Exploring the Diagnosis Process and Educational Services for Children with Autism Spectrum Disorder and Visual Impairment

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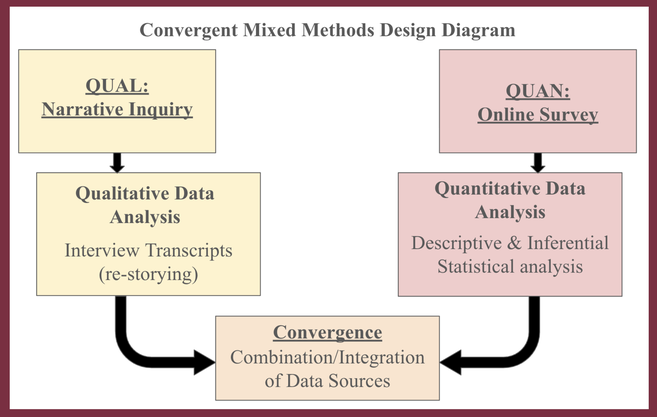
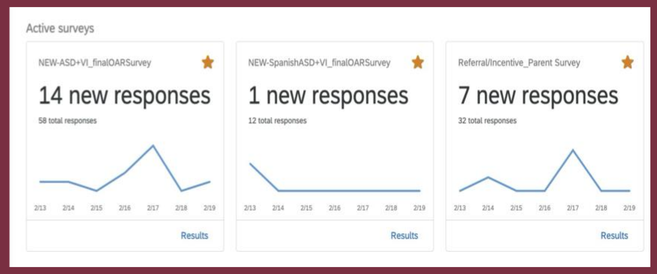
Abstract

This national study investigates the processes behind a co-occurring Autism Spectrum Disorder (ASD) and visual impairment (VI) diagnosis in school-age children through parental-reported experiences. Early diagnosis and intervention are critical for improving developmental outcomes and ensuring access to appropriate resources and support services (Okoye et al., 2023). To examine this relationship, we worked on a Qualtrics survey aimed at collecting both numerical and descriptive data on the assessment, diagnosis, and service provision of ASD and VI across the 50 states and Puerto Rico. A distribution list was compiled, including medical and educational professionals, hospitals, clinics, schools for the blind, and state deaf-blind projects to help reach eligible families. The survey included an invitation for respondents to volunteer to participate in follow-up interviews. Data collection is ongoing. The findings aim to show typical diagnostic steps, reveal possible obstacles, and highlight patterns in accessing services. The results aim to inform healthcare providers, educators, and families about opportunities to improve early identification and collaboration.

Background

Autism spectrum disorder (ASD) is a neurodevelopmental condition involving differences in social communication and behavior (Hodges et al., 2020). Early diagnosis is important because it allows families to access services and special education support that can improve developmental outcomes. However, the diagnosis of ASD in children with visual impairment (VI) can be complex. Many autism assessments rely on observing visual behaviors in children (Chahin et al., 2020). So the potential to equate ASD behaviors such as visual avoidance, inconsistent response to voice, and failure to point or play with toys in children with visual deficits is a concern for diagnosticians (Kuban et al., 2009). There is limited research on how to assess for ASD in children with sensory impairments, and what is out there has not focused much on parental experiences. Being able to understand these experiences can help identify gaps in assessment and service systems. For that reason, this study explores diagnostic pathways and education service access for children through parental accounts.





Participant Summary (n=19)

Category	Subcategory	n (%)
Parents		
Race/Ethnicity	White (not hispanic)	14 (74%)
	Hispanic/Latino	2 (11%)
	African American/Black	1 (5%)
	Asian/Asian American	1(5%)
	Other	1 (5%)
Sex	Female	16 (84%)
	Male	3 (16%)
Age	Median (range)	43 (25-62)
Family Composition	Two-Parent Family Home	15 (79%)
	One-Parent Family Home	4 (21%)
Children		
Grade Level	Elementary (K-5)	8 (44%)
	Middle (6-8)	5 (28%)
	High School (9-12)	5 (28%)
Primary Diagnosis	VI First	14 (74%)
	ASD First	5 (26%)
Other Disabilities	Yes	15 (79%)
	No	4 (21%)

Methods

This study employed a mixed-methods design, incorporating both quantitative and qualitative data. To recruit participants, we compiled a distribution list that included email contacts from personal networks, hospitals and clinical institutions, schools for the blind, state DeafBlind projects, and relevant social media pages. The goal of the study was to obtain responses from at least one parent in all 50 states and Puerto Rico. Therefore, we ensured that at least one contact from each category was identified for every state and territory. The survey was developed and administered using Qualtrics. It was available in both English and Spanish to increase accessibility for a broader population of parents. The survey invited parents to participate in follow-up interviews to collect qualitative data from across the states. The interviews will follow a Narrative Inquiry design, where participants will be asked to share their stories or journey through the diagnosis process with minimal structured questioning. Interviews will be recorded, transcribed, and de-identified for analysis.

Results and Takeaways

Data collection for this study is currently ongoing. We are in an active recruitment of participants and data. Survey responses are being collected til end of March. Interviews are being scheduled to begin End of March/ beginning of April. Our table presents information about survey respondents thus far.

References

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