

Strength for the Journey: Helping couples with a child with special needs

Rev. Brad Lee, LMFT
Director, The Special Needs Family Institute



## Isaiah 61:1

The Spirit of the Sovereign LORD is on me, because the LORD has anointed me to proclaim good news to the poor. He has sent me to bind up the brokenhearted, to proclaim freedom for the captives and release from darkness for the prisoners

## The Special Needs Marriage Defined

The special needs marriage is one in which one or more children are born with (or adopted) or later receive a diagnosis, be it physical, developmental, or behavioral, that affects the normal or typical flow of married life and connection.



# The Special Needs Marriage: Three Views

- The Long-View: The Golden Years
  - Start with the End in Mind
  - Financial Impacts
  - ► The Ultimate Question



# The Special Needs Marriage: Three Views

- The Short-View: Important vs. Urgent
  - The Continuum Strain (Time)
  - Extended Vigilance (The Firehouse)
  - A Neurological Perspective (Hypervigilance)



## The Special Needs Marriage: Three Views

- The Attachment-View: Typical vs. Specialized
  - ► An Example of Conflict
  - Disruption, Interruption and Erosion
  - Cumulative Stress and Trauma

### A Pragmatic Approach: Conduits of Strength on the Journey

- The power of Story (Narrative)
- Little wins; Big gains (Reframing)
- Connection and Intimacy (Creative Attachment)
- Diagnosis as Sanctification (Spiritual/Liminal)



#### References

- Caicedo C. (2014). Families with special needs children: Family health, functioning, and care burden. *Journal of the American Psychiatric Nurses Association*. 20(6):398-407. doi:10.1177/1078390314561326
- Carter, E. W., (2022). A place of belonging: Including individuals with significant disabilities in faith communities. *Inclusive Practices.*, *I*(1), 6–12. https://doi.org/10.1177/2732474520977482
- Daire, A. P., Munyon, M. D., Carlson, R. G., Kimemia, M., & Mitcham, M. (2011). Examining distress of parents of children with and without special needs. *Journal of Mental Health Counseling*, 33(2), 177–188. doi:10.17744/mehc.33.2.qu73p03176337xx1.
- Demarest, S., Marsh, R., Treat, L., Fisher, M. P., Fisher, M. P., Dempsey, A., Junaid, M., Downs, J., Leonard, H., Benke, T., & Morris, M. A. (2022). The lived experience of parents' receiving the diagnosis of CDKL5 deficiency disorder for their child. *Journal of Child Neurology.*, 37(6), 451–460. <a href="https://doi.org/10.1177/08830738221076285">https://doi.org/10.1177/08830738221076285</a>
- Douglas, T., Redley, B., & Ottmann, G. (2016). The first year: the support needs of parents caring for a child with an intellectual disability. *Journal of Advanced Nursing*. 2(11), 2738–2749. https://doi.org/10.1111/jan.13056
- Freedman, B., Luther, G., Zablotsky, B., and Stuart, E. (May 2011). Relationship status among parents of children with autism spectrum disorders: A population-based study. *Journal of Autism and Developmental Disorders*, 42, 539-548. Doi:10.1007/s10803-011-1269-y.
- Goff, B. S. N., Springer, N., Foote, L. C., Frantz, C., Peak, M., Tracy, C., Veh, T., Bentley, G.E., & Cross, K. A. (2013). Receiving the initial down syndrome diagnosis: A comparison of prenatal and postnatal parent group experiences. *Intellectual and Developmental Disabilities*, 51(6), 446-57.

### References, Cont.

- ▶ Hardwick, L. (2021). *Disability and the church*. Intervarsity Press.
- Larson, Elizabeth. (Spring, 2006). Caregiving and autism: How does children's propensity for routinization influence participation in family activities? *OTJR: Occupation*, *Participation and Health*, 26(2) 69-79.
- Laufer, A., & Isman, E. (2021). Posttraumatic Growth (PTG) among parents of children with special needs. *Journal of Loss and Trauma*, 27(1), 18–34. https://doi.org/10.1080/15325024.2021.1878336
- Levers, L. L. (2022). *Trauma counseling: Theories and interventions for managing trauma, stress, crisis and disaster*. Sringer Publishing Company.
- Long, L. J., (2022). Hope and PTSD. *Current Opinion in Psychology*., 48. https://doi.org/10.1016/j.copsyc.2022.101472
- Luijkx, A., van der Putten, A. and Vlaskamp, C. (2017). Time use of parents raising children with severe or profound intellectual and multiple disabilities. *Child: Care, Health and Development, 43*:4, 518-526. Doi: <a href="https://doi-org.ezproxy.liberty.edu/10.1111/cch.12446">https://doi-org.ezproxy.liberty.edu/10.1111/cch.12446</a>.
- Negash, S., Nalbone, D. P., Wetchler, J. L., Woods, S., & Fontaine, K. L. (2015). Intimacy in the midst of caregiving: Examining relationship and sexual satisfaction of parents raising children with special needs. *Journal of Family Psychotherapy*, 26(3), 190–209. <a href="https://doi.org/10.1080/08975353.2015.1067532">https://doi.org/10.1080/08975353.2015.1067532</a>

## References, Cont.

- O'Hanlon, E. E. (2013). Religion and disability: The experiences of families of children with special needs, *Journal of Religion*, *Disability & Health*, *17*(1), 42-61, DOI: 10.1080/15228967.2012.731874
- 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
- Rodgaard, E., Jensen, K., Miskowiak, K. W., & Mottron, L. (2021). Autism comorbidities show elevated female-to-male odds ratios and are associated with the age of first autism diagnosis. *Acta Psychiatrica Scandinavica.*, 144(5), 475–486. https://doi.org/10.1111/acps.13345
- Sacchi, L., Merzhvynska M, & Augsburger M. (2020). Effects of cumulative trauma load on long-term trajectories of life satisfaction and health in a population-based study. *BMC Public Health*. 20(1):1612. Doi: 10.1186/s12889-020-09663-9
- Timmons, L., & Ekas, N. V. (2018). Giving thanks: Findings from a gratitude intervention with mothers of children with autism spectrum disorder. *Research in Autism Spectrum Disorders.*, 49, 13–24. <a href="https://doi.org/10.1016/j.rasd.2018.01.008">https://doi.org/10.1016/j.rasd.2018.01.008</a>
- Tuğba, O., Gülendam, K., & Seval, K. (2022). Relationship of gratitude and coping styles with depression in caregivers of children with special needs. *Journal of Religion and Health*, 61(1), 214-227. https://doi.org/10.1007/s10943-021-01389-1

### **Autism Specific Resources**

- ▶ 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
- 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). <a href="https://doi.org/10.1007/s10882-021-09832-7">https://doi.org/10.1007/s10882-021-09832-7</a>
- Brown, M., Whiting, J., Kahumoku-Fessler, E., Witting, 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. <a href="https://doi.org/10.1111/fare.12375">https://doi.org/10.1111/fare.12375</a>
- Critchley, E., Cuadros, M., Harper, I., Smith-Howell, H., & Rogish, M. (2021). A parent-sibling dyadic interview to explore how an individual with autism spectrum disorder can impact family dynamics.

  \*Research in Developmental Disabilities., 111. https://doi.org/10.1016/j.ridd.2021.103884
- 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

## Autism Specific Resources, Cont.

- 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. <a href="https://doi.org/10.1080/20473869.2025.2504437">https://doi.org/10.1080/20473869.2025.2504437</a>
- 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. <a href="https://doi.org/10.1080/20473869.2024.2341196">https://doi.org/10.1080/20473869.2024.2341196</a>
- Salama, R. A., Sharmin, A. R., Hamouda, H., Al-Hashmi, F., Hamdy, H. A., & Wadid, N. A. (2025). Caregivers' perspectives on the healthcare experiences of children with autism spectrum disorder and associated family impacts in Ras Al Khaimah, UAE. *Archives of Psychiatric Nursing.*, 58. https://doi.org/10.1016/j.apnu.2025.151966
- 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. <a href="https://doi.org/10.1016/j.ridd.2021.104066">https://doi.org/10.1016/j.ridd.2021.104066</a>
- 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

#### Questions...Feedback...Connection

- specialneedsmarriage@gmail.com
- www.walkingwithkaydan.com
- ► Twitter: @CSLCHSnMore

