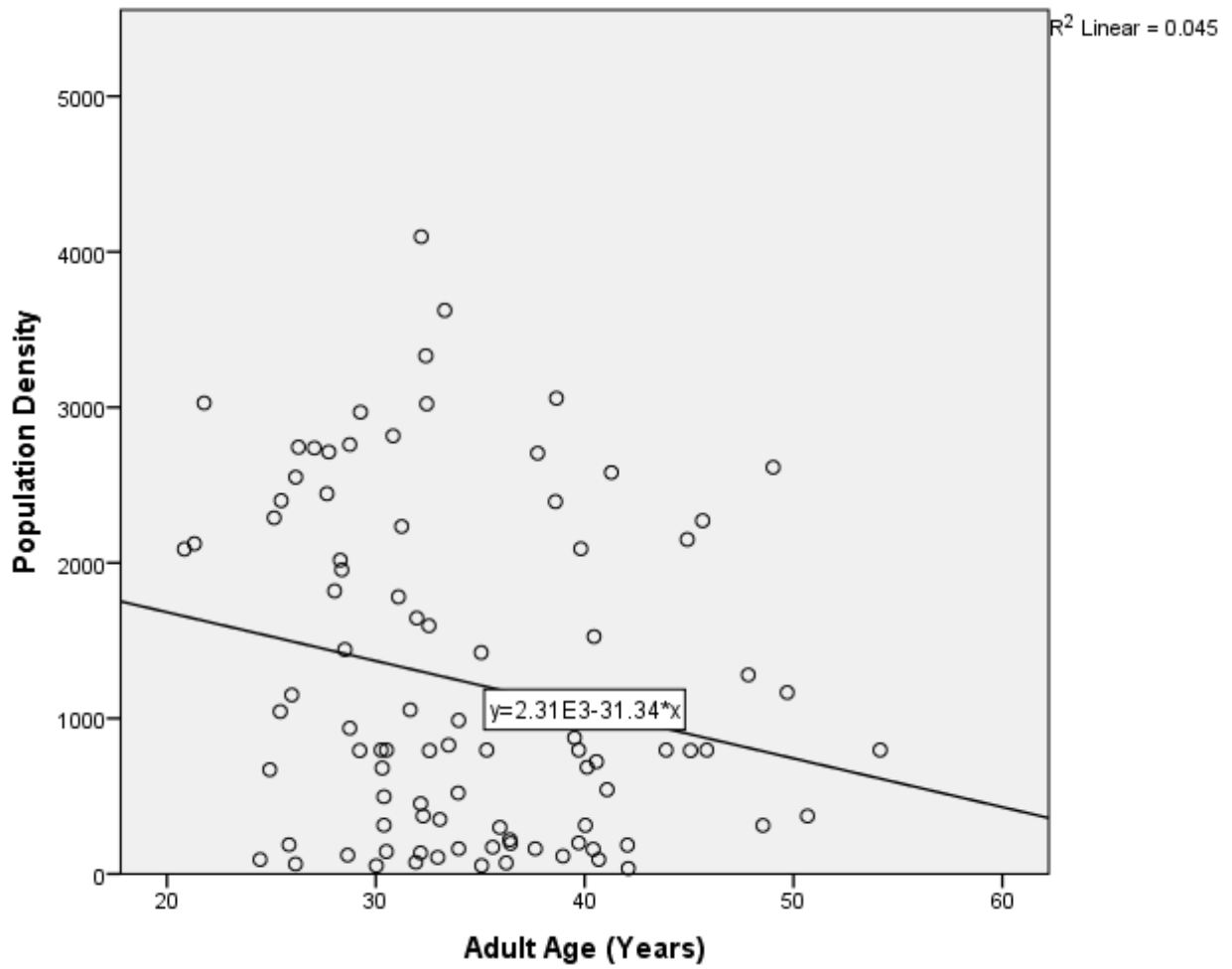


FIGURE 5, Graph of Correlation between Population Density and Mother's Highest Level of Education

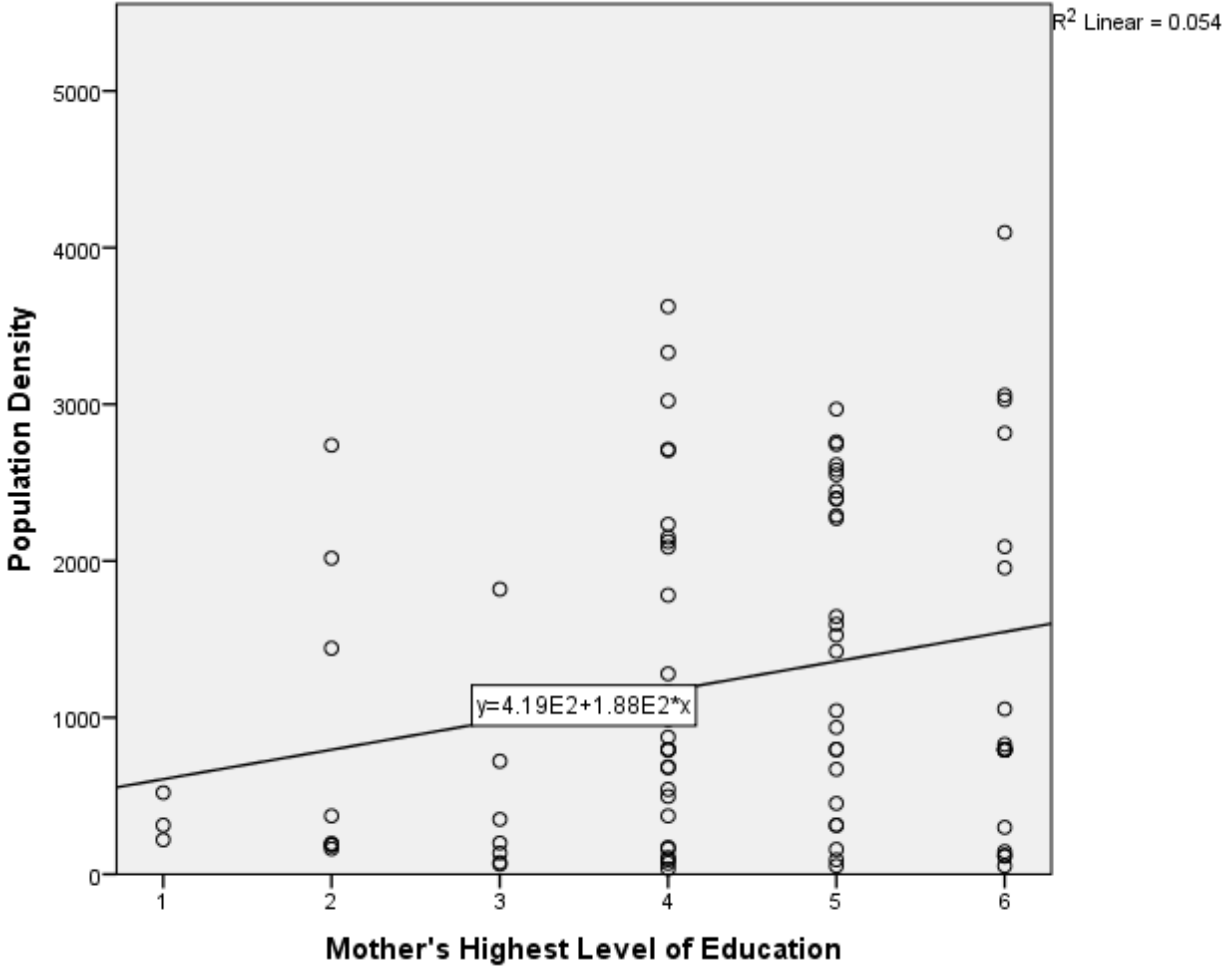


FIGURE 6, Graph of Number of Services Received

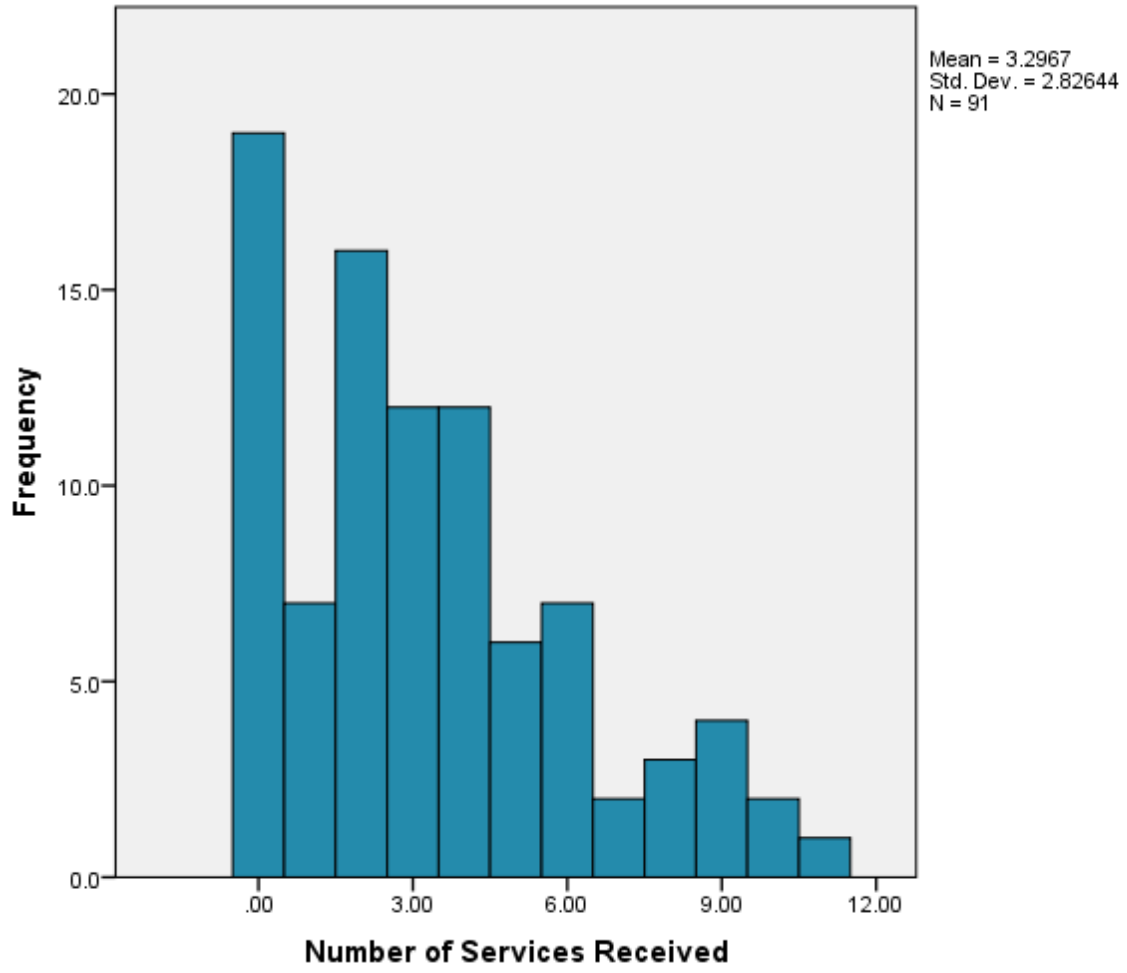


FIGURE 7, Graph of Correlation of Population Density and Number of Services Received by IQ score (All Participants)

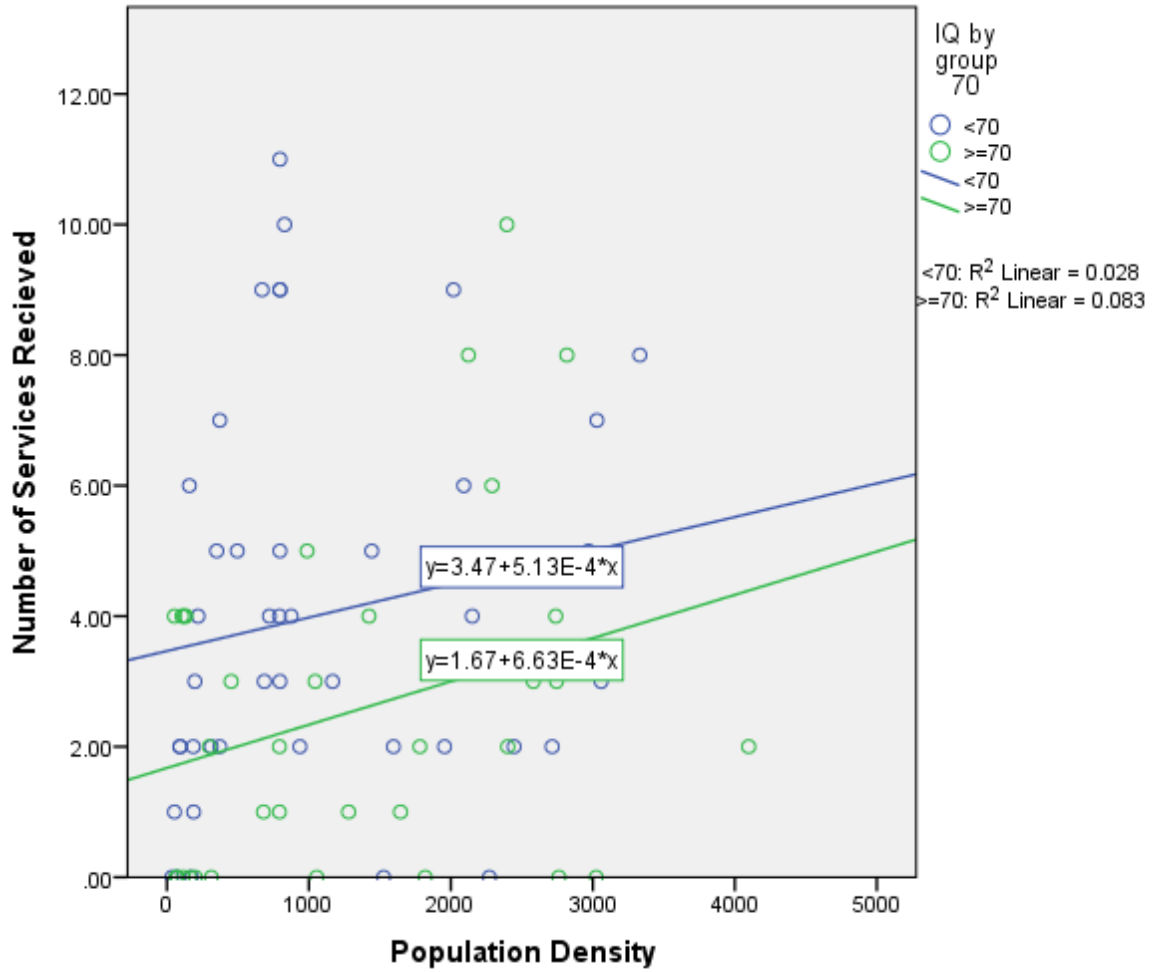
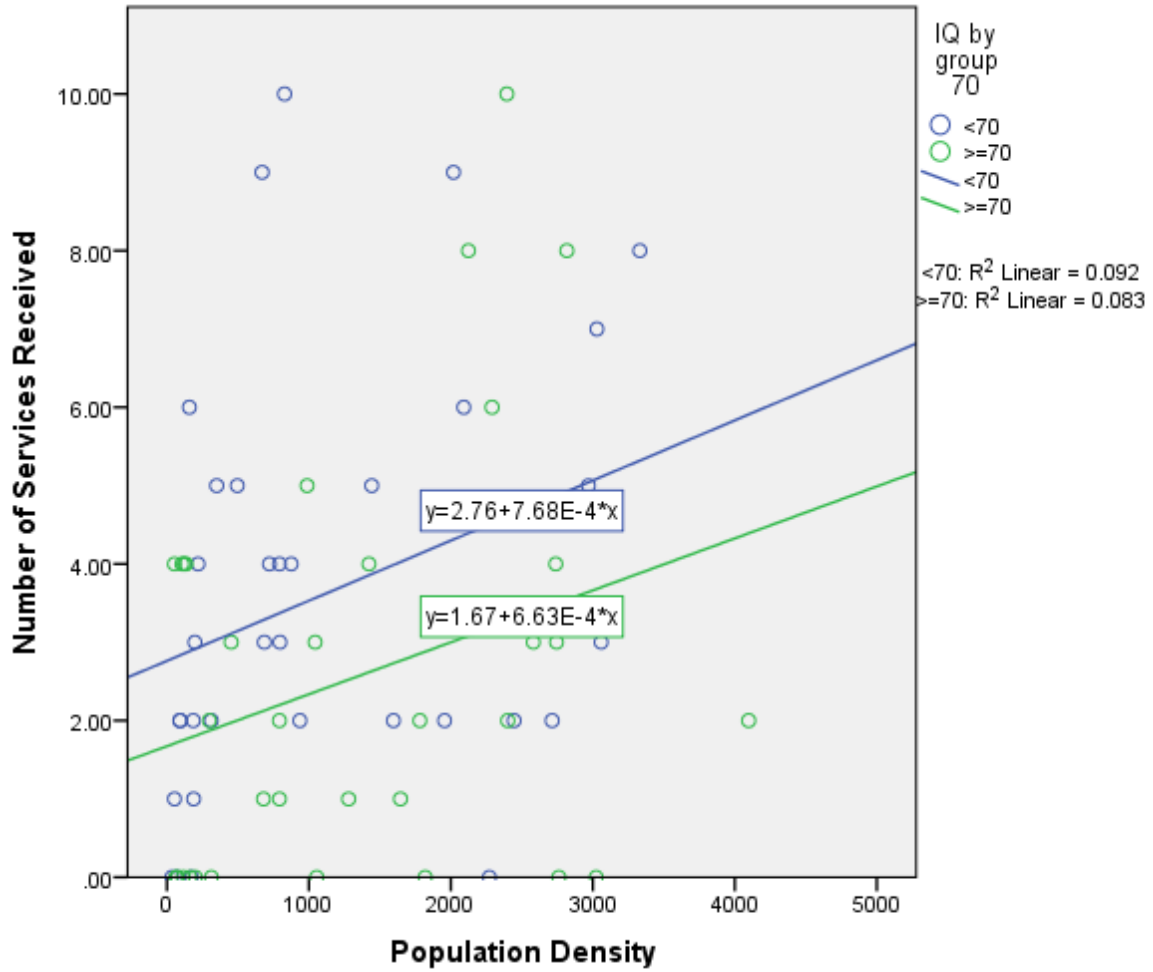


FIGURE 8, Graph of Correlation of Population Density and Number of Services Received by IQ score (Participants Living a with Family Member or a Guardian)



TABLES

TABLE 1, Types of Services Utilizing in the Past Two Years

Type of Service	Frequency
Medical Services for diagnosis or evaluation	43.3%
Transportation assistance	33%
Social work services	31.9%
Psychological or Mental Health services or counseling	30.8%
Instruction or help with independent living skills	29.7%
Job Coaching	28.6%
Help in finding a job, training in job skills, or vocational education	27.5%
Respite Care	26.4%

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