

Putting Research to Work for Military Families



Focus:
Civilian

Understanding the Experience of Stigma for Parents of Children With Autism Spectrum Disorder and the Role Stigma Plays in Families' Lives

Kinnear, S. H., Link, B. G., Ballan, M. S., & Fischbach, R. L. (2016). 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. doi:10.1007/s10803-015-2637-9

SUMMARY: Parents of children with autism spectrum disorder (ASD) tend to have experiences and perceptions of stigma. This study built and tested a conceptual model for stigma and surveys parents of children with ASD to explore the pathways of the stigma experience.

KEY FINDINGS:

- Stigma and autism-related behaviors of the child are the largest contributors to the challenges parents of children with ASD face.
- Parents reported experiencing stigma with some frequency, including experiences with isolation and exclusion from family and friends.
- Stereotypes and peer rejection were found to be associated with stigma but were not found to be directly associated or significant predictors of a parent's difficulty of having a child with ASD.

IMPLICATIONS FOR MILITARY PROFESSIONALS:

Military professionals could:

- Partner with other professionals who specialize in ASD to develop curriculum for Service members and their families who may experience stigma
- Facilitate support groups for Service members and their families who have children with ASD so as to relieve potential feelings of isolation and exclusion

IMPLICATIONS FOR PROGRAMS:

Programs could:

- Encourage activities such as journaling and blogging for Service members and families to have a way to process experiences and perceptions constructively
- Provide literature to community organizations to raise awareness about stigma, ASD, and military life

IMPLICATIONS FOR POLICIES:

Policies could:

- Recommend professional development for those working with Service members and children with ASD
- Promote programs that are providing educational materials and information about stigma and ASD

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METHODS

- The Interactive Autism Network at the Simons Foundation Autism Research Initiative sent mailers to its 1,460 participants-parents with one child with ASD-and a final random sample of 554 was selected.
- Focus groups and interviews were held to identify focus areas for the study's survey, which was cognitively tested, piloted with 20 individuals, and finalized for phone surveys lasting 20-30 minutes.
- Measures included: child's autism-related behaviors, parent's perception of public stereotypes, autism causes and characteristics, frequency of rejection of child by peers, isolation from friends and family, overall assessment of difficulty of stigma in parent's lives, and general stigma-related questions.

PARTICIPANTS

- Participants included 502 parents in the Interactive Autism Network, a 91% response rate.
- Almost all participants (95%) were mothers between 28 and 65 years old ($M = 43.7$, $SD = 5.36$) and most (70%) were college graduates with 82% being White and 84% having at least one additional child.
- Of the children with ASD, most were male (86%, with a 6:1 ratio boys to girls), 88% were verbal and 97% were enrolled in school.

LIMITATIONS

- The study was cross-sectional, making causation difficult to assess, which is important to the testing of directionality in the study's conceptual model.
- The sample was homogenous in terms of race and educational attainment, which makes generalizability difficult and may not represent how different groups experience stigma.
- There were few fathers in the study and it is unclear how fathers of children with ASD experience stigma compared to the vast majority of mothers in the study.

AVENUES FOR FUTURE RESEARCH

Future research could:

- Explore a longitudinal design to examine how parents of a child with ASD experience stigma over time
- Expand the sample to include more diversity in race and educational attainment as there may be different factors in the social components of stigma that may be experienced differently
- Study how fathers perceive stigma as a parent of a child with ASD as well as studying parent dyads to see whether and how they perceive stigma as a couple

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