

National Core Indicators® Data Highlight

What Do NCI Data Tell Us About the Impact of COVID-19 on Families Who Have a Family Member with IDD Living at Home?*

According to the results 2020-2021 COVID-19 Family Supplements, many family respondents experienced disruptions in their lives including losing a job (AFS: 28%; CFS: 35%) and having trouble feeding their families (AFS: 15%; CFS: 14%).

Why does it matter? COVID-19 is continuing to disrupt the lives of families around the country but poses particular challenges to families who have a child or adult with IDD living at home. In addition to job loss, income loss, and food insecurity experienced by a troubling number of AFS and CFS respondents, approximately two thirds of all families noted that their services changed in the 2020-2021 cycle, and almost half of those families noted that changes “were not good for my family.” Further 25% of AFS respondents and 30% of CFS respondents indicated that they did not have enough staff support to meet the needs of their families. Those services needed but not available included social supports, ADLs, behavior support and someone to talk to when they feel lonely. To compensate for the challenges facing families, many states moved to pay families to provide support, launched virtual services, and created new communication strategies—among other accommodations.



Questions to ask: How can states use the data from the NCI-IDD AFS and CFS COVID supplements to revise current emergency planning policies and procedures? How can states use the data to reassess current state family support policies and practices in light of the challenges faced during the pandemic? Has the state convened families to solicit suggestions on what has worked and what hasn't worked during the pandemic? Has the state taken advantage of the flexibility in service provision allowed during the Public Health Emergency such as virtual service provision, paying family members to be caregivers, and increased access to self-directed services and supports? If these changes have proven beneficial to the well-being of families and people with IDD, is the state considering making them permanent? What new and different family communication strategies deployed during the pandemic were most effective and how might they be permanently embedded in state practice?

Want to know more?

The Arc (n.d.). *Covid Resources for People with Disabilities, Families, and Service Providers.*

<https://thearc.org/covid/>

Diament, M. (2020). *Pandemic Hitting Families of Those with Disabilities Harder.* Disability Scoop.

<https://www.disabilityscoop.com/2020/08/28/pandemic-hitting-families-disabilities-harder/28849/>

Suarez-Balcazar, Y. Mirza, M., Errisuriz, V.L., Zeng, W., Brown, J.P., Vanegas, S., Heydarian, N., Parra-Medina, D., Morales, P. Torres, H. and Sandy Magaña, S. (2021). *Impact of COVID-19 on Mental Health and Well-Being of Latinx Caregivers of Children with Intellectual and Developmental Disabilities.* International Journal of Environmental Research and Public Health. 18(16).

USA.gov. Disability Services. (n.d.) *Caregiver Support.* <https://www.usa.gov/disability-caregiver>

*Data in this Data Brief come from the Child Family Survey (CFS) which canvasses families with children living at home and the Adult Family Survey (AFS) which is circulated to families who have an adult family member living at home.