

National Core Indicators[®] COVID-19 Bulletin With Infographic

Indicators of isolation and loneliness among people with IDD – how to help during the COVID-19 pandemic



To aid the intellectual and developmental disability (IDD) community in this unprecedented time, we are sharing some National Core Indicators (NCI) data from the 2018-19 In-Person Survey. These data, though not collected during the pandemic, point to areas where states might be able to help mitigate feelings of social isolation and loneliness among people with intellectual and developmental disabilities (IDD)—feelings that may be heightened by the COVID-19 pandemic and resulting stay-at-home orders.

NCI staff selected seven indicators—many of which were new for the 2018-19 data cycle—that speak to the ability of people to reach out to friends and family as well as the potential role of technology in helping people feel less isolated and in supporting their health and welfare.

Using Technology to Facilitate Connection

As people across the country self-isolate, practice social distancing, and adhere to stay-at-home orders from national, state, and local governments to prevent further spread of COVID-19, state IDD managers are busy working with the federal government and others to realign delivery systems, policies and regulations to respond to the pandemic. Some of these adjustments involve a heavier reliance on telehealth systems, virtual meetings, online portals and other technology to ensure the health and welfare of people using IDD community services.

While states are relying on technology to continue case management monitoring, technology also offers opportunities to help people with IDD stay connected with their families and loved ones. There are opportunities for public managers of IDD systems to reduce the social isolation of people receiving services—which is particularly important given that such isolation can lead to increased loneliness and depression and place people at increased risk of abuse.

Looking at the Data¹

2018-19 In-Person Survey data indicate:

Access to Technology



89% of respondents report being able to use phone and internet when wanted, independently or with assistance

State responses ranged from 71% to 95%



56% of respondents have a cell phone or smartphone

State responses ranged from 30% to 70%



Of those without cell phone or smartphone, **44%** said they would like to have a cell phone or smartphone

31% said they didn't have a one because it cost too much

10% said they didn't have a one because it wasn't allowed

Being Able to Communicate with Friends and Family

48% of respondents would like help to make or keep in contact with friends

State responses ranged from 22% to 72%



81% of respondents report having other ways of talking, chatting, or communicating with friends when cannot see them

State responses ranged from 64% to 88%



82% of respondents report that they can communicate with family when they want

State responses ranged from 30% to 93%



¹ For state specific data, see the 2018-19 In-Person Survey Report [here](#)

Possible Strategies

Here are some examples of how state officials, providers and others can use these data to develop strategies for enhancing access to communication technology.

If a state has a large proportion of respondents who do not have a cell phone or smartphone due to cost, the state and/or providers could explore ways to access affordable phone/internet plans. For example:

- Lifeline is a federal program that lowers the monthly cost of phone and internet. It provides subscribers a discount on monthly telephone service, broadband internet access service, or a voice-broadband bundled service purchased from participating providers. Medicaid recipients are eligible for Lifeline.
 - a. <https://www.fcc.gov/consumers/guides/lifeline-support-affordable-communications>
 - b. <https://www.lifelinesupport.org/>

If a state has a large proportion of respondents who want help to meet or keep in contact with friends—or a large proportion of respondents who do not have other ways to talk, chat or communicate with friends when they cannot see each other—the state might work with case managers and service providers to look at innovative ways to help people communicate.

- States might consider offering mini grants to provider agencies and/or technology developers to design innovative strategies to help people stay in contact with friends and loved ones.
- States and service providers could design education and training initiatives for individuals and/or DSPs aimed at how to use and support virtual communication tools like Zoom or Skype.

If a state has a large proportion of respondents who cannot see family when they want, state staff might consider strategies for case managers and providers to help families stay connected.

- Case managers can work with families to add periodic, recurring reminders into their calendars. These reminders can help families stay in touch with their family member.
- The Pioneer Network is organizing resources from members, including this useful resource from the Eden Alternative on tips to combat isolation and loneliness. While primarily directed at the elderly population, the resources may be of interest to managers and programs seeking support ideas for people with IDD, particularly those who are aging. <https://bit.ly/2Xm5gn1>
- If families can't visit their family member with IDD because of the need for social distancing, provider staff and/or case managers can arrange Zoom or other virtual meetings to make those connections.