

# Experience of stigma and its relationship to identification with the neurodiversity model for Indian parents of children with autism spectrum disorder

Sahita Manda, University of Michigan, School of Public Health; Elizabeth Buvinger, PhD, University of Michigan, Department of Psychology  
Shichi Dhar, University of Michigan, School of Public Health; Harika Veldanda, University of Michigan, College of Literature, Science, and the Arts

## Introduction

- ASD has been viewed extensively within the medical model, which aims to prevent and cure the condition and eliminate the deficits/impairments it gives rise to (Kapp et al., 2013).
- The social model of disability challenges the medical model (Jaarsma & Welin, 2011), pushing society to change in a way that reduces barriers for individuals with ASD.
  - The neurodiversity model adopts the social model of disability and proposes that ASD is a natural variation of human behavior that should be celebrated (Jaarsma & Welin, 2011).
- Currently, families of children with ASD face widespread stigma, including shame and social exclusion (Farrugia, 2009).
  - Much of the stigma originates from misconceptions about a child's autism-related behaviors as well as ASD's etiology (Kinnear et al., 2015).
  - Stigma leaves parents feeling blamed for their child's behavior (Neely-Barnes et al., 2011), isolated from society (Woodgate et al., 2008), and in general, distressed (Green, 2003).
- The neurodiversity paradigm has the potential to lessen the stigma associated with ASD and allow parents to shift their focus to their child's strengths and needs.
- Stigma associated with ASD is especially prevalent in India where there is a large emphasis on conformity to social norms (Juneja & Sairam, 2018).
- It is essential to investigate how such cultural values/beliefs evolve in different countries as well as how they change the way in which parents relate to their children with ASD.

## Method

- Anonymous cross-sectional survey through online platform Qualtrics
  - Includes validated measures from previous studies, such as the *Parental Stress Scale* (Berry & Jones, 1995), as well as constructed scales, such as the neurodiversity alignment measure
  - Three open-ended questions regarding parental goals and child strengths also collected
  - Offered in English, Hindi, Tamil
- Participants: parents of Indian origin residing in India with children aged 17 or younger diagnosed with ASD (N=82; full data n=56)
- Recruitment: public advertisements at autism-based organizations, schools, child development centers, parent groups, and autism social media support groups based in India

## Demographic Descriptive Statistics

Table 1  
*Sociodemographic Descriptive Statistics of Parent/Guardian*

Sample Characteristics	n	Mean ± SD
Age (years)	82	38.1 ± 6.06
Annual household gross income (Rs*)	68	309014.71 ± 616013.22
Relationship to child	n	% of Total Sample
Mother	66	81.48
Father	13	16.05
Guardian	2	2.47
Highest level of education	n	% of Total Sample
Less than higher secondary	17	21.52
Completion of higher secondary/diploma	17	21.52
College graduates	45	56.96
Marital Status	n	% of Total Sample
Married/with significant other	74	91.36
Religion	n	% of Total Sample
Hinduism	55	68.75
Christianity	21	26.25
Islam	4	5.00
No religion	4	5.00

Note. Sample size varies for each variable  
\*Rs = rupees, 76.14 Rs : \$1.00

## Demographic Descriptive Statistics

Table 2  
*Demographic Descriptive Statistics of Children*

Sample Characteristics	n	Mean ± SD	% of Total Sample
Gender			
Male	60		82.19
Female	13		17.81
Current age (years)	76	10.63 ± 4.23	
Age at initial diagnosis (years)	51	3.94 ± 2.47	
Number of comorbidities	58	2.00 ± 1.51	

Note. Sample size varies for each variable

## Results

Fig. 1. Preliminary bivariate correlational analysis results with selected variables

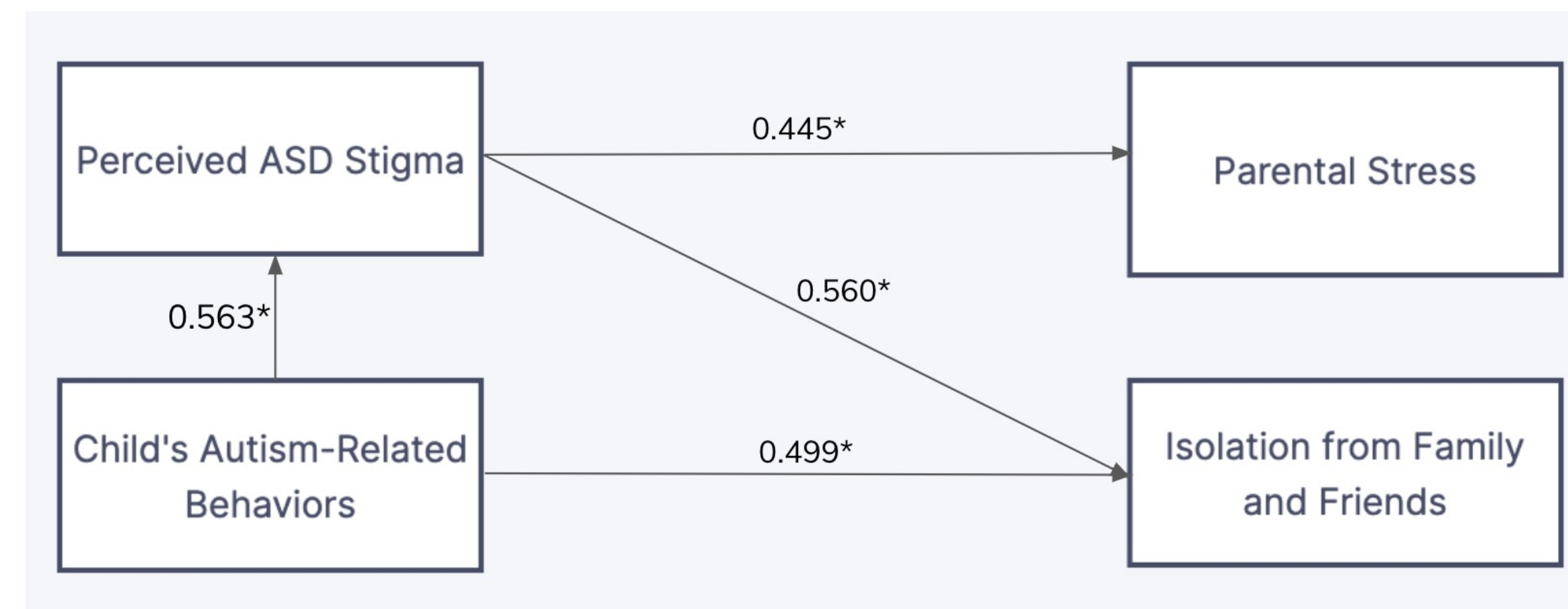


Fig. 1. Pearson correlation coefficients were determined using bivariate correlational analysis at a significance level of  $p < .01$  with SPSS software. Significant correlation coefficients are displayed in the figure.

Fig. 2. Mediation analysis with perceived ASD stigma, neurodiversity alignment, and parental stress measures

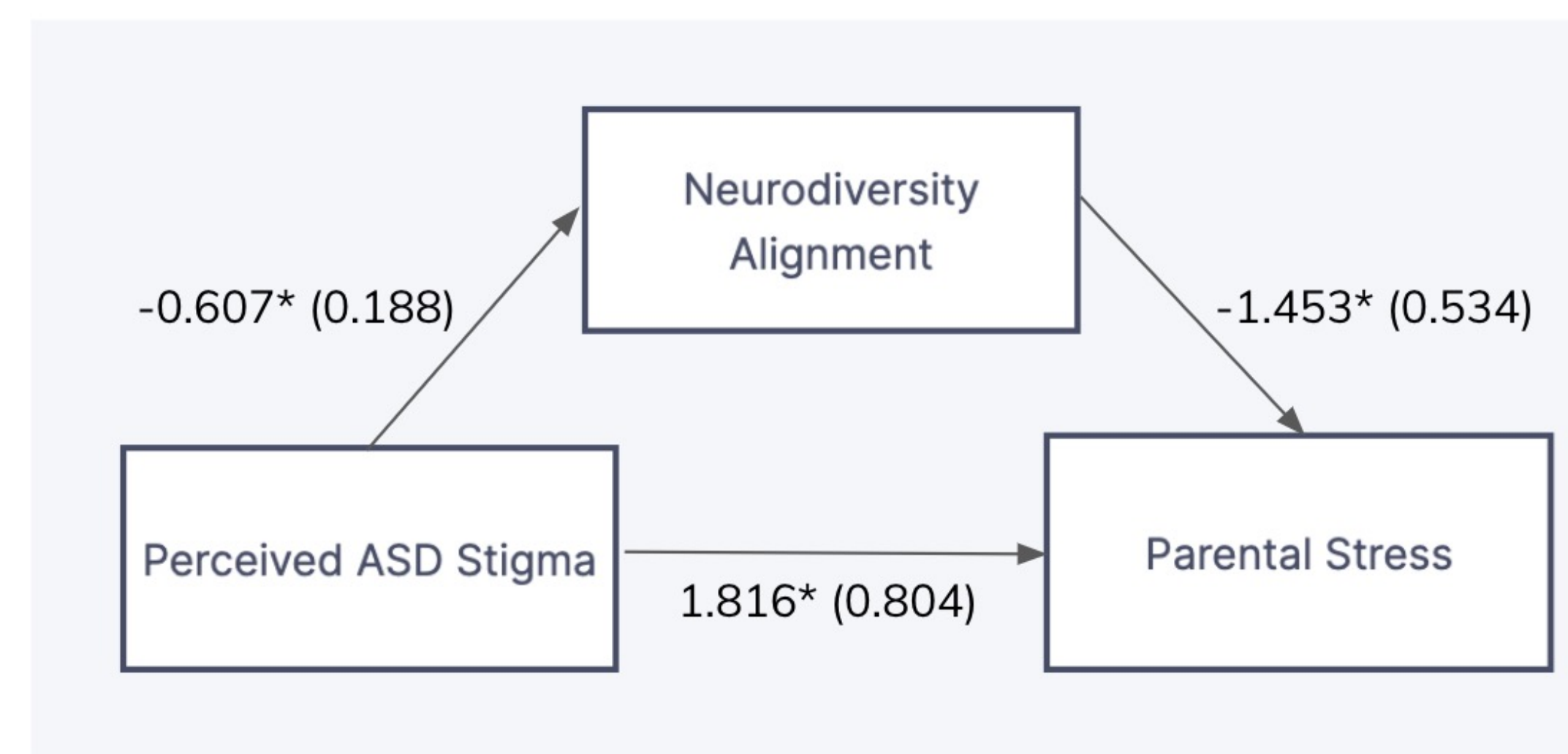


Fig. 2. Raw regression coefficients for associations between variables were determined at a significance level of  $p < .05$  with SPSS software. Significant coefficients are displayed in the figure with an asterisk. Standard errors of the coefficients are displayed in parentheses. The Sobel test was used to test whether a mediator carries the influence of the independent variable to the dependent variable, and mediation results were significant at  $p < .05$ .

## Results

Fig. 3. Mediation analysis with perceived ASD stigma, neurodiversity alignment, and isolation measures

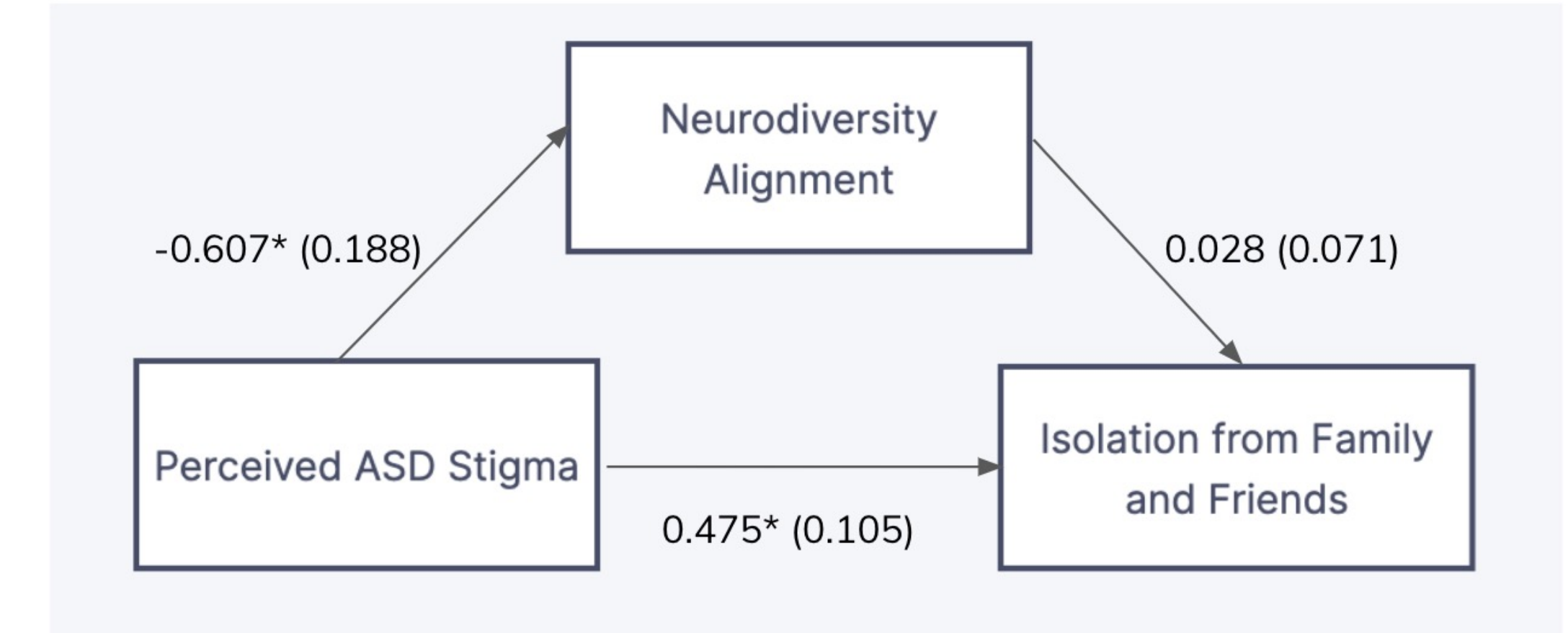


Fig. 3. Raw regression coefficients for associations between variables were determined at a significance level of  $p < .05$  with SPSS software. Significant coefficients are displayed in the figure with an asterisk. Standard errors of the coefficients are displayed in parentheses. The Sobel test was used to test whether a mediator carries the influence of the independent variable to the dependent variable, and mediation results were not significant at  $p < .05$ .

## Discussion

- Perceived stigma from ASD-related behaviors can compel parents to isolate from family and friends to avoid possible rejection or exclusion.
- While perceived ASD stigma predicts parental stress, a child's autism behaviors do not.
- Results of mediation analysis with perceived ASD stigma, neurodiversity alignment, and parental stress measures support hypothesis.
  - Demonstrate that social surroundings may have to be conducive to adopting a strength-based approach.
  - Results also support literature findings that neurodiversity paradigm is a positive and meaningful way to approach ASD (Kapp et al., 2013; Soukup, 2018), which has implications for reducing parental stress.
- Results of mediation analysis with perceived ASD stigma, neurodiversity alignment, and isolation measures do not support hypothesis.
  - Child's autism-related behaviors could be acting as a moderator variable on the relationship between neurodiversity alignment and isolation.
  - Alternatively, although aligning with the neurodiversity model allows parents to view their children positively, they may still want to isolate from family and friends due to societal stigma associated with ASD-related behaviors.

## Next Steps

- Conduct more complex mediation analyses incorporating the neurodiversity alignment variable
  - Does child's autism-related behaviors act as a moderator in the mediation models examined?
  - How does culture specifically play a role: focus on mediation model incorporating adherence to Asian values and neurodiversity alignment
- Investigate the impact of demographic characteristics on the relationships in the hypothesized model
- Qualitatively analyze responses to the three open-ended questions by conducting a thematic analysis (e.g. what are your child's strengths?)

## References

- Berry, J. O., & Jones, W. H. (1995). The Parental Stress Scale: Initial psychometric evidence. *Journal of Social and Personal Relationships*, 12(3), 463-472. <https://doi.org/10.1177/0265407595123009>
- Farrugia, D. (2009). Exploring stigma: medical knowledge and the stigmatisation of parents of children diagnosed with autism spectrum disorder. *Sociology of Health & Illness*, 31(7), 1011-1027. <https://doi.org/10.1111/j.1467-9566.2009.01174.x>
- Green, S. E. (2003). "What do you mean 'what's wrong with her?': stigma and the lives of families of children with disabilities. *Social Science & Medicine*, 57(8), 1361-1374. [https://doi.org/10.1016/s0277-9536\(02\)00511-7](https://doi.org/10.1016/s0277-9536(02)00511-7)
- Jaarsma, P., & Welin, S. (2011). Autism as a natural human variation: Reflections on the claims of the neurodiversity movement. *Health Care Analysis*, 20(1), 20-30. doi: 10.1007/s10728-011-0169-9
- Juneja, M., & Sairam, S. (2018). Autism spectrum disorder - An Indian perspective. In *Recent Advances in Autism* (pp. 1-15). essay, SMGroup.
- Kapp, S. K., Gillespie-Lynch, K., Sherman, L. E., & Hutman, T. (2013). Deficit, difference, or both? Autism and neurodiversity. *Developmental Psychology*, 49(1), 59-71. doi: 10.1037/a0028353
- Kinnear, S. H., Link, B. G., Ballan, M. S., & Fischbach, R. L. (2015). Understanding the experience of stigma for parents of children with autism spectrum disorder and the role stigma plays in families' lives. *Journal of Autism and Developmental Disorders*, 46(3), 942-953. <https://doi.org/10.1007/s10803-015-2637-9>
- Neely-Barnes, S. L., Hall, H. R., Roberts, R. J., & Graff, J. C. (2011). Parenting a child with an autism spectrum disorder: Public perceptions and parental conceptualizations. *Journal of Family Social Work*, 14(3), 208-225. <https://doi.org/10.1080/10522158.2011.571539>
- Soukup, S. (2018). *Neurodiversity: Exploring a biopsychosocial approach to stigma reduction for ASD* (Publication No. 10982422) [Doctoral dissertation, Palo Alto University]. ProQuest Dissertations Publishing.
- Woodgate, R. L., Ateah, C., & Secco, L. (2008). Living in a world of our own: The experience of parents who have a child with autism. *Qualitative Health Research*, 18(8), 1075-1083. <https://doi.org/10.1177/1049732308320112>