National Core Indicators®
COVID-19 Bulletin #3:
Data on Family Experiences

Understanding the emergency preparedness, crisis and respite services for children and adults with intellectual and developmental disabilities (IDD) and their families during the COVID-19 pandemic

Many families around the country have been spending more time at home together recently, as schools, workplaces and other activities have closed to contain the COVID-19 pandemic. Many parents are working from home, trying to master new technology and overcome the various challenges of working in a different environment. Children and teenagers may be getting their education online. Families of children and adults with IDD may face additional challenges as they support their family members at home. Because of COVID-19 guidelines for social distancing and states' executive orders, adults with IDD and their families may have temporarily lost access to regular respite and support services such as daytime activities and crisis supports. This bulletin examines NCI data on family emergency preparedness and access to crisis and respite services. Although these data were collected prior to the pandemic, they can help inform states about potential gaps in access to these services—gaps that are likely more dramatic now due to the pandemic.

In the best of times, the availability of crisis services is important to families whose family members have behavior and mental health issues. During this pandemic, crisis supports (e.g., mobile crisis

teams, clinic-based therapy, and telehealth) are presumably even more vital given the effects of prolonged isolation and anxiety. Prior to the pandemic, only 53% of families of adults with IDD living at home who responded to the National Core Indicators Adult Family Survey (2018-2019) said that they were able to get the crisis services they needed when they were needed. Of families with children with IDD living at home responding to the NCI Child Family Survey (2018-2019), 45% said they were able to get crisis services (IDD) when needed. These responses suggest that *prior to the current crisis, only half of families with adults with IDD and over half of families with children with IDD had access to crisis services when they needed them*.

Bringing crisis services to families in need during this challenging period requires alternative and creative strategies, especially given that access to such supports was a challenge even before the pandemic. Here are some innovative approaches:

- The use of telehealth to deliver crisis services was emerging as an alternative before the current crisis. The availability of behavior management and psychiatric services through digital means is one way to replace onsite crisis intervention. Since the beginning of the pandemic, many more states are using telehealth models in order to provide behavioral health services to people with IDD.

- Since families are most often the primary caregivers during stay-at-home orders, crisis assistance including individualized training and support for families via digital platforms on how to manage behavior issues are extremely helpful

- To monitor the well-being of families and family members with IDD, case managers are checking in more frequently using technology such as telehealth platforms and phone calls. Families, people supported, and states are reporting overall positive results with this approach to case management and will consider the benefits moving forward to rebuilding their systems of community supports and services.

- Providing education to families regarding how to access crisis hot lines and clearinghouses with lists of community crisis resources is helpful during the pandemic.

- Recognizing that families also need support for stress, anxiety and other mental health concerns is vital to supporting people with IDD during the pandemic.

- Some individuals may require placement in temporary crisis residences. It will be important that the crisis staff in those residences are eligible for overtime and hazard pay.

Access to respite services is also a critical resource during the pandemic given the isolation that many families are experiencing as well as potential burnout from the responsibilities of supporting family members at home. In the 2018-2019 Adult Family Survey, collected prior to the pandemic, 61% of families said they could always or usually get respite when needed; in the Child Family Survey, 66% of families said they could always or usually get respite when they needed it. That means that about one third of families don't always get the respite services they need when they need them.

In addition to the stress relief noted above, there are other important considerations regarding the need for respite:

- Because of the need for additional respite supports during the pandemic, many states have expanded the hours available for respite under the HCBS waivers and have made it possible for individuals to receive services and supports at home that otherwise would have been provided out of the home.

- Many states are implementing rate adjustments based on the need to pay DSPs providing respite and other services "enhanced" pay during this period.

- For people who are self-directing, states are allowing temporary increases in self-direction budgets to allow families to seek services outside of provider agencies.

- In addition to national clearinghouses, many states have also set up websites to guide family members to needed resources.

- Information on respite and other supports may also be available through the nearly 100 Parent Training and Information Centers (PTIs) and Community Parent Resource Centers (CPRCs) in the US and Territories.

- In many communities around the country, there are local aid networks that include a range of resources and supports to community members. These entities may include entities or individuals available to provide respite.

In addition to the availability of crisis and respite services, the Adult Family and Child Family surveys include questions about emergency preparedness. In the last data cycle collected prior to the pandemic, 62% of Adult Family Survey respondents said that emergency planning was discussed at their last planning meeting, and 42% of Child Family Survey respondents said emergency planning was discussed at their planning meeting.

- The current crisis is not a conventional emergency (e.g., hurricanes, fires, tornadoes, etc.) which typically are more immediate and short-lived with distinct starting and end points. With this pandemic, families will be facing challenges indefinitely. For the future, when developing emergency preparedness plans with families, including the learning from the pandemic and the resources and accommodations that should be mobilized will be helpful to families --

- Some of the preparation for this COVID 19 emergency for pandemics is like preparation for a more conventional emergency such as a hurricane. FEMA has put together an emergency guide for people with disabilities that covers important considerations, including preparing a personal/family assessment of services, supports, and supplies needed.

- The need for emergency support for families and people with disabilities is not just a problem in this country but in every country where this virus has hit. The World Health Organization has posted an emergency preparedness brief geared to the needs of people

with disabilities that includes measures such as expanding the pool of potential support staff and tips on sanitizing mobility aids and other equipment. –

- Many states have also [posted information for families and people with disabilities](#) regarding how to cope during this crisis.

Conclusion

Families with family members with disabilities may need additional support in times of emergency, as well as proactive emergency planning and crisis supports. **Going forward it will be important to explore alternative means to provide such supports during periods of isolation and to sharpen emergency planning to include necessary accommodations during a prolonged pandemic.**

References

American Psychological Association. (2020). *Advice for caregivers of children with disabilities in the era of COVID-19*. https://www.apa.org/research/action/children-disabilities-covid-19

ARCH, National Respite Network and Resource Center. (n.d.). *National Respite Locator.* https://archrespite.org/respitelocator

Assistant Secretary for Preparedness and Response. (2017). *Public Health Emergency: Personal Preparedness for Individuals with Disabilities: Sheltering in Place and Evacuation.* https://www.phe.gov/Preparedness/planning/abc/Pages/shelterinplace.aspx

California Department of Public Health. (n.d.). *Tips and Resources for Family Members and Caregivers of Children and Youth with Special Health Care Needs.* https://www.cdph.ca.gov/Programs/CID/DCDC/Pages/COVID-19/TipsandResourcesforFamilyMembersandCaregiversofChildrenandYouthwithSpecialHealthCareNeeds.aspx

Caregiver: Long-term Care Services & Supports. *Caregiver's New Telepsychiatry Program Delivering Improved Continuity, Quality of Care for Individuals with Dual IDD/Mental Health Diagnoses. https://cg-idd.com/at-caregiver-inc-telepsychiatry-helps-texans-with-dual-idd-mental-health-diagnoses/*

Center for Parent Information and Resources; Find your Parent Center https://www.parentcenterhub.org/find-your-center/

Connecticut Department of Aging and Disability Services (n.d.). Emergency preparedness for older adults and people with disabilities in Connecticut. https://portal.ct.gov/AgingandDisability/Content-Pages/Topics-A-Z/Emergency-Preparedness-for-Older-Adults-and-People-with-Disabilities-in-Connecticut

Edwards. E. (2020). *COVID-19 Changes to HCBS Using Appendix K: Approval Trends*. National Health Law Project. https://www.aahd.us/wp-content/uploads/2020/04/NHeLP_Trends-in-Appendix-K-Approvals.pdf

FEMA and the American Red Cross (n.d.) *Preparing for Disaster for People with Disabilities and other Special Needs.* https://www.fema.gov/media-library-data/20130726-1445-20490-6732/fema_476.pdf

Hewitt, A. (2020). It's time to recognize the essential value of direct support professionals. MINNPOST. https://www.minnpost.com/community-voices/2020/04/its-time-to-recognize-the-essential-value-of-direct-support-professionals/

Mutual Aid Networks (search a location). https://www.mutualaidhub.org/

NASDDDS (2020). *NASDDDS COVID-19 Response: Appendix K Emerging Patterns.* https://www.nasddds.org/uploads/files/Appendix_K_Emerging_Patterns_COV004-40720%201.pdf

Parent Help 123. *Support for You and Your Family (link to hotline).* https://www.parenthelp123.org/special-needs/support-for-you-and-your-family

University of Turku (2019). *Digital Parent Training for Child's Disruptive Behavior Successful in Primary Health Care.* Science Daily, https://www.sciencedaily.com/releases/2019/04/190412101249.htm

Walters, A., Winston, P., & Ghertner, R. (2020). *Virtual Case Management Considerations and Resources for Human Services Programs*. Assistant Secretary for Planning and Evaluation. (2020). https://www.parenthelp123.org/special-needs/support-for-you-and-your-family

World Health Organization. Disability considerations during the COVID-19 outbreak http://www.escif.org/files/covid-19-disability-briefing.pdf