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A Service Desert: Unmet Needs of Individuals with Autism and their Families

Un désert de services : besoins non satisfaits d'individus avec un trouble du spectre de l'autisme et leurs familles

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Abstract

Background: *Families face substantial barriers to timely assessment and intervention services for their children, particularly in remote areas. This study reports results of a survey in an effort to promote better service options for underserved children with autism spectrum disorder (ASD) and their families in the Inland Empire region of California.*

Method: *Parents, medical practitioners, and service providers (N = 90) completed surveys of unmet needs. Results were analyzed quantitatively and qualitatively.*

Results: *Only 13% of participants felt that service/healthcare needs were currently met; specific needs included: (1) increased access to a variety of services, (2) overcoming barriers to treatment and/or evaluation services, and (3) additional training and/or education for medical practitioners and service providers.*

Conclusions: *There is a critical need for increased access to comprehensive assessment and services. Recommendations include increased practitioner training and the development of comprehensive services such as an autism centre that focuses on research, education, and service in developmental disabilities.*

Résumé

Contexte : Les familles font face à des obstacles considérables pour accéder à des services d'évaluation et d'intervention pour leur enfant en temps opportun, particulièrement dans les régions éloignées. Cette étude présente des résultats d'un sondage dans afin de promouvoir de meilleures options de services pour les enfants ayant un trouble du spectre de l'autisme (TSA) et leurs familles mal desservis dans la région d'Inland Empire en Californie.

Méthode : Des parents, des médecins et des dispensateurs de services (*n = 90*) ont complété des sondages concernant les besoins non satisfaits. Les résultats ont été analysés quantitativement et qualitativement.

Résultats : Seulement 13% des participants sentaient que les besoins en services/soins de santé étaient présentement satisfaits ; les besoins spécifiques incluaient : (1) un accès accru à une variété de services, (2) surmonter les obstacles aux traitements et/ou aux services d'évaluation, et (3) des formations et/ou une éducation supplémentaire pour les médecins et les dispensateurs de services.

Conclusions : Il est crucial d'augmenter l'accès à une évaluation et des services complets. Les recommandations incluent une formation accrue des praticiens et le développement de services complets tels qu'un centre en autisme qui se concentre sur la recherche, l'éducation et les services dans le domaine des troubles du développement.

Mots-clés : trouble du spectre de l'autisme, évaluation, intervention, services complets, formations aux praticiens.

Introduction

Autism spectrum disorder (ASD), a neurodevelopmental disorder characterized by social communication difficulties and restricted and repetitive behaviours, is currently estimated to affect 1 in 44 children (Maenner et al., 2021). The importance of early intervention for addressing these difficulties has been well-documented (Boyd et al., 2010). For example, a systematic review examining early intervention found that those identified at a younger age received more hours of treatment and subsequently demonstrated increased developmental gains (Bradshaw et al., 2015).

Barriers to Timely Diagnosis and Early Intervention

Despite the importance of early intervention, many families face barriers to timely identification. Lower socioeconomic status (SES), residence in a rural area, identification as Black or Latinx, and parent immigrant status have been associated with later age of diagnosis (Fountain et al., 2011; Magaña et al., 2013). In a study characterizing these barriers for Latinx families, Zuckerman and colleagues (2014) found that Latinx parents of children with ASD cited (1) lack of accurate community resources about ASD, (2) challenges with accessing care due to poverty, and (3) inconvenience, time-intensiveness, and confusion associated with the health service system. Similarly, Iland and colleagues (2012) found that among 96 Latinx mothers of children with ASD in California, the majority reported high levels of unmet support needs, including difficulties with understanding the medical and social services systems (84.0%), finding a professional to make a diagnosis (70.8%), and family members/elders thinking there was no problem, suggesting that they could be missing key signs of ASD (69.2%).

For immigrant families, practical (e.g., access to insurance, knowledge about the healthcare and education systems, transportation, language barriers) and cultural (e.g., beliefs, values) factors contribute to disparities in timely ASD diagnosis (Lin et al., 2012). This may include interpreting children's behaviours differently from healthcare professionals or teachers, the majority of whom are White, potentially missing early signs of ASD, and/or limiting communication around the diagnosis (Blacher et al., 2019). Additional contributing factors to these disparities include (1) weak outreach efforts and limited culturally-competent practices within healthcare, (2) lack of trust in services and providers, and (3) greater reliance on family members over professionals (Barrio et al., 2019). In sum, research suggests that racial/cultural background, SES, geographic location, and parent immigrant status critically impact the age of ASD diagnosis and subsequent access to services.

Inland Southern California

The Inland Empire (IE) region of Southern California represents a geographical area facing many of these barriers. The IE, a region east of Los Angeles County, includes San Bernardino and Riverside Counties, each with estimated populations over 2 million (U.S. Census Bureau, 2021). According to projections from 2020 U.S. Census data, approximately half of these counties' populations are Hispanic or Latinx, compared to 18.5% of the United States. Similarly, the percentage of people in the IE who speak a language other than English at home is estimated to be greater than 40.0% (the United States as a whole = 21.5%). The median household income (in U.S. dollars) is lower across the IE (San Bernardino = $65,761; Riverside = $70,732) than for California as a whole ($78,672). Additionally, almost 10% of people under age 65 in San Bernardino and Riverside Counties do not have health insurance, compared to 9% in the state of California and 10% in the United States broadly (U.S. Census Bureau, 2021). The IE is also home to a large immigrant population. According to estimates from the U.S. Census Bureau, more than 20% of the population is foreign born (compared to 13.5% nationwide), and the majority of these immigrants have limited English proficiency.

Taken together, the IE is home to many children and families who experience increased risk (due to the population make up of this geographic region) for delayed diagnosis of ASD and access to treatment (Fountain et al., 2011; Mandell et al., 2009). However, the barriers faced by families in trying to access timely ASD assessment and intervention have not yet been characterized. The aim of the present study was to examine the service needs of children with ASD from the perspectives of parents, service providers, and medical practitioners. Research questions included:

1. What are the current assessment and evaluation needs of children with ASD and their families in a largely remote desert region?
2. What are the current intervention and healthcare needs of children with ASD and their families in this geographical area?

Methods

Participants

Participants ($N = 90$) included parents of children with ASD ($n = 55$), service providers ($n = 20$), and medical practitioners ($n = 15$) in the IE who completed an anonymous online survey about ASD services in the region. For parents, the mean age of their child was 4.4 years (range = 3-29; standard deviation = 5.1); most (60%) reported that their child had co-occurring diagnoses, with 21.2% reporting an intellectual disability. Among parent respondents, 62% indicated that their child was currently receiving services for ASD (e.g., behavioural therapy, speech services, etc.). ASD service providers reported being: board certified behaviour analysts (BCBAs) or behaviour technicians (30%); organization leaders (30%); or managers/coordinators (24%). The majority of medical practitioners specialized in psychiatry (67%). See Table 1 for participant demographics. All participants consented at the outset of the survey, which took place prior to the COVID-19 pandemic.

Table 1

Participant Characteristics (N = 90)

Characteristic	Majority Percentage or Mean
Parents (n = 55)	
Age of Child	Mean = 13.0 years (range: 3-29; SD = 5.1)
Age of Child at Diagnosis	Mean = 4.4 years (range: 1-14; SD = 3.1)
Additional Diagnoses	Yes 60.0% *Of those reporting additional diagnoses:* ADHD 48.5% Anxiety/OCD 24.2% ID 21.2% Epilepsy 9.1%
Service Providers (*n* = 20)	
Role/Position	BCBA/Behaviour Technician 30.0% Director/CEO/President of Service Company 30.0% Manager/Coordinator of Service Company 25.0% Other 15.0%
Services Provided	Assessments/Evaluations 80.0% Interventions 85.0%
Medical Practitioners (*n* = 15)	
Field/Specialty	Psychiatry 33.3% Psychology 20.0% Neurology 13.3%

Frequency of Working with Individuals with ASD	Occasionally 46.7% Weekly 46.7% Daily 6.7%
Services Provided	Medical 40.0% Assessment/Evaluation 40.0% Intervention 13.3%

Data Collection and Measures

Survey items were developed to determine the accessibility and quality of ASD-related assessment and treatment in the IE and included Likert scale, multiple choice, and open-ended items. At the survey outset, participants were directed to the set of items corresponding to their role (i.e., parent, service provider, or medical practitioner). Items were drafted by a panel of advanced doctoral students in Education with specialized training in ASD and reviewed by a Ph.D. level clinician and researcher with extensive experience in serving individuals with ASD and their families in the region. Final items were translated into Spanish by a native Spanish-speaker, and the survey was offered in both English and Spanish. Notably, only one participant's primary/survey language was Spanish.

Assessment Services

To examine assessment/evaluation needs for children with ASD, parents were first asked, "Do you feel that the assessment/evaluation needs of individuals with ASD and their families in the Inland Empire are currently met?" (Response options: yes, maybe, no). Parents were then asked the open-ended question: "What assessment services are missing in the Inland Empire for individuals with ASD and their families? What could be done to better meet their needs?"

Intervention and Healthcare Services

To examine intervention and healthcare needs for children with ASD in the IE, parent, service provider, and medical practitioner perspectives were assessed. Parents and service providers were asked, "Do you feel that the intervention needs of individuals with ASD and their families in the Inland Empire are currently met?" (Response options: yes, maybe, no). They were then asked the open-ended question, "What intervention services are missing in the Inland Empire for individuals with ASD and their families? What could be done to better meet their needs?" Medical practitioners were asked the same questions, substituting the word "healthcare" for "intervention."

Parents were also asked whether their child was currently receiving services for autism and whether there were services missing (response options: yes, no). Medical practitioners were asked about their level of comfort in working with individuals with ASD at different ages (Likert scale 1-5 from extremely comfortable to extremely uncomfortable), whether their training program prepared them to work effectively with individuals with ASD (response options: yes, maybe, no), and how important it is that medical providers receive training specific to ASD (Likert scale 1-5 from extremely important to not at all important).

Procedures

The anonymous online Qualtrics survey was distributed between June 2019 and April 2020. Participants were recruited through a university autism centre mailing list, individual outreach, and print flyers distributed at community events in the IE (e.g., resource fair). All research procedures were approved by the Institutional Review Board. Participants were given the opportunity to enter their email address in a separate, unlinked survey (i.e., maintaining confidentiality and anonymity of responses) to participate in a drawing for an e-gift card.

Data Analysis

Descriptive statistics were generated using IBM SPSS Version 24.0. For open-ended responses, a qualitative, theme-based approach was utilized (i.e., conventional approach; Hsieh & Shannon, 2005). Emerging themes were first identified independently by two graduate student coders. The coding pair then conducted consensus coding to finalize a complete list of relevant themes for each response item. Next, the coders independently examined each response for the presence of the finalized themes. Due to the variety of responses and in order to capture the richness of the data, *all* themes endorsed by the respondent were coded (i.e., each respondent could endorse multiple themes). Intercoder agreement for each item ranged from 80.0% to 93.3% with an average reliability of 85.5% across items. Following independent coding, consensus coding was conducted to resolve any discrepancies in themes. Results of descriptive statistics and qualitative theme coding are organized by research question.

Results

Assessment Services

Of the 55 parents surveyed, 40% ($n = 22$) indicated that the assessment needs of individuals with ASD in the IE are not currently met (see Figure 1). Based on qualitative coding, parents most frequently endorsed difficulties obtaining testing (35%; $n = 19$) including long wait times, barriers to testing accessibility (e.g., financial, geographic), and a need for more providers. Additional themes endorsed were needs for (1) coordinated care (24%; $n = 13$), (2) better communication with parents (22%; $n = 12$), (3) ongoing support for families (20%; $n = 11$), and (4) addressing poor quality assessment practices (18%; $n = 10$). These questions were not asked of service or medical providers. See Table 2 for highlighted parent quotes.

Table 2

***Parents**: What Assessment Services are Missing for Individuals with ASD and their Families? What Could be Done to Better Meet their Needs?*

Theme	Sample Quote(s)	Number of Responses (*n*)
Difficulty obtaining testing (e.g., wait time, accessibility, financial barriers)	"Early intervention is key, yet there is a case overload for [assessment] in the [school district]. Therefore, our young kids aren't receiving the evaluations/assessments needed for a diagnosis that will enable Special Education services and a greater chance of progress."	19
Need for connected/coordinated care (e.g., collaboration between assessment and treatment centres and schools)	"[We need more] follow through with assessment via referrals and matching programs to individuals and families. Resources seem scant and families have to hunt for them."	13
Better communication with parents (e.g., reduce jargon, make easier to understand)	"[We need an] explanation of assessments and a road map of sorts to be given to families as to what they need to do after assessment."	12
Provide ongoing support to parents (e.g., support groups, academic/school-based assistance)	"Need more support groups." "More ongoing support for parents."	11
Poor quality assessment practices (e.g., misdiagnosis, failure to identify)	"So many people are not getting the right diagnosis."	10

Intervention and Healthcare Services

The majority of total respondents (52%, *n* = 46) indicated that the intervention and/or healthcare needs of individuals with ASD in the IE are not currently met. Only 15% of parents (*n* = 8) and 21% of service providers (*n* = 4) felt that intervention needs were currently met, and no medical providers felt that healthcare needs were currently met (see Figure 1). For parents, 75% (*n* = 41) reported that there are services currently missing that they wish their child were receiving. These included social skills training, speech therapy, mental health services, applied behaviour analysis (ABA), transition services (e.g., vocational/postsecondary support), parent education, dietary/feeding therapy, recreational activities, and alternative services (e.g., music therapy).

In terms of what could be done to better meet treatment needs, respondents frequently endorsed the need for increased access to services, including specific interventions, access in specific regions of the IE (e.g., High Desert), and recreational/social events for children with ASD. Similarly, respondents endorsed needs for underserved families in particular (e.g., financial barriers, geographic barriers, families struggling with homelessness). Many recommended increased practitioner training and education (e.g., diagnostic criteria, evidence-based practices). See Table 3 for highlighted quotes.

Table 3

All Respondents: *What Intervention/Healthcare Services are Missing for Individuals with ASD and their Families? What Could be Done to **B**etter Meet their Needs?*

Theme	Sample Quote(s)	Number of Responses (*n*)
Increased access to services (e.g., timely access, long waitlist)	"All therapy services are in short supply. It is a wasteland out here." - *Parent* "Resources for parents are needed, as well as services in remote areas such as the low desert and the high desert." - *Service Provider*	27 parents 8 medical practitioners 12 service providers
Increased access to services for underserved families (e.g., outreach, family support, expanded funding)	"More information about intervention services that are available for ASD." - *Parent* "There are many low-income families in the region, and ABA services are very costly…families would benefit from free events, workshops, and resources." - *Service Provider*	8 parents 2 medical practitioners 4 service providers
Practitioner training/education (e.g., greater practitioner awareness of ASD diagnostic criteria, training in evidence-based practices)	"[There are] inexperienced and unqualified employees [who] are not trained properly…[there is a] fast turnaround on employees." - *Parent* "There was no specific training for autism… [I] became interested and studied extensively on my own." - *Medical Practitioner*	5 parents 4 medical practitioners 2 service providers

Increased access to evaluations/assessments (e.g., better/easier, shorter waitlist)	"We need more assessment/diagnostic options. This is a must to get services through medical insurance (i.e., diagnostic report)." - *Service Provider*	4 parents 3 service providers
Longer-term services throughout the lifespan (e.g., adult services)	"More adult services are needed." - *Parent*	5 parents
Individualized services for particular children/concerns (e.g., high-functioning children, eating problems)	"It's harder for children on the higher functioning side of autism to get help." - *Parent*	4 parents
More coordinated, comprehensive care (e.g., better communication between the school district and other professionals)	"…greater comprehensive care (i.e., system approach)." - *Medical Practitioner*	1 medical practitioner

When asked about their comfort working with individuals with ASD, medical providers indicated less comfort with providing services to younger children with ASD; 53% ($n = 8$) reported feeling uncomfortable providing services to children ages 15 months to six years. In contrast, only 7% ($n = 1$) reported feeling uncomfortable providing services to individuals ages 18+ with ASD. Interestingly, 60% of medical practitioners ($n = 9$) felt that their training prepared them to work effectively with individuals with ASD. Many medical practitioners indicated that more time, exposure, and practice devoted to ASD could have better prepared them to support these individuals. Medical providers were unanimous in their belief that ASD-specific training is important, with 71% ($n = 10$) indicating that ASD-specific training is extremely important.

Discussion

While previous studies have demonstrated significant barriers to services for children from marginalized communities (e.g., Latinx, immigrant, low-income), little work has specifically documented the unmet needs of the diverse families in the large area of Southern California known as the IE. Overall, this study highlights the unmet assessment and treatment needs of families with children with ASD. Notably, only 26% of parents indicated that assessment needs are currently met, and only 14% of all respondents indicated that treatment needs are currently met. Together, participants responded with similar recommendations for improving the ASD service system: (1) increased access to a variety of services (e.g., coordinated services, timely access), (2) overcoming barriers to treatment and/or evaluation services (e.g., financial hardship), and (3) additional training and/or education for medical practitioners and service providers.

Addressing barriers to services and establishing a system of increased *quantity* and *quality* of services for families with children with ASD has the potential to improve the service system in the IE. These results have several implications for policy and practice, especially for similar geographic regions (e.g., remote deserts).

First, there is a clear need for more providers who have specific training and comfort in providing high-quality assessment, intervention, and healthcare services for children with ASD, including both evidence-based practices as well as a wider variety of service options (e.g., recreational services, social skills training). Medical practitioners indicated discomfort with serving individuals with ASD of certain age groups, supporting the need for ASD-specific training across developmental levels. Second, there is a need for improved access to care (e.g., addressing socioeconomic and geographic barriers) for families of youth with ASD. Future research in service delivery options (e.g., telehealth and at-home/mobile assessment) as well as increased provider training in the region could overcome geographic barriers. These results also underscore the need for advocacy in funding developmental evaluations for at-risk families who face barriers to receiving assessments.

Third, there is a need for better coordination of care between service providers and systems (e.g., schools and clinics). This could be achieved by professional development, ongoing training, and networking events for school-based professionals, medical practitioners, and service providers that encourage positive communication, shared missions, and awareness of community resources. Finally, there is a need for ongoing support, outreach, and education for parents of youth with ASD (e.g., parent support groups, dissemination of resources). These resources could connect parents with knowledge about navigating the complex assessment and service delivery network, as well as with social support from other parents.

One recommendation to address many of these unmet needs is a university-based centre for autism services, resources, and research. This would create a hub for training, services, research, and information for individuals with disabilities and their families. One specific example of this is a University Centre for Excellence in Developmental Disabilities Education, Research, and Service (UCEDD). Although two such centres (UCEDDs) exist in southern California (Los Angeles and San Diego), these are not easily accessible to the IE given the remote nature of the region. A centre of coordinated services and education could serve to enhance the capacity of the IE community to support residents with ASD. A more immediate recommendation is the provision of increased training for service providers and medical practitioners on best practices for working with individuals with ASD. Though strategic long-term solutions must be developed, better training and support for professionals can enhance the overall quality of support for families affected by ASD.

Limitations

Like any study, this study has limitations that should be considered when interpreting results. First, general restrictions of survey methodology should be noted. Although wording of questions was carefully chosen to avoid misleading or biased responses, participants may have interpreted questions differently depending on their unique perspectives. Second, the sample size was relatively modest, and may not accurately represent the diverse population of the IE. Further, many parents were recruited through existing service systems (e.g., regional centres, autism service providers) and therefore responses were likely based on their experiences with the service system from this perspective. Future studies should expand this work by recruiting samples of parents who are awaiting an autism evaluation and can speak to that experience, although difficulties in finding such families must be acknowledged. The medical practitioners were overwhelmingly from the field of psychiatry and the service providers were all in the field of behaviour therapy, despite widespread recruitment efforts across various fields. Medical and service providers from other specialties (e.g., pediatricians, speech therapists) may have different perspectives that are not represented in the current sample.

Notably, despite widespread recruiting for this study and the availability of the survey in Spanish, only one respondent primarily spoke Spanish; however, it is unknown how many of the English-speaking respondents were also Latinx. Nonetheless, it is important to note that even this sample of predominantly English-speaking families had poor access to services and it is critical that all services be available to Spanish-speakers as well. Finally, in an attempt to make the survey as accessible and non-invasive as possible, many background characteristics (e.g., self-identified ethnicity, household income) were excluded from the survey. A larger sample may have provided a more nuanced understanding of differences in perspectives between parent groups (e.g., Latinx vs. white parents; Spanish-speakers vs. English-speakers).

Implications

This study examined the assessment and treatment needs for families with children with ASD living in a largely desert region of Inland Southern California. While future research is needed to explore these barriers with specific demographics (e.g., Spanish-speaking families), the findings of the current study provide valuable recommendations more broadly for policy and practice in other regions or countries with similar demographics. Together, better coordination between assessment and intervention, training for medical practitioners and service providers, and addressing barriers to services (e.g., geographic, financial) would improve systems of care for children with ASD and their families.

Key Messages from this Article

People with Disabilities. You deserve the highest quality care to help you reach your full potential, including medical care, educational services, and appropriate therapy.

Professionals. In your work supporting individuals with autism, it is important to consider any barriers they experience to service provision (e.g., geographic barriers, financial hardships). By receiving ongoing training and collaborating with other providers, you can enhance treatment for those you serve.

Policymakers. Policy that promotes training for service providers and medical practitioners, in addition to the development of an interdisciplinary university assessment and treatment centre will reduce many of the barriers to service delivery in this region.

Messages clés de cet article

Personnes ayant une incapacité. Vous méritez des soins de la plus haute qualité pour vous aider à atteindre votre plein potentiel, incluant des soins médicaux, des services éducatifs et une thérapie appropriée.

Professionnels. Dans votre travail de soutien auprès d’individus ayant un trouble du spectre de l’autisme, il est important de considérer tout obstacle que ceux-ci peuvent vivre pour accéder à des services (p. ex., obstacles géographiques, difficultés financières). En recevant une formation continue et en collaborant avec d’autres prestataires, vous pouvez améliorer le traitement de ceux que vous servez.

Décideurs. Une politique qui favorise la formation des fournisseurs de services et des médecins, en plus du développement d’un centre universitaire interdisciplinaire d’évaluation et de traitement, réduira de nombreux obstacles à la prestation de services dans cette région.

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