

Psychologists' research offers ways to help families, caregivers and children cope during the pandemic.

Parents and caregivers of children and youth with disabilities¹ are facing unique challenges as a result of COVID-19. For example, while social distancing has been widely promoted as the best strategy to avoid transmission, that advice may not be realistic for people who care for children and youth with disabilities who may require therapy or assistance with daily tasks. Meanwhile, children's clinical services and other treatments are being disrupted with the closures of schools, medical settings and caregiving agencies. Families' ability to obtain critical medical supplies can become difficult as resources become scarce².

In addition, while children overall seem to be less likely to show symptoms of COVID-19, those with disabilities may fall into the category of "high risk" due to secondary health conditions,³ further adding to caregiver stress related to fears of infection and contagion. Should a child with a disability become sick or need medical care during the pandemic, many parents worry about rationing⁴ of care and supplies as another threat to their child's safety. Stressors like these intensify enacted or perceived experiences of stigma and discrimination.⁵

Strategies to ease stressors

Research by psychologists points to several important ways parents and caregivers of children and youth with disabilities can cope with the challenges created by the COVID-19 pandemic.

Communication is key

Stay informed, but don't overdo media. While it is important to keep up to date on the rapidly changing information on COVID-19 in your community, the oversaturation of information can add to stress. To stay informed and keep your family up to date while remaining safe, identify a few trusted sources for accurate updates and limit social media.

Talk to your children and other family members about COVID-19. Choose a safe, comfortable place and time to openly discuss the reason for the changes to their lives. Social narratives, which draw on text and pictures to talk about situations and responses, can be a useful tool (links to social narratives on COVID-19 appear below). Remember, children may have difficulty expressing their feelings in words and sometimes anxiety, fear and frustration can be expressed through challenging behaviors. Other children may express these feelings through play. Answer their questions and assure them of the shared goal to keep everyone safe. Revisit the topic periodically to be sure they understand what's happening around them.

Check-in with your child’s school, teachers and therapists about how educational and therapeutic service delivery may change in the coming weeks. If schools offer distance-learning opportunities to students without disabilities, the same support should be offered to students with disabilities. Don’t feel pressured to exactly replicate school and therapy at home. With flexibility, you may identify new ways to learn and grow together that would be more difficult in a typical time.

Check-in with your child’s health-care provider by calling or using telehealth services if available. If your child has a chronic or acute medical condition, talking with the healthcare provider can guide decisions about how to access needed equipment, supplies, medications, etc., and whether it is best to visit a healthcare facility or stay at home.

Prioritize self-care

Stay connected with others virtually. With many people needing to shelter in place, keep up social ties with others by planning regular times to call family and friends. Self-isolation, quarantine and shelter-in-place are only temporary ways of being. Email, texting, video chatting and social media also offer ways to engage. Seek support from those around you. For example, you might ask a friend to deliver food or medicine to your home.

Be kind to yourself. Since previously available respite options may no longer be available, focus on what can help you feel restored. This might mean taking short breaks from the immediate stress of the situation. This might mean spending some time watching animal videos to give yourself a brief mental break.

Seek help. Disability or condition-specific organizations and support groups can provide helpful information, social support and reduce feelings of stigma.⁶ Reach out to local organizations to see if they offer virtual support groups or have active email listservs that send out information and resources.

Be prepared. While difficult to consider, establish a plan of care for your child and other family members should you become ill. Typical secondary caregivers may be unavailable. Determining your plan prior to needing it provides a sense of security and reassurance at a time fraught with uncertainty.

Reassuring your child

Foster calm. In times of change, opportunities to engage in calming behaviors become especially important, so schedule coping and calming activities into a child’s day and consider ways to introduce new calming behaviors.

Create routines. If previously established routines have been disrupted, create new routines for your child. This can help your child feel more secure and understand what is expected of them. This can also be an important way to introduce new behaviors — such as handwashing or behaviors in line with social distancing — into daily habits.

Be empathetic. Acknowledge that your child may not have their usual school or disability-related equipment, which may lead to added difficulties, discomfort or pain. Validate their feelings and try reaching out to therapists and other families in similar situations to brainstorm ideas to address any discomfort and/or sensory, communication, and movement challenges to the extent possible.

Show the love. Children with disabilities may internalize feelings that they and/or their care needs are burdensome to their parents. During this stressful and uncertain time in which parents may be wearing the hats of employee, teacher and caregiver, simultaneously, this feeling may be heightened. Remind your child of your unconditional love and joy of getting to spend extra time with them.

Encourage them to talk about their feelings. Children with disabilities often experience feelings of social isolation from their peers, and social distancing policies related to COVID-19 may amplify these feelings. Give your child opportunities discuss these feelings and brainstorm ways for your child to interact with others through texting, phone calls, and video chatting and other virtual platforms.

Research⁷ suggests that the experience of raising a child with atypical development can foster strengths including flexibility in handling uncertainty, creative problem-solving and resilience. These strengths can be an asset when faced with new challenges such as COVID-19.

Footnotes

¹ Feizi, A., Najmi, B., Salesi, A., Chorami, M., & Hoveidafar, R. (2014). Parenting stress among mothers of children with different physical, mental, and psychological problems. *Journal of Research in Medical Sciences: The Official Journal of Isfahan University of Medical Sciences*, 19(2), 145.

² Campbell, V. A., Gilyard, J. A., Sinclair, L., Sternberg, T., & Kailes, J. I. (2009). Preparing for and responding to pandemic influenza: Implications for people with disabilities. *American Journal of Public Health*, 99(S2), S294-S300.

³ Halfon, N., Houtrow, A., Larson, K., & Newachek, P. W. (2012). The changing landscape of disability in childhood. *Future of Children*, 22(1), 13-42.

⁴ National Council on Disability COVID-19 Letter to HHS OCR. (2020, March 18). Retrieved from: <https://ncd.gov/publications/2020/ncd-covid-19-letter-hhs-ocr>

⁵ Priestley, M. & Hemingway, L. (2006). Disability and disaster recovery: A tale of two cities? *Journal of Social Work in Disability and Rehabilitation*, 5(3/4), 23-42.

⁶ Bogart, K. R., & Hemmesch, A. R. (2016). Benefits of support conferences for parents of and people with Moebius syndrome. *Stigma and Health*, 1(2), 109-121. doi: 10.1037/sah0000018

⁷ Steiner, A. M. (2011). A strength-based approach to parent education for children with autism. *Journal of Positive Behavior Interventions*, 13(3), 178–190. <https://doi.org/10.1177/1098300710384134>