

National Core Indicators® Data on Life Activities



Strategies to help address social isolation and life disruption among people with IDD during the COVID-19 pandemic



The current federal, state and local advisories to stay at home and social distance to reduce the spread of COVID-19 place particular burdens on people in the IDD service system, who are more vulnerable to the effects of disrupted routines, isolation, and loneliness. It will be important for providers, families, and friends to find ways to compensate for diminished social interaction and increased risk for feeling of aloneness.

Prior to the pandemic, more than three-quarters of people with intellectual and developmental disabilities (IDD) surveyed for National Core Indicators (2018-19) reported being able to go out and do the things they like to do in the community, and a majority (ranging from 70% to 90% across states) reported having enough they liked to do when at home. As physical distancing restrictions have required that many people spend all or almost all of their time "at home," so the need to find things to do becomes even more important. It will take creativity to devise alternative ways to adjust to these new circumstances, including using a telehealth and other digital platforms as well as person-centered planning approaches to determine activities to help people feel productive and feel like they're working toward their goals, despite being primarily "at home."

- Brenda Smith and her son Derek developed [videos](#) on how to use person-centered planning tools to determine what is important to and for Derek during quarantine and to make a meaningful plan that can help Derek achieve his goals during quarantine.

Person centered thinking approaches such as Charting the LifeCourse can help people to establish new routines and to identify activities that can be both educational, fun and help maintain key relationships. The Ohio Department of Developmental Disabilities is using the Charting the LifeCourse Integrated Supports Star to help people with I/DD and their families create a vision of a good life during this tumultuous period. Ohio has also provided a guide to exploring activities and interests that can comprise a [Meaningful Day](#).

Feelings of disengagement will inevitably be heightened during this pandemic, especially if people are unsure why their routines have changed. Families, friends and provider staff can step in by explaining why these events are occurring. Providers should also take advantage of tools that have been developed around the country to assist participants to engage with friends, to participate in virtual activities and games, and to join educational sessions.

- [Explaining disruptions in everyday language](#) may help recipients of in-home supports and services understand the reasons for the changes to everyday routines. [Social stories](#) offer a way of helping people understand the changes that are happening. Social stories are structured to communicate information in a way that is understandable to the audience. They are most commonly used to support communication with children, youth, and adults with autism to help them understand the nature of the crisis and how best to regulate their feelings and response.
- Support Development Associates (SDA) developed a list of questions that can facilitate conversations between friends, families and provider staff to adjust [daily rituals](#) to adhere to social distancing guidelines with minimum disruption.
- [The Arc](#) has created a resource page for day program providers that gives them step-by-step information on how to make the transition to presenting the training for participants content online. The Arc also has [plain language](#) materials that help people with IDD to understand what the coronavirus is and why they need to maintain a physical distance from others.
- There are new opportunities to get open access to virtual cultural sites, humanities programs, and the arts. For example, [Cirque Du Soleil](#) and the [Royal Opera House](#) have been uploading free weekly content on YouTube, while the [Smithsonian](#) offers virtual tours of exhibits and collections from a desktop or mobile device.
- Staff at the [St. Louis Arc](#) have developed a series of games and interactive sessions to keep the people they support to stay engaged, motivated, and positive. They have devised home-based scavenger hunts, family feud games, and gratitude sessions. They have also sponsored [Launch](#)—an interactive, private pay program that helps young adults to explore their futures, including employment, with the assistance of one-on-one counseling. It is available to all, not just people in St. Louis.

- Staff can encourage the use of [videoconference calls](#) through platforms like [Zoom](#) to connect people with family members, loved ones, and close friends. Alternatively, phone calls, Facetime (on Apple devices), Skype, or Facebook video chat are other means that can be used to keep people connected to their social networks.
- [ADvancing States](#) created a resource that is updated regularly for state aging and disability agencies and providers on steps that have been taken to mitigate social isolation. The site includes a list of resources and activities that may offer social engagement and mental stimulation, including different media avenues to contact family members, links to ‘visit’ [national parks virtually](#), along with links to [meditation](#) and [emotional support](#) applications that are free of charge for the year.

Many state DD agencies are requiring case managers/service coordinators to increase contact with people through health and welfare check-ins. In this way, they can ensure that people aren’t experiencing health or mental health crises are receiving needed supports and services and determine whether telehealth support should be made available. Further, public managers and providers should explore ways of redeploying community integration staff to providing support, recreation, and other activities virtually.

Conclusion

In conclusion, the needs of people receiving IDD services during these times of isolation will vary and should be addressed on a person-centered basis that allows for the differences in the reactions people will experience. Responses should include increased contact with individuals to ensure health and safety, exploration of a range of free cultural and other resources available on the internet, development of activities, games and other efforts to engage participants, thoughtful redeployment of day program staff to reach people with activities virtually and increased emphasis on maintaining key relationships.

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