

Supporting Families/Caregivers Raising Children with Special Needs

**An Exploration of Systemic Barriers, Caregiver Strain and
Marital Stress**

Brad Lee, LMFT

Director, Special Needs Family Institute

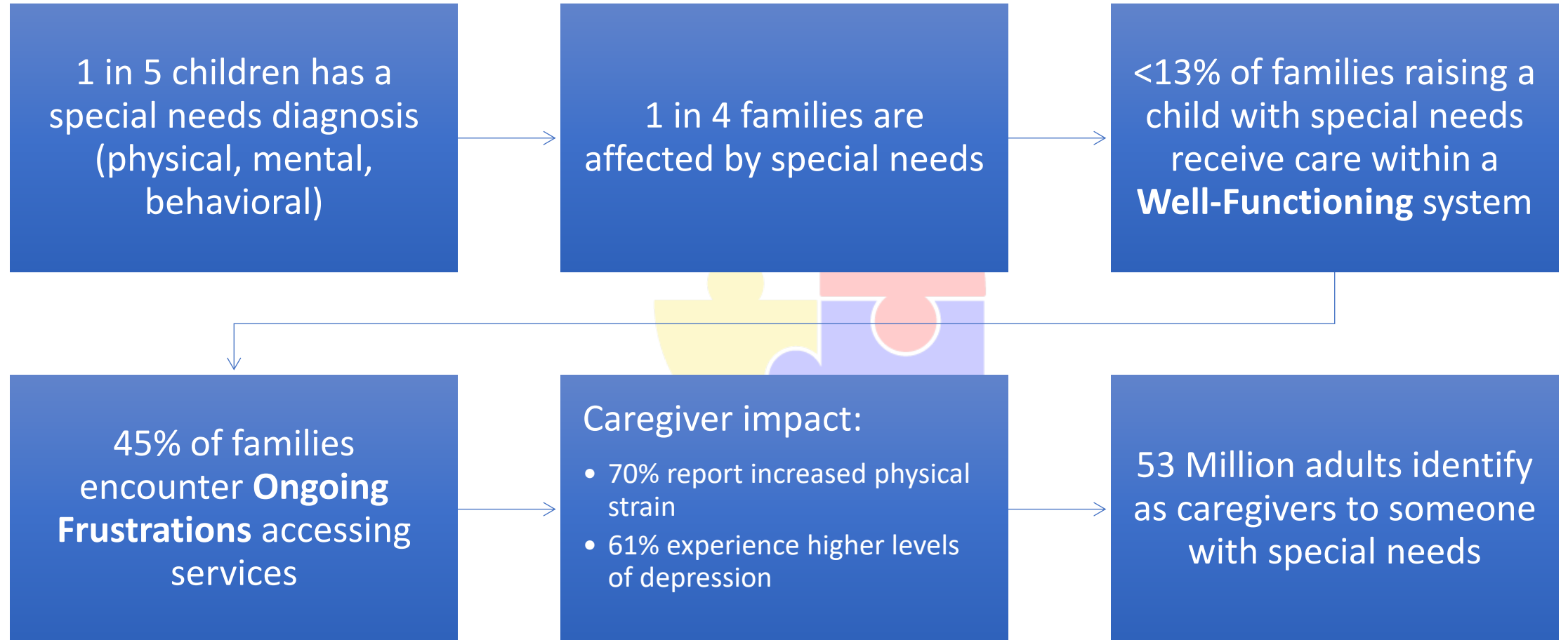
Nashville, Tennessee

Outline

- Opening Data
- Systemic Barriers
- Caregiver Strain: Diagnosis and Behaviors
- Marriage and Family Impacts
- A Key Discovery
- Autism and Tylenol
- Conclusion
- Questions



Macro Data



Autism Spectrum Disorder (ASD): Diagnosis Rates



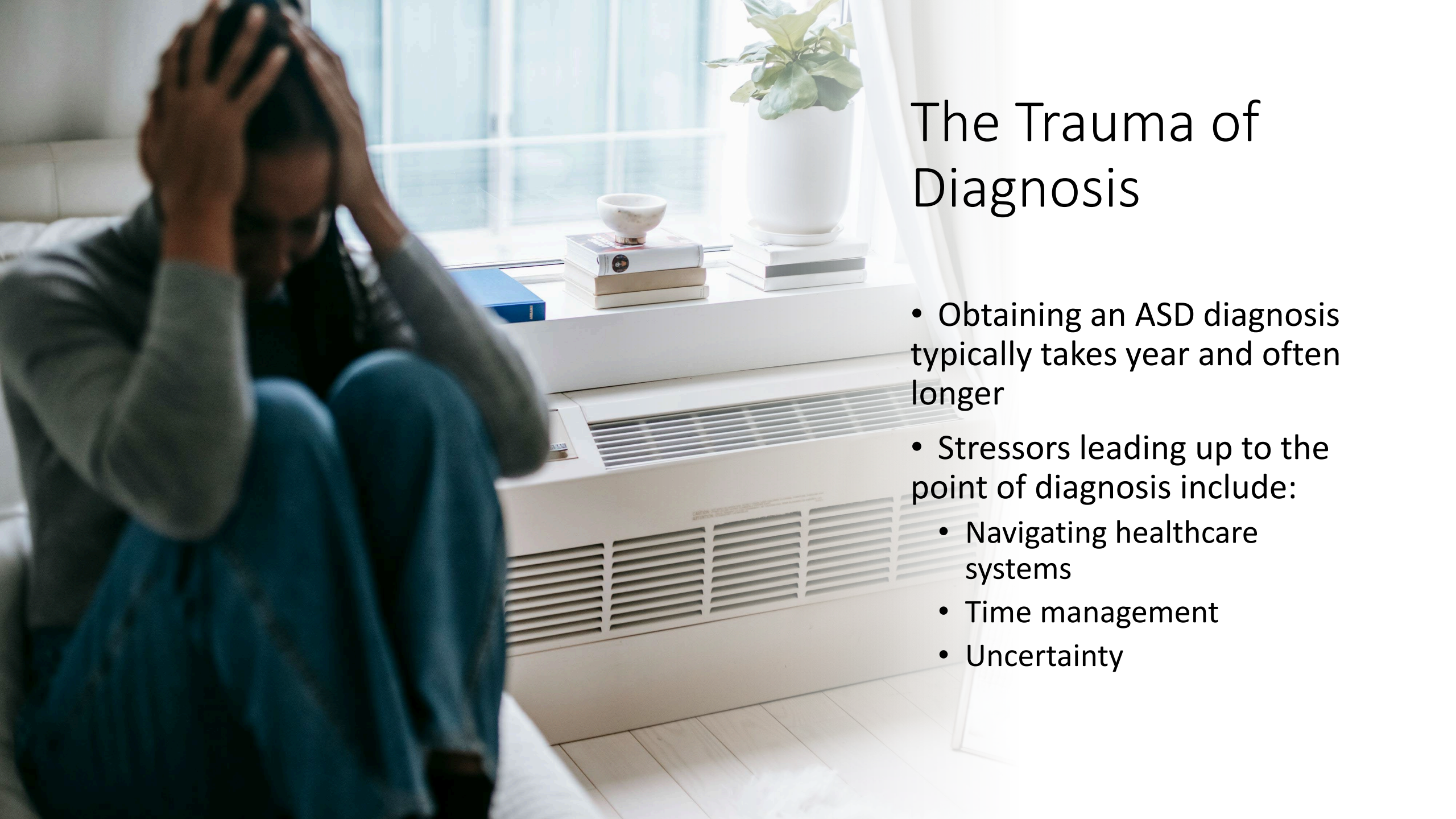
1 in 150 (2000)
1 in 88 (2008)
1 in 59 (2014)
1 in 36 (2020)
1 in 31 (2025)



The Challenge of Health Care Access

- A daunting task
- Support services are an even greater challenge to access
- Lack of providers
- 1 in 3 parents report psychological distress





The Trauma of Diagnosis

- Obtaining an ASD diagnosis typically takes year and often longer
- Stressors leading up to the point of diagnosis include:
 - Navigating healthcare systems
 - Time management
 - Uncertainty

Diagnosis as Trauma

- Receiving a special needs diagnosis can be categorized as a traumatic event
- Experienced emotions are commensurate with trauma
- Cumulative stressors and increased demands can contribute to the development of traumatic stress and even stress disorders
- Isolation is a primary challenge





Behaviors: The Ultimate Stressor

- Public displays of negative behaviors exacerbate embarrassment and stigma for parents
- Behaviors associated with ASD correlate with anxiety and depression in parents
- Anxiety and depression is higher in parents of children with ASD compared to other disorders





Behavioral Distinctives

- Boys' changes in mood are correlated to parental levels of depression
- Girls' socially isolating behaviors are associated with parental depression
- Girls' impulsive behaviors are significantly linked to parental anxiety





Adaptive Families

- Families must learn not only to adapt to the child with special needs, but also adapt to each other in the context of the changes and challenges that the family system experiences
- The child with special needs is not the only one that changes but the entire family system



Impacts on Moms

- Married mothers report greater marital tension and conflict
- Single mothers experience increase demands as a single parent
- BOTH experience guilt and feelings of inadequacy as a parent or partner or both



Marital Adjustment: The Determining Factor

- Marital adjustment is the determining factor that predicts a couple's ability to cope with the stress of raising a child with ASD/special needs
- Marital adjustment is the ability to adapt relationally to each other amidst the challenges and stressors of raising their child with ASD/special needs



A man and a woman are sitting on a couch, facing each other in a therapy session. The man, on the left, is wearing a light blue button-down shirt and has a beard. He is looking at the woman with a thoughtful expression, his hand resting on his chin. The woman, on the right, is wearing a light green top and glasses. She is looking at the man. A clipboard with a pen is visible on the man's lap. The background is a bright, out-of-focus indoor setting.

Structural Family Therapy (SFT)

- SFT has shown to produce a 50% increase in marital adjustment
- SFT helps reduce parental stress by 1/3

Siblings

- Siblings are often overlooked but are important to family functioning
- Siblings are definitively impacted having a brother or sister with ASD as they are exposed to the same stressors as parents





Siblings

- The specific needs of siblings can be overlooked as attention shifts to caring for the child with ASD
- When parents recognize and cultivate the relationship with their typical children the result is often siblings that experience feeling:
 - More secure within the family system
 - Respected
 - Informed
 - Involved



Sibling Benefits

- Typical siblings develop relational skills specific to their sibling relationship
- Typical siblings are innovative in navigating social settings in the context of their sibling bond
- The relationship between typical and ASD siblings can be closer than expected



A Shift



Many studies correlate parental stress with coping strategies versus the impact of parental stress with marital satisfaction

A Shift and Hallmark Discovery

- Many studies correlate parental stress with coping strategies versus the impact of parental stress with marital satisfaction
 - **Fathers** note parental stress related to **marital factors**
 - **Mothers** note their parental stress correlated to their **child's behaviors**





Tylenol and Autism:
Correlation vs. Causation

Conclusion

- Autism continues to be a prevalent neurodivergent diagnosis
- Based on the recent trend diagnoses will likely continue to increase
- The demand for services and support is overwhelming and will only increase as well



Conclusion

- The impacts of an ASD diagnosis are profound and immediately impacting
- The emotions experienced by parents when receiving a special needs diagnosis are associated with trauma and can lead to traumatic stress symptoms and even stress disorders
- The stress experienced by parents is related to the overwhelming demands placed upon them to care for the child with special needs as they attempt to balance other life and family demands
- Child behaviors are a dominant stressor for parents impacting both their coping mechanisms and the marital relationship



Conclusion

- As families struggle to cope with the stresses and demands of raising a child with special needs the need for awareness, inclusion, and accommodation will continue
- Specialized therapeutic strategies and interventions are needed to better support families affected by ASD
- Focusing on both parents, as well as the marriage relationship and not solely on parenting strategies, will bolster resilience and marital adjustment in families affected by ASD



References

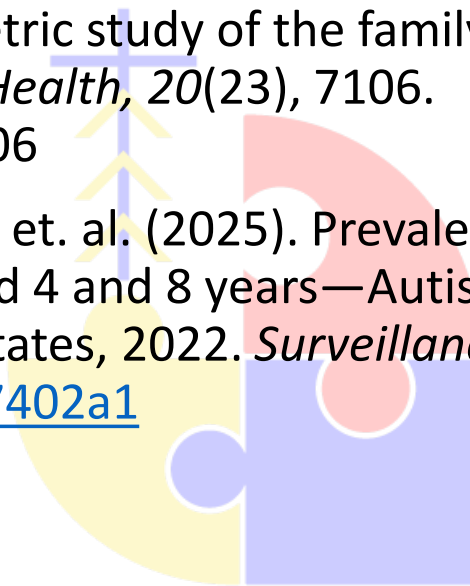
- American Psychiatric Association. (2022). *Diagnostic and statistical manual of mental disorders* (5th ed., text rev.; DSM-5-TR). American Psychiatric Publishing.
<https://doi.org/10.1176/appi.books.9780890425787>
- AlHorany, A. K., Hassan, S. A., Juhari, R., & Aljaberi, M. A. (2024). Effectiveness of integrative structural family therapy and double ABCX model on marital adjustment and parenting stress among parents of children with autism: Randomized controlled trial. *Child & Family Behavior Therapy*, 47(1), 1–31.
<https://doi.org/10.1080/07317107.2024.2395296>
- Bent, C. A., Barbaro, J., & Dissanayake, C. (2020). Parents' experiences of the service pathway to an autism diagnosis for their child: What predicts an early diagnosis in Australia? *Research in Developmental Disabilities*, 103. <https://doi.org/10.1016/j.ridd.2020.103689>
- Bitsika, V., & Sharpley, C.F. (2022) Associations between mildly impaired autistic boys' and girls' challenging behaviour and parental anxiety and depression. *J Dev Phys Disabil* 34, (1013–1029).
<https://doi.org/10.1007/s10882-021-09832-7>
- Brown, M., Whiting, J., Kahumoku-Fessler, E., Whiting, A. B., & Jensen, J. (2020). A dyadic model of stress, coping, and marital satisfaction among parents of children with autism. *Family Relations*, 69(1), 138-150. <https://doi.org/10.1111/fare.12375>

References (Cont.)

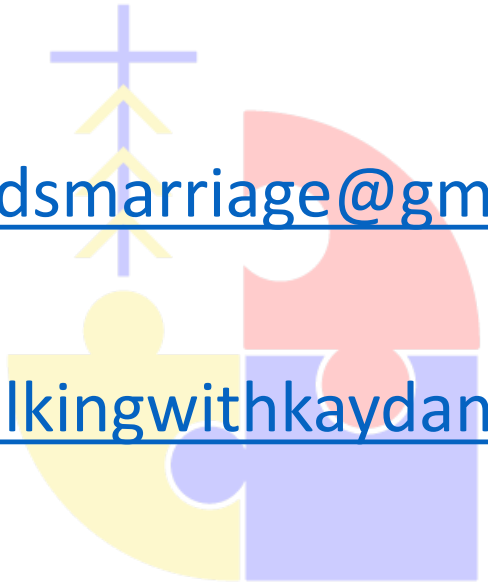
- Godfrey, G. D., Downes, N., & Cappe, E. (2024). A systematic review of family functioning in families of children on the autism spectrum. *Journal of Autism and Developmental Disorders*, 54(3), 1036-1057. <https://doi.org/10.1007/s10803-022-05830-6>
- Olcay Gul, S., Ardic, A., Olgunsoylu, B., & Unal, Y. (2017). Posttraumatic stress symptoms and related Variables in Families of Children with Disabilities. *International Journal of Early Childhood Special Education*., 9(2), 111–127. <https://doi.org/10.20489/intjecse.375107>
- Ostfeld-Etzion, S., & Ben-Artzi, E. (2025). Guilt and maternal depression among married and single mothers of children with autism spectrum disorder: moderation analysis. *International Journal of Developmental Disabilities*, 1–10. <https://doi.org/10.1080/20473869.2025.2504437>
- Rizvi, A. Z., & Batool, S. S. (2024). A qualitative study on perspective of parental stress and lower marital quality among parents of children with autism spectrum disorder. *International Journal of Developmental Disabilities*., 1–20. <https://doi.org/10.1080/20473869.2024.2341196>
- Schmeer, A., Harris, V. W., Forthun, L., Valcante, G., & Visconti, B. (2021). Through the eyes of a child: Sibling perspectives on having a sibling diagnosed with autism. *Research in Developmental Disabilities*., 119. <https://doi.org/10.1016/j.ridd.2021.104066>

References (Cont.)

- Serrano, L., Vela, E., & Martín, L. (2023). Analysis of the functioning of families of children with autism spectrum disorder: A psychometric study of the family APGAR scale. *International Journal of Environmental Research and Public Health*, 20(23), 7106. <https://doi.org/10.3390/ijerph20237106>
- Shaw, K. A., Williams, S., Patrick, M. E., et. al. (2025). Prevalence and early identification of autism spectrum disorder among children aged 4 and 8 years—Autism and developmental disabilities monitoring network, 16 sites, United States, 2022. *Surveillance Summaries*. 74(2), 1-22. DOI: <https://dx.doi.org/10.15585/mmwr.ss7402a1>



Contact & Connect



specialneedsmarriage@gmail.com

www.walkingwithkaydan.com

www.specialneedsfamilyinstitute.com