Parenting Children with Disabilities: Why Parental Mental Health Matters

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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 increased socio-emotional and cognitive development, along with improved 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.

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 neurodiverse 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. In this paper, we will delve into these potential changes corresponding with evidence that supports the importance of various factors on parental mental health including proper sleep, nutrition, physical movement and getting outside, time management, mindfulness, and social support.

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). 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 (Gorlin et al., 2016). Inevitably, parental sleep is further impacted by these difficulties (Mihaila & Hartley, 2018; Mörelius & Hemmingsson, 2014). It is essential to ameliorate parents' sleep challenges due to the mental health implications of lacking rest; even modest changes in one's amount of sleep 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 laying 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; National Sleep Foundation, 2020, 2022, 2023; Lack et al., 2017).

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 specifically 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 each time 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 symptoms of depression and anxiety, as well as 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. 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 can 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 by considering 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). 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 parents articulated the necessity of routines to provide structure in their families' lives, they still wanted time for spontaneity (Smith & McQuade, 2021). Furthermore, parents expressed 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 on parents of autistic children, parents 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 in which they notice 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. These relationships can be between a parent and their family, friends, or members of a support group (Hammarberg et al., 2014). Additionally, parents can seek social support from mental health professionals;

seventy-five percent 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 alternative support groups, both online and in-person, through directories such as https://www.cde.ca.gov/sp/se/qa/caprntorg.asp; regularly scheduling time to speak with a trusted loved one; and seeking professional counseling through multiple avenues including this directory https://www.psychologytoday.com/us (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 effect between parental mental health and outcomes for children with disabilities, supporting the wellbeing of parents can positively impact the whole family (Ferraioli & Harris, 2012). A Parental Wellness Reflection Tool was created and is available to aid in this effort by offering a variety of incremental changes that parents can choose from, based on their resources and needs, to support their mental wellbeing.¹

¹ Parental Wellness Reflection Tool available at <u>wellnessforparents.com</u>

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