A Review of Access to Diagnostic Services for Black children on the Autism Spectrum

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INTRODUCTION

Autism Spectrum Disorder (ASD) is a type of developmental disability. ASD can cause language, behavior, interaction and communication challenges to those affected. In the US, the prevalence of ASD is 1 in 54 children. For certain demographic groups, ASD diagnosis is delayed. Studies have identified that race, ethnicity, and income level impact access to ASD diagnostic services. Few investigations to our knowledge have looked at the way that racial discrimination and implicit bias may impact these diagnostic process for Black children.

My project is based on a dissertation completed by Dr. Elizabeth Morgan on the strategies used to access these services by Black mothers with children on the autism spectrum. Her initial study utilized critical race theory to identify which forms of cultural capital Black mothers used to access the disability services and advocate for their children.

OBJECTIVE

To identify the potential relationship between racial discrimination and access to Early Intervention or ASD Diagnosis testing for Black children.

METHODS

STRENGTHS & LIMITATIONS

Strengths:
- Synthesizing findings from a wealth of information from real parents & children who have had these experiences
- My study has developed some “next steps” for guiding future research or intervention practices

Weaknesses:
- I was only able to work with the literature available
- Can’t make any correlations
- Doesn’t tell the full story
- Time restraints of the program

SUMMARY & CONCLUSION

This project was a great opportunity for me to expand my knowledge of disabilities, disabilities resources, and health disparities. I would like to first and foremost thank my mentor, Dr. Elizabeth Morgan for her knowledge on this topic and ongoing support for both my future and the future of the black community. I would also like to thank Dr. Janice Enriquez and Dr. Harolyn Belcher for their mentorship and assistance throughout the duration of my project.

RESOURCES

Please email the researcher for a list of citations at: mmgardne@gmail.com
"A Review of Access to Diagnostic Services for Black children on the Autism Spectrum"

- Autism Spectrum Disorder (ASD) is a type of developmental disability
  - ASD can cause language, behavior, interaction and communication challenges to those affected.
  - In the US, the prevalence of ASD is 1 in 54 children.
- For certain demographic groups, ASD diagnosis is delayed.
  - Studies have identified that race, ethnicity, and income level impact access to ASD diagnostic services
  - Few investigations to our knowledge have looked at the way that racial discrimination and implicit bias may impact these diagnostic process for Black children.
- My project is based on a dissertation completed by Dr. Elizabeth Morgan on the strategies used to access these services by Black mothers with children are on the autism spectrum.
  - Her initial study utilized critical race theory to identify which forms of cultural capital Black mothers’ used to access the disability services and advocate for their children.
To identify the potential relationship between racial discrimination and access to Early Intervention or ASD Diagnosis testing for Black children.
METHODS

STEP 1
Searched EbscoHost & Scopus Databases

STEP 2
Filtered peer review articles

STEP 3
Searched using key terms:

1. Early Intervention
2. Autism
3. Discrimination
4. Disparities
5. African-American (AA)
6. AA Children

STEP 4
Screened articles based on abstract

FINAL RESULT
23 total articles chosen for the review
RESULTS

Factors Contributing to Delayed Diagnosis

Healthcare Access
- Lack of health insurance
- Lack of access to specialists
- Limited time constraints
- Lack of access to transportation

Income Level/Poverty Status
- Poverty status is an indicator of ASD Service Knowledge
- Without a diagnosis, parents cannot afford access to intervention services

Medical Provider Bias/Communication
- Parents did not feel their knowledge valued or heard by provider
- General providers lacked ability to do an assessment or recommend one

Education System Bias
- Children with behavior problems are not given assessment recommendations
- Assumed behavior problems were the fault of the parent

Knowledge of ASD Services
- Many Black parents were unaware of ASD services available
- Parents also did not know how to navigate these systems

Culture & ASD Stigma
- Some cultures may describe a “delay” differently than a medical provider
- Stigma regarding mental health & disability persisted in the community
SUMMARY & CONCLUSION

Opportunities for Intervention

To improve ASD intervention access & knowledge:
Targeted & culturally responsive ASD training materials
Education & Emotional management training for families prior to, and after diagnosis

To improve relationships with medical providers / health systems:
Improved provider empathy, listening skills.
Improved overall knowledge of assessment process

To improve parental autonomy and internal strength
ASD services should implement support groups
Improved parental voice & strength in the disability system overall
• Strengths:
  – Synthesizing findings from a wealth of information from real parents & children who have had these experiences
  – My study has developed some “next steps” for guiding future research or intervention practices

• Weaknesses
  – I was only able to work with the literature available
    • Can’t make any correlations
    • Doesn’t tell the full story
  – Time restraints of the program
    • I wasn’t able to study as in depth as I would have wanted
This project was a great opportunity for me to expand my knowledge of disabilities, disabilities resources, and health disparities. I would like to first and foremost thank my mentor, Dr. Elizabeth Morgan for her knowledge on this topic and ongoing support for both my future and the future of the black community. I would also like to thank Dr. Janice Enriquez and Dr. Harolyn Belcher for their mentorship and assistance throughout the duration of my project.

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