

COVID in the Community

The Impact of the Pandemic on Individuals with Intellectual and Developmental Disabilities and their Communities of Support

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Project Team

The project team has no disclosures to report



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Today's Discussion



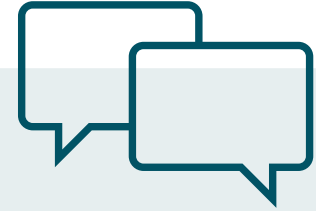
Background



**Data
Insights**



Learnings



Discussion

Background

In response to the COVID-19 pandemic, NCI-IDD added state-optional COVID-19 supplements to NCI-IDD surveys.

The supplements shed light on the experience of people with disabilities and their families at the beginning of the pandemic, and their interactions with services during that time.





People with Intellectual and Developmental Disabilities

The NCI®-IDD In-Person Survey (IPS) is completed with adults with IDD age 18+ receiving at least one paid service (in addition to case management) from the state Developmental Disability (DD) service system. It is conducted via direct conversation with the person receiving services –face-to-face or via videoconference.

Participating states during the 2020-2021 cycle included AL, AR, CA, CO, FL, GA, HI, IL, IN, KS, KY, MI, MO, NC, NE, NH, NJ, NV, OH, OR, PA, SD, TN, VA, WI



Families of People with Intellectual and Developmental Disabilities

NCI®-IDD Family Surveys are mail-out surveys to families (or where applicable, to guardians) of people who receive at least one paid service from the state DD agency in addition to case management. Respondents may complete the survey on paper or online.

The following states used the 2020-21 AFS COVID-19 Supplement: AZ, DE, FL, GA, LA, MD, MN, MO, NJ, PA, VA; the following states used the 2020-21 FGS COVID-19 Supplement: AZ, DE, GA, IN, KY, MD, NJ, PA; the following states used the 2020-21 CFS COVID-19 Supplement: AZ, CO, MN, MO, NC, OR, SD, TX, VA, WI.

Key Findings

43% made decisions **on their own** about changes in their daily schedule

65%



saw friends or family (non-co-habitants) less often

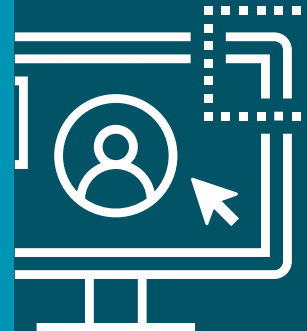
37%



reported feeling worried or anxious than before COVID-19

28%

enjoyed using technology more often




- 57% spoke with case managers/service coordinators via videoconference
- 51% spoke with health professionals using telehealth services
- 36% participated in online social groups
- 20% joined exercise programs online



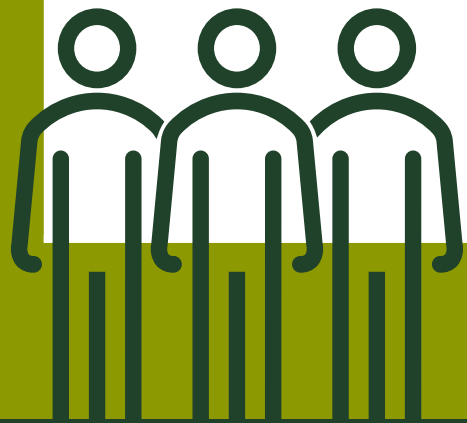
- **99% reported there was always or sometimes a mask available when needed**
- **85% noted that their staff and caregivers regularly used PPE**

People with Intellectual and Developmental Disabilities

29% reported **reduced household income due to COVID-19** (AFS)

21%  received insufficient information about changes, and reductions in services (FGS)

51% used videoconferencing to connect with health care professionals; **91%** had the equipment to do so (AFS)



89% report that staff who came into their home **followed appropriate health and safety protocols** (CFS)

Key Findings

Half



Just 52% of families felt they had enough staff present when needed

(CFS)

Families of People with Intellectual and Developmental Disabilities

18%

of responding state agencies put direct support professionals (DSPs) on furlough at some point during 2020

53%



reduced DSPs on payroll during 2020

40%

reported a decrease in adults with IDD enrolled or approved for services in 2020

- Only 86% of provider agencies required DSPs to wear masks / PPE
- More than 40% of responding agencies reported **not having** consistent supplies of PPE for DSPs and people receiving services
- 40% sought or requested donations of homemade PPE



Staff Stability Survey

Key Findings

1:3

of responding state agencies closed sites in response to COVID-19



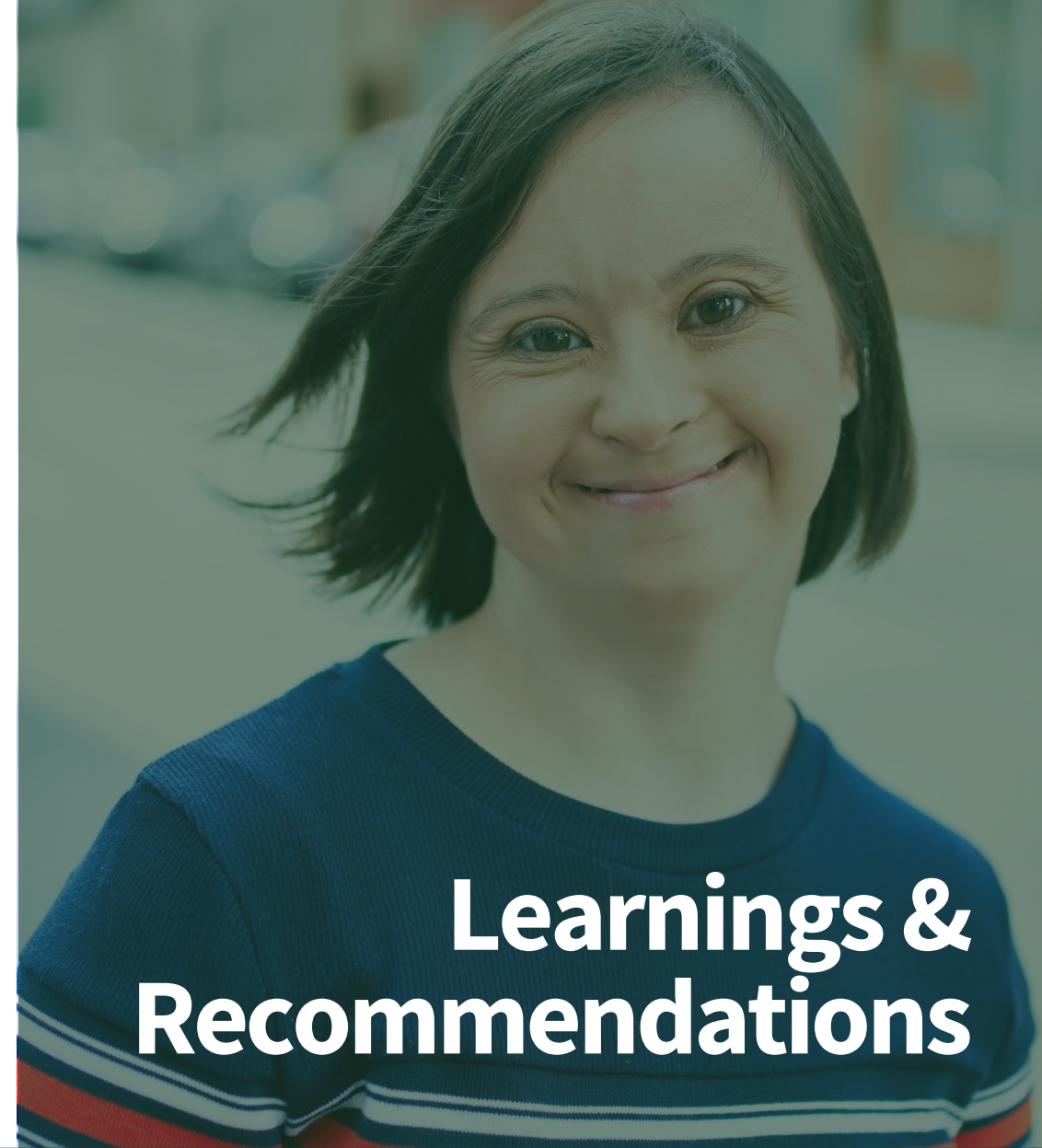
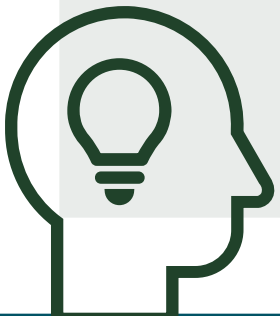
- 47% stopped delivery of some supports temporarily or permanently
- 15% reported paying family members to serve as support providers

- **Modernize technology** coverage policy with CMS, balancing privacy, access, and availability
- Develop **plain language resources** and multi-modal communication
- Spotlight the importance of **trauma-informed service delivery and access to mental health treatment**
- Work with federal partners to **create uniform data architecture** to understand rates of infection, vaccine, long-COVID, incidents of abuse, neglect, and exploitation etc. for individuals served



Learnings & Recommendations

- **Recognize the loneliness and isolation** experienced by families and improve communication protocols
- Reduce the need for **congregate residential and day programs**
- Increase opportunities for **self-direction**
- **Honor the contributions of DSPs** by creating an occupation category at the Department of Labor
- **Support federal legislation** to increase wages, training and benefits for DSPs



Learnings & Recommendations

References

- [2020-21 NCI-IDD Family Surveys COVID-19 Supplement National Report Special Edition](#)
- [2020-21 NCI-IDD In-Person Survey COVID-19 Supplement National Report Special Edition](#)
- [2020 Staff Stability Survey Report COVID-19 Supplement National Report Special Edition](#)



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