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ORIGINAL ARTICLE

# “You Had This Clean Window, But It was Glued Shut”: Identifying the Needs of Parents and Providers of Children and Youth with Autism Spectrum Disorders in Rural Areas Through a Life Course Perspective

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## Abstract

Research on Autism Spectrum Disorders (ASD) has found significant disparities in access to services and outcomes in rural communities. Little is known about service providers and families of children with ASD who reside in rural communities. The purpose of this study was to learn and describe the barriers and unmet needs experienced by parents and providers providing support to children with ASD in rural communities through a life course perspective. Eight parents and eight service providers participated in the focus groups from rural counties in Illinois, United States. Parents discussed barriers to accessing and coordinating services, from ASD diagnosis to transition and future planning. Overall themes highlighted the scarcity of qualified professionals trained to work with and serve children and youth with ASD and the resourcefulness caregivers and providers need to fill the gaps in education, health care, transition, and future planning. We present recommendations shared by parents and providers on ways to improve access to services and support for families in rural areas. The current study reports important implications for policy and practice regarding services and support for families of children and youth with ASD residing in rural communities.

**Keywords** Autism · Parents · Providers · Rural Communities · Disparities

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Despite recent advancements in the early identification and treatment of autism spectrum disorders (ASD), there are numerous populations for which research is underdeveloped and desperately needed. Much of the research on ASD to date has taken place in urban, well-populated areas near research universities or medical centers (Interagency Autism Coordinating Committee (IACC), 2019). Much less is known about the state of ASD service needs in less populated areas with lower access to established research universities or medical centers. The limited research so far finds that individuals with ASD residing in rural communities experience significant disparities in access to services and outcomes (Antezana et al., 2017; Zhang et al., 2017). It is critical to examine the experiences of families of children and youth with ASD and the service providers who reside in these communities to address these disparities. By identifying the barriers, challenges, and successes experienced by children with ASD and their families through a life course perspective, more informed approaches can address the significant disparities. In this paper, we take a life course perspective to characterize the needs and experiences of caregivers of children and youth with ASD and incorporate the views of service providers who provide care in rural communities.

## Life Course Theory for Children and Youth with ASD

Life-course theory examines the life course of individuals through a historical, social, and cultural contextual lens. Transitions are critical events that can change one’s life course (Elder, 1985). In their commentary, Bethell and colleagues (2014) argued that adopting a life course perspective for children with special health care needs is critical to ensure that vulnerable healthcare systems step away from acute episodic care that is reactive and instead approach care that is preventive. Existing literature has well documented the dire need to adopt a preventive approach to supporting children and youth with ASD and their families in rural communities. However, the ASD and rural communities are not well studied through the lens of life course theory.

Caregivers of children with ASD experience multiple critical transitions, including receiving a diagnosis, advocating for services, transitioning to adulthood, and future planning. However, such transitions or turning points are often studied separately. Past studies on the experiences of rural families of children with ASD primarily focused on diagnosis and treatment (Hoogsteen & Woodgate, 2013; Hutton & Caron, 2005). A life-course approach can examine experiences from diagnosis to treatment, transition, and future planning, thus providing a holistic view of these families’ experiences. More importantly, we can identify pivotal points to empower children and families by looking at these critical transitions. Although the life-course theory covers the entire lifespan, researchers have conceptualized the lifespan as having four functional phases (Halfon et al., 2014): Phase 1 Generativity, which focuses on the preconception and prenatal developmental period; Phase 2 Acquisition of capacity which focuses on the early childhood, adolescent, and early adulthood period; Phase 3 Maintenance of function which focuses on the middle adulthood period; and Phase 4 Managing decline which focuses on the older age period. With a focus on diagnosis, treatments and services, and transition and future planning, this paper reflects Phase 2 of the life-course.

## ASD diagnosis in Rural Communities

Diagnosis during the early childhood stage can be key in obtaining services and supports that contribute to positive outcomes for children with ASD. The diagnosis of ASD is typically provided after an interdisciplinary evaluation that considers developmental and medical history, physical examination, family report, child assessment, and observations across multiple settings (Prelock et al., 2003). The diagnostic evaluation can include several professionals, including but not limited to developmental and behavioral pediatricians, neurologists, psychiatrists, psychologists, speech-language pathologists, occupational therapists, and social workers. Caregivers, in general, will typically have more consistent and regular contact with general practitioners (e.g., well-child visits). Caregivers are more likely to express early concerns about their child's development to pediatricians and general physicians due to a limited number of health professionals (Health Resources and Service Administration, 2019). However, these providers (e.g., pediatricians, general physicians) can often overlook early ASD symptoms and may be less likely to make the necessary referrals for specialist services (Wong et al., 2017). Furthermore, pediatricians and general physicians may adopt a "wait and see" approach when the availability of developmental pediatricians or other specialists in the area is limited (Edwards et al., 2021).

Overall, rates of diagnosis are lower in rural areas when compared to urban areas (Dickerson et al., 2017), and when children from rural areas are diagnosed, they are typically diagnosed much later than children from urban areas (Kalkbrenner et al., 2011; Rhoades et al., 2007). A primary reason cited for lower rates of diagnosis is lower access to trained professionals who can make a diagnosis (Elder et al., 2017). The availability of qualified providers who can diagnose ASD is limited in rural areas, directly affecting access to ASD diagnoses. Yet, more information is needed to understand the ASD diagnostic experiences in rural communities. For example, we do not know what caregivers do when they are concerned about their child's development and do not have access to qualified providers.

## ASD Services in Rural Communities

The limited quantity of health care and educational providers, which contributes to the lower availability and access to ASD diagnostic services, also affect the availability and access to treatment services and supports for children and youth with ASD in rural communities. Crimmins & Heggs (2016) posited that a cycle of challenging factors contributes to the significant disparities that individuals with disabilities face in rural communities. The main factors identified included challenges in transportation, social exclusion, lack of medical specialists, lower quality of medical care, and other sociodemographic factors (i.e., health insurance, race/ethnicity, and socioeconomic status; Rubin & Merrick 2013). For families of children with ASD, these factors affect their access to diagnostic services and impact their access and receipt of quality services.

National data shows stark differences in access to services and treatments among families of children with ASD in rural communities when compared to urban communities. A review of data from the Simons Foundation Powering Autism Research for Knowledge (SPARK) initiative found that children with ASD who lived in rural areas were less likely to receive behavioral and speech/language therapy, received lower intensity of treatment services, and were more likely to receive behavioral treatment services at school than at home compared to children with ASD who lived in urban areas (Monz et al., 2019). Furthermore, caregivers of children with ASD who lived in rural areas were more likely to report that treatment was “not available in area” as a barrier to receiving treatments than caregivers of children with ASD who lived in urban areas. These striking differences suggest that children with ASD who reside in rural areas may be at a significant disadvantage in receiving the recommended treatment approaches in natural, least restrictive environments (National Autism Center, 2015).

## Transition and Future Planning in ASD

Preparing for transition and future planning is important for youth with ASD to ensure continuity of healthcare, continuity of education or vocation, continuity of housing and independent living, and financial well-being. Youth with ASD have reported significant worry about transitioning into adulthood as they encountered physical changes, new situations and expectations, and increased responsibilities (Cheak-Zamora et al., 2018). Disparities in transition planning have been well-documented for youth with ASD, with the loss of services reported as the most significant impact (Cheak-Zamora et al., 2013; Eilenberg et al., 2019). High school programs, particularly programs in rural areas, may not adequately prepare youth and their families for transition and school exit (Kraemer et al., 2020). Furthermore, healthcare providers report limited knowledge and skills to care for transition-age youth and adults with ASD within their practice (Zerbo et al., 2015). For youth with ASD and families in rural communities, access to high-quality transition and future planning supports may be even more challenging due to the limited availability of trained and knowledgeable educators, providers, and community resources. To date, limited information is available on how families and professionals address transition and future planning for youth with ASD.

The current study examines the barriers and unmet needs of children and youth with ASD and their families. We do this through a life course perspective (Phase 2 Acquisition of capacity) to explore critical transitions and identify critical resources and supports. We emphasize Phase 2 within the life course perspective as it reflects on the development of a child from infancy through early adulthood and the pivotal or transitional points that a child/youth with ASD and their family would encounter (Drmic et al., 2017). We specifically focus on life course transitions during early childhood and transition to adulthood. Our research questions are the following: (1) What are the barriers and unmet needs for rural families of children with ASD through key transitions (i.e., Diagnosis, Treatments and Services, Transition, Future Planning)? (2) What are the consequences of such unmet needs? (3) What are potential solutions to support families during these transitional points?

## Methods

The current study centers around focus groups conducted as part of a larger needs-assessment project on rural families of children with ASD in a Midwestern state. Focus groups are efficient tools for exploratory research, with substantial data emerging through interactions between participants in such a format (Nyumba et al., 2018; Vaughn et al., 1996). In our analysis of focus group data, we present the experiences of rural caregivers of children and youth with ASD. Caregivers of children with ASD are often at the forefront of managing their child's health care services, advocating to have their needs met, and sometimes implementing treatment strategies. On the other hand, providers can provide critical information on systemic challenges they face in providing care to rural families. In this study, we consider providers as any educational, health care, or other professional who provides information, resources, or services to children and youth with ASD and their families. Therefore, we invited both parents and providers to our focus groups. We do not attempt to compare parent and provider perspectives. However, because parents and providers have different goals and experiences with children with ASD, we held separate focus groups for parents and providers to ensure that participants would have similar roles with children and youth with ASD (Hennink, 2014).

## Participants

Parents of children and youth with ASD under 22 years of age and service providers within rural counties in Illinois were recruited to participate. We selected this age range for the children and youth with ASD as this would reflect the ages served by the educational system under the Individuals with Disabilities Education Act (2004). After youth with ASD exit the K-12 system upon graduation or by their 22nd birthday, youth transition into adult services, a markedly distinct system and experience for youth with ASD. Rural counties were defined by the Federal Office of Rural Health Policy (2016). Parents were recruited through schools, community agencies, and service providers. Providers were recruited through a listserv and contacts with community agencies. A flyer with study information was emailed to parents who received services and providers who provided services and had provided an email address to the corresponding school, agency, or service provider. These contacts were identified through our engagement of a statewide stakeholder advisory group (discussed below).

Participant characteristics are displayed in Table 1. Overall, we had eight caregivers of eight children/youth with ASD. The children and youth with ASD were between 7 and 18 years of age, with four youth currently in transition planning or who had already transitioned. Providers reflected a range of professions, with some providing services in early childhood, while others providing services across the lifespan. Parent and provider participants were White (100%) and resided across three rural counties in Illinois: Adams, Coles, and Effingham. These counties reflected a majority White population (92.0%, 91.0%, and 96%, respectively), with each county including populations under 67,000 (Census Bureau, n.d.). Household income was not available for the participants, so we report the median household income for each county (Adams = $48,454; Coles = $41,907; Effingham = $54,655), which were lower than that of the U.S. ($57,652). These counties have also been designated as health profession shortage areas for primary care (Adams, Cole), dental health (Adams, Cole, Effingham), and mental health (Effingham). Furthermore, Adams and Effingham counties are considered medically underserved areas, whereas Adams and Coles counties include medically underserved populations (i.e., low income).

## Procedure

The focus group script was developed through an extensive review of the literature, meetings with a statewide stakeholder advisory board, and a review of ASD needs assessments conducted in other states. The stakeholder advisory board included nine individuals and a range of professional fields and personal experiences with ASD across the life course. We held two meetings with the stakeholder advisory group to identify priority questions and to learn about the general services and experiences in rural communities. The final scripts for the parent and provider focus groups were adapted from the New Hampshire ASD needs assessment with feedback from stakeholders (New Hampshire Council on Autism Spectrum Disorders et al., 2014). The scripts for the parent and provider focus groups are included in Appendix A and B, respectively.

Two experienced investigators (developmental psychologist, social worker) led the focus group discussions. The focus groups were semi-structured to provide parents and providers with an opportunity to share openly. The focus groups took place at local community agencies that were easy to access and had parking available at no charge. The focus group discussion focused on the following topics: (1) Experience in accessing an ASD diagnosis and sources of information related to the diagnosis, (2) Access to and barriers to receiving services, (3) Transition/future planning, and (4) Impact of ASD on families. A total of three focus groups were conducted. The parent focus group included a total of 8 participants and lasted approximately 150 min. Two focus groups were held with service providers, one included 3 participants and another included 5 participants, with a total of 8 participants. Each provider focus group lasted approximately 90 min. All participants were compensated with a $15 Amazon gift card for their time. All three focus groups were audio-recorded and transcribed to identify common themes.

**Table 1** Characteristics of Focus Group Participants

| Parent Group | Child Age | Child Gender | Child Diagnosis |
|---|---|---|---|
| PA1 | 12 years | Male | ASD, Intellectual Disability |
| PA2 | 18 years | Male | ASD, Intellectual Disability, Schizoaffective Disorder |
| PA3 | 17 years | Male | ASD, Apraxia |
| PA4[a]<br>PA5[a] | 13 years | Male | ASD |
| PA6[b] | 15 years | Female | ASD |
|  | 15 years | Female | ASD |
| PA7 | 11 years | Male | ASD |
| PA8 | 7 years | Male | ASD |

| **Provider Group** | **Profession** | **Degree** | **Service Age Range** | **Years in Profession** |
|---|---|---|---|---|
| PR1 | Resource Specialist[c] | MSW | Lifespan | 20 + years |
| PR2 | Special Education Teacher | BA | 3–5 | 6–9 years |
| PR3 | Special Education Teacher | BA | 3–5 | 1–2 years |
| PR4 | Early Childhood Education Coordinator | BA | 3–5 | 15–19 years |
| PR5 | Early Childhood Education Coordinator | MA | 3–5 | 20 + years |
| PR6 | Speech-Language Pathologist | MS | 0 to 22 | 15–19 years |
| PR7 | Resource Specialist[c] | Not reported | Lifespan | 15–19 years |
| PR8 | Speech-Language Pathologist | PhD | 0 to 22 | 20 + years |

*Note.* [a] – Mother and father from the same family; b – Mother to twins with ASD; c – In Illinois, resource specialists provide support to individuals with disabilities and their families by connecting them with community services and programs, and important information related to other sources of support (e.g., Medicaid waivers)

## Data Analysis

### Data Analysis Approach

A qualitative approach in data analysis is appropriate for exploring topics about which we have little information. We used inductive content analysis (Hsieh & Shannon, 2005) as our analytical strategy. Inductive content analysis allows themes to emerge from the data itself, rather than imposing predetermined ideas onto the data. Specifically, we used a two-cycle coding approach (Saldaña, 2016). In the first cycle, two researchers read through the transcripts and identified codes independently. Next, the two researchers finalized the list of codes and their definitions together. The two provider focus groups generated 41 codes, while the parent focus group generated 64 codes. In the second cycle, the two researchers coded independently using the code list. After they completed the independent coding, they then met to compare their coding results. One researcher presented their codes on each segment of the focus group transcripts, and then the other researcher shared whether she disagreed. At times of disagreement, they discussed and came upon an agreement. The process of obtaining reliability was iterative and dynamic instead of linear (Morse et al., 2002). Thus, we did not calculate a percentage of agreement. All data were analyzed using Microsoft Excel (Meyer & Avery, 2008).

### Trustworthiness and credibility

To ensure the trustworthiness and credibility of the analysis, we adopted four strategies: analyst triangulation, constant comparisons, reflexivity, and community expert review. Triangulation is a commonly used strategy to ensure the credibility of the analysis. Analyst triangulation (Patton, 2014) or otherwise referred to as investigator triangulation (Carter et al., 2014), was achieved by involving two researchers from different professional backgrounds (psychology and social work) in the data analysis process. The two researchers constantly compared the consistency and accuracy in their application of codes, selection of quotes, and interpretation of the results to further ensure the study's credibility.

The authors' subjectivity and positionality were taken into consideration throughout the study and manuscript development. Specifically, the authors' experiences working with underserved families of children with autism and disabilities shaped the data analysis process. All four authors have worked closely with underserved families of children and adults with ASD and other intellectual and developmental disabilities in both research and clinical settings. The authors have personal experience with family members with disabilities, including personal experience with epilepsy and family challenges navigating healthcare systems. However, we recognize that we do not reside in rural communities, nor do we have the first-hand experience raising a child with ASD. Therefore, we reached out to community members, specifically parents of children with ASD and providers in rural Illinois, to conduct an expert check of our analysis (Given, 2008). Community experts' responses indicated agreement with the results, and one member added an emphasis on the need for supports and resources for siblings.

### Data saturation

Data saturation is critical in qualitative analysis. Although it is a gold standard in qualitative research, there is yet to be a consensus on how to define and reach data saturation in qualitative inquiry. Guest et al., (2017) examined the number of focus groups needed for reaching saturation and concluded that over 80% of all themes could be discovered with two to three focus groups. Some argue quantifying the number of interviews needed for data saturation is not always feasible or possible (Bernard, 2012). Fusch and Ness (2015) share the same concern of using a numerical standard to guide sampling for qualitative inquiry since one size does not fit all. One method of data saturation that considers the study context and purpose indicates that “probing needs to continue until the researcher feels they have reached saturation, a full understanding of the participants’ perspectives” (Saunders et al., 2018). To this point, we continued probing participants during the focus groups until we felt we had a full understanding of their perspectives.

## Results

We present the findings across four general categories and highlight specific themes that emerged across the focus groups. We include illustrative quotes within each theme and feedback from community members who completed an expert review of our findings. Quotes are presented by the corresponding code for the parent (PA#) and provider (PR#) as detailed in Table 1. We conclude with recommendations shared by parents and service providers on improving the quality of information, services, and experiences for children and families through the life course from early childhood to emerging adulthood. We include additional quotes for each section in Table 2.

## Access to and barriers to ASD diagnoses

### Parents

Overall, parents reported significant challenges in accessing and receiving a diagnosis for their child. The barriers reported included long waiting lists, significant distance and time required to access diagnostic services, lack of qualified providers in the regions, and the ambiguity of their child’s diagnosis. Parents often felt uncertain about where to go for answers about their child’s developmental delays as most clinical services were at a significant distance in larger metropolitan cities, as one parent mentioned:

> Part of the hard, difficulty of the people who diagnose and telling us what’s out there, is that like areas like this, you have to GO somewhere to get [a] diagnosis. It’s not like that there is somebody half an hour away who knows your community (PA1).

Another parent reported on the complexities of obtaining an accurate diagnosis, needing to travel to a neighboring state to obtain a thorough explanation for her son’s symptom presentation.

> So, then we went for second opinion, we went to [local university clinic]. [Local university clinic] was like: “No I don’t think he is on the spectrum, I think he has apraxia.” So he had two different diagnoses. And then we went to [Other] Hospital in [Indiana] where they did have a multidisciplinary team, and

**Table 2** Summary of Themes Identified from Parent and Provider Focus Groups

| Theme | Parent Quotes | Frequency |
|---|---|---|
| Access to and Barriers to ASD Diagnoses | "… my pediatrician was a wait and see. It was like, 'let's just wait and see'. And I am like 'no'. Let's not wait and see." (PA8)<br>When [child's name] got diagnosed, [doctor's name] was it. You waited six months to get in to see him. Because there is nobody else. (PA1) | 27 |
| Information Sources After ASD Diagnosis | With us being rural, like we didn't have a public library in our town. The Early Intervention Clearinghouse had … a pretty rich amount of autism resources there. And they would ship it to your home which made it really nice because I get that stuff and I drop it back off in the public library and they'd send it back. So it was like no cost as a parent to get. (PA3)<br>I think it starts with the physician. The very first visit with physician. That's your introduction right there…They don't even have that many directions and resources to point you to, but they can get you at least meeting with other parents. And I feel like the fact that we had to find each other just sort of figure out these secrets, figure out these services, figure out these agencies, that point of authority was missing. (PA5) | 66 |
| Access and Barriers to Treatment and Services | I would say with autism, it's developmental, but it is also a comorbid …with mental health… but when I called our mental health provider, when our son was little to get support, she says: well, that is a pretty rare diagnosis. I am like, it is 1/110. She was like, we can offer him counseling. I said: I don't know if that is going to really work. He is nonverbal. (PA3)<br>We are the only children on the case managers' caseload that comes to my house. And they do three, four, five counties each. We are the only children on their caseload. Why? Because I had a loud mouth and I was breaking down and I was on the phone every day. (PA6) | 155 |
| Transition and Future Planning | But what we are finding is that there is no group homes for adults or young people, as you know, that really is specific to this condition, and this is a very common condition… it is not like we are talking about such rarities. But again, they are like at a loss. (PA2)<br>I want him to have a full life, where he is happy, and I don't know that that's gonna be the thrift store, but right now, he is earning 10 dollars … It is all about connecting and making relationships with people in your own community, and people that know your kid and know your family, because, really, once they know you and they know your kid… I guess I feel like, this area can be very accepting if they know you, because sometimes you can get over a lot of hurdles if people just see potential. (PA3) | 48 |
| Impacts on Families | When you are in the trenches, and you are going through a period with your child when you are exhausted in every way a human being can be, you don't have the energy to look around where I am gonna call, who do I talk to, who can help me. (PA2)<br>It has been great for me to realize, and it has taken a long time, it's ok to say no to things, like, nope we can't handle that. We went to a party yesterday, now we need to unwind today. And I think that's good for like all the kids. I think has made a much better parent … I'm much more aware of like positive reinforcements, I pay so much more attention to the good things they do, because it is like such a celebration. (PA4) | 99 |

**Table 2** (continued)

| Theme | Parent Quotes | Frequency |
|---|---|---|
| Recommendations for ASD Throughout the Life Course in Rural Communities | And it would be really nice, if that EI concept continue to where, it's not just about treatment, it's about someone who is guiding you, and informing you of what's next … your step in the process, what services are there, what you need to be thinking about. 14 and half, with the school district legally obligated to say "Ok now let's start thinking about adulthood" is way too late. (PA2)<br>Getting more things where you can bring it to the community, even if the provider can't come there, but if they can do it web based, and do consultation, so families aren't having to trek that far to do things. (PA3) | 20 |
| **Theme** | **Provider Quotes** | **Frequency** |
| Access to and Barriers to ASD Diagnoses | Quite often, we don't really know that they had autism because of the services for evaluation and screening for kids before they turn 5 and 6 is so slim (PR4)<br>They (parents PR2 served) go to XX medical group (in town), the XX center (in Missouri, 2 h driving distance), and there is a new one in Iowa (4 h 30 min driving distance). Some go down to St. Louis (2 h 15 min driving distance) for diagnosis (PR2). | 16 |
| Information Sources After ASD Diagnosis | Past parents can help if they are willing to connect with current parents in our program. (PR4)<br>That with parents, they are really relying a lot on Facebook. So you know, I try to at least put information out. There is a special need Facebook group that I am part of, because I am also a parent. And, so put things out there. (PR7) | 6 |
| Access and Barriers to Treatment and Services and The Impacts on Families | But randomly a family or an organizer said we want to do this (organize play or sports group for children with special needs), but it's not because it's funded or supported. It's because that band aid or putting out fires or I want my kids to have this so I am going to try to design this. And that's how services are organized in that around here (PR7).<br>It's just a matter of trying to get them extra help, that's the hard part because they don't have the means to get somebody to watch this kid to do this, or you know travel there to do this and this. There is just so much going on. (PR2) | 230 |
| Transition and Future Planning | I am thinking of transitions, that would be the same as having training and funding to be able to do the training and knowing what to do at that age for referrals (PR1)<br>I would say [Agency name] worked pretty good with the high school, with some transition where they can do kind of bonus work study with them as they transition out of high school. But I would say they are about the only agency who is really doing much in terms of transition in this area. (PR8) | 20 |
| Recommendations for ASD Throughout the Life Course in Rural Communities | An app for parents for resources. Even for PECS, you know quick PECS for. You know if they are somewhere and they need to do a quick PEC, how can they do that. (PR1)<br>I think first training the staff…. So, we can at least start with providing the educators and people who work with the students trained, so they can get information to the parents' home. (PR3) | 2 |

> they said, "They are both right, he does have apraxia and he does have autism, but this is what you need to do." (PA3)

### Providers

Providers also confirmed the lack of clinicians within reasonable distance providing diagnostic services. Many families they served traveled out of Illinois for a diagnostic assessment, primarily because there were no specialized ASD diagnostic services available in their community. Specifically, in both focus groups, providers shared examples of families traveling up to two hours and half for a diagnosis. Additionally, providers acknowledged the scarcity of screening and diagnosis services before children turns five (e.g. see first provider quote in Table 2).

## Information sources after ASD diagnosis

### Parents

When asked about the type of sources for information about ASD, parents reported that their primary sources were physicians, teachers, therapists, and other parents. A few parents reported that they received a list of resources when their child was diagnosed with ASD; however, the utility of the resource list was dependent on other factors, as one mother explained:

> They offered us like a support group like two hours away. I'm like, my kids climbing out of the car, you know we are not gonna drive… two hours to go to something where we can't even get him there (PA3).

Parents reported that they created their own information sources by establishing groups on social media where parents could consult with other parents on the services, supports, and resources they found helpful.

### Providers

Providers, on the other hand, cautioned that parents who often relied on parent groups on social media might pursue treatments and interventions based on anecdotal reports instead of scientific support. Providers reported they often provided parents with curated lists of resources or articles about best practices for children with ASD. They explained, "If you read something about certain research thing, you have to look at where the research was done at and how accurate that information is compared to what you are doing" (PR2).

## Access and Barriers to Treatment and Services

### Parents

After receiving a diagnosis, parents reported similar challenges in obtaining services, including the most often recommended services for ASD. One mother remarked:

> A lot of times they make recommendations for certain therapies or for ABA. And it's not accessible in this area... it's very challenging cause people can tell you what your child needs, but if it is not something you can get, then you are just… spinning your wheels and then you are trying to get it whatever way you can and meet their needs. It's just physically, emotionally, and mentally like taxing as parents, cause … you are trying to get your kids' needs met, but you can't find the stuff you need to meet it. It's hard (PA3).

Parents also reported that in addition to the lack of qualified service providers in their community, services were often in silos, with little to no communication between educators, pediatricians, speech pathologists, and other providers. The lack of professional coordination resulted in parents adopting the role of case managers and coordinators for their child's services, often with little background or experience in navigating the complex systems of care. One parent reported that they felt resistance from educational and other service providers in obtaining the services needed for their child with ASD. "You have to beg for everything, not just ask. And then you have to follow up and push them again. And be very grateful" (PA4).

Furthermore, the quality and training of service providers in the region were also limited. Many parents reported that educators and health care professionals were ill-equipped to manage ASD symptoms and other complexities such as mental illness and other comorbidities (e.g., apraxia).

Many parents learned from their experiences to create the opportunities and supports for their child with ASD due to the lack of supports available. Parents of older children also reflected on how the service landscape has changed over time.

There are just things that have evolved … as a parent, you are thankful and so happy for the parents behind you, but it also makes you resentful at times, because [why] couldn't my kid …[get] what we were asking for … it was really like, you had this clean window but it was glued shut. And you couldn't get it open to get what you needed. (PA3)

## Providers

Providers shared a different side of this experience as they faced many systemic challenges in obtaining the necessary training to support children with ASD. For example, special education teachers highlighted the lack of funding available through the local school districts for professional development or specialized training on ASD. Even if funding was available, special education teachers often could not take time off during school hours. There were very few substitute teachers who were available and willing to substitute for a special education class. This was compounded by the fact that many trainings on evidence-based educational practices were located in large urban cities in Illinois or out of state.

Similar to parents' concern of services functioning in silos, providers also addressed the lack of training on autism in other health professions who may serve this population. One provider shared: "our mental health program, I help do trainings through them, but they are constant referral, because they are not trained to work with children with autism as well" (PR7). Another provider with over 20 years of experience reflected on how it would enhance care if there is better collaboration with physicians and psychiatrists.

> I think as a professional I would really like is better interaction with the medical professionals to make sure that they are doing like M-CHAT screening at every wellness check at 18 and 24 months that then they could make a referral. But working with some of the psychiatrist in terms of them understanding the medication to use and not to use with this population because of the chemical sensitivity. So, I wish we had a better network among the professionals who are actually treating these individuals to share some of their knowledge and experiences in a better way. Em, that way I think families will get a more consistent service delivery. (PR8)

In addition to lack of inter-professional collaboration, providers also discussed a host of systemic challenges they face advocating for better training and services for families they serve. One provider pointed out the lack of full-time providers designing and implementing services: "Ok, em a lot of smaller districts or special ed co-ops are designing (autism team), and there is people interested in, you know, ok I will be part of the team. But once again, they are not getting that time away from their other job or the time away from their 100% full responsibilities to actually be part of that team." (PR6).

A few providers discussed how school district-level support for provider training on autism is often lacking. "it's educating administrators, educating superintendent, educating the principals and making that okay. But it's only ok if their budget line" (PR7).

## Transition and Future Planning

### Parents

Parents discussed the fears, worries, and challenges they anticipated in preparing for their child's transition into adult services and planning for the future. There was a recognition that there were few services available to youth with ASD to develop vocational skills within the school system as part of their Individualized Education Program (IEP) and through community organizations. Parents helped fill this gap in supports by creating specific opportunities for their children with ASD. For example, one parent reported that they sought out volunteer opportunities during the summers and helped their child obtain basic work skills by working at a local thrift store. However, this experience did not reflect a competitive employment opportunity as he only received store credit for hours worked. This parent stressed the struggle of considering guardianship while also valuing her son's independence and the importance of identifying and building on his strengths for his future.

> It is about making it real and how they can do it, and when you are talking about guardianship, those are huge decisions to make, because, you don't want to say,

> oh you can't be if they can… I mean there's things that you can find, it is just, letting them see what their strengths are versus their weaknesses (PA3).

Parents also talked about how crucial information was to understand the broad impact of their children transitioning into adulthood. As one mother reported:

> Our parents helped us pay for a lawyer, so we could take our son to court and have him declared incompetent, so we could be his legal guardians, because, nobody tells you that oh when they are 18, they can open a credit card, they are legally liable for the things they do (PA2).

A few parents reported that they did not want to impose additional responsibilities on the siblings as they grew older in terms of future planning. For example, parents recognized that guardianship for their child with ASD should be a choice for the sibling and not an expectation. The following reflection supports this concern:

> And I don't want my daughter to feel like she can't go away and live her life, and live a full life, because that is not what she was born to be, she wasn't signed on to be, this is my responsibility. (PA3)

Other concerns with future planning involved housing for the youth with ASD. One family had reported significant challenges in identifying a residential placement for their youth with ASD that would be able to provide support for both ASD and mental health concerns. Most options were limited in scope to older age adults or would only address mental health diagnoses.

### Providers

Providers reported that many parents, even teachers, and other providers were unaware of all that was involved in preparing for educational and healthcare transitions. Although Illinois requires that transition plans are developed as part of the student's IEP by the time the student is 14 ½ years old, parents and teachers were often uninformed about the details about transition plans or how to begin planning for the student's eventual exit from the K-12 system, including information about community supports and services. A provider commented:

> That [is] something I am very frustrated with the transition planning area, and we work on parent education, working on lot of teacher education, because the teachers don't realize that the resources that are out there. I would say it's very very minimum (PR7).

## Impact on families

### Parents

The lack of specialized ASD training was pervasive across systems of care, leading to a reactionary approach to services. Parents reported that they often turned to emergency departments to access health care for their child with ASD because there were few options available for preventive care. For example, one parent reported that they had to travel four hours to Chicago to secure an appointment with a psychiatrist. There was a 4-month wait for an appointment with their local psychiatrist. The lack of specialized services was even more pronounced for children with ASD who were nonverbal.

Parents also reported the financial impact on their families as a result of insufficient services and support. A few parents faced challenges in maintaining a professional job due to scheduling appointments for their child(ren) with ASD and the limited availability of childcare support. For example, one mother obtained her master's degree in speech-language pathology before having her twin daughters, who were later diagnosed with ASD. After the diagnosis, she was unable to maintain her career and focused on caring for her daughters. These challenges resulted in parents taking on lower-wage jobs that offered flexibility in their schedules to care for their child with ASD. Another mother left her professional career after her son was born to care for him. However, she then had to go back into the workforce as the family could not manage with one salary. To help manage the care for her 7-year-old son with ASD and two other children, she took a job as a cashier at a retail store due to the flexible hours available. Although this job offered some financial support to the family, standing for long periods of time caused a significant physical strain on her chronic pain condition. A community expert review (parent) shared that it was important to also consider the impact on siblings and the significant need to provide supports and resources for siblings as they care for and experience life with a sibling with ASD.

Parents experienced significant stressors and lack of resources that became a significant learning experience, which informed their current decision-making as caregivers. The lack of resources pushed parents to create resources among themselves. By creating their own support system when none were available, parents were empowered to take charge of their child with ASD and their family. This network served as a source of social-emotional support and helped parents better understand their child with ASD. Parents developed recreational activities for their children with ASD, including playgroups, dance and theater groups, music classes, social skills groups with LEGO ® toys, and other social activities with other children with ASD. Parents enjoyed these activities as they felt they provided a judgment-free safe space where their child's behavior would be accepted. Through these activities, parents connected with other parents who faced similar experiences with their child with ASD, thus creating a sense of solidarity. This allowed parents to resolve some of the frustration they felt in navigating the complex systems of care and establish a more positive approach.

### Providers

Providers acknowledged the impact of lack of ASD services and support on families and empathized with the demands parents faced in navigating the health and educational system, including coordinating therapies, medical appointments, and responsibilities for the siblings. One provider's comment echoed parents' experiences with the reactionary service approach due to the lack of resources and services.

> I think it's a lot of putting out fires. A lot of reactive. So, by the time a family gets to me …I am looking at just kind of help[ing] prioritize. You know, who do you need to speak to, what would be the best (PR7).

The impact of ASD was increased by barriers families faced with childcare, as one provider commented:

> A lot of parents have to be a stay at home, at least one stay at home parent… cause daycares can't provide for them. They don't have the funds to hire a staff member to be with that child, or to be in a room like twenty kids. Or … well there is no special ed room, I am not saying that there needs to be that, but there needs to be some type of funding to get like a para[professional] with that child all day so they can attend daycare and parent could work (PR2).

## Parents' Recommendations for ASD throughout the Life Course in Rural Communities

One of the primary challenges that parents reported was the coordination of services. Parents who had utilized early intervention services recalled positive experiences with the family-centered care coordination they received until their child's third birthday. Once their child exited the early intervention system, parents reported facing numerous challenges learning how to navigate and negotiate for services. As one mother reported:

> There is no point of entry system once you leave early intervention. And if the schools are inadequately prepared with that information, it's almost you the parent are educating the district, when you are already exasperated and tired and wiped. And you are seeking that help for yourself (PA3).

Other parents echoed the recommendation for coordination of services and the need for a one-stop-shop where families could be connected to the available services and supports, including Medicaid waivers, therapists, and recreational programs. Many of the services and supports that parents called for are aligned with services often provided by social workers. For example, social workers can help identify areas of need for children with ASD and their families, conduct research about available resources in the communities, provide referrals to resources and services, and advocate for children and families. As one parent explained:

> They don't have the answer right then, they can hunt it down, because they're a social worker, they are the clearinghouse for the services. They are doing the networking in terms of professional services. They are the ones … who advise you [on] … all that stuff that you don't know is coming till it's in your lap (PA2).

## Discussion

Understanding the experience of families of children and youth with ASD who reside in rural areas is critically important to address the significant disparities that have been identified within rural communities. In this research study, we examined the experiences of parents of children and youth with ASD and service providers who participated in providing education, care, and services to individuals with ASD and their families. A close look at their experiences through a life course lens, from diagnosis to transition and future planning, brings us insights into which services are lacking for these families. Semi-structured focus groups were conducted in rural counties in Illinois to gather information about participants' experiences in obtaining/providing a diagnosis, accessing/delivering services and supports, and the impact of ASD on the family through a life course perspective.

### Challenges and Resilience of Rural Parents Navigating Systems of Care through Transitions

Overall, families reported significant challenges in accessing services from early childhood through the transition to adulthood. Critical transitional events such as receiving a diagnosis, obtaining services in the educational and healthcare systems, transition out of pediatric care and the educational system, and future planning are significant in determining families' well-being. The lack of resources available in rural communities compounded with the distance families need to travel for services made accessing care and support particularly challenging.

Echoing findings from prior studies (Crimmins & Heggs, 2016), parents and providers attributed these challenges due to the lower resources available in the rural communities, specifically with the availability of trained, qualified health care professionals and lower financial resources to sustain the systems of care. A few parents and providers disclosed a systemic challenge was the lack of qualified health professionals who could provide specialized health care to children and youth with ASD. The lack of trained mental health professionals who can also provide services to individuals with ASD prevents families from accessing mental health care quickly. This challenge has been noted by others who have found that children with ASD in rural counties make more visits to the emergency departments than children with

ASD in urban counties (Zhang et al., 2017). These differences may be attributed to the lower availability of preventive mental health services and community-based outpatient supports.

Another barrier reported by parents was the limited scope of services or services available for a limited age range. One parent remarked on the considerable value of early intervention, with the recommendation that these comprehensive services be made available beyond the child's 3rd birthday. Additional concerns were also raised about the availability of adult supports for their children once they exited the K-12 system. For example, adults with ASD may need housing and residential supports. However, two parents discussed how residential services in their community were only available for older adults or adults with psychiatric conditions, and staff was unprepared and untrained to support adults with ASD. Other families of children with disabilities in rural areas have also reported similar experiences in accessing age-limited services and the challenges in planning for long-term supports for their adult children with ASD (Dew et al., 2013; Marsack & Perry, 2018).

Although families faced significant challenges in obtaining information and accessing services in the education and health care systems, many families also reflected on the resilience and empowerment they experienced in advocating for their child with ASD. Parents' resourcefulness was evident through their development of playgroups for children with ASD and informal support groups for parents. Other studies of families of children with ASD in rural communities have also identified strong protective factors emerging from the "sense of community" that develops among the parents of children with ASD (Young et al., 2019).

## Policy and practice implications

Numerous efforts are needed across all systems of care to improve the outcomes for families and children with ASD who reside in rural communities. This calls for increasing the availability and inclusion of ASD and related topics across coursework, continuing education, professional development, and training for education and health care providers (Johnsson et al., 2017). Efforts are being made in this area, including the use of technology and telemedicine to conduct diagnostic assessments (Goldstein et al., 2017; Juárez et al., 2018; Margolis et al., 2018), promote and deliver evidence-based practices to professionals and families (Antezana et al., 2017; Young-Pelton & Doty, 2013), and provide training to caregivers in rural communities (Bearss et al., 2018; Lindgren et al., 2016). Training should also address issues related to the dual diagnosis of ASD and mental health conditions. Between 40 and 70% of individuals with ASD are reported to have a co-occurring mental illness (Eaves & Ho, 2008; Nah et al., 2018; van Steensel et al., 2011). The high prevalence of mental illness and ASD calls for more informed providers to address the needs of these individuals. For example, Project ECHO (Extension for Community Healthcare Outcomes) can assist providers in rural communities with consultation services for complex cases with experienced providers (Mazurek et al., 2017, 2019). Greater awareness and dissemination of information about educational and health care policies are needed to inform parents, community members, educators, and health care providers.

Family and individual outcomes could be enhanced by improving the transition and future planning process and supporting siblings who care for individuals with ASD. Among caregivers of adults with ASD, future planning was positively related to greater satisfaction among caregivers (Burke & Heller, 2016). Despite the importance of future planning and its impact on the quality of life of individuals with ASD (Pfeiffer et al., 2017), caregivers of individuals with ASD face greater barriers in accessing information and financial support for future planning when compared to caregivers of individuals with other disabilities (i.e., Down Syndrome; Lee et al., 2019). Involving siblings within the future planning process can be a pragmatic approach to improving the quality of life of individuals with ASD and their caregivers. Studies have found that when siblings are involved in the caregiving process for individuals with disabilities, the effects extend beyond the individual with a disability, with positive impacts on maternal well-being, including greater health, lower stress, and greater family cohesion (Seltzer et al., 1991). Programs that can build upon existing sibling support and reduce barriers to future planning can improve the quality of life and health of individuals with ASD and their caregivers.

In addition to strengthening the service systems throughout the life course, interventions need to emphasize the importance of critical transitions and communication between service providers across these transitions. Parents recommended a one-stop-shop where parents can obtain services and get connected. The benefits of the one-stop-shop model for rural health and human services delivery have been discussed (Gutierrez et al., 2010). However, further evidence on how this service delivery model may benefit rural families of children with autism are needed.

## Limitations and future directions

Although the present study provides an overview from parents and service providers of children and youth with ASD on their experience within rural communities, our findings may not represent families in other rural communities. For example, all participating parents and service providers were White and were representative of the racial/ethnic composition of the rural counties included in this study. However, parents and service providers from distinct racial/ethnic backgrounds may report different experiences within rural communities. The barriers faced by parents in obtaining diagnostic assessments and services are also limited to families who were able to travel to a local community organization and share their time with the research team. Thus, this study may not capture the perspectives of families with higher caregiving needs and fewer resources. This study also captures the perspective of parents and providers of children and youth with ASD. The perspectives of children, youth, and adults with ASD were not captured in the current study. Their perspectives are important to consider within rural communities as they may highlight significant experiences and areas for support needs. Furthermore, we also acknowledge that the study has limited representation of the life course as our focus was on children and youth with ASD who were within the K-12 educational system (Phase 2 – Acquisition of capacity). Thus, our study does not capture the experiences of caregivers, providers, or adults with ASD within the middle adulthood and older adulthood periods of the life course. The findings should be viewed as a steppingstone for additional studies with larger samples and broader representation throughout the life course. The findings may not be generalizable given the limited number of participants.

A few methodological limitations are also worth noting. First, our sample was limited to parents and providers who responded affirmatively to our email recruitment attempts; therefore, the views presented in this paper may not reflect the views of other parents and providers in rural counties in Illinois. More focus groups would have helped increase the credibility of the study. The challenge in recruiting parents in itself, however, reflects the challenges rural families face such as lack of childcare and distance. Future studies with rural parents of children with ASD may consider providing childcare and plan for sustained community engagement to overcome barriers rural parents may face participating in research studies. Additionally, we could not perform other ways of triangulation such as data triangulation (Carter et al., 2014). Data triangulation using both interviews and focus groups may result in a better understanding of families' experiences.

More research and review of current practices are needed to examine how different professionals can address the needs of rural communities, including educators, social workers, physicians, and community health workers. Different methodologies for delivering information, education, and therapeutic services can also be explored to determine their role in addressing the significant disparities that affect rural communities. This includes conducting high-quality, rigorous evaluations on the use of technology, telemedicine, and telehealth practices and their impact on children and youth with ASD and their families in rural communities.

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## Declarations

**Conflict of Interest** The authors have no conflicts of interest to declare that are relevant to the content of this article.

**Ethics approval** The study was reviewed and approved by the University of Illinois at Chicago Institutional Review Board. The study was performed in accordance with the ethical standards described by the 1964 Helsinki Declaration.

**Consent to participate** Written informed consent was obtained from all participants.

**Consent for publication** The authors affirm that human research participants provided informed consent for publication of the content presented in the manuscript.

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