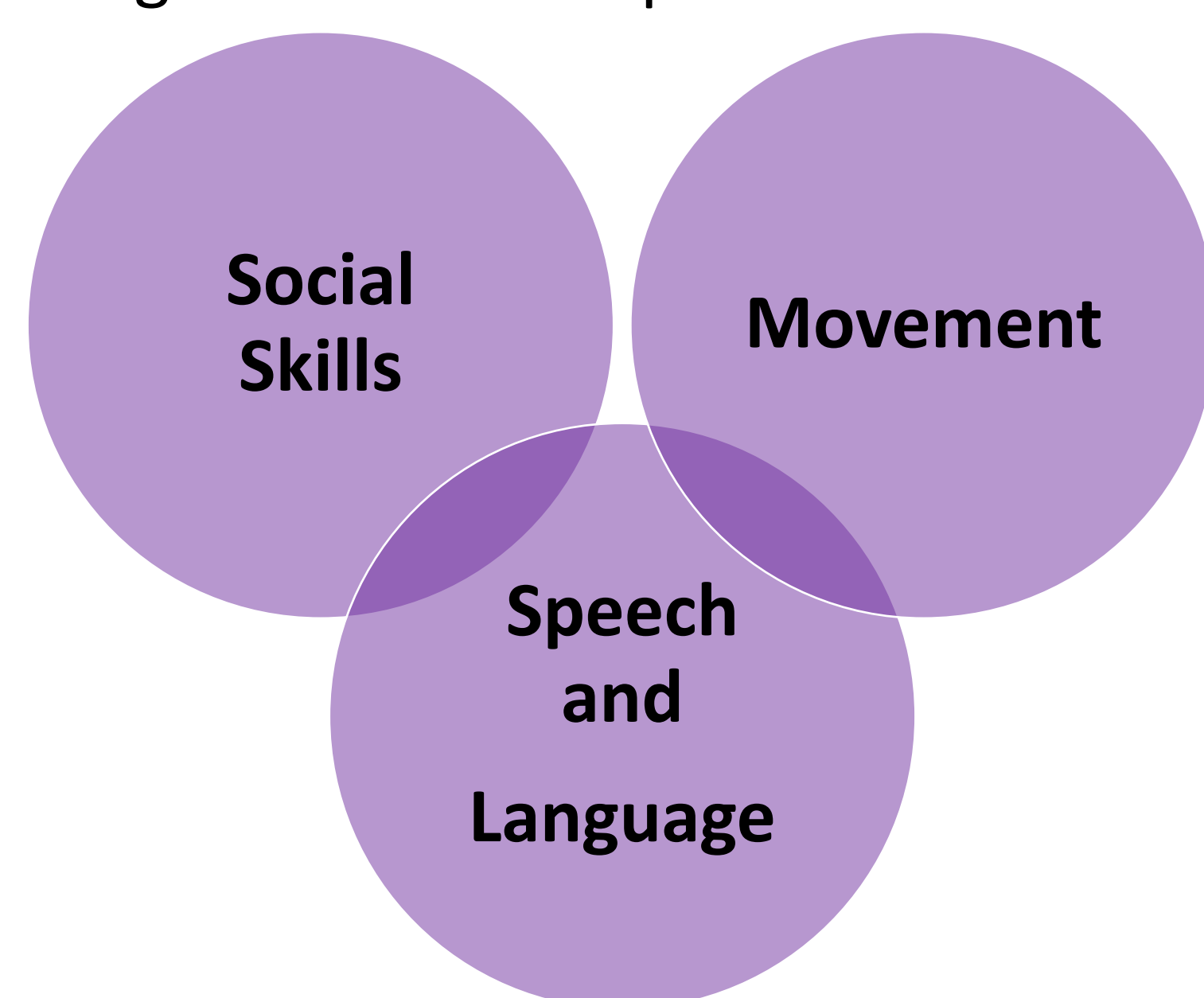


Introduction

The University of Connecticut A.J. Pappanikou Center for Excellence in Developmental Disabilities Education, Research, and Service (UConn UCEDD) is one of the 67 national UCEDDs created under The Developmental Disabilities Assistance and Bill of Rights Act of 2000. The Center conducts research and provides trainings to ensure persons with disabilities across their lifespan are active participants of their communities.

Background & Significance

The purpose of this research project is to create an educational resource to address the stigma of Autism Spectrum Disorder (ASD) in communities of color.



These needs create challenges for the health care community in regard to the provision of services available for those with ASD. This lack of services negatively impacts their ability to achieve good health and a high quality of life. In addition to the health disparities experienced by those with ASD because of their disability, some may also experience disparities because of the intersectionality of their social determinants of health, in particular race and socioeconomic status. (7)

Objectives

- Gain a better understanding of the source and impact of the stigma surrounding ASD in communities of color
- Increase knowledge of ASD to improve community awareness in communities of color
- Provide information to help families experiencing these health disparities become stronger advocates for quality healthcare

Methods

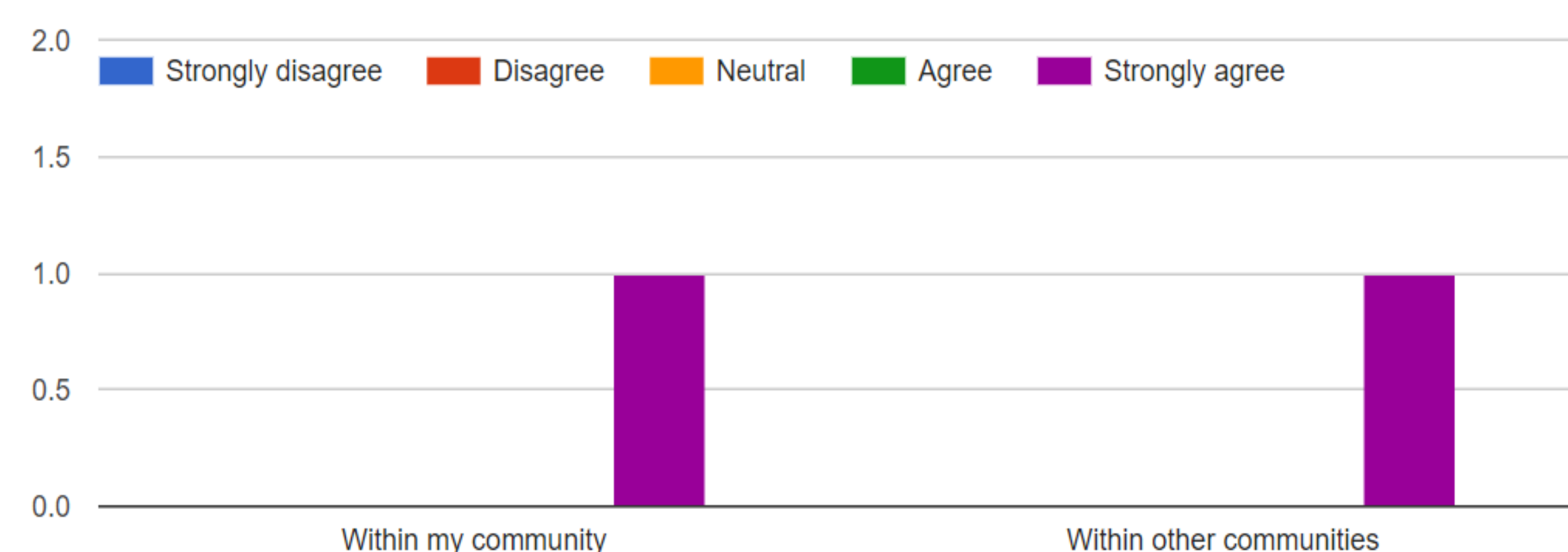
Research conducted was based on:

- a literature search
- family perspective questionnaire

The questionnaire was emailed to several families to capture the beliefs and experiences of families of color with a child with ASD. It is concise and culturally competent to gather sufficient data and encourage participation among various communities.

Results

There is a stigma surrounding autism in communities of color.



Literature and data indicate that:

- There is a stigma surrounding ASD in communities of color that is both internal and external to the family unit, and exists in healthcare and education settings
- African American children received ASD diagnoses 1.6 years later than Caucasian children (2)
- African American children were 2.6 times more likely to be misdiagnosed than Caucasian children (2)
- Families expressed a lack of acceptance of and a lack of knowledge of ASD within their communities (2)

Literature also indicates that Black and Latino parents were less likely than White parents to report that their healthcare providers (6):

- helped them feel like partners
- spent enough time with their children
- were sensitive to their family's values and customs

Discussion/Conclusions

ASD diagnostic delays can be attributed to poor health care access, but we need to identify if the stigma such as embarrassment and fear impacts people that have proper access. Early ASD intervention help individuals better integrate into society but lack of quality patient-physician interactions within communities of color thwart this possibility. The following prevents physicians from understanding behaviors in these communities and aspects of the stigma surrounding ASD:

- lack of cultural competency
- unequal treatment in health and community care
- distrust of clinical health care

Another factor impacting health outcomes of these communities is the stigma within them, which stem from: limited economic resources, lack of support systems, & knowledge gaps in ASD symptoms and care. Working to eradicate the stigma must include efforts to understand the source of the fear, embarrassment, and other beliefs surrounding ASD diagnoses. Defining and identifying the stigma will help end the generational, perpetuating cycle of difficulties they experience and is a good step towards improving health outcomes for these communities.

Next Steps

Parents can use this to advocate for their children and help to reduce the stigma in their communities. In particular families will have information including :

- the components of effective communication between HCPs and families
- components of quality health care
- components of effective education on ASD

Further research to understand the intersections of disability, race/ethnicity, and socioeconomic status is essential to improving the trust and breaking the cultural barriers between communities of color and physicians. Future research in this area should include parent advocacy groups such as: Autism Speaks, Innovative Autism Services, and CT Parent Advocacy Center to educate and empower more families of color to be advocates for ASD and help improve health equities for all populations.

Acknowledgements

The authors would like to acknowledge the support of the Department of Health Career Opportunity Programs, UConn Health; Community Based Education, UConn Health; the Aetna Foundation; Newman's Own Foundation; the Connecticut Health Foundation; Connecticut State Legislative Fund; The Hartford; William and Alice Mortensen Foundation; John and Valerie Rowe Health Professions Scholars Fund; and the Friends of the Department of Health Career Opportunity Programs Fund.

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