

Reimagining Support for Autistic Indigenous Children in the United States: Addressing Under-Identification and Service Gaps

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Abstract: Although the original purpose of this article was to provide a comprehensive review of services provided for autistic children among Indigenous communities in Texas, USA, the authors' encounter with a significant paucity in availability of data and relevant reports on Indigenous services for ASD spurred the choice of a perspective article instead as it allows a more critical view into the pitfalls surrounding the state of autism services. The meager documentation availability presents a dilemma for both researchers and Indigenous communities since it often leads to misrepresentations of data, and limits understanding of existing support systems. This perspective article addresses these issues and serves to highlight the complexity of collecting data among Indigenous populations across the United States. Specifically, it emphasizes the challenges faced in Texas, shedding light on the various barriers such as variations in cultural identity, government trust, cultural awareness, and disability identity that impede data-collection efforts in providing effective services to Indigenous populations. We advocate for a radical transformation in understanding how to approach and report the prevalence of possible ASD autism among Indigenous children to provide effective and tailored services. Ultimately, this transformation aims to secure the necessary data to provide services that effectively complement the existing support systems within individual Indigenous communities to enable their fullest and most equitable participation in society. The discussion calls for a comprehensive roadmap to achieve the goal of increasing Indigenous data collection and availability while the conclusion outlines a suggested roadmap to achieve the goals of increasing data generation and available services to Indigenous communities, and ultimately, improving services for Indigenous children with ASD in Texas and their families.

Keywords: autism, healthcare access barriers, resource allocation, healthcare disparities, ASD

Introduction

Rationale Underlying Terminology Use

While acknowledging the term "Autistic person" embraced by self-advocates, for the context of this paper the term "ASD" is predominately used as it aligns with the term and criteria utilized in policy-making, diagnosis, and governmental support systems based on the constellation of symptoms identified within this population, as outlined by the American Psychological Association and DSM-5-TR.¹ We wish to emphasize that this does not necessarily reflect the authors' view that Autistic individuals are, or should be, considered 'disordered' by society. However, as the diagnosis of ASD is required by stakeholders in relation to data collection efforts to determine the necessity of medical services and support services for children, the term ASD is used throughout this paper to best describe the need for more data collection effort regarding the prevalence and accessibility of services for Autistic Indigenous children in the United States.

Defining ASD and Impact on Diagnoses

As defined by the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5), ASD is characterized by persistent difficulties in social communication and interaction, along with restricted, repetitive patterns of behavior, interests, or activities, leading to significant impairment in various areas of functioning, with symptoms typically emerging in early

developmental stages and not attributable to other developmental disorders like intellectual disability or global developmental delay.¹ This definition is the standard used by psychologists and specialists in the United States when determining a diagnosis, and the definition used by the Centers for Disease and Control and Prevention (CDC) in their efforts under the Autism and Developmental Disabilities Monitoring (ADDM) Network, which is used to track ASD prevalence in areas of the United States.²

ASD has garnered significant attention within the research community and an increase in support systems for the broader public due to its increasing prevalence, and it continues to pose significant challenges with far-reaching implications for affected individuals and their families.^{3–5} Challenges include navigating complex healthcare systems, accessing essential services, addressing specific health risks associated with ASD, managing increased financial strain, and combating social stigmas.⁴ The difficulties are especially pronounced for individuals from the most economically disadvantaged backgrounds, as an ASD diagnosis can intensify existing socio-economic hurdles within their families, affecting access to healthcare, education, and contributing to higher levels of poverty among those affected. This creates a domino effect, compounding the challenges they face.^{4,5} One of the gravest concerns surrounding ASD pertains to the under-identification and under-resourcing of specific demographics within the United States. In particular, Indigenous and Hispanic pediatric populations in Texas are disproportionately affected by these disparities, as evidenced by studies showing significant disparities in access to autism resources compared to White children with ASD nationally, highlighting critical inequities in healthcare provision.^{5,6}

Existing Data & Trends

When examining the prevalence of ASD in Indigenous pediatric populations, a complex picture emerges. Despite the growing body of research on ASD and relevant resources for various ethnic groups in the United States, there is a paucity of information regarding its specific impact on Indigenous communities, particularly in Texas.^{5,7,8} This lack of data hampers the full utilization of available services, despite the known fact that these populations face unique challenges in recognizing and addressing ASD. These unique challenges include differences in understanding neurodevelopmental disorders and limited access to culturally competent diagnostic resources.⁹ These challenges not only endanger the well-being of Indigenous children but also underscore broader disparities in healthcare access and service utilization among marginalized communities.^{8,9}

Existing literature on the prevalence of autism in Indigenous communities remains limited and often masked within broader statistics. While studies have reported lower rates of ASD diagnosis among Indigenous children when compared to non-Indigenous populations, there is a need for a deeper understanding of the complexities involved in identifying autism in diverse cultural contexts.¹⁰ For example, considerable confusion surrounding the reporting of ethnicity persists even when individuals have the opportunity to complete census forms themselves. Indigenous individuals may face ambiguity in identifying their ethnic and racial backgrounds, as the Census Bureau categorizes them under AI (American Indian) and AN (Alaska Native) regardless of citizenship status, while many may choose to identify as Hispanic on the census. The proportion of Indigenous individuals who opt to identify as Hispanic in Texas is notably significant, largely attributed to the historical context of Texas being a part of Mexico.¹¹ The scarcity and ambiguity regarding the accuracy of data raises concerns about the ability to effectively assess the scale of the issue regarding the under-representation communities of Indigenous populations in Texas with ASD.

Furthermore, the complex nature of addressing the needs of Indigenous communities is underscored by the diverse array of cultures and languages they encompass. A poignant illustration of this complexity is found within the Navajo community, an Indigenous population whose reservation lies within the corners of Colorado, Utah, Arizona, and New Mexico. It has been reported that an absence of a designated term for ASD or autism in the Navajo language presents substantial obstacles in both diagnosis and the establishment of supportive networks by federal or state entities.¹² This linguistic gap has been reported by stakeholders to impede effective communication and complicate the communication of identified ASD-related behaviors and traits between educators and healthcare professionals and the parents of a child with possible ASD. Conversely, others have suggested that rather than a lacking of a specific word for autism or ASD, it is rather a misunderstanding by US stakeholders of the Navajo concept of Hozho, which avoids using negative medical language or diagnoses such as ASD which imply there is a need to fix or “cure” a pattern of behavior.¹³ In this context, pushing a diagnosis of ASD as a disability may be viewed as a colonial construct infringing on the culture of a given Indigenous group, a sentiment that has been echoed by others in how to understand disabilities within Indigenous communities of Canada.¹⁴

Respecting an Indigenous group's unique conceptualization and support systems for individuals who, according to Federal and State guidelines, may meet the diagnosis criteria for ASD, does not entail withdrawing support entirely. Instead, it presents an opportunity to improve communication about what an ASD diagnosis entails and how a formal diagnosis can facilitate access to resources addressing the array of behavioral, social, and physical health challenges associated with ASD. The process of improving communication ought to involve learning about existing support systems within the Indigenous community in the United States. Importantly, it should also be communicated that a formal diagnosis of ASD may facilitate access to federal support systems that are available for individuals diagnosed with ASD, enabling Indigenous people with ASD to surmount societal barriers and fully engage in community life. This approach aims to shift perceptions away from viewing an ASD diagnosis as a stigma towards recognizing it as a pathway to vital support and resources, thereby empowering Indigenous individuals with ASD to thrive within their communities. Only by first acknowledging the lack of accurate data and communication of ASD among Indigenous groups in the United States will entities be able to provide equitable services to these communities.

Barriers to Care Between Indigenous Communities

With more than 500 federally recognized Indigenous groups dispersed throughout the United States, understanding their diverse cultural perspectives on ASD is essential for crafting effective support strategies.¹⁵ While the US Office of Management and Budget categorizes them broadly as "American Indian/Alaskan Native", this umbrella term only provides an approximate count and fails to capture the nuanced needs of each group. Just as there is no universal solution for addressing the needs of any single racial demographic in the country, different Indigenous communities will require tailored approaches. The challenges in accessing care and the understanding of ASD for Alaska Native groups, for instance, are likely to differ significantly from those faced by Indigenous communities in New York State or Texas. By conducting targeted research that acknowledges and respects the diversity among Indigenous groups, policymakers, healthcare providers, and educators can develop tailored strategies and interventions that are culturally sensitive and responsive to the specific needs of each community. This approach is essential for ensuring equitable access to ASD diagnosis, treatment, and support services across all Indigenous populations in the United States.

For the purposes of this perspective paper, we focus primarily on the Indigenous population in the state of Texas to illustrate the complexities of accurately representing data and the unique obstacles various Indigenous peoples encounter in obtaining care and receiving a fair representation in data collection efforts by the United States. However, it is crucial to acknowledge that each group has distinct barriers to care and may have existing support systems that may affect how stakeholders prioritize services. Understanding these differences is paramount for developing inclusive and effective support strategies for individuals with ASD across diverse Indigenous communities.

Addressing Diverse Indigenous Needs in Texas

Currently, the United States federal government recognizes three distinct and active Indigenous reservations in Texas: the Alabama-Coushatta of Texas, the Kickapoo Traditional Tribe of Texas, and the Ysleta del Sur Pueblo. While these groups have access to Federal government resources, it is noteworthy that urban Indigenous Texans who do not live on reservations do not have access to these resources.¹⁶ Additionally, federally recognized tribes do not fully represent the growing revivalism of Indigenous groups, which are leading their own efforts to revive tribes thought to have been eradicated generations ago.¹¹ Furthermore, within the categories of federally recognized tribes, non-federally recognized tribes, and urban-based Indigenous Texans, there exists an additional complexity. This pertains to Indigenous Texans who often opt instead to self-identify as Hispanic rather than American Indian. This trend is notably significant within Indigenous communities in Texas, which is influenced by the historical context of Texas once being a part of Mexico.^{11,16} Addressing the diverse needs of Indigenous communities in Texas will require recognition not only of federally recognized tribes but also of the broader spectrum of Indigenous identities, including urban Indigenous Texans and those who identify as Hispanic due to the historical context of the region. Therefore, it is essential to establish an Indigenous-led board to oversee and conduct this study, ensuring that the research is guided by and responsive to the diverse needs and perspectives of Indigenous communities in Texas.

Accessing Healthcare

Studies focusing on healthcare barriers in the United States have reported common challenges such as socioeconomic constraints, geographic limitations in rural areas, shortages of healthcare providers, language and cultural barriers, as well as systemic obstacles within the healthcare system. Addressing these barriers requires collaborative efforts aimed at improving healthcare infrastructure, workforce capacity, health literacy, cultural competence among providers, and implementing policies to reduce financial barriers to care.^{4,17} While not tailored exclusively for the Indigenous community, these findings hold significance within the context of potential barriers. This is especially pertinent for individuals residing on reservations, as they experience geographical isolation and frequently encounter challenges related to limited access to wifi.¹⁷

The barriers to accessing healthcare services for Indigenous pediatric populations with ASD are multifaceted and encompass various dimensions. Geographical remoteness, limited transportation options, and financial constraints are significant obstacles to receiving timely and appropriate care. Additionally, cultural beliefs and stigma can contribute to delays in seeking help, as Indigenous families may be hesitant to engage with formal healthcare systems.⁹ These barriers are further exacerbated by a lack of culturally competent healthcare providers, which can impede trust and communication between patients and practitioners.

Given the substantial presence of Indigenous populations identifying as Hispanic in Texas, it's crucial to address the specific disparities faced by Latinx children with ASD. Research has repeatedly reported health care literacy and the availability of health insurance as a major factor in accessing healthcare for diagnosing ASD earlier and accessing proper support among Hispanic populations in the United States.⁶ This may in part, explain why Hispanic populations report significantly lower rates of ASD diagnosis in the United States, particularly in Texas.¹⁸ Interestingly, a study by the Texas Educational Agency and Health Resources and Services Administration revealed findings that could be particularly relevant to understanding ASD diagnosis rates among Indigenous communities in Texas. The study found lower ASD diagnosis rates in school districts with higher percentages of Hispanic children, even after considering socioeconomic and healthcare factors. This discrepancy suggests that factors contributing to the lower ASD prevalence among Hispanic populations in Texas may be influenced by the unique barriers and cultural differences experienced by Indigenous communities, who form a significant portion of the Hispanic population in the state.¹⁸ These findings emphasize the critical need to comprehensively grasp and tackle the unique hurdles encountered by Indigenous and Latinx communities in obtaining ASD diagnosis and support services. They underscore the necessity for thorough data analysis that takes into account the influence of self-identification on understanding ASD prevalence and necessary services. This highlights the urgency for culturally sensitive interventions aimed at guaranteeing equitable healthcare access and outcomes for all children in Texas. However, further research specifically comparing healthcare barriers between Indigenous pediatric populations with ASD and generalized healthcare barriers is needed to fully understand the scope of disparities and inform effective interventions.

Despite recent economic development efforts such as increased control over natural resources and trading with Asia, Indigenous Americans remain among the most economically vulnerable groups in the United States, with a poverty rate of 26.4% compared to 11% for non-Hispanic whites.¹⁹ Without considering the specific cultural factors that Indigenous families in Texas may face when accessing services for ASD, these numbers regarding SES alone are typically associated with significant barriers to care in accessing services for ASD.^{10,20} However, despite higher ASD diagnosis in higher SES categories, studies have indicated that significant racial and ethnic disparities in ASD diagnoses persist, suggesting that SES alone does not explain the differences.^{10,20} This finding holds implications for Indigenous communities in Texas, where lower SES demographics often reside and where there are lower rates of ASD diagnosis.^{21,22} While SES may contribute to lower observed rates of ASD prevalence in these communities, this does not account for major factors such as cultural differences and healthcare accessibility.

The relationship between Indigenous Americans with possible ASD and access to healthcare is particularly complex, and is important to consider in light of the fact that for the vast majority of the population in the United States, a Primary Care Physician (PCP) is the best chance to receive such an earlier diagnosis. At the very least, a referral by a PCP to a specialist would be needed to receive an early diagnosis. Moreover, studies have frequently reported that the most important aspect to long-term success among individuals with ASD is access to early intervention services.^{23,24} In this

context, it is important to understand the dynamics between Indigenous Americans and their PCP. The historical mistreatment and marginalization of Indigenous Americans have engendered a deep-seated mistrust of mainstream institutions, including healthcare providers. This mistrust stems from a legacy of government policies that systematically undermined Indigenous rights and well-being.^{9,25} This historical context profoundly influences the communication dynamics between Indigenous Americans and PCPs, especially regarding an ASD diagnosis. For many Indigenous communities, the concept of health and wellness is deeply rooted in cultural traditions and beliefs, such as the aforementioned concept of Hozho, with similar concepts reported across Indigenous communities in North America. When a PCP communicates a possible diagnosis of ASD, it may be perceived by Indigenous Americans as implying a need for “fixing” or “curing”, which may contradict their cultural understanding of health and well-being. This discrepancy in interpretation can lead to miscommunication and reduce the chance of a caregiver to follow up on a referral to achieve a diagnosis.^{13,14} This poses a challenge for PCPs and other stakeholders who seek to facilitate early intervention services for individuals with ASD.^{23–25} To address these complexities, healthcare providers must adopt culturally sensitive approaches that acknowledge and respect Indigenous perspectives on health and well-being. This involves recognizing possible ASD traits and incorporating cultural competence training for healthcare professionals to more effectively communicate the services that are available to best support their child. By bridging these cultural divides and promoting mutual understanding, healthcare providers can better support Indigenous Americans in accessing the care and resources they need, including early intervention services for ASD.

Data Gaps Within Indigenous Communities

In the realm of healthcare access and ASD services for Indigenous populations, it is imperative to recognize and address the multifaceted barriers that hinder their ability to receive adequate care. These barriers, ranging from geographical challenges to historical mistrust of healthcare systems, significantly impact the health outcomes of Indigenous communities. However, a glaring issue exacerbating these disparities is the scarcity of data concerning Indigenous populations in the United States. The consequences of this data gap are profound and far-reaching. Without accurate and comprehensive data on Indigenous Americans, policymakers lack the necessary insights to pinpoint at-risk demographics, evaluate program efficacy, and allocate resources effectively. As a result, healthcare interventions and policies do not adequately address the unique needs and challenges faced by Indigenous communities, perpetuating existing disparities in healthcare access and outcomes, an issue that is critical to address in understanding how to support Indigenous Americans with ASD.^{7,8,26}

Big Data & Power: Navigating the Nexus of Policy and Data Sovereignty

Without accurate data, it is virtually impossible for policymakers to effectively identify the specific vulnerabilities of Indigenous communities in order to provide effective funding and support. While it is undeniable that the lack of data is a significant barrier to providing effective services for Indigenous Americans with ASD, addressing this issue must also consider the importance of data sovereignty for Indigenous communities. Data sovereignty refers to the concept that people have the inherent right to govern and control the collection and use of their data. In the context of this perspective, data sovereignty acknowledges the inherent right of Indigenous communities to govern and control the collection, ownership, and application of their data.²² It ensures the preservation of cultural, historical, and spiritual significance embedded in Indigenous data, empowering communities to make decisions aligned with self-determination. The significance of data sovereignty and the invaluable nature of data have been accentuated in influential documentaries such as *The Great Hack*, which not only enhance public awareness regarding data's worth but also advocate for individuals' rights to ownership of their data.²⁷ This assertion gains particular relevance when contemplating marginalized communities like Indigenous communities, who have endured historical marginalization and exploitation by entities that exploit such powers. By exercising control over their data, Indigenous communities can tailor interventions to address specific needs, establish governance structures for data management, and address historical injustices related to data exploitation and marginalization. Balancing the need for data to improve services for Indigenous Americans with ASD with respect for data sovereignty is essential for ethical and effective engagement with Indigenous communities. This delicate balance has been referred to as a “double edged sword”, recognizing that data is needed for addressing inequities in the United States, while also promoting the rights of Indigenous communities to own their data.²⁸

Recommendations & Opportunities

As of 2024, The White House has announced several initiatives aimed at providing increased funding to Indigenous tribes in the United States, with the focus on creating more equitable outcomes in education and healthcare.²¹ Notably, these initiatives do not specify the focus on improving data collection measures and data diplomacy with various communities in order to understand the most effective policies. However, past efforts by US officials to engage with tribal governments for an accurate census count and improved services often lack the cultural sensitivity necessary for effective outreach, as highlighted in testimony before the Senate in the Voting Rights Project by, a senior special counsel and founding individual member of the Native American Voting Rights Coalition.²⁹ He emphasized the need to have Indigenous populations as active members in both the data collection process and the training of others in the data collection process:

Some of the best trainers to help prepare for Census 2020 can be readily drawn from Native professionals who work in tribal or community offices, or from among the local Native educators²⁹

Discussion

A limitation of this perspective lies in the constraints inherent in a literature review-based approach. While we have synthesized valuable insights, empirical data directly from Indigenous communities in Texas will offer additional perspectives and nuances that could further inform our proposed roadmap. Engaging directly with Indigenous communities through interviews and consultations is essential to capture their lived experiences and preferences accurately. However, we firmly advocate that the collection of empirical data and interviews should be gathered by an Indigenous led task force to ensure the most accurate and respectful results. By integrating these considerations, we hope to develop solutions that are not only effective but also culturally appropriate.

In response to the need for more data and ASD services for the Indigenous populations of Texas, we call for a comprehensive roadmap to improve data collection services and tailored care approaches. Building upon previous research and initiatives targeted at addressing the under-identification of Indigenous pediatric populations with ASD, we can draw upon diverse strategies. This roadmap must delineate a clear and structured strategy aimed at enhancing healthcare access and services for these communities. It should be tailored to consider the unique cultural, linguistic, and geographical factors that influence healthcare delivery to Indigenous families.

We propose a transformative approach to data collection in Indigenous communities, emphasizing community-based participatory research and culturally sensitive methodologies. This paradigm shift aims to integrate Indigenous perspectives directly into the research process, ensuring that data collection respects community values and preferences. Furthermore, we emphasize the importance of ethical research practices and support for Indigenous sovereignty over data. By implementing novel strategies, we seek to uphold ethical standards and empower Indigenous communities in controlling their own data. Our perspective also seeks to impact policy by advocating for more inclusive and respectful research practices. This approach prioritizes Indigenous rights and community well-being, aiming to influence policy frameworks that better support Indigenous populations affected by ASD in Texas and beyond.

We hope that this perspective serves as a foundational step for federal agencies and data interpreters to recognize the critical need for enhanced data collection efforts. It underscores the necessity of an Indigenous-led task force to ensure data accuracy and respect cultural nuances, thereby avoiding potential misrepresentations. Moving forward, there is a clear imperative to deepen the understanding of cultural factors influencing data collection and interpretation. This understanding will enable the formulation of more effective and culturally sensitive services that meet the unique needs of Indigenous communities affected by ASD in Texas and beyond.

Conclusion

In order to address the complex challenges faced by Indigenous populations affected by ASD in the State of Texas and across the United States, a comprehensive roadmap has been developed as a reference for policymakers and relevant stakeholders. The detailed roadmap is especially pertinent to and meant for states that have not yet adopted transformation strategies described here. This roadmap focuses on establishing an Indigenous-Led Taskforce, identifying knowledge

gaps, implementing known strategies, and ensuring continuous evaluation and improvement. By following this roadmap, tailored, data-driven strategies that prioritize data-sovereignty of Indigenous people can be enhanced to improve healthcare access and services for Indigenous pediatric populations with ASD, taking into account their unique cultural, linguistic, and geographical factors.

Establishment of Indigenous-Led Taskforce

- Create an Indigenous-led task force dedicated to gathering comprehensive data on the diagnosis, prevalence, challenges, and available services for Indigenous populations with ASD in the State of Texas. This task force will collaborate with federal, state officials, and Native-led initiatives to address unique challenges, including differences in funding between urban-based and both Federally and non-Federally recognized reservation-based populations.

Emphasizing Data Ownership Structures

- Highlight potential data ownership structures within the roadmap to prioritize Indigenous data sovereignty and ensure culturally appropriate data management practices.

Identify Knowledge Gaps

- Collaborate with Native-led task forces and government officials to identify core research areas and data gaps related to Indigenous communities affected by ASD.
 - Have stakeholders identify key gaps in data among ASD professionals and policymakers to communicate and continue collaboration with the Indigenous-led Taskforce to ensure effective funding.
 - Tailor data analysis and collection methods to distinguish unique needs across Urban Indigenous groups, federally recognized populations on reservations, and populations on non-federally recognized reservations.
- Identify and understand awareness and opinions of ASD diagnosis across different federally recognized tribes to identify if tailored ASD awareness efforts may improve access of support services.

Focus on Known Strategies

- Educate healthcare professionals on culturally sensitive practices to ensure respectful and effective care delivery for Indigenous populations.
- Promote the use of telehealth and telemedicine to overcome barriers to healthcare access for reservation-based communities. Continue to offer access to Wifi and wireless communications for extremely rural communities.
- Provide caregiver support and improve the dissemination of information about available resources and support services for children with symptoms of ASD.
- Continue to promote awareness of ASD in initiatives led by Indigenous groups, catered to the specific Indigenous communities conceptualization of ASD.

Continuous Evaluation and Improvement

- Establish mechanisms for ongoing evaluation and improvement of initiatives, policies, and services to ensure they remain responsive to the evolving needs of Indigenous communities affected by ASD.
- Implement bi-annual discussions between relevant stakeholders such as Indigenous representatives, healthcare professionals, government agencies, and ASD-support services to amend data collection and support services as needed in addressing Indigenous pediatric populations with ASD in Texas and across the United States.

Long-Term Sustainability

- Address the sustainability of initiatives by identifying funding sources and fostering ongoing collaborations between stakeholders.
- Disseminate findings through academic journals, reports, and accessible media to inform and engage relevant stakeholders.

By following this roadmap, we can work towards enhancing tailored, data-driven strategies to improve healthcare access and services for Indigenous pediatric populations with ASD while considering their unique cultural, linguistic, and geographical factors.

Disclosure

The authors report no conflicts of interest in this work.

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