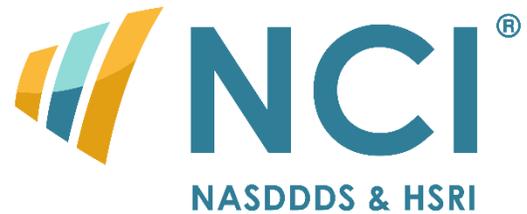# National Core Indicators®
COVID-19 Bulletin #5:
Data from the Adult Family Survey

Using NCI data to understand the challenges that families of people with IDD may be facing during the pandemic

The formal system of services for people with intellectual and developmental disabilities (IDD), including supports for families with children and adults with IDD living at home, has grown steadily throughout the past three decades. Although the IDD system is heavily invested in residential services, national results of the 2018-2019 NCI In-Person Survey indicate that more adults with IDD live at home with families (38%) than in any other residential arrangement. (Across participating states, NCI survey results show the percentage ranges from 11% to 67%.)   We can conclude, therefore, that more than a third of people with IDD receiving services nationally have been following CDC social distancing guidelines, limiting out-of-home activities and outings, and practicing other preventative actions with their families for weeks if not months during the pandemic. A survey conducted by the University of Pittsburgh on the experiences of family caregivers in general (e.g., caring for aging parents, spouses with physical disabilities, children with health challenges, etc.) during COVID-19 indicates that they were more likely than noncaregivers to experience isolation, anxiety and depression, exhaustion, food insecurity and financial distress. Family caregivers who

identify as part of a minority racial or ethnic group, younger family caregivers, and lower-income family caregivers experienced these same consequences but more intensely than higher-income white families. [Another study looked at the impact of the pandemic on family caregivers of children with intellectual and developmental disabilities (IDD)](#). The results indicated that caregivers of children with IDD experienced more depression, anxiety, and stress than families without children with IDD. Further, caregivers with children with IDD reported a reduction or loss of supports for their child's education goals, a reduction or loss of resources to assist with child care, and increased financial strain.

This bulletin examines what we know about the experiences of families who live with an adult family member with IDD based on responses to NCI's [2018-2019 Adult Family Survey (AFS)](#). We review characteristics and outcomes that signal challenges these families may have faced and continue to face during COVID-19.

Demographic Factors to Watch

The NCI Adult Family Survey goes to family members living with an adult with IDD who is receiving services from their state DD service system. Of the people who responded in 2018-2019, 28% had an annual household taxable income under $25,000; nearly half (46%) reported an annual household taxable income under $50,000. In terms of the age of respondents, 75% of respondents were 55 or older. Finally, 40% of respondents described their own health as poor or fairly good.

This information is important because, as noted in the research described above, caregivers with lower household incomes experienced more challenges during the pandemic; older caregivers may have increased vulnerability to the virus; and people reporting health challenges may experience even more isolation.

- States have been proactive in communicating to families and people with IDD the [suggested steps that families can take to meet the challenges posed by the pandemic](#) including practicing good hygiene, developing new routines, staying healthy through exercise and good nutrition, taking time off from screens, and finding creative ways to have fun. States have developed and implemented communication strategies, kits, and other resources to continually provide vital information to families and people with IDD to assist them in staying healthy during the pandemic.

- Given that a sizable number of family respondents reported a moderate to low household income, financial disruption during the pandemic could endanger the family's stability. Families may need support to access information on [unemployment benefits, on stimulus payments](#), and [tax consequences of Economic Impact Payments and other financial supports available during the pandemic.](#)

- [Research summarized by the Family Caregiver Alliance](#) suggests that the stress of caregiving can have serious physical and emotional consequences. The NCI results indicate that, even before the pandemic, a substantial number of family respondents reported health that was poor or fairly good. The added stress of the pandemic may very well have exacerbated

existing health conditions. Continued contact with families to ensure they have sufficient support is important to prevent possible reduction in health status and to lessen the likelihood of families being in crisis or emergency situations that would require out of home placements.

Behavior Crises

When asked whether their family member needed support for self-injurious, disruptive and/or destructive behaviors, 43% of respondents said that some or extensive support was needed. When asked whether they could get crisis or emergency services when needed (if they had requested such services in the past year), 47% said no. Eleven percent (11%) of respondents reported that they did not feel prepared to handle the needs of their family member in an emergency such as a medical emergency or natural disaster. The ability to secure crisis support when serious behavior issues arise may be even more difficult during the pandemic. The subject of the availability of crisis services was covered in a previous NCI COVID Bulletin but is summarized again here.

- During the pandemic, the use of telehealth has been expanded. As described in an article by the Behavioral Health Center of Excellence, to make telehealth useful to families who are unable to secure in-home crisis services, families may need support and training on how to use the technology. Clinical staff may also need additional training and support in order to use telehealth to perform assessments and assist families and the person with IDD in implementing specific interventions.

- As exemplified by this crisis resource webpage from the Minnesota Department of Human Services, in the absence of traditional crisis services, famlies should have access to a variety of crisis lines—including peer support lines, text crisis lines, crisis phone lines. Nationally, case managers have increased the frequency of contact using remote check-ins with people and their families as needed during the pandemic to assess their well-being and need for additional supports.

- The American Psychological Association provides a range of strategies to relieve stress and anxiety for caretaking families coping with family members in crisis .

Access to Services

During the pandemic, some services—including day services, community integration, and other important supports—were shuttered or circumscribed because of the national public health emergency. Following CDC guidance, some families may also have chosen to reduce or eliminate in-home supports. NCI data show that some family respondents had noted problems with access to services and supports even prior to the pandemic.

1. When asked if their family gets the supports they need, 22% said no (state responses ranged from 15% to 38%).

2. Of those who said they needed additional services: 57% said they needed respite, 28% said they needed more regularly scheduled support for their family member, and 10% said they needed support or training to use assistive technology.

3. 40% of respondents said they sometimes, seldom, or never are able to get/use respite services, if needed.

4. Regarding services they were receiving, 29% of respondents said they received out-of-home respite, and 54% said they received day or employment supports outside the family home.

The combination of the magnitude of support needs, gaps in services, and reliance on out-of-home supports prior to the pandemic suggests that these same families faced and are facing increased caretaking demands during the pandemic. Additionally, 74% of respondents noted that their family member needed some or extensive support for personal care activities (for example, bathing, dressing, eating) and 95% said their family member needed some or extensive support for other daily activities (for example, scheduling, managing money, or shopping).

- As described in a presentation from The Arc, many day programs have "reimagined" their day programs and have found ways to engage adults with disabilities in their own homes and in smaller groups around their communities. By ensuring that families are made aware of these alternative programs and how to gain access, states may assist in preventing potential crisis situations.

- Returning to the first principles of family support is particularly important during this pandemic. These principles include that families have the information they need, are given choices and control over the supports they need, and that their expertise regarding the needs of their family member is recognized. The American Association on Intellectual and Developmental Disabilities and the Arc joint position paper lays out a comprehensive list of the foundations of family support.

- One way to minimize the impact of disruptions in services and supports is to give families more control and flexibility. Self-direction is an option that provides families and people with IDD more control by giving them the ability to manage a budget and hire staff independently of service provider organizations. As this inventory of self-direction programs from Applied Self-Direction demonstrates, every state in the US has at least one self-direction program. Self-direction can increase the family's independence, choice, and control and expand their options beyond traditional service delivery modes.

- Some states that previously did not allow payments to family caregivers sought and received CMS approval to pay family members to provide care and support to their family member with IDD. Prior to the pandemic, 36% of families reported that a family member was paid to provide support to their family member with IDD. The Centers for Medicare and Medicaid Services – through the Appendix K procedure (which allows for temporary amendment of waiver application requirements) allowed states to amend their waivers to include payments directly to family members.

Family Connections

Like many people around the country, families with adult family members with disabilities living at home have experienced life-changing event—such as being cut off from routines, support systems, and friends. In the past, families have sought out support from peers in support groups and family networks where they could share information, resources, and assistance. The NCI Adult Family Survey results showed that prior to the pandemic, 15% of respondents were taking part in family-to-family networks.

- As described in an article from the Center for Parent Information and Resources, it is important to make information available to families regarding support groups, local disability advocacy organizations, community organizations and other groups that can provide information and personal support, advice, and reassurance. Case managers can play a critical role in sharing resources like these and helping families to access them.

- It is also important that siblings of people with disabilities reach out to sibling support groups for information, advice, and connection. Families could be connected to websites and other resources regarding local and state sibling networks; a compilation of resources can be found on the Sibling Leadership Network website. Again, equipping case managers to provide these resources is critical.

- Publicly funded family support centers and services can be particularly important during this period given their mission to provide information, funding, and training to families with family members with disabilities. Getting information about these vital resources to families would increase their opportunities for success during the public health emergency and beyond.

Conclusion

NCI data from the Adult Family Survey in this bulletin demonstrate areas where families of people with IDD may need additional information to access supports and services during the COVID-19 pandemic.   Any renewed attention to the needs of families during a pandemic should also build on the strengths of the family support model—including flexibility, family-centered planning, choice, empowerment, self-determination, and capacity building. As we develop a greater understanding of the experiences of family members during the pandemic, it will be important to explore opportunities to strengthen the family support infrastructure to ensure that the gains that have been made in family support can be maintained during challenging times.

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