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**PARENTS' EXPERIENCES NAVIGATING THE DIAGNOSTIC PROCESS FOR
CHILDREN WITH AUTISM SPECTRUM DISORDER**

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A thesis submitted to the University Honors Program
in partial fulfillment of the requirements for the
Honors certificate with Thesis

Approved by
Dr. Valerie Boyer
Program Director of Communication Disorders and Sciences

Southern Illinois University - Carbondale
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Biographical Note

Grace Lafo is a first-generation undergraduate student in the communication disorders and sciences and linguistics programs at Southern Illinois University Carbondale (SIUC), studying minors in psychology and American Sign Language. At SIUC, she received the Chancellor's Scholarship and is a member of the University Honors Program. She received a REACH Grant to support a student-led research project in an area of interest during her third year at SIUC. Lafo plans to attend graduate school to become a speech-language pathologist.

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Abstract

The diagnostic process for autism spectrum disorder (ASD) can pose many barriers for families, especially within rural communities where there is a lack of adequate diagnostic and therapy services available. Factors such as cultural stigma, medical professionals, financial constraints, and travel have previously been reported as barriers for pursuing a diagnosis within rural geographic regions. The current study was conducted to identify obstacles that parents face within rural southern Illinois while on the path to receive an accurate diagnosis of ASD for their child. This study also aimed to determine what resources were being provided to parents at the time of diagnosis and what supports assisted families throughout the diagnostic process.

Participants included eleven families of children with ASD residing in southern Illinois who had been diagnosed between 2013 and 2019, with one outlier diagnosed during the early 2000s. A qualitative research design was used with a semi-structured interview of eight open-ended questions regarding experiences with the diagnostic process. The interviews were analyzed using Qualitative Data Analysis Miner Lite to find common themes across parent responses. The current study's results were consistent with existing research, with experiences and perspectives varying significantly across families. The findings from this study will be used to improve the diagnostic process within southern Illinois by better informing service, teaching, and research at Southern Illinois University Carbondale's Center for Autism Spectrum Disorders (CASD).

Keywords: autism spectrum disorder, diagnostic process, rural, southern Illinois

Parent's Experiences Navigating the Diagnostic Process for Children with Autism Spectrum Disorder

Autism spectrum disorder (ASD) is a life-long neurodevelopmental disorder characterized by impaired communication, repetitive behaviors, and restricted interests—all of which affect daily functioning (American Psychological Association, n.d.). Skills, needs, and levels of functioning vary across individuals diagnosed with ASD. According to the CDC (2020), 1 in 54 children has been diagnosed with ASD and it is more than four times as common in boys than girls, but appears across all racial and ethnic groups and in every socioeconomic status level.

It is widely accepted that the earlier a child is screened and diagnosed with ASD, the better the outlook for their development (Antezana et al., 2017; Sacrey et al., 2020). Parents generally raise concerns about ASD for their child between 18 and 24 months of age and as of 2016, the median diagnosis of children was 4 years old (Martinez et al., 2018). According to Smith-Young et al. (2020), parents play a key role in obtaining services because their children are usually minors at diagnosis. Children who are not screened until later childhood tend to report greater difficulty in social interaction and feel isolated (Yi et al., 2020). The diagnostic process for ASD generally consists of evaluations conducted by a multidisciplinary team which may include physicians, psychologists, speech-language pathologists, and occupational therapists (American Psychological Association, n.d.). To gather the information necessary to diagnose ASD, diagnosticians may conduct interviews about behavior and developmental history, formally assess cognitive abilities, and observe an individual. Although the American Academy of Pediatrics has suggested that all children are screened for ASD at both 18 and 24 months, screening rates remain low in many regions across the United States (Zwaigenbaum et al., 2015). Families experience barriers to obtain a diagnosis for their child, including medical

professionals, parent denial, ineffective screening tools, financial and time constraints, stigma, and lack of awareness within the public (Hidalgo et al., 2015). According to Sacrey et al. (2020), a child would ideally be diagnosed before 2 years of age so as to receive early intervention, which is believed to benefit the child's development. Research suggests that early intervention may encourage development and prevent additional delays (Coogle et al., 2013).

Previous studies have yielded results suggesting that families in rural areas experience challenges with the diagnostic process for ASD. For example, these families experience a lack of providers in their area and therefore must travel long distances to reach a provider. Martinez et al. (2018) outlined that low-income, rural, and non-English speaking populations have difficulties with accessing early screenings and diagnoses. In rural communities, families tend to struggle with delays in diagnosis, lack of local services, geographic distance, reduced awareness, and inadequately skilled providers (Antezana et al., 2017; Parsons et al., 2020). Southern Illinois is a rural community that is considered the general bottom third of the state, and it consists of approximately 20 counties. A visualization of southern Illinois can be seen in Figure 1 below.

Figure 1

Southern Illinois Map



Because of its rural nature, the researchers of the present study hypothesized that families experience barriers on the path to receive a diagnosis for their child that are comparable to previous findings. Southern Illinois University (SIU) is located in Carbondale, IL within Jackson County and hosts the Center for Autism Spectrum Disorders (CASD) (SIU, 2021). The CASD trains undergraduate and graduate students studying communication disorders and sciences, psychology, and behavior analysis therapy. The center aims to train students within these disciplines while encouraging collaboration and service to the southern Illinois community.

The purpose of this study was to determine parents' experiences with the autism diagnostic process with their children in southern Illinois, a rural geographic area. This study aimed to answer the following research questions: (1) What are parents' overall perspectives of the diagnostic process in southern Illinois?; (2) What barriers do parents face on the path to diagnosis in southern Illinois?; (3) How did the time frame and the child's age at diagnosis affect parents' perspectives?; (4) What support systems helped parents through the process?; (5) What resources were suggested or provided at the time of diagnosis?; (6) How does the rural community of southern Illinois affect the diagnostic process?; and (7) What specific suggestions do parents have on areas of problem surrounding the diagnostic process? With the findings from this study, the CASD will better inform its service, teaching, and research missions.

Methodology

Participants

The current study included 11 families with children diagnosed with ASD. The participants were recruited from the Southern Illinois University Carbondale Center for Autism Spectrum Disorders (CASD) and the Autism Society of Southern Illinois. From the CASD, parents of children who had been diagnosed within the past five years were contacted. A flier

with the study's information was distributed to families that are affiliated with the Autism Society of Southern Illinois. Diagnostic stories were collected from 12 children (one family had two children diagnosed with ASD). The age at diagnosis ranged from 16 months to 6 years old. The family with two children received diagnoses for both in the late 90s and early 2000s, but all other participants' children were diagnosed within the last eight years. More specifically, the latter diagnoses took place between 2013 and 2019. The 11 families recruited were from four counties in southern Illinois, including: Jackson, Williamson, Franklin, and Union counties.

Design/Procedures

This research study was a qualitative research design with a semi-structured interview, which consisted of eight questions targeting our seven research questions. The interview was initially tested with two pilot families. With the results from the pilot, the interview was modified to obtain better answers for our research questions. Sample questions from the interview included:

- “What are your general perspectives on the diagnostic process? Are they more positive or negative?”
- “Do you believe where you live impacted the process? If so, how?”
- “Do you personally have any suggestions for improvements for the diagnostic process in southern Illinois?”

Due to the restrictions posed by COVID-19, the study was conducted virtually; Consent forms were exchanged via email and interviews were conducted via Zoom and telephone. Interviews were recorded and transcribed for analysis purposes. To protect confidentiality, recordings were deleted after transcription. Families were compensated with \$30 gift cards for their time and input.

Data Analysis

Analysis was completed through a software program called Qualitative Data Analysis (QDA) Miner Lite. Interview transcriptions were entered into QDA Miner Lite and eight codes were created based on the seven research questions. The codes were designated as follows: (1) age of diagnosis, (2) time to diagnosis, (3) perspectives overall, (4) resources post-diagnosis, (5) rural community impact, (6) suggestions to improve diagnostic process, (7) barriers through diagnostic process, and (8) support systems through diagnostic process. The researchers assigned codes to parent responses in transcriptions. Previous research suggests that coding along themes can help detect priorities and focus the analysis of qualitative data (Vaughn & Turner, 2016). After coding was completed, QDA Miner Lite was used to run an analysis to yield the results, which determined the frequency of these codes appearing across all interviews and depicted the research questions being answered. The researchers used QDA Miner Lite to complete a coding retrieval to find “themes,” which are responses within codes that appeared frequently. For example, the code about barriers commonly received responses related to financial struggles, so this would be labeled as a theme. To support the common themes, quotes which were indicative of parents’ responses were pulled.

Results

The results from the QDA Miner Lite analysis can be found in Table 1 below.

Table 1

Results from QDA Miner Lite Analysis

Category	Code	Description	Count
RQ1	age of diagnosis	How old was the client when they received their diagnosis?	22
RQ1	time to diagnosis	From initial concerns to diagnosis, how long did the process take?	25
RQ2	perspectives overall	Do parents generally view the process negatively or positively?	66

Category	Code	Description	Count
RQ3	resources post-diagnosis	What services were recommended for the child after diagnosis? Or what were the parents able to access/find on their own?	89
RQ4	rural community impact	How does being located in a rural area affect the ability to receive a diagnosis and services?	76
RQ5	suggestions to improve diagnostic process	Do parents have any suggestions on how we can improve the diagnostic process in Southern Illinois?	35
RQ6	barriers through diagnostic process	What difficulties did parents face while seeking a diagnosis for their child? Waitlists? Travel? Finances?	102
RQ7	supports systems through diagnostic process	What supports helped parents through the diagnostic process? Therapists, family, doctors?	75

Note. “RQ” stands for research question. Count is how many times this code was assigned across all interviews.

Overall Perspectives

The analysis yielded results that suggested that parents’ perspectives were generally mixed. Some parents were content with specific aspects of the process, including the support they received throughout the process and the age of their child at diagnosis. One parent highlighted the benefit of receiving a diagnosis while her child was young: “I think her being diagnosed so young gave me time to accept and further look for resources and help and catch it so young while her brain is still growing and developing.” Other parents were unhappy with the long time frame of the diagnosis and feeling as if they were not able to find adequate help locally. One parent remarked on his negative perspective: “But they did not tell us what to do. They just said he had autism and they were going to put him on this pill.”

Barriers to Diagnosis

Consistent with previous literature, this study found that geography was a barrier for families with children with ASD. A parent resorted to traveling as far as Chicago multiple times

to receive a diagnosis for their child because there were no available appointments locally at the time. She commented: "Not all parents have the resources to travel to Chicago three times. We had to go three different times for the diagnosis." Many parents traveled to St. Louis, which while closer than Chicago, is still inconveniently far. Families indicated that they experienced difficulties with finances. This was more related to intervention than diagnostics. One participant explained the financial toll it took on her family: "We're thankful that we have insurance, but even with that process, we're still paying thousands and thousands of dollars every year until we meet a deductible." Parents cited a lack of knowledge was a barrier across multiple situations. While some admit they were unknowing themselves, others claimed that doctors in the area were not knowledgeable. These reports suggested that the doctors were not helpful and tended to take the "wait-and-see" approach, suggesting the child would simply grow out of it. To speak to this, a parent suggested: "One of the reasons that a lot of people I know didn't want to get a diagnosis is because they didn't know what they were supposed to be looking at, so parents don't know." Another common barrier was service availability, which includes the availability of both diagnostic services and therapy. The shortage of providers in southern Illinois creates an additional difficulty because many families in the area seek services there, which causes the waitlists to build up. Results yielded that parents typically had to drive out of state to St. Louis to receive help for their child. More specifically, in the area there is a lack of therapy services such as applied behavior analysis (ABA) therapy. A parent commented on the lack of availability for services in southern Illinois: "We lost availability to get help because they are so limited around here and where we work isn't close to where services are offered."

Time Frame/Age

Parents reported that while there may be an abundance of early intervention therapy in the area, there is a lack of programs for older children and adults. In one instance, a parent had spent so much time waiting for a diagnosis that by the time her child received one, he was too old to receive ABA therapy locally. She commented: "I called a couple of places that do [ABA] therapy that wouldn't take him because he was so old and they only see kids up through 5." Most parents were satisfied with the age at which their child was diagnosed, as a parent shared: "He was diagnosed at 18 months... Having [an early diagnosis], I actually think it was probably better for me to know early." Another theme that appeared concerned long waitlists for diagnostics and therapy. When parents are eventually able to receive a referral for diagnostics from their doctor, they are unable to schedule an appointment for their child to be assessed for several months. One participant stated: "So [the pediatrician] sent in the referral to the doctor up in St. Louis. It took him about six months to get him up there."

Support Systems through Diagnosis

Some parents reported that their child's doctor acted as a barrier because of their lack of knowledge concerning ASD, but other parents listed the doctor as a support system throughout the process. A parent commented on the proactiveness of a doctor in the area:

Once, I had a doctor and he didn't specialize in it, but he had a patient come in with autism, and he didn't like that the mom knew more about autism than he did, so he went home and he studied it, and now he is one of the better doctors in the area.

Often, children were in therapy or early intervention before they received their diagnosis, so parents relied on their therapists for referrals and general questions they had. Many of the families' early intervention therapists visited their homes, which facilitated strong bonds. A

parent stated: “The ladies in early intervention were really supportive, they kinda reminded us that he just got a diagnosis. He was the same loving little boy, but things were going to be different for him.” Family members were often strong support systems and in many cases, the parents themselves were advocates for their children seeking a diagnosis. One participant remarked: “I think as a parent, I felt like we really had to be pushing for it and advocating for the services.” The education system helped families through the process because parents felt as if they were able to easily reach out to teachers or school therapists. Commenting on the support offered by the educational system, a parent stated: “He has always had a strong support with the Tri-County Education system that he is in.” Most notably, parents suggested that other families with children diagnosed with ASD were the best supports, because they shared similar experiences and were often able to offer some guidance. One parent shared: “[We know someone] with an autistic daughter that has kind of helped guide me sometimes if I ask her questions.”

Resources at Diagnosis

Before diagnosis, most children already were receiving speech-language, physical, and occupational therapy services, but ABA was typically recommended at diagnosis. A parent shared the recommendations they received: “They recommended ABA therapy and any kind of speech therapy.” Doctors often recommended genetic testing to determine the cause and how to better treat it. One participant commented: “We got the diagnosis and then the doctor that diagnosed her at Cardinal Glennon recommended genetic testing.” Specifically, many parents reported that southern Illinois lacked services and diagnostics. Parents traveled to St. Louis, Belleville, or Edwardsville. Many parents reported that this was a difficulty when both parents worked. A parent shared:

I know in St. Louis, they gave us a folder that was full of information and some resources, which included SIU mostly, just because of where we are located and it's so rural so there's not a lot of resources.

Unfortunately, parents commonly responded that they received no resources at diagnosis.

Typically, these parents were those that had a negative overall perspective on the process because they had no direction to go to help their child. Two parents specifically stated: "We didn't really get anything," and "I didn't get any [resources]." In addition, because families had to travel to receive a diagnosis, their diagnosticians were not able to provide recommendations for therapies and resources that were local to the family, creating a feeling of lack of direction. Also, one parent reported that they were not provided with resources that were specific to the needs of their child: "[The psychologist that diagnosed him] told us to look into general kinds of therapies because she wasn't familiar with what we have down here."

Rural Community Impact

Parents resorted to traveling to St. Louis, central Illinois, or even Chicago to seek a diagnosis for their child. Typically, parents went to St. Louis because it was the option with the least amount of travel. One parent recalled looking into Nashville, Tennessee for diagnosticians, which would have been crossing the state borders once again. Again, the interviews yielded suggestions that there was a lack of availability of both diagnostics and services in southern Illinois, as one parent cited: "There was nothing around here that was helpful in helping him in getting a diagnosis." Not only does St. Louis serve southern Illinois, but also a large majority of Missouri, which is also rural. Due to the large number of families flocking to St. Louis for an ASD diagnosis, the waitlists there are longer. A participant commented: "When Knights of

Columbus is the only thing available to so many people that are around in this area—not just in southern Illinois, but other areas in Missouri or wherever—I understand why they're so busy.”

Suggestions

Parents suggested that the availability of both local diagnostics and services be increased. In turn, this would lessen the waitlists and increase the number of children being diagnosed earlier. The sheer size of southern Illinois requires the establishment of several service providers throughout the area that can help this population, so parents do not struggle with travel or lack of services. One parent stated:

The only other thing is that my little guy was on the waiting list for ABA therapy for two and a half years, so he only got a very short amount of ABA therapy. I wish there was something different with that.

A parent also recommended the use of telehealth services be increased:

I mean, it would be nice, especially with all of this telehealth that is available now, if there was that availability to have even some telehealth services so that if it was provided through St. Louis... so that people from here wouldn't have to travel up there.

Parents that encountered financial struggles recommended that we try to offer services or a program that is state-funded or that can help families that do not have insurance or cannot afford therapy costs. For example, a participant shared, “So there needs to be something more affordable that is maybe provided by the state or has some funding behind it that can support families.” Most importantly, parents encouraged education. A parent indicated a need for education for all special needs: “I feel like in everyday life, there should be more information about not just autism, but all special needs, but I don't know how we can do that.” One parent specifically suggested we provide advocacy training to families to help them understand their

rights and to teach them how to stand up for their child. Others stated that we should implement training for doctors and teachers to show them how to identify ASD and how they can help, with one participant mentioning,

I think doctors need to know what to look for. Somehow, the doctors have to be taught that these are the [symptoms] and if they start happening, it's a problem. I have only found one pediatrician around here who knows what to look for.

Discussion

Overall, parents reported rather mixed perspectives on the diagnostic process in southern Illinois. Families identified barriers in the diagnostic process that were consistent with previous findings in rural areas: finances, geography, lack of services, and lack of education (Antezana et al., 2017). Some families reported positive diagnostic experiences with receiving an early diagnosis for their child, meaning they are more likely to obtain crucial early intervention services. As for the waitlists, parents often complained about the long waitlists for diagnostics at SIU and in St. Louis. Previous studies found that the average time between parents' initial concerns and receiving a diagnosis is between two and four years, despite recommendations that five months should be the maximum wait time (Smith-Young et al., 2020). Additionally, Yi et al. (2020) stated that waiting for a diagnosis of ASD for a child can be stressful and emotional, but information can help alleviate these burdens. The researchers suggest that families be provided with educational materials about ASD while on the waitlist, but also warn that it may be unethical to share information about a condition that has not yet been diagnosed. Reports about interactions with the medical community were mixed; while some doctors were listed as a support throughout the process, others preferred to take a more passive role by suggesting a "wait-and-see" approach, suggesting that the child would "grow out of" the delays and behaviors

that are characteristic of ASD. The “wait-and-see” approach can be detrimental to the developmental of the child because services to address the child’s needs are typically not sought out after this recommendation from a doctor. This forces the child to go without crucial services during a period of critical development. This is not restricted to southern Illinois; Hidalgo et al. (2015) stated that some physicians dismiss parents’ concerns and suggest the “wait-and-see” approach, which typically upsets parents and causes them to view the diagnostic process negatively. However, it is important to remember that not every medical professional assumed such a passive role. As for support systems throughout the process, findings were also consistent with existing literature, with family, early intervention therapists, doctors, and the educational system being listed (Antezana et al., 2017). In past studies regarding rural communities, educational systems were cited as one of the best supports. While parents in the current study claimed that teachers were helpful, responses about the educational system were rather underwhelming compared to previous literature. The current study found that parents were dissatisfied with the resources they received upon diagnosis, and often felt as if diagnosticians left them without any direction, which is consistent with existing research (Smith-Young et al., 2020). In southern Illinois, it appears that there are many service providers for early intervention and there are school therapists, but parents suggested that there is a need for services targeted towards older children, adolescents, and adults. What services are currently available for individuals with ASD who are no longer in school? ASD is a lifelong disorder, meaning an individual diagnosed with ASD will most likely require some form of assistance throughout their life. Yi et al. (2020) found that parents felt as if their child’s diagnostic assessment was too short and not detailed enough to appropriately evaluate their child’s capabilities. Many participants from the current study admitted they shared the same opinion, often feeling as if their doctor was

not able to understand their child completely in such short assessment sessions. They suggested that assessments for ASD be longer and more in-depth. One parent specifically mentioned the possibility of implementing telehealth services to better serve the southern Illinois region. Antezana et al. (2017) found that telehealth can provide an alternative form of therapy and possibly diagnostics. However, while this option may be more convenient and affordable for families, it may not always be accessible; families in rural communities are not able to access stable internet or computers. Fortunately, the CASD at SIU was reported as a resource within the region, suggesting that SIU can help the local community, and that with the findings of this study, the CASD can continue to improve diagnostics and therapy services.

Limitations

First and foremost, this study was affected by limitations caused by COVID-19; initially, interviews were planned to be conducted in-person. To abide by social distancing guidelines, families were interviewed via Zoom and telephone, which was actually beneficial for parents who lived far away from where the researchers were based or for those who worked. However, recruitment was hindered because families were contacted via email, which made scheduling interviews and exchanging consent forms more time-consuming and challenging. Therefore, the study had fewer participants than expected. Another limitation this study encountered included recruitment that is not representative of the population of families in southern Illinois with a child diagnosed with ASD. Both the CASD and the Autism Society of Southern Illinois are based out of Carbondale, IL in Jackson County. Therefore, typical participants recruited from these groups tended to be families from the surrounding counties. Meanwhile, southern Illinois consists of around 20 counties, while the participants from this study came from four counties.

Recommendations

To improve upon the current study or to further the research in this area, one should first expand on the counties represented so as to yield results that are more representative of the population within the entirety of southern Illinois. Perhaps expansion of recruitment can allow the generalization of the findings from the current study. Recruiting from ASD groups around southern Illinois can facilitate the recruitment from other counties. Researchers in the future may want to look into conducting reliability checks on transcription analysis. At the time of this paper, the researchers of the current study have not conducted reliability checks. Additionally, to increase the number of participants, one might consider converting the interview into a survey. This may make the study more accessible to parents and researchers would be able to easily gather information from a more widespread population. However, an important consideration is the quality of responses received from parents. A conversational interview may encourage parents to give longer and more detailed answers, and gives the researchers the option of asking a parent to expand on a topic of interest. On the other hand, an online survey may elicit shorter answers.

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