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Insights into healthcare services for youth with autism spectrum disorder transitioning to adulthood: a focus on rural Atlantic Canada

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Abstract

Individuals with neurodevelopmental disabilities, such as autism spectrum disorder (ASD) often require unique healthcare services. As adolescents age out of the pediatric health system, accessing appropriate healthcare becomes more challenging during the transition to adulthood. This challenge is amplified for individuals with ASD living in rural areas where access to healthcare services is limited. The aim of this qualitative study was to explore the experiences of stakeholders, including individuals with ASD, parents of individuals with ASD, and service providers, during the transition to adulthood in rural communities.

Methods

We recruited 26 individuals including 16 youth, 6 parents and 4 service providers through convenience and snowball sampling methods from Canadian Atlantic provinces. Semi-structured interviews were conducted, focusing on barriers and challenges encountered during the transition.

Results

Thematic analysis was employed to identify patterns and themes within the data. Three central themes emerged from the data including transport to and from care, limited resources, and continuity of care.

Conclusion

The findings underscore the significant challenges faced by individuals with ASD and their families during the transition to adulthood in rural areas. By understanding and addressing these challenges, stakeholders can work towards implementing informed policies to ensure equitable access to healthcare services for individuals with ASD transitioning to adulthood in rural areas.

Keywords Healthcare, Rural areas, Autism, Transition, Stakeholders' experiences

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Autism spectrum disorder (ASD) is as a neurodevelopmental disorder characterized by restricted and repetitive behaviour and deficits in social communication [1, 2]. The prevalence of ASD diagnosis has continued to rise each year across the world, and has drawn attention to what some have called an 'autism epidemic' [3]. According to the Public Health Agency of Canada, approximately one in 50 youth (2%) under the age of 17 have been diagnosed with ASD in Canada [4]. Most individuals diagnosed with ASD require some form of ongoing support including mental health, spanning from childhood into adulthood. However, as adolescents age out of the pediatric health system, accessing appropriate health care becomes more challenging during the transition to adulthood [5].

The transition from adolescence to adulthood is marked by many changes and uncertainties as adolescents' roles, relationships, and responsibilities in their communities begin to shift [6]. The transition does not solely impact the individual; but it affects the entire family. Parents often struggle with their evolving roles in their children's lives, adapting to a shift from direct caregiving to more supportive and guiding roles [7]. These adjustments, coupled with the uncertainties and challenges faced by their adult children, contribute to heightened stress levels within families. Families and individuals often experience increased anxiety, relationship difficulties, and frustration during this transition [7].

For adolescents with disabilities, the transition to adulthood poses additional challenges which may necessitate ongoing and specialized support beyond what typically-developing peers require [8]. In a previous project, we identified three major themes related to barriers to healthcare services for adolescents with disabilities transitioning to adulthood. First, accessibility and quality of care was highlighted as a significant barrier due to issues such as long waitlists to visit healthcare providers, high costs associated with services such as behaviour therapy, limited number of healthcare providers with specialized care knowledge, and geographic barriers due to a lack of providers in rural areas. Additionally, tensions regarding changes in guardianship, categorization of high versus low functioning, and eligibility for services were described by stakeholders. Lastly, navigating available services, transitional planning, and inter-provider communication present significant barriers [9]. A holistic approach integrating coordinated care strategies is imperative to effectively support adolescents with disabilities as they navigate the transition to adulthood [8, 10–12].

The challenges associated with the transition to adulthood are expected to be exacerbated for individuals living in rural and remote areas. Approximately 20% of Canadians live in rural or remote regions [13]. The uneven distribution of specialists and resources exacerbates these challenges. This particularly impacts families in rural areas seeking healthcare services [14]. The combination of geographic barriers and disparities in access to specialized care compounds the difficulties faced by rural communities, limiting their ability to access crucial support services. Individuals living in poverty, and individuals with chronic health conditions encounter significant hurdles in accessing adequate healthcare, leading to poorer health outcomes [15].

Challenges during transitions in rural areas often revolve around limited access to resources and specialized services. Adolescents in rural areas encounter obstacles in accessing mental health and specialized health services [15]. Regarding challenges to receive services in rural areas, geographic isolation remains a primary barrier. Sparse population density leads to fewer healthcare facilities and specialists, resulting in longer travel times and financial strain for families seeking specialized medical care, therapies, or mental health services [16]. Moreover, the shortage of healthcare providers and professionals in these regions often translates to longer wait times for appointments and reduced availability of timely interventions, impacting the overall quality of care [17].

Understanding the experiences of adolescents with ASD, and their families during the transition to adulthood is critical in addressing the unique challenges they encounter. Although there is literature related to access to services in rural areas, there is very limited information considering transitions in rural areas. Particularly, limited literature exists that focuses on the transition experiences of youth with ASD in rural areas, highlighting the urgent need for research in this domain. Resolving these challenges requires a comprehensive exploration of stakeholder experiences involving adolescents, families, and healthcare providers. By exploring these experiences, the current study aims to fill the gaps in the literature and promote policy change to support access to services for this population.

Methods

Research design

This study utilized a qualitative approach with the aim of exploring the experiences of stakeholders including individuals with ASD, their parents, and service providers during the transition to adulthood in rural communities. We used an interpretive description approach [18], grounded in a constructivist epistemology, which views individuals' experiences as socially constructed to understand the context.

Sample

The recruitment strategy was convenience sampling through emailing organizations supporting individuals with ASD in the region as well as posting posters on bulletin boards in community centres. Snowball sampling was also used by asking prospective participants to share information about the project with their communities.

Youth between the ages of 15–25 years were eligible for the study if they were able to communicate verbally. Parents were eligible if they had one or more children who had been diagnosed with ASD. Service providers were eligible if they had worked with an individual diagnosed with ASD for a minimum of one year. All participants were required to live in rural/remote areas in Atlantic Canada.

Data collection

Following ethical approval by the Dalhousie University Behavioural Ethics Board, data collection in this study involved conducting interviews with stakeholders. Stakeholders were asked to participate in a 60-minute interview. Interviews were scheduled at times that were convenient for participants. The interviews were conducted virtually using Teams platform or over the phone to allow for communication with participants living in remote locations. The interview guide and questions were developed by our research team members in collaboration with two parents of individuals with ASD who provided us with input. The interviews followed a semi-structured format, incorporating open-ended questions. The same questions were used for each group of stakeholders, with minor wording changes. The questions focused on exploring barriers and challenges encountered during the transition to adulthood. The examples of questions were: Please share a story about a time when an individual with ASD in rural areas tried to access services; How could they access the resources they need; What made it easier or harder; How could they navigate the healthcare during transitions to adulthood; What steps can they take to ensure they receive the right care at the right time?

To ensure anonymity, pseudonyms were used to refer to participants in all interview transcripts. Interviews were audio recorded by researchers to capture participants' responses accurately to ensure fidelity to participants' perspectives in the analyses. A research assistant transcribed the interviews verbatim, capturing the nuances and details of the participants' responses.

Data analysis

A thematic analysis was undertaken to explore, analyse, and interpret patterns and themes within the dataset among all participants, regardless of their stakeholder groups. First, a research assistant transcribed all the interviews. Two research assistants independently read the first two transcripts to code concepts line by line using NVIVO software. Any discrepancies or disagreements in coding were resolved through discussion between the two coders. In instances where consensus could not be reached, a third research assistant settled disagreements to ensure coding accuracy and consistency. A code book was created, allowing the two coders to continue coding of the rest of transcripts. After coding all transcripts, the research team met to organize the similar concepts into several categories. Then the similar categories were merged together to develop overarching themes. This approach provided a comprehensive understanding of the data and facilitated the exploration of key themes which contributed to the interpretation of the research findings.

To enhance the credibility of findings, member checking was implemented, allowing participants to review and validate the preliminary analysis. Triangulation, by incorporating multiple perspectives, was employed to strengthen the robustness of the analysis. Reflexivity was practiced throughout the research process, with the research team maintaining awareness of potential biases and engaging in critical reflection to minimize their influence on data interpretation.

Results

A total of 26 participants were included in this study after meeting eligibility requirements. The participants were drawn from three distinct groups: 16 youth with ASD, 6 parents of individuals with ASD, and 4 service providers. The youth with ASD were aged between 16 and 23 years, with an average age of 19.5 (SD =3.5). Parents of youth with ASD were aged between 46 and 63 years, while their adult children with ASD ranged in age from 16 to 20 years, with an average age of 18 (SD =1.5). The service providers were between 40 and 56 years old, with their years of experience in the field of ASD ranging from 8 to 11 years, and their average years of experience was 8.7 (SD =1.47). Two service providers were behavioural therapists, one was a psychologist, and another was a speech language pathologist. All participants were living in rural areas in Atlantic Canada, including 11 in Nova Scotia, 5 in Newfoundland and Labrador, 2 in Prince Edward Island, and 8 in New Brunswick.

The data collected from the stakeholders revealed three central themes including: (a) transport to and from care (e.g., long commutes, limited access to public transportation, and poor user-friendly infrastructure); (b) limited resources (e.g., services only in metropolitan regions, the lack of specialized services, limited funds); and (continuity of care (e.g., transitional supports, service providers training, preparation of parents). The themes and categories can be seen in Table 1.

Transport to and from care

Individuals with ASD may require specialized services and supports. Receiving these services while living in

Table 1 Experiences of transitioning to adulthood for individuals with ASD in rural areas

Themes	Transport to and from Care	Limited Resources	Continuity of Care
Categories	Long Commutes	Services Only in Metropolitan Regions	Transitional Supports
	Limited access to Public Transportation	The lack of Specialized Services	Service Providers Training
	Poor User-Friendly Infrastructure	Limited Funds	Preparation of Parents

rural areas can be difficult as rural communities are often isolated from essential healthcare services. Participants in this study highlighted the long commutes, limited access to public transportation, and poor user-friendly infrastructure as factors that affect the reachability of resources.

Long commutes

The majority of participants underscored the considerable commute times to access healthcare services, especially for individuals residing in rural areas. The need for transportation to manage lengthy commutes for health services was emphasized. For example, Betty, a parent of an individual with ASD, expressed these challenges by saying, "*People in rural areas sometimes have to drive upwards of 4 hours to access services*." Moreover, Carol, another parent, highlighted the necessity of proximity to services by sharing, "*being in [a metropolitan] area in particular [helps with], having access to resources at least within 30 minutes of something that you can get access to, whether it's community supports or programs*." These responses show the impact that long commutes have on families and individuals with ASD who seek healthcare.

Additionally, Mark, an individual with ASD, shared an example of the extraordinary lengths that individuals in rural areas must take to receive healthcare. He said, "*my ex is actually from a small town and anytime she had to go to a clinic, she had to drive like 4 hours to get her to the closest one*." This underscores the significant challenges individuals and families face in accessing healthcare services due to long commute times, particularly in rural areas. Uneven geographic access to specialists and resources creates further impediments for individuals in accessing essential care, with long commutes potentially consuming most of their time.

Limited access to public transportation

Participants expressed concerns about the limited availability of public transportation, which significantly reduces individuals' ability to access healthcare services, especially in rural areas where metropolitan transit buses do not extend their routes. The absence of convenient transportation options compounds the challenges faced by individuals with ASD transitioning to adulthood.

Kim, a service provider, highlighted the overarching issue, stating, "*being in rural areas and maybe not having access to transportation can be a huge thing as well*." This sentiment was echoed by other service providers like Della, who emphasized the difficulties in rural areas by stating, "*in more rural areas, figuring out transportation is harder*." These quotes illustrate the difficulties faced by both healthcare providers and families when there is a lack of public transportation options available.

Furthermore, Betty, a parent of an individual with ASD, shed light on the limitations of existing public transportation, emphasizing that "*the access-a-bus doesn't go all the way to my place*." This sentiment was echoed by another parent, Carol, who emphasized the practical challenges posed by inadequate public transport. Carol, remarked that, "*metro [*metropolitan*] transit bus doesn't come out to our place either, so he [my son with ASD] wouldn't be able to take that bus*." These statements underscore the limited reach of existing transportation services, which fail to adequately serve individuals with ASD and their families residing in rural areas. The limited public transportation in rural regions exacerbates the isolation and barriers to care experienced by individuals with ASD and their families. Without reliable transportations, individuals struggle to coordinate travel to and from appointments, further complicating their access to healthcare services.

Poor user-friendly infrastructure

The poor quality of existing public infrastructure emerged as a prominent challenge in accessing healthcare services for individuals with ASD transitioning to adulthood in rural areas. Participants highlighted the quality of public transportation as a factor to exacerbate the already complex process of accessing healthcare services.

Many participants noted that taking public transportation was difficult due to sensory overload. One individual with ASD, Mark, noted, "*public transportation is very hard for me, as I do not like being in crowds*." This sentiment was echoed by Sebastian, another adult with ASD, who stated that *"noises make me anxious, so I avoid public transportation*." Such sensory sensitivities can create significant challenges in accessing healthcare. Parents also discussed the challenges associated with taking public transportation for their children. Similarly, Madison, a parent discussing the experience of her son with ASD by saying, "*he [my son with ASD] can do only short rides on [the] bus*." These illustrate the poor user-friendliness of public transportation, which may limit how individuals with ASD can independently attend their healthcare appointments.

For individuals with physical or sensory disabilities, the accessibility of pedestrian infrastructure and proximity to bus stop locations can also affect their experience. Some of participants highlighted the lack of sidewalks and pedestrian-friendly infrastructure, which significantly restrict mobility options for individuals with ASD. Ben, a parent of an individual with ASD, pointed out that "*he [my son with ASD] can't walk to the places, because the road is busy and there's no sidewalk*," illustrating the physical or sensory barriers that impede safe and accessible travel to healthcare service locations.

These quotes indicate that the poor quality of viable transportation and pedestrian infrastructure hinder the ability of individuals with ASD and their families to easily access healthcare services.

Limited resources

The accessibility and availability of programs and services for individuals with ASD transitioning to adulthood vary significantly between metropolitan and rural regions. Participants emphasized several key areas of disparities in the accessibility to resources across different geographic areas, including services only being available in metropolitan regions, the lack of specialized services, and limited availability of funds.

Services only in metropolitan regions

The concentration of programs and services in urban centers adds to the challenge of accessing healthcare services for individuals with ASD living in rural areas during the transition to adulthood. For example, Ben, a parent of an individual with ASD, underscored the urban-centric nature of services, noting, "*community services are [located in places] where people go, ... they're in city, I think most places are*." Without programs in rural areas, families are forced to travel long distances to access resources. This was echoed by all service providers and some youth as well.

Participants also expressed frustration over the limited expansion of pilot programs beyond metropolitan regions, preventing individuals in rural areas from accessing innovative services. Charlotte, a parent of an individual with ASD, highlighted the frustration stemming from the centralization of services in metropolitan regions, stating,

> *"Whenever we have services, it's always piloted, created, established in metro, and often it stays in metro. They don't do pilots anyplace else, so a lot of our folks can't access those beautiful, wonderful, things that are going on with autism in metro - they start an EIBI program [early intensive behavioural intervention program], where did they start it? In metro."*

Comparing the broader range of services available in metropolitan to rural areas illustrates the stark differences in resource availability based on geographic location. Such lack of geographical equity in resource allocation perpetuates disparities in service accessibility and restricts individuals' ability to benefit from relevant programs.

The lack of specialized services

Specialized services and care are primarily accessible in urban areas, posing challenges for individuals with ASD living in rural areas. Participants expressed concerns about the number of specialized service providers available in rural communities, questioning whether their children's needs would be adequately met outside of the urban centers. Parents of individuals with ASD such as Jill articulated these concerns, expressing uncertainty about her son's ability to access necessary supports in their small town. Jill stated:

> *"I don't see myself leaving [our small town], and I want [my son with ASD] to be close to me, but I don't know that he's gonna have his [special] needs met here… I'm like, oh, am I gonna have to move to like a big city when he turns 20, so that he can access like programs and stuff? I don't want to do that. But I also know that he needs to leave the nest, and I want him close to me."*

The limited access to specialized services in rural areas provokes some dilemma and limits families' autonomy about where to continue living. Other participants further highlighted the logistical barriers associated with accessing specialized clinics and services in rural areas. For example, Renee, a parent stated that "*the neighborhood, the [nearest] hospitals don't have, you know, these special services for people with disabilities.*" This makes it difficult to access informed care without traveling to urban regions. Similarly, another parent, Claire, shared her experience when her child required emergency medical care. She said "*the people at ER [here] do not know how to work with people with autism. They don't understand it*." This shows that there is a significant gap in the specialized services and care available in rural areas, exacerbating the challenges faced by individuals with ASD residing outside urban regions during their transition to adulthood.

Limited funds

Financial constraints were noted by stakeholders as a factor which can influence accessing essential services for individuals with ASD and their families. Participants underscored the exorbitant costs associated with private services, which often exceed families' financial capabilities. Lily, an individual with ASD, shared her first-hand experience by highlighting the financial burden for individuals with ASD. She said:

> *It's [ABA is] not covered under insurance. Because unless it's billed through a psychologist like a registered certified psychologist, it's not insurable. And we didn't realize it was going to come to that, and it's not like we're hurting for money, but $800 a month is a lot of money for anyone.*

This sentiment was echoed by Theresa, a parent of an individual with ASD, who highlighted the financial strain of accessing private services, noting that while private therapy may have the high quality, "*we are not in a financial environment where we can just, you know, continue to use private, unfortunately we need to depend on other publicly funded supports*." Participants noted the loss of provincial financial support, upon their children reaching adulthood, which exacerbates accessing to essential services. Lauren, a service provider, mentioned "*they [individuals with ASD] lose that [financial support] when they turn 18*.". This loss of financial support can worsen the strain on families already dealing with the high costs of care.

Some participants underscored the challenges faced by low-income families, who primarily live in rural areas. For example Lauren, a service provider, stated, "*the financial barrier is a huge piece, so for families that are low income [who often live in rural areas], it can be more challenging to navigate those systems, to find like the time to do it [therapy], you know if you're working two or three jobs, it can be hard to do that piece as well*." This shows that there is an added cost for individuals who live in rural areas as there is a disparity in the distribution of resources across various geographical areas.

When asked about the focus of future efforts to support families of individuals with ASD, Kate, a parent of an individual with ASD, stated "*I think, it all comes down to, you know funding and being able to access the funding.*" This highlights the importance of continuation of receiving adequate financial supports during transitioning to adulthood.

Continuity of care

Continuity of care for individuals with ASD during the transition to adulthood is crucial for ensuring consistent support and successful adaptation to new challenges and responsibilities. The quality of continued care for individuals with ASD can be influenced by factors, including the transitional supports, the training of service providers, and the preparation of parents.

Transitional supports

Participants expressed disappointment over the absence of a structured transition process for individuals with ASD as they age out of pediatric care. Thea, a parent of an individual with ASD, shared her surprise, stating, "*at 18, I would not expect that the autism team would have closed up shop, I was surprised to find out that they were ending their support*." This was a common sentiment among parents who noticed an abrupt halt in check-ups and services as their children reached adulthood. For example, Julie, a parent of an individual with ASD stated, "*they [the clinic] stopped taking my calls, they stopped, making appointments, they just stopped*." This sudden cessation of support services around the ages of 18 to 19, with no transitional plan or access to adult services, left individuals with ASD and their families feeling abandoned by the healthcare system.

Service providers training

Parents of individuals with ASD raised their concerns regarding the inadequate training of service providers particularly in rural areas, where generic services are often the only available option. Jill, a parent of an individual with ASD, expressed her frustration by stating that, even though mental health resources were minimal in her region, they were hands on in the beginning but the support tended to drop in quality quickly. She stated that, "he [my son's service provider] would look at me, or [would] just say, like really basic things, I'm like, yes, obviously I tried that." This indicates the lack of ASD-related trainings among providers, which further complicates the challenges faced by individuals with ASD and their families during transitions.

Other parents of individuals with ASD such as Claire, further highlighted the necessity of training among professionals. She expressed that, "*the people at the addictions office had no training in autism*." This lack of training can hinder the support individuals with ASD receive, especially during the critical transition to adulthood. Properly trained professionals are essential in providing tailored guidance and services that address the unique challenges faced by young adults with ASD as they navigate this significant life stage.

Thea, a parent of an individual with ASD, underscored the broader issue, by stating, "*some of that [my son's] anxiety has been caused over the years by adults in the professional fields, who are not trained to deal with kids on the spectrum*." When healthcare professionals lack up-to-date knowledge about ASD, this can create additional stress for parents and individuals with ASD by making their interactions with the healthcare system more complicated and time-consuming.

Preparation of parents

Stakeholders indicated that individuals with ASD and their parents encounter significant challenges due to the lack of comprehensive navigational support during transitions, leaving them feeling ill-equipped to manage the complexities of ASD care. For example, Della, a service provider, expressed frustration over the scarcity of accessible information for parents, highlighting their difficulty in obtaining crucial details about transitioning their children to adult care. She stated, "*parents [are] being frustrated with not being able to get information about transitioning*." This frustration reflects a broader systemic issue, where parents are not informed and prepared about critical aspects of their child's care.

Lily, an individual with ASD, noted the importance of early guidance and support, advocating for accessible information about available services as early as grade ten to support individuals with ASD and their parents. She described that, "*they [service providers] do that with other [neuro-divergent] kids, like when they get there [at a certain age], they have guidance like this is what's out there*." Access to information is crucial in ensuring that individuals with ASD can make informed decisions about their future. This early access to information can aid in smoother transitions to adulthood and helps in planning for post-secondary education, employment, and independent living.

Selena, a parent of an individual with ASD, emphasized the necessity for long-term support, noting the overwhelming burden on parents. She stated, "*we need life coaches for children with autism, we need people to advocate, [because] the parents are exhausted*." This sentiment underscores the need for supportive structures within the healthcare system to alleviate the stress and uncertainty experienced by parents.

The lack of preparations of those with ASD and their parents during transitions exacerbates the already daunting task of managing care. Addressing this issue requires the implementation of proactive measures to equip individuals with the knowledge and resources needed to effectively support individuals with ASD during the transition to adulthood.

Discussion

The purpose of this project was to investigate the unique challenges faced by individuals with ASD and their families during the transition to adulthood in rural areas. While some research has examined barriers to accessing healthcare during life transitions, the novelty of this study lies in its focus on the underexplored context of rural communities. Geographic isolation and limited access to specialized healthcare services compound the difficulties of transitioning to adult care for individuals with ASD. Our findings revealed three central themes: transportation barriers, limited resources, and continuity of care. Specifically, long commutes and inadequate public transportation hinder access to essential services; the concentration of specialized resources in urban centers creates disparities; and the abrupt cessation of paediatric services, coupled with insufficient provider training, disrupts continuity of care.

The first challenge to accessing healthcare faced by rural-living individuals with ASD is arranging transportation to and from care facilities. We found that during the transition to adulthood, individuals with ASD, their families, and service providers reported a lack of public transportation options and long commutes can make attending appointments difficult and disrupt their daily lives. These findings are in line with previous research examining the experiences of families in rural communities with complex care needs, which identified that transportation was a significant barrier to accessing care [19–26]. Rural families in North America may live over 100 km from specialists, making it challenging to access necessary medical services [27]. It has been shown that although residing in Canadian rural areas may offer a potential sense of community to help build capacities, a major challenge lies in the accessibility, reachability, and availability of services [28–30]. The current findings have significant implications for the design and implementation of services and support systems that address the needs and priorities of underserved communities. The lack of accessible public transportation options that extend to rural areas forces families to rely on personal vehicles, adding to the financial burden due to fuel costs and vehicle maintenance [31]. For families with lower socioeconomic status, these expenses can be prohibitive. The routes in rural areas can be challenging to navigate, especially during adverse weather conditions, further complicating access to necessary healthcare services [24].

In addition to limited access to public transportation, poor user-friendly infrastructure hinders individuals' ability to use these options. Participants reported a lack of walkable routes to service centres, and overwhelming sensory environments when utilising public transportation. This finding is supported by prior literature which has found that public transport is often not accessible to individuals with ASD due to difficulties with spatial navigation, heightened anxiety, and sensory overload, all of which are common issues in individuals with ASD [25, 32]. Individuals with ASD may struggle with necessary actions such as navigating to a bus stop without help or safely crossing the road alone [25], which can impede their ability to use public transport without creating more disability-friendly services. Additionally, increased independence is often a critical goal for individuals with ASD transitioning to adulthood [33]. However, without the ability to use public transport to attend medical appointments and other essential services, these individuals may remain dependent on their parents or caregivers for transportation. This dependency not only limits their sense of autonomy but also may complicate plans as appointments must be planned around multiple individuals' availability.

The second challenge identified by stakeholders in this study in accessing healthcare services during the transition to adulthood in rural areas was the significant disparity in the availability of resources and services compared to metropolitan areas. Parents and individuals with ASD reported feeling underserved in terms of resources such as new EIBI programs and other community services. While there is limited information about the accessibility of healthcare services specifically for youth with ASD in rural areas, our findings align with existing literature on healthcare accessibility in rural areas for the general population [34–37]. The distribution of healthcare services across Canada shows significant differences between rural and urban areas [38, 39]. In urban settings, there is a higher density and concentration of services, including educational support, healthcare, and social programs tailored for individuals with ASD and their families [34, 37]. The scarcity of such services in rural areas may pose a substantial barrier to accessing healthcare during the transition to adulthood. Previous interviews with rural-dwelling families and healthcare service providers have similarly reflected the sentiment that a major barrier to accessing mental health care for children and adolescents in rural areas was the shortage of human resources. Limited numbers of mental health specialists and other specialised services results in long waiting lists and referrals to providers in metropolitan regions, requiring a long commute [34].

Our findings also suggest that individuals with ASD in rural areas may face a lack of specialised healthcare services during transition to adulthood. The provision of mental health care services for individuals with ASD requires specialised knowledge. Participants reported worry that their children would be unable to access specialised supports and ASD-informed care in rural communities, leading them to need to relocate to more metropolitan areas once they reach adulthood. These results are supported by research suggesting a lack of ASD and other mental health-specific care in rural regions [21, 24, 40]. Additionally, individuals with ASD are more likely to experience comorbid mental health conditions such as anxiety disorders, mood disorders, and other neurodevelopmental disorders [1]. An increase in healthcare professionals in rural regions who are equipped with the knowledge and skills to address the unique challenges faced by people with ASD is needed. Mental health resources are particularly scarce in rural areas, which is concerning given the prevalence of mental health issues among individuals with ASD [37, 40, 41]. The lack of adequate support systems and mental health services not only affects the individuals directly but also places additional stress on their families.

The third major challenge faced by rural-dwelling youth with ASD and their families during the transition to adulthood is a lack of continuity of care. Our findings that parents and youth feel abandoned or underprepared for the transition to adult care are in line with previous literature emphasising the need for long-term support across this pivotal period. Despite the fact that youth with ASD are at increased risk for numerous physical, mental, and behavioural health issues during the transition to adulthood [42], their access to healthcare services decreases once they reach adulthood. This lack of access is further amplified in individuals of low socioeconomic status and minority backgrounds [43]. In fact, youth with ASD are half as likely to receive transitionary care services as youths with other complex healthcare needs [44]. The absence of structured transition processes and transitional supports leaves individuals and their families feeling abandoned, as evidenced by participants' disappointment when paediatric services abruptly end. This gap in services is particularly significant for individuals with ASD, who often require consistent and specialised care to navigate new challenges and responsibilities effectively [45]. Without a transitional coordinator to guide families through the complexities of adult services, the stress on both the individuals with ASD and their families is immense. This lack of support can lead to feelings of being overwhelmed and unprepared. One explanation for the decrease in access to healthcare in adulthood is a lack of adult healthcare providers who feel confident caring for patients with neurodevelopmental disorders due to inadequate education in this area [46–49]. This reflects the concerns of participants in this study and highlights the urgent need for solutions such as targeted training for service providers to ensure individuals with ASD continue receiving appropriate care during and after the transition to adulthood. Furthermore, collaborative relationships within providers can play a key role in the transition to adulthood by offering support, guidance, and advocacy in navigating complex medical systems. They help young adults to become more self-sufficient, equipping them with the necessary resources and knowledge to manage their healthcare independently [50, 51].

Moreover, there is a necessity for parents of individuals with ASD to be adequately prepared for their child's transition to adulthood. Our findings echo prior literature that underscores the importance of early guidance and support, as illustrated by the parent participants' frustrations over the scarcity of accessible information about available services and preparing their children for independence. Parents play a significant role in the coordination of the care their children receive, and this continues during the transition to adulthood [52, 53]. Additionally, the transition to adulthood can bring unique stressors for parents. The health and well-being of parents often worsens as their children with ASD transition into adulthood [54, 55]. During the transitionary period, parents often experience heightened levels of uncertainty, anxiety, and depression [55]. Similar to our findings, studies have found that parents of individuals with ASD highlight their worries that their children will struggle to manage their healthcare needs independently and remain safe as adults [56]. Proper preparation and access to detailed information about services can greatly aid in smoother transitions, enabling individuals with ASD and their parents to plan for the future. The stress experienced by parents, coupled with their expressed need for long-term support structures such as transitionary care experts and advocates, underscores the broader systemic issues that require urgent attention to ensure a more seamless transition to adulthood for individuals with ASD.

Limitations

Our study has several limitations that should be considered when interpreting the results. First, we did not collect information about racial or ethnic identity of participants and the small sample size limits the generalizability of our findings. Future research should include a larger, more diverse sample to provide a broader understanding of the transition experiences of individuals with ASD in rural areas. Second, our participants included service providers from different disciplines, which could introduce variability in their perspectives and experiences. Furthermore, probably the youth participants lacked sufficient experience in independently seeking health services during transitions due to family support. Given that the scope of this project was not comparing the views of each group of stakeholders, a more focused approach, examining potential differences in viewpoints among stakeholders in detail, might yield more precise insights. Third, our sample was predominantly female, which may bias the findings as gender-specific experiences and perspectives could differ. Finally, the types of services, transitional supports, or specialized care participants received varied, potentially shaping their perspectives on transitioning to adulthood. A more controlled approach to the types of services examined could help clarify these influences.

Future directions

To build on the findings of this study and address its limitations, future research should consider several key directions. First, larger-scale studies with more diverse samples are needed to enhance the generalizability of the results. Including participants from different geographic regions and socioeconomic backgrounds will provide a more comprehensive understanding of the transition experiences of individuals with ASD. Second, conducting multiple interviews throughout the transition process can offer deeper insights into how these experiences evolve over time. Third, interviewing navigators or coordinators who assist with transitions could provide valuable perspectives on the systemic challenges and potential solutions for improving continuity of care. Additionally, targeted training for service providers on the unique needs of individuals with ASD and collaborative interprofessional work, especially in rural areas, is essential to enhance the quality of care during this critical life stage. Implementing these future directions will help create a more robust body of knowledge to support the development of effective interventions and policies for this vulnerable population.

Conclusion

This study sheds light on the unique challenges faced by individuals with ASD and their families during the transition to adulthood in rural areas. Our research fills a significant gap in the existing literature, which has largely overlooked the specific issues related to mental health care transitions in rural settings. We discovered that transportation barriers, limited access to specialized resources, and a lack of continuity of care are the primary obstacles for this population. The novelty of our project lies in its comprehensive exploration of these issues within the context of rural communities, highlighting the importance of access to resources in shaping these experiences. Our findings underscore the necessity for inclusive care models that are better equipped to handle the unique needs of rural-dwelling individuals with ASD. By providing detailed insights into these challenges, we aim to inform policy changes that will improve access to essential services and support for this underserved population.

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Authors' contributions
Dr Ghanouni was an associate professor at the time of this study, and conducted the study, collected, and analyzed the data, and contributed to writing the manuscript. Tara was involved in analyzing the data and writing sections of the manuscript.

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Data availability
All data is available and included in the manuscript.

Declarations

Ethics approval and consent to participate
The ethics approval was obtained by our university behavioural research ethic board and all participants gave informed consents before attending the study. Youth below 18 gave assents and their parents/guardians provided consents. All interviews were performed in accordance with relevant guidelines and regulations.

Consent for publication
NA.

Competing interests
The authors declare no competing interests.

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