## Parenting Children with Disabilities: Why Parental Mental Health Matters

Willa Giffin, Elizabeth Nye, & Kiley Krekorian Hanish

### Introduction

Parents of children with disabilities often face greater caregiving challenges, report higher stress levels, and experience more mental health difficulties than parents of typically developing children (Martin et al., 2019; Woodman & Hauser-Cram, 2013; Zhao et al., 2021). Research shows a bidirectional effect between the psychological health of parents and outcomes for their children with disabilities (Catalano et al., 2018; Ferraioli & Harris, 2012). Furthermore, research suggests that positive parental mental health is associated with improved socio-emotional functioning, cognitive development, and wellbeing in children (Catalano et al., 2018; Phua et al., 2020). Therefore, it is paramount to address and support the mental health of parents of children with disabilities for the benefit of the entire family. In this paper, we delve into evidence-based suggestions that are associated with improved parental mental health, including changes to support proper sleep, nutrition, physical movement and getting outside, time management, mindfulness, and social support. <sup>1</sup>

## **Having Quality Sleep**

Sleep is necessary for everyday functioning and getting fewer than eight hours of rest per night can have negative consequences on one's mental health, including decreased mood, reduced motivation, and increased stress (Martin et al., 2019; McQuillan et al., 2019). In general, it is common for parents to get less sleep than individuals without children (Divine et al., 2022). Compounding this, children with disabilities often experience sleep-related challenges at higher rates than their typically developing peers. Consequently, the sleep of parents of children with disabilities is further impacted by their children's sleep difficulties (Gorlin et al., 2016; Mihaila

-

<sup>&</sup>lt;sup>1</sup> It is important to mention the perspectives of the authors of this paper because our privileged positions as white, middle class women influence our discussion on this topic. While one author is an autistic mother of two neurodivergent children, the remaining authors are neurotypical and do not have children at this time. Because of this, we sought out additional input from parents of children with disabilities and providers who work with this population to further inform the delivery of our research. We want to convey compassion and understanding that the resources, time, and energy required to improve one's mental health are not always feasible or equally accessible. We hope that this paper can serve to highlight the importance of mental health, while noting that even *one small* change, where possible, may be beneficial.

& Hartley, 2018; Mörelius & Hemmingsson, 2014). It is essential to ameliorate parents' sleep challenges due to the mental health implications of lacking rest. Even modest sleep-related changes can have mental health benefits (Divine et al., 2022). Some strategies parents can employ to get better sleep include creating a nightly wind down routine (such as taking a warm bath, drinking caffeine-free tea, dimming the lights, or reading a book); keeping a consistent sleep schedule; leaving the bedroom and doing something relaxing if unable to fall asleep after more than 30 minutes of lying in bed; avoiding caffeine six hours before going to sleep; reducing use of electronics one hour before going to bed; trying a white noise app or machine; and sleeping in a dark space (Center for Disease Control and Prevention, 2016; Drake et al., 2013; Lack et al., 2017; National Sleep Foundation, 2020, 2022, 2023).

## **Maintaining Balanced Nutrition**

Quality of life ratings have been linked to dietary patterns. Research shows that nutritious diets correlate with improved emotional wellbeing, while diets that are high in saturated fats correlate with increased anxiety and depression (Bremner, 2020; Govindaraju et al., 2018). Reciprocally, an increased amount of stress negatively impacts eating habits, which has been demonstrated in a study on parents of children with disabilities (Polfuss et al., 2021). Thus, these issues compound each other. It is important to consider this cycle between food consumption and wellbeing when supporting parental mental health. Even small changes to one's diet can make a difference. For instance, including the skins when eating fruits and vegetables can increase one's intake of fiber; high-fiber diets support healthy gut microbes, which are associated with positive mental health outcomes (Gopinath et al., 2016; Wilson, 2022). Some additional suggestions for improving nutrition include using smaller bowls and spoons when eating foods that are high in processed sugar; drinking at least one glass of water after completing a daily habit (such as eating a meal or leaving the restroom); making extra food for leftovers; packing a lunch ahead of time; and limiting alcohol and drug consumption (Bailey, 2017; Reiland, 2021; U.S. Department of Agriculture and U.S. Department of Health and Human Services, 2020; Wansink et al., 2006).

## **Engaging in Physical Movement and Getting Outside**

There is ample research surrounding the mental health benefits of physical movement, including decreased depression, reduced anxiety, and increased life satisfaction (Carek et al., 2011; Zhao et

al., 2021). Parents tend to engage in lower rates of physical activity than adults without children (Abell et al., 2019). This pattern is exacerbated for parents of children with disabilities, as is exemplified by a study revealing that parents of children with Down syndrome engage in less exercise than parents of typically developing children (Diaz, 2020). Based on the research demonstrating that physical activity may be an important contributor to mental health, it can be extremely beneficial for parents to incorporate more movement into their routines. In addition to the health-promoting effects of exercise in general, exposure to the outdoor environment when exercising also contributes to positive mental health outcomes, such as reducing stress (Triguero-Mas et al., 2017). Some suggestions for increasing physical activity include scheduling exercise ahead of time; taking the stairs when possible; and stretching while watching television (Bailey, 2017; Bright Horizons Education Team, 2021). Additionally, parents may increase time spent outdoors through building exercise into their daily lives while playing outside with their children; taking walks during lunch breaks; and completing errands by foot or bicycle (Bright Horizons Education Team, 2021).

# **Developing Time Management Techniques**

Feeling stressed and sensing a lack of control over one's time are known contributors to symptoms of burnout and decreased wellbeing (Aeon et al., 2021; Yang et al., 2021). Parents of children with disabilities tend to have especially full calendars as they navigate the demands of daily life, along with their children's various therapies, lessons, and appointments (Smith & McQuade, 2021). For example, a qualitative study revealed that parents of autistic children expressed a desire for stability in their daily lives, but also conveyed that their schedules often became too busy and excessively regimented. While these parents articulated the necessity of routines to provide structure in their families' lives, they still wanted time for spontaneity (Smith & McQuade, 2021). Furthermore, parents report desiring time to "just [be] present with [their child]" (Muddle et al., 2022, p. 23), rather than feeling the need to constantly be doing things that are productive or therapeutic. Therefore, it may be helpful for parents to employ time management techniques such as scheduling time for breaks, unexpected events, or just being with their child; making a to-do list in order of the most immediate priorities and creating a to-don't list of things that can be addressed later on; utilizing a virtual calendar app that is shareable between family members; and reaching out for help when needed (Chapman &

Rupured, 2020; Indeed Editorial, 2022; National Health Services UK, 2018; Opong & Lee, 2022).

## **Practicing Mindfulness**

Research suggests that mindfulness practices reduce anxiety and depression, while fostering stress resilience (Sevinc et al., 2019; Zhu et al., 2021). Mindfulness encapsulates a variety of interventions that combine elements of meditation, relaxation, and awareness of one's thoughts and feelings (Ferraioli & Harris, 2012; Zhu et al., 2021). In a systematic review examining the experiences of parents of autistic children, those who practiced mindfulness reported decreased stress levels, along with increased general health and quality of life (Catalano et al., 2018). Parents can incorporate mindfulness into their routines by exploring a mindfulness app such as Insight Timer, Calm, or Headspace; keeping a journal to write about their experiences, thoughts, and sensations; practicing being present during at least one daily activity (such as while driving, eating breakfast, or washing the dishes); setting a timer for three minutes and focusing on their breath; practicing breathing with a longer exhale than inhale; trying a body scan meditation (noticing the sensations in their body, starting from their toes and traveling up to their head); and trying the 5-4-3-2-1 grounding technique (acknowledging five things they can see around them, four things they can touch, three things they can hear, two things they can smell, and one thing they can taste) (Goodman et al., 2019; Medical News Today, 2020; Stew, 2011; Walsh et al., 2019).

## **Seeking Social Support**

Feeling isolated has been shown to strongly predict higher stress levels for parents of children with disabilities (Jeong et al., 2013). Social support serves to mediate this stress and isolation, which is essential for the mental and physical health of parents of children with disabilities (Catalano et al., 2018; Smith & McQuade, 2021). Human connections provide emotional, informational, and practical assistance that are associated with wellbeing (Hammarberg et al., 2014). These relationships can be between a parent and their family, friends, or members of a support group. Additionally, parents can seek social support from mental health professionals; in fact, 75% of people who pursue these services report experiencing the benefits of therapy, including increased life satisfaction, feelings of empowerment, and better interpersonal

communication skills (American Psychological Association, 2022). Furthermore, peer-to-peer parenting support groups, both in-person and through social media, have been proven to foster meaningful relationships, while building communities of understanding and shared experiences (Bray et al., 2017; Dew et al., 2019). Therefore, parents may increase their sense of social support in various ways including joining a Facebook group with other caregivers of children that share the same diagnosis; finding support groups, both online and in-person, through directories such as <a href="https://www.cde.ca.gov/sp/se/qa/caprntorg.asp">https://www.cde.ca.gov/sp/se/qa/caprntorg.asp</a>; regularly scheduling time to speak with a trusted loved one; and seeking professional counseling through applicable avenues, including this directory <a href="https://www.psychologytoday.com/us">https://www.psychologytoday.com/us</a> (Dew et al., 2019; Lin et al., 2022).

### **Conclusion**

It is crucial to address the wellbeing of parents of children with disabilities due to the elevated mental health challenges faced by this population. Research demonstrates specific areas of need that, when addressed, are associated with supporting positive mental health. These areas include proper sleep, nutrition, physical movement and getting outside, time management, mindfulness, and social support. Based on the bidirectional effects between parental mental health and outcomes for children with disabilities, supporting the wellbeing of parents can positively impact the whole family (Ferraioli & Harris, 2012). An online Parental Wellness Tool was created and is available to aid in this effort by summarizing the aforementioned incremental changes that parents can choose from, based on their resources and needs, to support their mental wellbeing.<sup>2</sup>

\_

<sup>&</sup>lt;sup>2</sup> Parental Wellness Tool available at <u>wellnessforparents.com</u>

#### References

- Abell, L. P., Tanase, K. A., Gilmore, M. L., Winnicki, A. E., Holmes, V. L., & Hartos, J. L. (2019). Do physical activity levels differ by number of children at home in women aged 25–44 in the general population? *Women's Health (London, England)*, *15*, 1745506519871186–1745506519871186. https://doi.org/10.1177/1745506519871186
- Aeon, Faber, A., & Panaccio, A. (2021). Does time management work? A meta-analysis. PloS One, 16(1), e0245066–e0245066. https://doi.org/10.1371/journal.pone.0245066
- American Psychological Association. (2022). Understanding psychotherapy and how it works.https://www.apa.org/topics/psychotherapy/understanding
- Bray, L., Carter, B., Sanders, C., Blake, L., & Keegan, K. (2017). Parent-to-parent peer support for parents of children with a disability: A mixed method study. Patient Education and Counseling, 100(8), 1537-1543. https://doi.org/10.1016/j.pec.2017.03.004
- Bremner, J. D., Moazzami, K., Wittbrodt, M. T., Nye, J. A., Lima, B. B., Gillespie, C. F., Rapaport, M. H., Pearce, B. D., Shah, A. J., & Vaccarino, V. (2020). Diet, Stress and Mental Health. Nutrients, 12(8), 2428. https://doi.org/10.3390/nu12082428
- Bailey, R. (2017). Promoting Physical Activity and Nutrition in People With Stroke. The American Journal of Occupational Therapy, 71(5), 1-5. https://doi.org/10.5014/ajot.2017.021378
- Bright Horizons Education Team. (2021). Finding time to exercise: Tips for busy working parents. Bright Horizons. https://www.brighthorizons.com/family-resources/exercise-and-the-working-parent
- Carek, Laibstain, S. E., & Carek, S. M. (2011). Exercise for the Treatment of Depression and Anxiety. International Journal of Psychiatry in Medicine, 41(1), 15–28. https://doi.org/10.2190/PM.41.1.c
- Catalano, D., Holloway, L., & Mpofu, E. (2018). Mental Health Interventions for Parent Carers of Children with Autistic Spectrum Disorder: Practice Guidelines from a Critical Interpretive Synthesis (CIS) Systematic Review. International journal of environmental research and public health, 15(2), 341. <a href="https://doi.org/10.3390/ijerph15020341">https://doi.org/10.3390/ijerph15020341</a>
- Centers for Disease Control and Prevention. (2016). Tips for Better Sleep. Centers for Disease Control and Prevention Sleep and Sleep Disorders. https://www.cdc.gov/sleep/about\_sleep/sleep\_hygiene.html

- Chapman, S., & Rupured, M. (2020). Time Management: 10 strategies for Better Time Management. University of Georgia Extension.

  https://extension.uga.edu/publications/detail.html?number=C1042&title=time-management-10-strategies-for-better-time-management
- Dew, A., Collings, S., Dowse, L., Meltzer, A., & Smith, L. (2019). 'I don't feel like I'm in this on my own': Peer support for mothers of children with intellectual disability and challenging behaviour. Journal of intellectual disabilities: JOID, 23(3), 344–358. https://doi-org.libproxy2.usc.edu/10.1177/1744629519843012
- Diaz K. M. (2020). Physical inactivity among parents of children with and without Down syndrome: the National Health Interview Survey. Journal of intellectual disability research: JIDR, 64(1), 38–44. <a href="https://doi.org/10.1111/jir.12680">https://doi.org/10.1111/jir.12680</a>
- Divine, A., Blanchard, C., Benoit, C., Downs, D. S., & Rhodes, R. E. (2022). The influence of sleep and movement on mental health and life satisfaction during the transition to parenthood. Sleep health, 8(5), 475–483. https://doi-org.libproxy1.usc.edu/10.1016/j.sleh.2022.06.013
- Drake, C., Roehrs, T., Shambroom, J., & Roth, T. (2013). Caffeine effects on sleep taken 0, 3, or 6 hours before going to bed. Journal of clinical sleep medicine: JCSM: official publication of the American Academy of Sleep Medicine, 9(11), 1195–1200. https://doi.org/10.5664/jcsm.3170
- Ferraioli, S. J. & Harris, S. L. (2012). Comparative Effects of Mindfulness and Skills-Based Parent Training Programs for Parents of Children with Autism: Feasibility and Preliminary Outcome Data. Mindfulness, 4(2), 89–101. https://doi.org/10.1007/s12671-012-0099-0
- Goodman, V., Wardrope, B., Myers, S., Cohen, S., McCorquodale, L., & Kinsella, E. A. (2019). Mindfulness and human occupation: A scoping review. Scandinavian journal of occupational therapy, 26(3), 157–170. https://doi-org.libproxy2.usc.edu/10.1080/11038128.2018.1483422
- Gopinath, Flood, V. M., Kifley, A., Louie, J. C. Y., & Mitchell, P. (2016). Association between Carbohydrate Nutrition and Successful Aging over 10 Years. The Journals of Gerontology. Series A, Biological Sciences and Medical Sciences, 71(10), doi:10.1093/gerona/glw091

- Gorlin, J. B., McAlpine, C. P., Garwick, A., & Wieling, E. (2016). Severe childhood autism: The family lived experience. Journal of pediatric nursing, 31(6), 580-597.
- Govindaraju, T., Sahle, B. W., McCaffrey, T. A., McNeil, J. J., & Owen, A. J. (2018). Dietary Patterns and Quality of Life in Older Adults: A Systematic Review. Nutrients, 10(8), 971. https://doi-org.libproxy1.usc.edu/10.3390/nu10080971
- Hammarberg, K., Sartore, G., Cann, W., & Fisher, J. R. (2014). Barriers and promoters of participation in facilitated peer support groups for carers of children with special needs. Scandinavian journal of caring sciences, 28(4), 775–783. <a href="https://doi.org/10.1111/scs.12110">https://doi.org/10.1111/scs.12110</a>
- Indeed Editorial. (2022). 14 time-management techniques to improve productivity.

  Indeed.https://www.indeed.com/career-advice/career-development/time-management-techniques
- Jeong, Y. G., Jeong, Y. J., & Bang, J. A. (2013). Effect of social support on parenting stress of Korean mothers of children with cerebral palsy. Journal of physical therapy science, 25(10), 1339-1342.
- Lack, L., Scott, H., Micic, G., & Lovato, N. (2017). Intensive Sleep Re-Training: From Bench to Bedside. Brain sciences, 7(4), 33. https://doi.org/10.3390/brainsci7040033
- Lin, G. X., Goldenberg, A., Arikan, G., Brytek-Matera, A., Czepczor-Bernat, K., Manrique-Millones, D., Mikolajczak, M., Overbye, H., Roskam, I., Szczygieł, D., Ustundag-Budak, A. M., & Gross, J. J. (2022). Reappraisal, social support, and parental burnout. The British journal of clinical psychology, 61(4), 1089–1102. https://doi-org.libproxy1.usc.edu/10.1111/bjc.12380
- Martin, C. A., Papadopoulos, N., Chellew, T., Rinehart, N. J., & Sciberras, E. (2019). Associations between parenting stress, parent mental health and child sleep problems for children with ADHD and ASD: Systematic review. Research in developmental disabilities, 93, 103463. <a href="https://doi.org/10.1016/j.ridd.2019.103463">https://doi.org/10.1016/j.ridd.2019.103463</a>
- Medical News Today. (2020). Grounding techniques: Step-by-step guide and methods. Medical News Today. <a href="https://www.medicalnewstoday.com/articles/grounding-techniques#methods">https://www.medicalnewstoday.com/articles/grounding-techniques#methods</a>
- McQuillan, M. E., Bates, J. E., Staples, A. D., & Deater-Deckard, K. (2019). Maternal stress, sleep, and parenting. Journal of family psychology: JFP: Journal of the Division of

- Family Psychology of the American Psychological Association (Division 43), 33(3), 349–359. https://doi-org.libproxy1.usc.edu/10.1037/fam0000516
- Mihaila, I., & Hartley, S. L. (2018). Parental sleep quality and behavior problems of children with autism. Autism: the international journal of research and practice, 22(3), 236–244. https://doi.org/10.1177/1362361316673570
- Mörelius, E., & Hemmingsson, H. (2014). Parents of children with physical disabilities—Perceived health in parents related to the child's sleep problems and need for attention at night. Child: Care, Health and Development, 40(3), 412-418. https://doi.org/10.1111/cch.12079
- Muddle, S., McElwee, J., Vincent, R., Birdsey, N., & Best, L. (2022). Talking with Parents of Children with Learning Disabilities: Parents' Ideas about the Circle of Security Parenting Programme. British Journal of Learning Disabilities, 50(1), 19-28. https://doi.org/10.1111/bld.12371
- National Health Services UK. (2018). Easy time-management tips. NHS. https://www.nhs.uk/mental-health/self-help/tips-and-support/time-management-tips/
- National Sleep Foundation. (2020). How to make a sleep-friendly bedroom. National Sleep Foundation. https://www.thensf.org/how-to-make-a-sleep-friendly-bedroom/
- National Sleep Foundation. (2022). Screen use disrupts precious sleep time. National Sleep Foundation. https://www.thensf.org/screen-use-disrupts-precious-sleep-time/
- National Sleep Foundation. (2023). National Sleep Foundation releases recommendations to be your best slept self® this summer. National Sleep Foundation. https://www.thensf.org/national-sleep-foundation-releases-recommendations-to-be-your-best-slept-self-this-summer/
- Opong, D., & Lee, J. W. (2022). These strategies can help working parents build support and reclaim some time. https://www.npr.org/2022/03/14/1086480869/parents-are-exhausted-these-strategies-can-help-you-build-support-and-win-back-t
- Phua, D. Y., Kee, M., & Meaney, M. J. (2020). Positive Maternal Mental Health, Parenting, and Child Development. Biological psychiatry, 87(4), 328–337. https://doi-org.libproxy2.usc.edu/10.1016/j.biopsych.2019.09.028

- Polfuss, M., Marston, E., Pridham, K., Brown, R., & McPherson, A. C. (2021). Relationship between Stress and Feeding Behaviors in Parents of Children with Developmental Disabilities. Childhood obesity (Print), 17(7), 457–466. https://doi.org/10.1089/chi.2020.0356
- Reiland, L. (2021). Tips for drinking more water. Mayo Clinic Health System. https://www.mayoclinichealthsystem.org/hometown-health/speaking-of-health/tips-for-drinking-more-water
- Sevinc, G., Hölzel, B. K., Greenberg, J., Gard, T., Brunsch, V., Hashmi, J. A., Vangel, M., Orr, S. P., Milad, M. R., & Lazar, S. W. (2019). Strengthened Hippocampal Circuits Underlie Enhanced Retrieval of Extinguished Fear Memories Following Mindfulness Training. Biological psychiatry, 86(9), 693–702.https://doi.org/10.1016/j.biopsych.2019.05.017
- Smith, S. L., & McQuade, H. B. (2021). Exploring the health of families with a child with autism. Autism: the international journal of research and practice, 25(5), 1203–1215. https://doi.org/10.1177/1362361320986354
- Stew. (2011). Mindfulness Training for Occupational Therapy Students. The British Journal of Occupational Therapy, 74(6), 269–276. https://doi.org/10.4276/030802211X13074383957869
- Triguero-Mas, M., Donaire-Gonzalez, D., Seto, E., Valentín, A., Martínez, D., Smith, G., Hurst, G., Carrasco-Turigas, G., Masterson, D., van den Berg, M., Ambròs, A., Martínez-Íñiguez, T., Dedele, A., Ellis, N., Grazulevicius, T., Voorsmit, M., Cirach, M., Cirac-Claveras, J., Swart, W., Clasquin, E., ... Nieuwenhuijsen, M. J. (2017). Natural outdoor environments and mental health: Stress as a possible mechanism. Environmental research, 159, 629–638. <a href="https://doi.org/10.1016/j.envres.2017.08.048">https://doi.org/10.1016/j.envres.2017.08.048</a>
- U.S. Department of Agriculture and U.S. Department of Health and Human Services. (2020). Dietary Guidelines for Americans, 2020-2025. 9th Edition. DietaryGuidelines.gov.
- Walsh, K. M., Saab, B. J., & Farb, N. A. (2019). Effects of a Mindfulness Meditation App on Subjective Well-Being: Active Randomized Controlled Trial and Experience Sampling Study. JMIR mental health, 6(1), e10844. <a href="https://doi.org/10.2196/10844">https://doi.org/10.2196/10844</a>
- Wansink, B., van Ittersum, K., & Painter, J. E. (2006). Ice cream illusions bowls, spoons, and self-served portion sizes. American journal of preventive medicine, 31(3), 240–243. https://doi.org/10.1016/j.amepre.2006.04.003

- Wilson, K. (2022). How to use food to help your mood. Psyche. https://psyche.co/guides/how-to-use-food-to-help-reduce-your-risk-of-depression
- Woodman, A. C., & Hauser-Cram, P. (2013). The role of coping strategies in predicting change in parenting efficacy and depressive symptoms among mothers of adolescents with developmental disabilities. Journal of intellectual disability research: JIDR, 57(6), 513–530. https://doi.org/10.1111/j.1365-2788.2012.01555.x
- Yang, B., Chen, B. B., Qu, Y., & Zhu, Y. (2021). Impacts of Parental Burnout on Chinese Youth's Mental Health: The Role of Parents' Autonomy Support and Emotion Regulation. Journal of youth and adolescence, 50(8), 1679–1692. <a href="https://doi.org/10.1007/s10964-021-01450-y">https://doi.org/10.1007/s10964-021-01450-y</a>
- Zhao, M., You, Y., Chen, S., Li, L., Du, X., & Wang, Y. (2021). Effects of a Web-Based Parent-Child Physical Activity Program on Mental Health in Parents of Children with ASD. International journal of environmental research and public health, 18(24), 12913. <a href="https://doi.org/10.3390/ijerph182412913">https://doi.org/10.3390/ijerph182412913</a>
- Zhu, J. L., Schülke, R., Vatansever, D., Xi, D., Yan, J., Zhao, H., Xie, X., Feng, J., Chen, M. Y., Sahakian, B. J., & Wang, S. (2021). Mindfulness practice for protecting mental health during the COVID-19 pandemic. Translational psychiatry, 11(1), 329. https://doi.org/10.1038/s41398-021-01459-8