

University of Arkansas, Fayetteville

ScholarWorks@UARK

Psychological Science Undergraduate Honors
Theses

Psychological Science

12-2022

Assessing Treatment Access, Medication Use, Caregiver Strain and Emergency Service Use in Families of Youth with Autism

Emmaline Thorpe

Follow this and additional works at: <https://scholarworks.uark.edu/psycuht>



Part of the [Health Psychology Commons](#), [Medicine and Health Commons](#), and the [Other Psychology Commons](#)

Citation

Thorpe, E. (2022). Assessing Treatment Access, Medication Use, Caregiver Strain and Emergency Service Use in Families of Youth with Autism. *Psychological Science Undergraduate Honors Theses* Retrieved from <https://scholarworks.uark.edu/psycuht/32>

This Thesis is brought to you for free and open access by the Psychological Science at ScholarWorks@UARK. It has been accepted for inclusion in Psychological Science Undergraduate Honors Theses by an authorized administrator of ScholarWorks@UARK. For more information, please contact scholar@uark.edu.

**Assessing Treatment Access, Medication Use, Caregiver Strain and Emergency Service Use
in Families of Youth with Autism**

Honors Thesis submitted in partial fulfillment of the requirements of Honors Studies in
Psychological Science

By Emmaline Thorpe

Fall 2022

Psychological Science

J. William Fulbright College of Arts and Sciences

The University of Arkansas

Acknowledgements

I would like to express my deepest gratitude to Dr. Lauren Quetsch, director of the Family and Community Intervention (FCI) Laboratory at the University of Arkansas, who has been my most incredible mentor these past two years. Her guidance and direction in all my endeavors have given me the confidence to explore my research interest and allowed me to produce this thesis.

This endeavor would not have been possible without the support and generosity of Rebecca Bradley, a graduate student in the FCI lab. She has guided me every step of the way on this journey and deserves immense recognition for her involvement.

Next, I would like to thank Harlee Onovbiona and Emily-Anne Del Rosario, two other graduate students in the FCI lab. The support and opportunities they have provided me do not go unnoticed.

Lastly, I would like to thank Dr. Lindsay Ham and Dr. Michele Kilmer, who have generously agreed to serve on my honors thesis committee, and Dr. Daniela D'Eugenio, my honors council representative. Their time and dedication to my research interest hold my most profound appreciation.

Table of Contents

Abstract	4
Introduction	5
Method	10
Participants	11
Measures	11
Analysis Plan	13
Results	15
Discussion	16
Referances	24
Tables and Figures	33

Abstract

Background: Families with autistic youth utilize emergency services (e.g., police, emergency department) at greater rates than neurotypical peers. While research has recently explored this phenomenon, unknowns remain in how pharmaceutical, therapeutic, family (e.g., caregiver strain), and child factors (concurrent challenging behaviors) may influence the likelihood of this population resorting to emergency care. **Method:** The current study recruited caregivers ($N = 55$) of youth with autism and co-occurring challenging behaviors (ages 2 – 22) to complete an online survey regarding their use of emergency services, child medication and therapy, and caregiver strain. Caregivers were compensated for their time. **Results:** Outcomes revealed no significant relations between medication and emergency service use. Most caregivers reported pursuing treatment for disruptive behaviors and that those services (e.g., therapies, school services) were accessible and affordable in their community; however, no significant relation to emergency service use was found. Lastly, no association was found between caregiver strain and endorsement of emergency service use. **Conclusions:** Emergency services are by definition public organizations that respond to and deal with emergencies. Further work should be done to understand why families of autistic youth experience higher rates of interpreted emergencies. Furthermore, future studies may benefit from qualitative explorations of family challenges and supports.

Assessing Treatment Access, Intervention Use, and Emergency Services in Families of Youth with Autism

Autism spectrum disorder is a neurodevelopmental condition characterized by atypical social communication and restricted and/or repetitive interests and behaviors (APA, 2022). The current prevalence rate of autism is about 1 in 44 children, and research over the past decade has suggested a considerable increase in diagnoses each year (CDC, 2020). Youth with autism and their families will often utilize a wide range of medical and therapeutic services throughout their lifetimes (Farmer et al., 2014). For many, these services may include emergency interventions such as the emergency room and police services. In fact, an estimated 20% of youth with autism will interact with police by age 21 (Rava et al., 2017) and are four times more likely to visit the emergency room compared to neurotypical peers (Liu et al., 2017). The prevalence of children being diagnosed with autism makes studying treatment and service use, particularly acute services used in emergency situations, of great clinical importance.

Individuals with autism often experience co-occurring mental health conditions which likely contribute to the high rates of service use in this population (e.g., Tint et al., 2017). Research has found that 70% of children and adolescents with autism have a minimum of one comorbid psychological condition – with diagnoses of social anxiety, depression, and attention-deficit/hyperactivity disorder among the most reported (Simonoff, 2008). Furthermore, approximately 50% of youth with autism also experience challenging behavior such as aggression, self-injury, property damage, or other dangerous behaviors (Doubet et al., 2015; Matson & Nebel-Schwalm, 2007). Importantly, these rates are significantly higher than both typically developing peers and peers with intellectual disability without autism (Wiggins et al., 2015).

Given the complex symptoms and challenging behavior that may be present among children with autism, families of autistic youth often utilize medical and behavioral interventions. Pharmaceutical intervention is particularly prevalent in the U.S., with around 53% of children with autism (aged 6-17 years) taking at least one psychotropic medication at any given time (Witwer & Lecavalier, 2005). For children with comorbid conditions, prescription medication use is even higher. Coury and colleagues (2012), found that 80% of children with autism and an additional psychiatric condition (e.g., oppositional defiant disorder) were taking medication. These high rates of medication use come with important considerations. For example, Risperidone and Aripiprazole are two of the most common medications prescribed to youth with autism who have co-occurring challenging behavior. Despite holding approval from the Food and Drug Administration, neither medication targets the core symptoms of autism which may be driving the challenging behavior (e.g., sensory integration difficulties, inflexibility, emotion dysregulation), and families report high levels of adverse side effects (e.g., weight gain, heart problems, tardive dyskinesia; Houghton, 2017). However, past research has also indicated that families feel these medications are effective at managing some co-occurring symptoms (e.g., hyperactivity, inattention) and reducing challenging behaviors (Doyle & McDougle, 2012) In this case, it is possible that medication may serve a way to aid in situations where families already feel overwhelmed with challenging behavior but may not alleviate the need for emergency service use if behaviors are extreme (Hoge et al., 2022)

Outside of pharmacology, behavioral therapies are often recommended for youth with autism. Zablotsky and colleagues (2015) found that 62% of children with autism (aged 0-17 years) received some form of intervention for core autism features or comorbid issues, including applied behavior analysis (ABA) in addition to social skills, cognitive behavioral, speech and

language, occupational, and physical therapies. These treatments often include outpatient, school-based, and in-home interventions. Recent controversy has arisen due to child involvement in ABA and long-term psychological outcomes (e.g., post-traumatic stress disorder; Kupferstein, 2018). Yet, strong evidence exists for alternative evidence-based behavioral treatments in reducing behavioral crises and promoting long-term positive outcomes (Will et al., 2018). Utilizing treatment services may greatly reduce or eliminate crisis situations that may otherwise occur for families of autistic youth.

Despite high rates of pharmaceutical use and therapy involvement, a large portion of autistic youth still do not have access to evidenced-based care (Zhang & Cummings, 2020). Although strong efforts have been made to expand autism services across the U.S., accessibility to services is not always guaranteed. Indeed, a lack of trained providers, socioeconomic disparities in early diagnostic services, and lack of insurance coverage prevents many of these families from getting services (Bishop-Fitzpatrick & Kind, 2017; Haller et al., 2022; Zhang & Cummings, 2020). Furthermore, for those families lucky enough to be able to access care, approximately 30% of caregivers report that their child's developmental needs are still not being met by their current treatment and services (Zablotsky, 2015). While problematic, it is still promising that a majority of families do report significant gains in their child's progress (Zablotsky, 2015). Yet, one reason that services may not be adequately addressing the needs of autistic youth for about a third of families is that many providers feel inadequately trained in autism care but are expected to provide therapy regardless (Matson & Jang, 2014). Results of a study which surveyed therapists from community mental health clinics indicated that they perceived their work with autistic children as challenging and frustrating due to their limited training in autism symptomatology (Brookman-Frazer, 2012). It stands to reason that the lack of

accessible, quality autism services may limit treatment effectiveness for challenging behaviors and leave families to face continued child behavioral crises.

Importantly, when these crises occur, research has demonstrated that families of autistic youth frequently turn to emergency department (ED) services (Gurney et al., 2006; Liu et al., 2017). Indeed, children with autism are seen for psychiatric crises in the ED nine times more than children without autism (Croen et al., 2006; Kalb et al., 2012). Kalb and colleagues (2012) reported that severe problem behaviors (e.g., aggression, self-injury) were the primary reason for ED visits among children with autism thus leaving autistic youth with challenging behaviors more at risk for emergency utilization. This is further concerning given the lack of training for autistic youth needs by ED staff (Zwaigenbaum et al., 2016), placing youth at greater risk for behavioral escalation and psychiatric hospitalization compared to non-autistic peers (Kalb et al., 2012).

In addition to ED care, families may call police for assistance with behavioral episodes they feel unable to manage (Lamb et al., 2002). Specifically, by the age of 21 years, approximately 20% of youth with autism will interact with police, and an upward trend of police interaction will continue as autistic youth age (i.e., with autistic individuals having significantly more encounters with police in their lifetime than their neurotypical peers; Curry et al., 1993; Rava et al., 2017). In parallel with ED providers, police receive minimal to no formal training for interactions with autistic individuals (Gardner et al., 2019; Watson et al., 2019). Indeed, misunderstandings between autistic individuals and police, due to social communication challenges and lack of police accommodation, are not uncommon (e.g., Tomkins, 2020). Therefore, police involvement during behavioral crises may place an autistic child at risk for harsh treatment, unnecessary arrest, or even death (Tint et al., 2017; Tomkins, 2020).

Despite plentiful evidence that youth with autism utilize emergency intervention at increased rates, there is limited research exploring this population's use of emergency services in conjunction with pharmaceutical or therapeutic treatments. Previous research demonstrates a history of aggression towards others, having private insurance, a history of emergency department visits, and the prescription of two or more classes of psychotropic medications were the strongest predictors of emergency service use (Lui et al., 2019). However, the individual and family factors associated with emergency service use in the context of pharmaceutical and therapeutic interventions remain unclear. The current study seeks to explore the intersection of medication use, treatment access, and emergency service use in youth with autism. The current aims of this study are as follows:

1. Assess the relation between medication use and emergency service use for families of autistic youth.
 - a. Hypothesis 1: Families who utilize emergency services will have a higher rate of medication use for their autistic child than families who have not utilized emergency services.
2. Assess the relation between emergency service use for families of autistic youth and past disruptive behavior treatment use, as well as access and affordability of community-based services.
 - a. Hypothesis 2: Families who utilize emergency services will have lower rates of treatment service use for their child's challenging behaviors than families who have not utilized emergency services.

- b. Hypothesis 3: Families who utilize emergency services will have less access to community-based services for their child than families who have not utilized emergency services.
 - c. Hypothesis 4: Families who utilize emergency services will be less likely to be able to afford to community-based services than families who have not utilized emergency services.
3. Assess caregiver strain as it relates to emergency service use for families of autistic youth.
- a. Hypothesis 5: Families who utilize emergency services will have caregivers with higher levels of strain than families who have not utilized emergency services.
4. Explore current medication use for autistic youth in the sample.
- a. Hypothesis 6: Participants will report a range of medications used to treat comorbid psychological conditions.

Examining the relations among medication use, treatment access, caregiver strain, and emergency service use in youth with autism may allow further insight into the effectiveness of pharmaceutical intervention and therapeutic services as treatments. Assessing family-related risk factors (i.e., caregiver strain) allows us to better understand the clinical needs of families seeking emergency service use. Finally, understanding whether higher utility of therapy-based services is linked to less emergency service use may help spark further discussions about funding community-based treatments in underserved areas.

Method

The present study is a secondary analysis of a larger research project from the University of Arkansas's Family and Community Intervention Lab. The focus of that project was to determine individual, family, and environmental predictors of family emergency service utilization for children and adolescents with autism as well as satisfaction with emergency service encounters. The present study focused instead on specific variables (i.e., child medication, family treatment access, caregiver strain). The larger study received approval from the University's Institutional Review Board. Eligible participants were then recruited through autism clinics, online listservs, and research networks across the United States. Recruitment materials included a link to the online platform, REDCap, where participants first completed an online consent then filled out the study survey. Data collection took place from throughout 2022.

Participants

Participant eligibility included that the participant 1) was a legal guardian or caregiver (e.g., grandparent, stepparent, foster parent) of a youth with autism, 2) was at least 18 years of age, and 3) could read and write in English. Families were recruited regardless of emergency service utilization; however, if families endorsed emergency service use, it had to have occurred in the past 5 years. One caregiver per family completed the questionnaires. Although youth were not enrolled in the present study, caregivers could only complete the survey if their child met the following criteria: 1) the child was aged 22 years or younger, 2) the child was previously diagnosed with autism, and 3) that the child currently exhibited aggressive symptoms or other problem behaviors in the past month. If multiple children in the family were eligible to participate, caregivers were directed to complete the survey for only one child.

Measures

Demographics

Participating caregivers were asked to report demographic information about themselves and their family including their age, gender, relationship to the child, household income, and how many caregivers live in the home. Also, caregivers reported on their child's age, race/ethnicity, gender, and place of residence (in the family home vs. outside of the family home).

Medical History

Caregivers completed a 24-item questionnaire about their child's and the family's medical and psychiatric co-occurring conditions, including the child's current medications. Questions gave caregivers the option to indicate if their if their child has been diagnosed with a particular medical, developmental, or psychological conditions (e.g., ADHD/ADD, developmental delay, intellectual disability). Caregivers could choose to leave the checkbox blank if the condition did not apply to their child, or indicate "No formal diagnosis, but there is a concern." Caregivers were asked whether their child current takes any medication (*yes* or *no*). If caregivers selected "yes," they were prompted to write in their child's prescription and dosage.

Emergency Service Use

Caregivers were asked whether their child has interacted with police or other emergency services (e.g., emergency medical technicians, first-responders, emergency department) in the context of a behavior episode in the past five years (*yes* or *no*). If caregivers endorsed emergency service use, they were asked how many times their child has interacted with emergency services, and they were prompted to select what or which year/s their family used these services (2017 – 2022). Caregivers were also prompted to select the options that best described their encounters (i.e., "I have had to call the police or 911 due to my child's behavior," "Another caregiver or

adult has had to call the police or 911 due to my child's behavior," or "My child has encountered police or other emergency services due to behavior in a different way than what is listed above").

Service Use, Accessibility, and Affordability

Caregivers were asked, "Has your child ever received treatment for challenges or disruptive behaviors?" (*yes* or *no*). Respondents were also asked about the accessibility of services in their community: "Are services present and accessible in your community (i.e., are there programs for your child available and within a reasonable distance)?" (*yes* or *no*). Finally, participants were asked if they could afford these community-based services (*yes* or *no*).

Caregiver Strain

Caregiver strain was assessed using the Caregiver Strain Questionnaire (CGSQ; Brannan et al., 1997). The CGSQ is a 21-item measure that captures mental health, quality of life, maladaptive coping, social support, family functioning, and child functional impairment. Participants were asked to rate items on a 5-point Likert scale to reflect how much their family had been struggling with that problem over the past 6 months (1 = *Not at all*, 5 = *Very much*). Items included questions such as "Disruption of your family's social activities resulting from your child's emotional or behavioral problem?" A higher score indicates greater levels of caregiver strain while a lower score indicated lower levels of caregiver strain.

Planned Analyses

Hypothesis 1: Given the previous discussion of pharmaceutical intervention as a risk factor for increased emergency service use among youth with autism, it is predicted that families utilizing emergency services (group 1) will have a higher prevalence of medication use than families not utilizing emergency services (group 2). A chi-square analysis was used to determine if there was a significant difference between the groups for medication use.

Hypothesis 2: Given that autistic youth are more likely to be in contact with emergency services and that challenging behaviors may increase this likelihood (Kalb et al., 2012), it is predicted that families using emergency services (group 1) will have children who have not had treatment for child challenging behaviors as compared to families not utilizing emergency services (group 2). A chi-square analysis will be used to determine this hypothesis.

Hypothesis 3: Considering previous research indicating access to services and care in the community may be protective against emergency interactions (Tint et al., 2017), it is predicted that families using emergency services (group 1) will have less accessibility of treatment options than families not utilizing emergency services (group 2). A chi-square analyses was used to assess this hypothesis.

Hypothesis 4: If services for child challenging behaviors are not affordable for families of autistic youth, it is predicted that families who utilize emergency services (group 1) will be less likely to be able to afford treatment for child challenging behaviors than families who have not utilized emergency services (group 2). A chi-square analysis was run to determine this hypothesis.

Hypothesis 5: Given that caregivers feeling overwhelmed may be indicative of needing emergency care, it is predicted that families using emergency services (group 1) will have higher reported caregiver strain than families not using emergency services (group 2). A one-way ANOVA was used to determine this relation.

Hypothesis 6: Caregivers were asked to report the medication use of their child. Medications were sorted by classification, prescription-only status, and if the main use was for the treatment of disruptive behaviors or other psychological concerns (e.g., anxiety, depression, emotional dysregulation).

Results

Demographic Information

A total of 55 caregivers of youth with autism (ages 2 – 22 years; $M = 10.89$) consented and completed the online survey (see Table 1). Caregivers ranged in age from 23 to 65 years ($M = 40.21$), and most were married ($N = 42$; 76.4%). Participating caregivers were largely mothers ($N = 43$; 78.2%) with a household income ranging from below \$20,999 to over \$161,000. Many children were male ($N = 39$; 70.1%), white ($N = 35$; 63.6%), and non-Hispanic/Latinx ($N = 48$; 87.3%). A majority of caregivers reported that they had pursued treatment for disruptive behaviors ($N = 36$; 69.2%). Approximately half of participants reported that their child was currently taking a medication ($N = 23$; 48.9%).

Medication Use

The chi-square analysis revealed no significant relation between emergency service use and medication use, $X^2 = 0.22$, $p = .64$ (Fig. 1). Therefore, families utilized emergency services at similar rates regardless of medication status.

Challenging Behavior

The chi-square analysis indicated that there was no significant relation between child history of challenging behavior treatment and recent emergency service use, $X^2 = 0.004$, $p = .95$ (Fig. 2). Therefore, families utilized emergency services at similar rates regardless of treatment use.

Treatment Access and Affordability

Most caregivers reported the services (e.g., therapies, school services) were present and accessible in their community ($N = 39$; 71%) while others reported services were inaccessible ($N = 14$; 25%), with some missing data ($N = 2$). Most caregivers also reported that they could afford

these services ($N = 36$; 65%). Of this sample, accessibility was not significantly related to emergency service use, $X^2 = 0.002, p = .96$ (Fig. 3). Affordability was also not significantly related to emergency service use, $X^2 = 0.95, p = .33$ (Fig. 4).

Child and Family-Related Factors

A one-way ANOVA was conducted to explore the relation between recent emergency service use and caregiver strain (Fig. 5). Results of the ANOVA revealed that there was no significant difference in caregiver strain in families who endorsed emergency service use and those who did not, $F(1, 52) = 1.75, p = .19$.

Medication Exploration

When asked if their child took one or more medications, 48.9% of caregivers reported *yes* ($N = 23$). Of these participants, 82.6% reported what medications their child is taking and that they believe at least one medication to be effective ($N = 19$). In terms of medication classification, 35% of caregivers reported that their child was taking an anticonvulsant (e.g., Lamictal; $N = 7$), 40% reported their child taking a selective serotonin reuptake inhibitor (e.g., Fluoxetine, Prozac) or other antidepressant ($N = 8$), 30% reported having their child take a central nervous system stimulant (e.g., Adderall, Concerta; $N = 6$), 25% reported their child taking a cognition-enhancing medication (e.g., Guanfacine, Strattera; $N = 5$), 15% reported their child taking an antipsychotic ($N = 3$), and 10% report taking a sedative/antihypertensive drug ($N = 2$; see Table 2).

Discussion

The goal of the current study was to explore the relations between medication use, treatment access, caregiver strain, and emergency service use in youth with autism. The study's results found no significant association between medication use and recent emergency service

use. Additionally, there was no significant association between a history of disruptive behavior treatment and recent emergency service use. The relationship between service accessibility and affordability also did not appear to be significant. Further, results revealed no significant difference in caregiver strain among families who did and did not endorse recent emergency service use. Though the emergency services group has a slightly higher average score on the CGSQ, and this may be trending towards mean-level differences (Fig. 5), the current data does not support a significant difference between the two groups. Lastly, approximately half of the participants reported that their child is taking medication, a portion of which is psychotropic medication, commonly used with autistic youth.

Contrary to our hypotheses, the results of this study did not support significant associations between emergency service, treatment access, and family variables. Though research in this field is limited, these findings also contrast recent literature. For example, previous research has shown that taking medication is associated with a greater amount of emergency service use in youth with autism (Lunsky et al., 2017). More specifically, taking two or more psychotropic medications (e.g., antidepressants) has also been shown to predict emergency service use in this population (Lunsky et al., 2017). Notably, there are no official pharmaceutical treatments for autism, yet an estimated 65% of autistic youth take psychotropic medication (Spencer et al., 2013). Consistent with our findings, antipsychotics, medications targeting attention-deficit/hyperactivity disorder, and antidepressants are among the most commonly prescribed in the autistic population (Jobski et al., 2017). It should be noted that these medications are often used to treat psychiatric comorbidities associated with autism, not autism itself. Importantly, these comorbidities frequently include challenging and disruptive behaviors (Matson et al., 2008).

Since our study is the first to explore a sample of youth who all endorse challenging behavior, it is possible that medication is not a predictor of emergency service use in this acute sample. Nevertheless, higher ED utilization has been observed in those with autism who also present with a comorbidity (Benevides, 2020). This may account for the fact that 13% of all emergency department visits were related to psychiatric issues in youth with autism, compared to 2% of all visits by youth without autism (Kalb et al., 2012). Even after adjusting for comorbidities, youth with autism are hospitalized at a higher rate than neurotypical children (Dizitzer et al., 2020). Higher rates of emergency service use, coupled with the prevalence of comorbid challenging behavior, suggest the need for further research on treatment options that may include medication to meet the unique needs of youth with autism. Increasing our understanding of how these comorbidities are treated with medication and how they may present in the emergency room setting lays the groundwork for improving the pharmaceutical treatment of youth with autism.

Additionally, our results did not support a link between a history of treatment for challenging behaviors (e.g., ABA, occupational therapy) or service accessibility/affordability and emergency service use. As aforementioned, all families in this sample endorsed current challenging behavior; therefore, it is unsurprising that most caregivers endorsed pursuing treatment for challenging and disruptive behaviors ($N = 39$). Research has found that the presence of disruptive and physically aggressive behaviors in youth with autism increased the likelihood of hospitalization fivefold (Mandell, 2005). Further, a history of aggression has been shown to differentiate those who did and did not interact with police in previous research (Tint et al., 2017). Indeed, the proportion of youth in our study who endorsed recent emergency use was higher than most other currently reported base rates. We found 43% ($N = 23$) of our participants

had recent emergency service use, compared to 16 – 20% our youth reported in other studies (Rava et al., 2017; Tint et al., 2017). Given that families in our sample were all struggling with current disruptive behavior, this level of acute need may be responsible for the high rates of emergency service use we found.

Exploring the potential link between disruptive behavior treatment and subsequent emergency service use was important in the present study as past research has found service affordability to be linked to emergency service use, with significantly more families who are unable to afford services in their community endorsing police contact (e.g., Tint et al., 2017). Previous research also suggests that lack of access to community services is a risk factor for higher ED use (Zhang et al., 2017). Adequate family involvement in outpatient, school service, and in-patient interventions can lead to positive long-term outcomes for youth with autism (Zhang & Cummings, 2020). Additionally, research in the general population indicates youth involvement in community services is linked to decreased involvement with police/emergency services (Greenberg & Lippold, 2013; Thomas & Penn, 2002). Indeed, the relatively high rates of treatment use in our sample ($N = 24$) may be reflective of the majority of participants endorsing that services in their community are accessible ($N = 39$) and affordable ($N = 36$). For many American families though, a significant shortage of providers trained to provide evidence-based intervention to youth with autism is a substantial barrier to care (Zhang & Cummings, 2020). For families struggling with complex psychiatric and behavioral challenges who do not have access to services for their child, emergency services may be their only option. Indeed, individuals in the general population who do not have a uniform source of medical providers tend to default to the emergency department as their source of primary care (Baker et al., 1994), a statistic exacerbated in the autistic population (Deavenport-Saman et al., 2016).

Another finding of our current study was a lack of association between caregiver strain and endorsement of emergency service use. However, participants in the group that had used emergency services had slightly higher scores, on average, on a measure of caregiver strain (Fig. 5). One possible explanation for this is the presence of other unexplored factors that could have contributed to family emergency service use. For example, it is known that parents of children with autism and intellectual disabilities report higher levels of caregiver strain (Kirby et al., 2015), and these high levels of strain have been associated with lower well-being and perceived caregiver ability (Burke & Heller, 2016). Importantly, there is a high rate of comorbidity of autism and intellectual disabilities (Simonoff et al., 2008) meaning this factor, although not explored, may have also been an important variable to consider in combination with family emergency service utilization and caregiver strain.

An additional factor that may have differentially affected utilization of emergency services is the family's organization and problem-solving abilities to be able to utilize resources. For example, a lack of ability to maintain routines has been associated with higher parental stress and lower emotional well-being of children with autism (Alhuzimi, 2021). As such, previous research has identified both family distress and a lack of structured daytime activities as predictors for emergency service use (Lunsky et al., 2015; Tint et al., 2017). Further, higher caregiver strain has been associated with lower employment engagement (e.g., hours worked per week, days missed due to child's challenges) of these caregivers (Brannan et al., 2018). This may result in caregivers not qualifying for insurance benefits indicative of full-time employment to cover proper care for their child. Mothers of children with autism are also 6% more likely to be unemployed and earn 56% less than mothers of children with no health limitations (Cidav et al., 2012). This is significant, as families of children with autism experience higher economic

burdens than those without. Further, youth with autism whose caregivers have higher rates of caregiver strain and financial difficulty are more likely to have increased police involvement at baseline (Tint et al., 2017). These factors may result in caregivers' poor ability to manage their financial obligations, child caregiving needs, and personal lives, leading to higher caregiver strain. As a result, families may find themselves without access to a primary care provider and turn to emergency services when faced with a crisis. It is possible that the combination of these factors is more indicative of emergency service utilization than when the factors are explored independently.

The present study, though novel, has a number of limitations. The first being a small sample size. This investigation serves as a pilot for exploring child-, family-, and community-level factors that may be linked to emergency service use, and thus consisted of only 55 participants; therefore, it is possible that it was underpowered and could not detect a significant effect. As the ANOVA appeared to be approaching a mean-level difference, it is possible that given a larger sample size, outcomes may have yielded significant results. Due to the low power of the sample and the pilot nature of the grant, more complex analyses could not be run to determine the combined effect these variables may have played in family utilization of emergency care. It is also likely that other factors unexplored in the current study are at play in emergency service utilization (e.g., child with comorbid intellectual disability). Another limitation in the present study was that caregivers were asked about the child's *current* medication use but emergency service utilization could have happened *anytime* over the past 5 years. It is possible that medication use today differed at the time of an emergency service interaction in prior years and may not reflect concerns or challenging behaviors at that time.

Considering the study's limitations, it also had strengths. This is the first study to explore emergency service use in a sample of families who were recruited based on the endorsement of autistic youths' challenging behavior. As aggression is a notable predictor of emergency service involvement (Lunsky et al., 2015), our goal was to investigate the potential factors that differentiate families of autistic youth with challenging behavior who do and do not utilize emergency services. Further, while it is plausible that the results of this study are unique to this subset of the autistic population, future research efforts should consider comparing these results to a general autistic sample and a neurotypical sample. Research has suggested caregiver strain should also be evaluated in the context of multiple individual, family, and community factors (Brannan et al., 1997) which will be done at the completion of the larger study.

Future research should continue investigating the specific relations between the autistic population and emergency service use. While we know that associations exist between medication use, treatment access, and emergency services in prior research, it is not clear whether this applies to high-needs families (e.g., experiencing challenging behavior). From an individual and systems perspective, it remains important to identify factors that may help reduce non-essential emergency service utilization. One promising direction is that research indicates early identification of autism leads to reduced symptoms later in life and a massive reduction in healthcare costs (Jacobson et al., 1998). Beyond improving and increasing access to early diagnostic services, improving autism-specific training for providers in primary care and community-based settings may reduce the need for specialists and therefore reduce healthcare costs and allow for more accessible, evidence-based intervention (Siddiqua et al., 2022). Future research may also want to help train police and emergency service staff who may otherwise heighten the situation and increase the risk of harm for individuals with autism. Lastly, reduction

of strain and development of caregiver coping strategies may help reduce caregiver burden and, in turn, emergency service use (Osborne & Reed, 2010).

In conclusion, our study found no significant associations between emergency service use and the factors examined. While our figures are inconsistent with previous research done in this area, this phenomenon may be due to the subset of the autistic population we investigated. Therefore, it is important to investigate further factors that may contribute to reducing non-essential emergency service use, like increased access to care and reduced caregiver strain.

References

- Alhuzimi T. (2021). Stress and emotional wellbeing of parents due to change in routine for children with autism spectrum disorder (ASD) at home during COVID-19 pandemic in Saudi Arabia. *Research in Developmental Disabilities, 108*, 103822. <https://doi.org/10.1016/j.ridd.2020.103822>
- Baker, D. W., Stevens, C. D., & Brook, R. H. (1994). Regular source of ambulatory care and medical care utilization by patients presenting to a public hospital emergency department. *Journal of the American Medical Association, 271*(24), 1909–1912. <https://doi.org/10.1001/jama.1994.03510480033030>
- Benevides, T. W., Shore, S. M., Andresen, M.-L., Caplan, R., Cook, B., Gassner, D. L., Erves, J. M., Hazlewood, T. M., King, M. C., Morgan, L., Murphy, L. E., Purkis, Y., Rankowski, B., Rutledge, S. M., Welch, S. P., & Wittig, K. (2020). Interventions to address health outcomes among autistic adults: A systematic review. *Autism, 24*(6), 1345–1359. <https://doi.org/10.1177/1362361320913664>
- Bishop-Fitzpatrick, L., & Kind, A. J. H. (2017). A scoping review of health disparities in autism spectrum disorder. *Journal of Autism and Developmental Disorders, 47*(11), 3380–3391. <https://doi.org/10.1007/s10803-017-3251-9>
- Brannan, A. M., Brennan, E. M., Sellmaier, C., & Rosenzweig, J. M. (2018). Employed parents of children receiving mental health services: Caregiver strain and work–life integration. *Families in Society, 99*(1), 29–44. <https://doi.org/10.1177/1044389418756375>
- Brannan, A. M., Heflinger, C. A., & Bickman, L. (1997). The caregiver strain questionnaire: Measuring the impact on the family of living with a child with serious emotional

- disturbance. *Journal of Emotional and Behavioral Disorders*, 5(4), 212–222.
<https://doi.org/10.1177/106342669700500404>
- Brookman-Frazee, L.I., Drahota, A. & Stadnick, N. (2012). Training community mental health therapists to deliver a package of evidence-based practice strategies for school-age children with autism spectrum disorders: A pilot study. *Journal of Autism and Developmental Disorders*, 42, 1651–1661. <https://doi.org/10.1007/s10803-011-1406-7>
- Burke, M., & Heller, T. (2016). Individual, parent and social-environmental correlates of caregiving experiences among parents of adults with autism spectrum disorder. *Journal of Intellectual Disability Research*, 60(5), 401–411. <https://doi.org/10.1111/jir.12271>
- Cidav, Z., Marcus, S. C., & Mandell, D. S. (2012). Implications of childhood autism for parental employment and earnings. *Pediatrics*, 129(4), 617–623.
<https://doi.org/10.1542/peds.2011-2700>
- Coury, D. L., Anagnostou, E., Manning-Courtney, P., Reynolds, A., Cole, L., McCoy, R., Whitaker, A., & Perrin, J. M. (2012). Use of psychotropic medication in children and adolescents with autism spectrum disorders. *Pediatrics*, 130 Suppl 2, S69–S76.
<https://doi.org/10.1542/peds.2012-0900D>
- Croen, L. A., Najjar, D. V., Ray, G. T., Lotspeich, L., & Bernal, P. (2006). A comparison of health care utilization and costs of children with and without autism spectrum disorders in a large group-model health plan. *Pediatrics*, 118(4), e1203-e1211.
<https://doi.org/10.1542/peds.2006-0127>
- Curry, K. L., Posluszny, M. P., & Kraska, S. L. (1993). Training criminal justice personnel to recognize offenders with disabilities. *OSERS News in Print*, 5(3), 4-8.

- Deavenport-Saman, A., Lu, Y., Smith, K., & Yin, L. (2016). Do children with autism overutilize the emergency department? Examining visit urgency and subsequent hospital admissions. *Maternal and Child Health Journal*, 20(2), 306–314. <https://doi.org/10.1007/s10995-015-1830-y>
- Dizitzer, Y., Meiri, G., Flusser, H., Michaelovski, A., Dinstein, I., & Menashe, I. (2020). Comorbidity and health services' usage in children with autism spectrum disorder: A nested case–control study. *Epidemiology and Psychiatric Sciences*, 29, E95. <https://doi.org/10.1097/pec.0b013e3182767d96>
- Doubet, S. L., & Ostrosky, M. M. (2015). The impact of challenging behavior on families: I don't know what to do. *Topics in Early Childhood Special Education*, 34(4), 223–233. <https://doi.org/10.1177/0271121414539019>
- Doyle, C. A., & McDougle, C. J. (2012). Pharmacologic treatments for the behavioral symptoms associated with autism spectrum disorders across the lifespan. *Dialogues in clinical neuroscience*, 14(3), 263–279. <https://doi.org/10.31887/DCNS.2012.14.3/cdoyle>
- Farmer, J. E., Clark, M. J., Mayfield, W. A., Cheak-Zamora, N., Marvin, A. R., Kiely Law, J., & Law, P. A. (2014). The relationship between the medical home and unmet needs for children with autism spectrum disorders. *Maternal and Child Health Journal*. 18, 672–680. <https://doi.org/10.1007/s10995-013-1292-z>
- Gardner, L., Campbell, J.M., & Westdal, J. (2019). Brief report: Descriptive analysis of law enforcement officers' experiences with and knowledge of autism. *Journal of Autism and Developmental Disorders*. 49, 1278–1283. <https://doi.org/10.1007/s10803-018-3794-4>

- Greenberg, M. T., & Lippold, M. A. (2013). Promoting healthy outcomes among youth with multiple risks: Innovative approaches. *Annual Review of Public Health, 34*, 253–270. <https://doi.org/10.1146/annurev-publhealth-031811-124619>
- Greenwood-Ericksen, M. B., & Kocher, K. (2019). Trends in emergency department use by rural and urban populations in the United States. *Journal of the American Medical Association Network Open, 2*(4), e191919. <https://doi.org/10.1001/jamanetworkopen.2019.1919>
- Gurney, J. G., McPheeters, M. L., & Davis, M. M. (2006). Parental report of health conditions and health care use among children with and without autism: National survey of children's health. *Archives of Pediatrics & Adolescent Medicine, 160*(8), 825-830. <https://doi.org/10.1001/archpedi.160.8.825>
- Haller, K., Stolfi, A., & Duby, J. (2022). Comparison of unmet health care needs in children with intellectual disability, autism spectrum disorder and both disorders combined. *Journal of Intellectual Disability Research, 66*(7), 617–627. <https://doi.org/10.1111/jir.12932>
- Hoge, M. A., Vanderploeg, J., Paris, M., Jr, Lang, J. M., & Olezeski, C. (2022). Emergency department use by children and youth with mental health conditions: A health equity agenda. *Community Mental Health Journal, 58*(7), 1225–1239. <https://doi.org/10.1007/s10597-022-00937-7>
- Houghton, R., Ong, R. C., & Bolognani, F. (2017). Psychiatric comorbidities and use of psychotropic medications in people with autism spectrum disorder in the United States. *Autism Research, 10*(12), 2037–2047. <https://doi.org/10.1002/aur.1848>
- Jacobson, J. W., Mulick, J. A. and Green, G. (1998), Cost–benefit estimates for early intensive behavioral intervention for young children with autism—general model and single state

- case. *Behavioral Interventions*, 13, 201-226. [https://doi.org/10.1002/\(SICI\)1099-078X\(199811\)13:4<201::AID-BIN17>3.0.CO;2-R](https://doi.org/10.1002/(SICI)1099-078X(199811)13:4<201::AID-BIN17>3.0.CO;2-R)
- Jobski, K., Höfer, J., Hoffmann, F., & Bachmann, C. (2017). Use of psychotropic drugs in patients with autism spectrum disorders: a systematic review. *Acta Psychiatrica Scandinavica*, 135(1), 8–28. <https://doi.org/10.1111/acps.12644>
- Kalb, L. G., Stuart, E. A., Freedman, B., Zablotsky, B., & Vasa, R. (2012). Psychiatric-related emergency department visits among children with an autism spectrum disorder. *Pediatric Emergency Care*, 28(12), 1269–1276. <https://doi.org/10.1097/PEC.0b013e3182767d96>
- Kirby, A. V., White, T. J., & Baranek, G. T. (2015). Caregiver strain and sensory features in children with autism spectrum disorder and other developmental disabilities. *American Journal on Intellectual and Developmental Disabilities*, 120(1), 32–45. <https://doi.org/10.1352/1944-7558-120.1.32>
- Kupferstein, H. (2018), "Evidence of increased PTSD symptoms in autistics exposed to applied behavior analysis." *Advances in Autism*, Vol. 4 No. 1, pp. 19-21. <https://doi.org/10.1108/AIA-08-2017-0016>
- Lamb, H. R., Weinberger, L. E., & DeCuir, W. J., Jr. (2002). The police and mental health. *Psychiatric Services*, 53(10), 1266–1271. <https://doi.org/10.1176/appi.ps.53.10.1266>
- Liu, G., Pearl, A. M., Kong, L., Leslie, D. L., & Murray, M. J. (2017). A profile on emergency department utilization in adolescents and young adults with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 47(2), 347–358. <https://doi.org/10.1007/s10803-016-2953-8>

- Lunsky, Y., Paquette-Smith, M., Weiss, J. A., & Lee, J. (2015). Predictors of emergency service use in adolescents and adults with autism spectrum disorder living with family. *Emergency Medicine Journal*, 32(10), 787–792. <https://doi.org/10.1136/emmermed-2014-204015>
- Lunsky, Y., Weiss, J. A., Paquette-Smith, M., Durbin, A., Tint, A., Palucka, A. M., & Bradley, E. (2017). Predictors of emergency department use by adolescents and adults with autism spectrum disorder: a prospective cohort study. *BMJ open*, 7(7), e017377. <http://dx.doi.org/10.1136/bmjopen-2017-017377>
- Mandell, D. S., Novak, M. M., & Zubritsky, C. D. (2005). Factors associated with age of diagnosis among children with autism spectrum disorders. *Pediatrics*, 116(6), 1480-1486. <https://doi.org/10.1542/peds.2005-0185>
- Matson, J. L., Wilkins, J., & Macken, J. (2008). The relationship of challenging behaviors to severity and symptoms of autism spectrum disorders. *Journal of Mental Health Research in Intellectual Disabilities*, 2(1), 29-44. <https://doi.org/10.1080/19315860802611415>
- Matson, J. L., & Jang, J. (2014). Treating aggression in persons with autism spectrum disorders: A review. *Research in Developmental Disabilities*, 35(12), 3386–3391. <https://doi.org/10.1016/j.ridd.2014.08.025>
- Matson, J. L., & Nebel-Schwalm, M. S. (2007). Comorbid psychopathology with autism spectrum disorder in children: An overview. *Research in Developmental Disabilities*, 28(4), 341-352. <https://doi.org/10.1016/j.ridd.2005.12.004>
- Osborne, L. A., & Reed, P. (2010). Stress and self-perceived parenting behaviors of parents of children with autistic spectrum conditions. *Research in Autism Spectrum Disorders*, 4(3), 405–414. <https://doi.org/10.1016/j.rasd.2009.10.011>

- Rava, J., Shattuck, P., Rast, J., & Roux, A. (2017). The prevalence and correlates of involvement in the criminal justice system among youth on the autism spectrum. *Journal of Autism and Developmental Disorders*, 47(2), 340–346. <https://doi.org/10.1007/s10803-016-2958-3>
- Siddiqua, A., Janus, M., Mesterman, R., Duku, E., Georgiades, K., Saxena, F., Zhao, H., & Saunders, N. (2022). Primary care provider and child characteristics associated with age of diagnosis of autism spectrum disorder: A population-based cohort study. *Journal of Autism and Developmental Disorders*, 52(7), 2896–2910. <https://doi.org/10.1007/s10803-021-05165-8>
- Simonoff, E., Pickles, A., Charman, T., Chandler, S., Loucas, T., & Baird, G. (2008). Psychiatric disorders in children with autism spectrum disorders: Prevalence, comorbidity, and associated factors in a population-derived sample. *Journal of the American Academy of Child and Adolescent Psychiatry*, 47(8), 921–929. <https://doi.org/10.1097/CHI.0b013e318179964f>
- Spencer, D., Marshall, J., Post, B., Kulakodlu, M., Newschaffer, C., Dennen, T., Azocar, F., & Jain, A. (2013). Psychotropic medication use and polypharmacy in children with autism spectrum disorders. *Pediatrics*, 132(5), 833–840. <https://doi.org/10.1542/peds.2012-3774>
- Thomas, C. R., & Penn, J. V. (2002). Juvenile justice mental health services. *Child and Adolescent Psychiatric Clinics of North America*, 11(4), 731–748. [https://doi.org/10.1016/s1056-4993\(02\)00024-x](https://doi.org/10.1016/s1056-4993(02)00024-x)
- Tint, A., Palucka, A. M., Bradley, E., Weiss, J. A., & Lunskey, Y. (2017). Correlates of police involvement among adolescents and adults with autism spectrum disorder. *Journal of*

- Autism and Developmental Disorders*, 47(9), 2639–2647. <https://doi.org/10.1007/s10803-017-3182-5>
- Tomkins, L. (2020, June 25). Here's what you need to know about Elijah McClain's death. *The New York Times*. <https://www.nytimes.com/article/who-was-elijah-mcclain.html>
- Watson, A. C., Compton, M. T., & Pope, L. G. (2019) *Crisis response services for people with mental illnesses or intellectual and developmental disabilities: A review of the literature on police-based and other first response models*. Vera Institute of Justice.
- Wiggins, L. D., Levy, S. E., Daniels, J., Schieve, L., Croen, L. A., DiGuseppi, C., Blaskey, L., Giarelli, E., Lee, L.-C., Pinto-Martin, J., Reynolds, A., Rice, C., Rosenberg, C. R., Thompson, P., Yeargin-Allsopp, M., Young, L., & Schendel, D. (2015). Autism spectrum disorder symptoms among children enrolled in the Study to Explore Early Development (SEED). *Journal of Autism and Developmental Disorders*, 45(10), 3183–3194. <https://doi.org/10.1007/s10803-015-2476-8>
- Will, M. N., Currans, K., Smith, J., Weber, S., Duncan, A., Burton, J., Kroeger-Geoppinger, K., Miller, V., Stone, M., Mays, L., Luebrecht, A., Heeman, A., Erickson, C., & Anixt, J. (2018). Evidenced-based interventions for children with autism spectrum disorder. *Current Problems in Pediatric and Adolescent Health Care*, 48(10), 234–249. <https://doi.org/10.1016/j.cppeds.2018.08.014>
- Zablotsky, B., Pringle, B. A., Colpe, L. J., Kogan, M. D., Rice, C., & Blumberg, S. J. (2015). Service and treatment use among children diagnosed with autism spectrum disorders. *Journal of Developmental and Behavioral Pediatrics*, 36(2), 98–105. <https://doi.org/10.1097/DBP.000000000000127>

Zhang, Y. X., & Cummings, J. R. (2020). Supply of certified applied behavior analysts in the United States: Implications for service delivery for children with autism. *Psychiatric Services, 71*(4), 385–388. <https://doi.org/10.1176/appi.ps.201900058>

Zhang, W., Mason, A.E., Boyd, B., Sikich, L., & Baranek, G. (2017). A rural–urban comparison in emergency department visits for U.S. children with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 47*, 590–598. <https://doi.org/10.1007/s10803-016-2982-3>

Zwaigenbaum, L., Nicholas, D. B., Muskat, B., Kilmer, C., Newton, A. S., Craig, W. R., Ratnapalan, S., Cohen-Silver, J., Greenblatt, A., Roberts, W., & Sharon, R. (2016). Perspectives of health care providers regarding emergency department care of children and youth with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 46*(5), 1725–1736. <https://doi.org/10.1007/s10803-016-2703-y>

TABLE 1*Demographic Characteristics*

	Mean	Range	Frequency	Percent
Child Age (years)	10.89	2 -22		
Child Gender			39	70.9
Male			15	27.1
Female			1	1.8
Nonbinary				
Child Race			1	1.8
Asian American/Pacific Islander			16	29.1
Black/African American			3	5.5
Native American/Alaskan Native			35	63.6
White				
Child Ethnicity			7	12.7
Hispanic/Latino			48	87.3
Not Hispanic/Latino				
Home Type			14	25.5
Urban			28	50.9
Suburban			13	23.6
Rural				
Participant Relationship to Child				
Mother			43	78.1
Father			8	14.5
Grandparent			2	3.6
Stepparent			1	1.8
Foster Parent			1	1.8
Parent Age	40.21	23 - 65		
Parent Marital Status				
Married/Partnership			42	76.4
Divorced			5	9.1
Widowed			2	3.6
Single			6	10.9
Household Income				
Less than \$20,999			4	
\$21,000 - \$35,999			3	
\$36,000 - \$50,999			12	
\$51,000 - \$65,999			9	
\$66,000 - \$80,999			10	
\$81,000 – \$100,999			3	

	\$101,000 - \$130,999	7	
	\$131,000 - \$160,999	2	
	Over \$161,000	4	
Families Who Have Pursued Treatment for Disruptive Behaviors			
	Yes	36	69.2
	No	16	30.8
Children Currently Taking Medication			
	Yes	23	48.9
	No	24	51.1

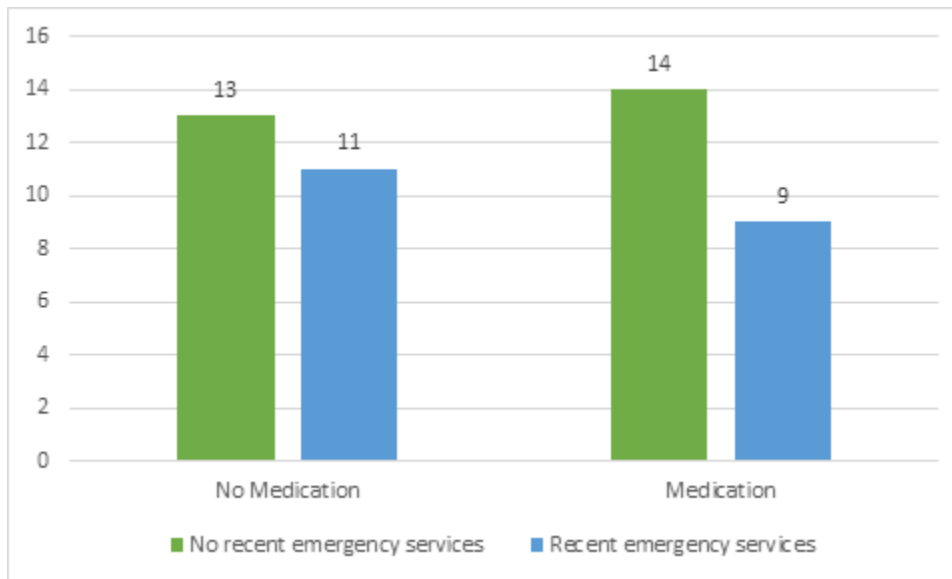
Notes. Total $N = 55$.

TABLE 2*Medication Data*

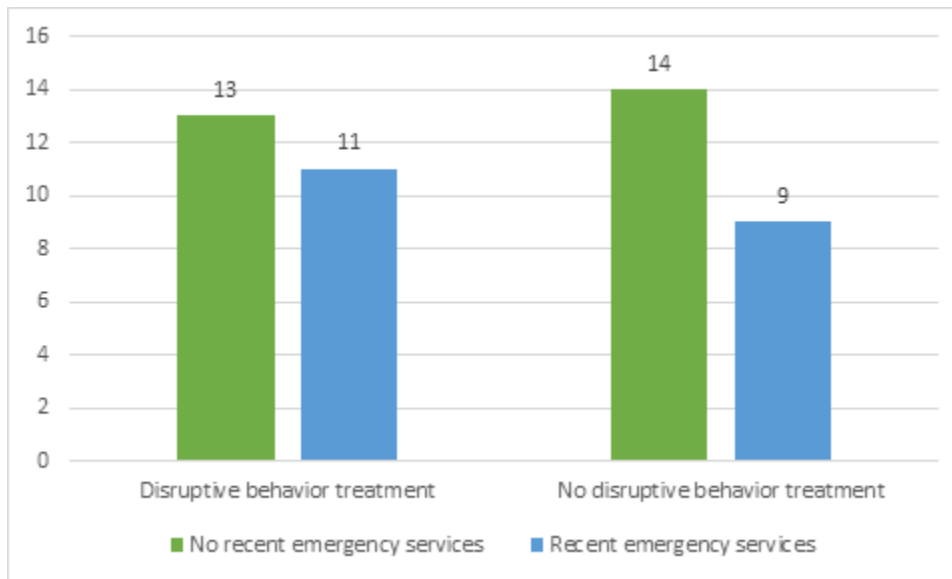
	Frequency	Percent
Child currently takes medication		
Yes	23	48.9
No	24	51.1
<i>Of children currently taking medication...</i>		
Caregiver Reports Medication is Effective		
Yes	20	86.9
No	*N/A	
<i>Of participants who reported what medications their child takes...</i>		
Number of Medications Child Takes		
1	7	35
2	5	25
3	2	10
4 or more	6	30
**Medication Classification		
SSRI/antidepressant	8	
Anticonvulsant	7	
CNS Stimulant	6	
Cognition-enhancing	5	
Antipsychotic	3	
Sedative/Antihypertensive	2	
Other	8	

Notes. Total N = 55. *Caregiver did not report. **Caregiver reported, yes.

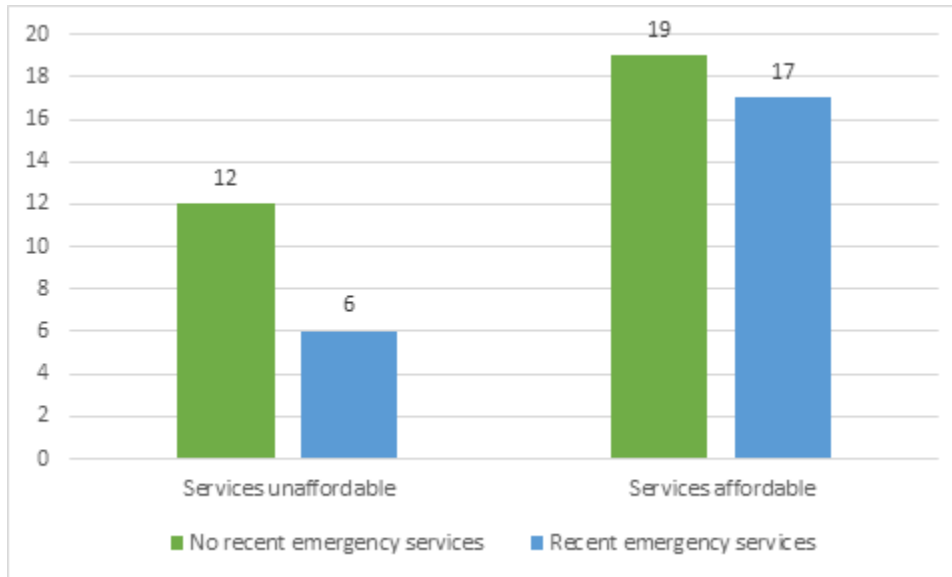
Figure 1

Medication and Emergency Service Use

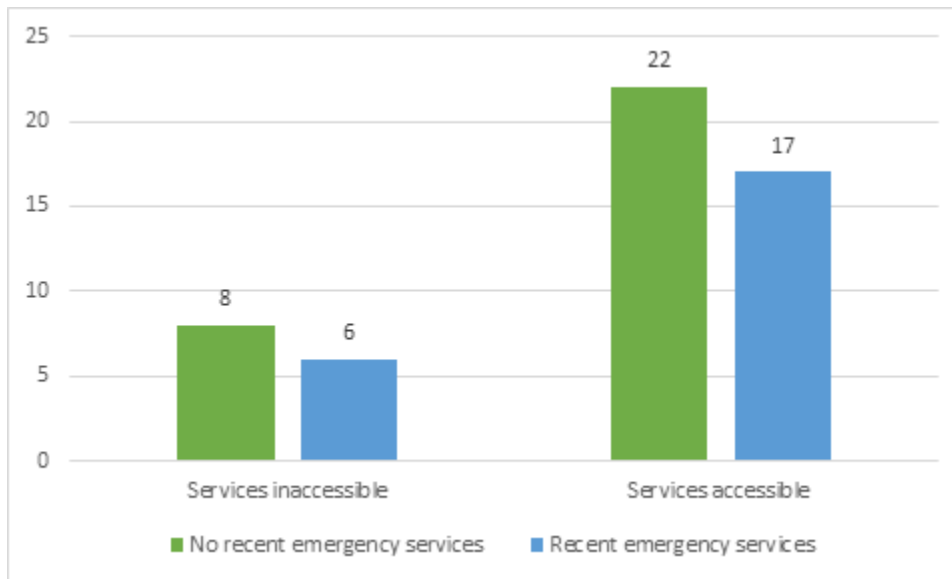
Notes. $X^2 = 0.22$, $p = .64$

Figure 2*Treatment and Emergency Service Use*

Notes. $X^2 = 0.004$, $p = .95$

Figure 3*Accessibility and Emergency Service Use*

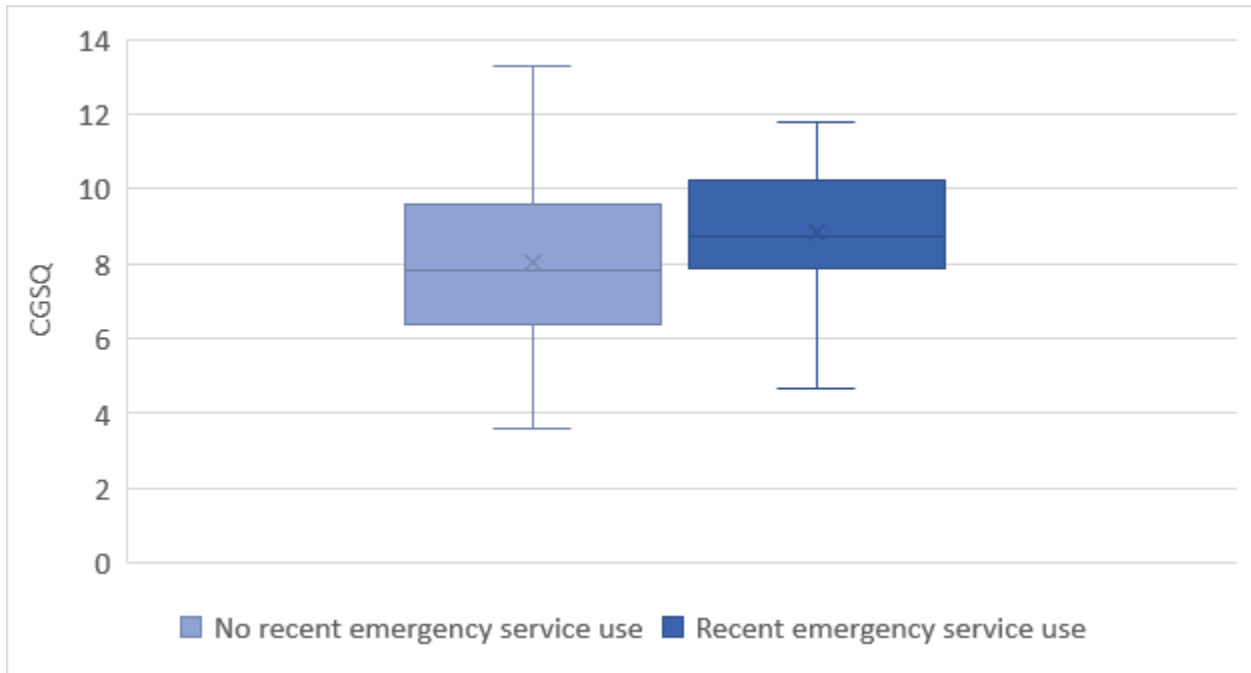
Notes. $X^2 = 0.002$, $p = .9$

Figure 4*Affordability and Emergency Service Use*

Notes. $X^2 = 0.95$, $p = .33$

Figure 5

Caregiver Strain and Emergency Service Use



Notes. $F(1, 52) = 1.75, p > .19$