



What Are the Barriers to Autism Diagnosis and Treatment for African American Children?

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V i r g i n i a C o m m o n w e a l t h U n i v e r s i t y

RATIONALE

Research literature suggests there are barriers to properly diagnosing African American children with autism, as well as barriers to these children receiving treatment.

The Agency for Healthcare Research and Quality (AHRQ) in 2011 reported that low income people, and people of color, experience the most barriers to care and receive care of poorer quality.

Disparities in treatment and diagnosis of this population may also be due to culture, the associated costs of treatment, financial limitations of public school systems, and the necessary dedication of time to treatments.

RESULTS

Barriers to the Diagnosis of Autism

Research Studies

- Evidence regarding disparities in autism diagnosis have often been inconclusive. In one study (Mandell, et al., 2002) the findings showed that Black children were identified with ASD years later than White children, and were often first diagnosed with a conduct disorder, adjustment disorder, or ADHD more so than White children. A later study of the same geographic area showed no ethnic disparity in the age of diagnosis (Mandell, et al., 2005).
- In a later study, it was hypothesized that Black children that meet the diagnostic criteria for autism would be less likely to have been identified in their health and education records (Mandell, et al., 2009). The results showed that Black children were less likely to have the autism documentation in their records than White children. These results suggest racial and ethnic disparities in the identification of children with autism.

Reasons for Diagnosis Disparities

- Parent education level can determine the knowledge of developmental milestones, and the ability to advocate for ones child to receive a diagnosis.
- Racial differences in diagnosis can be due to institutional factors like limited access to health care, prejudices and beliefs of the clinician, and the families interpretation of the child's symptoms.
- Clinicians may be more likely to diagnose autism in White children and intellectual disability in Black children due to research that suggests a lower prevalence of intellectual disability in White children.

Barriers to Autism Treatments

Culture

- Culture can influence how the family perceives treatment options. Families may base the choice of treatment for a child on the belief of the cause of the diagnosis, and this can vary across cultures.
- African American families may be hesitant to attribute symptoms to mental health issues and therefore not seek this type of treatment. Stigma on mental health issues in the African American community may also play a role.
- Expectations of the role of the parent and provider may vary across cultures. In some cultures parents do not expect, or may not want to have a role in the treatment of the child. They may expect therapists,

doctors, and schools to be the primary providers of the treatment plan, and therefore lessen their involvement.

The Cost of Autism Treatments

- Due to the high incidence of co-morbidity with other disorders, children with autism have higher health care costs since they must access more healthcare services then children with other health problems, or those without health problems.
- Medical expenditures for children with autism are up to 6 times higher than medical expenditures for children with other health care needs.
- Even with insurance, public or private, there are significant out of pocket costs for autism treatments. This is especially true for in-home behavior therapy (Figure 1).

Limitations of Public School Systems

- Special Education services and treatment services for children with ASD differ by race and ethnicity. There is also a disparity in the use and quality of services in predominantly minority school systems.
- Staff at schools, and the money associated with caring for children with ASD in school programs are a consideration. Significant time by staff implementing interventions may not always be possible because of school system limitations.
- Poor African American parents may have no choice but to send their children to dilapidated schools, where the teachers may lack experience, and they are less involved in the neighborhood school activities, including activities that would help improve parent involvement and awareness.
- Because school systems for minority children often do not have appropriate staff numbers or skilled staff to implement intensive interventions, many parents may be forced to seek a combination of public and private funded interventions for their children.

Time and Dedication to Treatments

- A barrier to some interventions, besides cost, is time and dedication that must be given to the treatment for better outcomes. African Americans who may live in poverty may not have sufficient time to dedicate to treatments due to work schedules, transportation, and the lack of paid leave time.

CONCLUSIONS

- There is limited information in recent literature that addresses how culture and race can cause unique challenges and barriers to autism interventions and diagnosis for African Americans.
- Diversity and cultural factors need to be considered by health care providers, school systems, and others who serve children with ASD who are ethnic minorities. Things to be considered are belief systems associated with culture, socioeconomic differences, and specific barriers to treatment.
- Future research should focus on how to overcome barriers to autism treatment, so that there is equality in access, and treatment options for children from ethnically diverse cultures.

Next Steps:

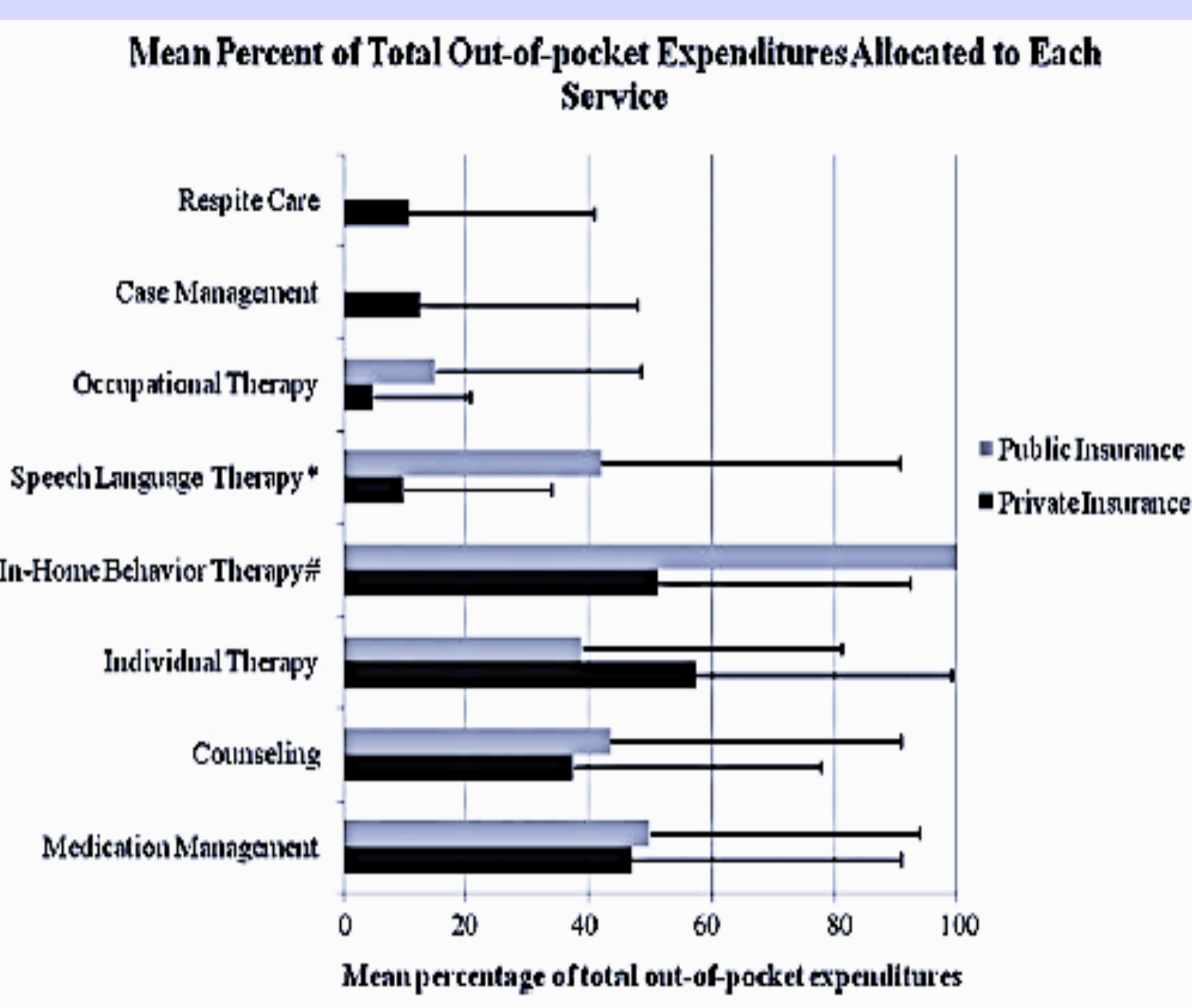
The research question deserves further study. A survey for parents of children with autism from various backgrounds is currently under IRB review. The survey will consist of questions to gather concise data on barriers to autism treatment for children. The survey will be in English and Spanish.

Barriers to Autism Treatment
1. What is your race? Please choose one or more.
☐ White
☐ Black or African American
☐ Asian
☐ Hispanic
☐ Other
2. What is your approximate average household income?
☐ \$0-\$24,999
☐ \$25,000-\$49,999
☐ \$50,000-\$74,999
☐ \$75,000-\$99,999
3. What is your gender?
☐ Male
☐ Female
4. What language do you mainly speak at home?
☐ English
☐ Spanish
5. What was the age of your child when they were diagnosed with autism spectrum disorder?
6. Did your child receive a different diagnosis first? If so what was it?
7. Do you feel that you have sufficient access to interventions/treatments for your child? If no why?
☐ No transportation
☐ Work schedule
☐ No insurance
☐ Co-pays
☐ Cost of treatments
☐ Too far away
8. What type of treatments or interventions do you use for your child?
☐ Special Education
☐ ABA Therapy
☐ Other Behavioral
☐ Counseling
☐ Medicines
☐ Psychiatry
☐ Biomedical
9. Do you have private insurance or Medicaid?
☐ Private Insurance
☐ Medicaid

Figure 2. Proposed "Barriers to Autism Treatment" Survey

REFERENCES

- Mandell, David, S., et al. (2009). Racial/ethnic disparities in the identification of children with autism spectrum disorders. *American Journal of Public Health*, 99(3), 493-498.
- Bernier, Raphael, et al. (2010). Psychopathology, families, and culture: Autism. *Child and Adolescent Psychiatric Clinics of America*, 19(4).
- Tregnago, Megan K., et al. (2012). Systematic review of disparities in health care for individuals with autism spectrum disorders in the United States. *Research in Autism Spectrum Disorders*, 6, 1023-1031.
- Tincani, Matt, et al. (2009). Race, culture, and autism spectrum disorder: Understanding the role of diversity in successful educational interventions. *Research and Practice for Persons with Severe Disabilities*, 34 (3-4), 81-90.
- Young, April, et al. (2009). Public vs. private insurance: Cost, use, accessibility, and outcomes of services for children with autism spectrum disorders. *Research in Autism Spectrum Disorders*, 3, 1023-1033.
- Agency for Healthcare Research and Quality (AHRQ). *National Disparities Report 2011*.



Mean percentage of total out-of-pocket expenditures.

Figure 1. Mean percentage of total out-of-pocket expenditures used on each service for privately and publicly insured groups. [5]