

Strategies for Responding to the COVID-19 Pandemic

Living Well Grant

Variations in access to and quality of home and community-based services (HCBS) across the country can put the well-being of people with intellectual and developmental disabilities (I/DD) living in their communities at risk. To address these pressing needs, the Administration for Community Living (ACL)¹ issued Living Well-Model Approaches for Enhancing the Quality, Effectiveness and Monitoring of HCBS for Individuals with I/DD (Living Well) grants, with two key goals:

- Increase community integration and independence of individuals with I/DD; and,
- Improve the quality of HCBS.

The ACL administers Living Well grants through the Projects of National Significance program. The ACL awarded eight five-year grants across two cohorts in 2017 and 2018 to identify, develop, and evaluate model approaches that address the two goals. The Living Well grantees are: Alaska, Georgia, Idaho, Indiana, Missouri, New Hampshire, Virginia, and Wisconsin. ACL contracted with the Lewin Group, as a sub-contractor to New Editions Consulting, to conduct a cross-site evaluation of the eight grants.²

This issue brief focuses on the impact of COVID-19 in the eight states awarded the Living Well grant in 2017 and 2018. Throughout this brief, the recipients of Living Well grants and their respective project teams are referred to as “grantees.”

Background

Impact of COVID-19 on Individuals with I/DD

From its onset in the U.S. in the spring of 2020, the COVID-19 pandemic exacerbated many of the challenges faced by individuals with I/DD living in HCBS settings and the systems that support them, including concerns about health and safety, abuse and neglect, and social isolation.

Notably, people with disabilities are two to four times more likely to be injured or die in disasters than people without disabilities due to inadequate community-wide planning or access to assistance.³ Further, some people with disabilities report higher levels of social isolation than people without disabilities,⁴ a notion only intensified by physical distancing and personal protective equipment (e.g., face covering) measures in place. Additionally, ensuring adequate information is effectively communicated with individuals with I/DD during this time is increasingly challenging, especially as information

1 The Administration on Intellectual and Developmental Disabilities (AIDD) oversaw the Living Well grants when they were awarded in 2017 and 2018. The Administration on Disabilities (AoD) now provides oversight to the grants within ACL.

2 Evaluation reports can be found here: <https://acl.gov/programs/program-evaluations-and-reports>

3 Frost, S. (July 2020). “Deadly Discrimination: The Forgotten Impact of Covid-19 On People with Disabilities.” Forbes. <https://www.forbes.com/sites/sfrost/2020/07/06/deadly-discrimination/#3eca6fbf2b93>

4 American Psychological Association. (May 2020). “How COVID-19 impacts people with disabilities.” American Psychological Association. <https://www.apa.org/topics/covid-19/research-disabilities>

is quickly changing.⁵

While the COVID-19 pandemic was not anticipated when ACL awarded Living Well grants, the public health crisis magnified gaps in effective systems of community monitoring for individuals with I/DD and provided opportunities for grantees to promptly respond to local and state needs.

Impact of COVID-19 on Living Well Grantees

All eight Living Well grantees reported varying experiences in executing project activities during the COVID-19 pandemic. Living Well grant leadership teams faced unprecedented decision making during the pandemic related to trainings, in-person events, and long-term sustainability plans for their grants, all of which were affected by a rapidly evolving landscape of how HCBS are provided. Despite various barriers, the grantees found innovative ways to reach target communities and stakeholders in order to maintain project momentum and deliver critical services.

COVID-19 Challenges

While each grantee experienced its own unique set of impacts from the pandemic, all shared similar challenges:

- Experiencing budgetary shortages, cuts, or concerns and competing priorities at the state agency level, especially when leadership changes occur;
- Scheduling and holding programs and trainings for individuals with I/DD, families, providers, and other stakeholders remotely;
- Maintaining consistent recruiting and participation of self-advocates in virtual settings;
- Suspending data collection and other community monitoring activities, such as in-person National Core Indicator surveys; and generally,
- Connecting with people remotely, particularly those experiencing gaps in technological access.

Innovations in Responding to COVID-19

Despite these challenges, grantees also reported innovative strategies to mitigate barriers and carry out Living Well activities. During these extenuating circumstances, grantees focused on a variety of opportunities that spanned employment, education and training, cross-systems collaboration, policy, and cultural competency. This document highlights key initiatives, newly developed or modified in response to the pandemic, from each grantee.

⁵ Johns Hopkins University. (April 2020). "COVID-19 poses unique challenges for people with disabilities." Johns Hopkins University Hub. <https://hub.jhu.edu/2020/04/23/how-covid-19-affects-people-with-disabilities/>

Grantee Spotlight: Alaska Governor's Council on Disabilities and Special Education

The Alaska Living Well team⁶ offered online participation in most in-person trainings and meetings that were held pre-COVID-19 to increase accessibility across the state. When the pandemic began and many in-person events were canceled, the team moved quickly to adapt their trainings to online webinars, some of which were co-led by self-advocates. Additionally, the Alaska Living Well team partnered with Alaska's University Center for Excellence in Developmental Disabilities to develop a training module for direct support professionals (DSPs) and care coordinators comprised of three webinars co-hosted by either self-advocates or parents of individuals with I/DD. The webinars, which cover blending of paid and unpaid supports for individuals to strengthen their ability to live meaningful lives in the community, and are now available on-demand.



Highlight: Alaska Living Well Team

Jillian, a young woman who participates in the Alaska Living Well team's activities, generally requires support and coaching to interact and speak with her peers. During the pandemic, the team implemented virtual engagement strategies to ensure individuals like Jillian stayed highly engaged via Zoom. The Alaska Living Well team successfully transitioned to virtual supports for people with I/DD in a manner that was highly engaging, as demonstrated by Jillian's enthusiasm and participation. Jillian, pictured above, shares her "love sign" with other Zoom participants and enjoys greeting every person as they join Zoom sessions.



Grantee Spotlight: University of Georgia Institute on Human Development and Disability

The Georgia Living Well team⁷ is working with five providers to increase community monitoring by implementing the Therap platform, including the General Event Reporting tool. The tool is used to collect and analyze incident reports and adverse incident data. In response to the pandemic, Therap identified several new indicators to add to the platform for providers to report data regarding COVID-19. In addition to these new data indicators in Therap, the Georgia Living Well team also developed and distributed a new training on COVID-19 for DSPs and frontline supervisors through the College of Direct Support, an online training curriculum and learning management system, as well as a slide deck on staying healthy during COVID-19 for providers to present to staff. The team also distributes new resources and current information to the providers via a weekly email as part of efforts to increase knowledge sharing and understanding of the impacts of COVID-19 in the state.



Grantee Spotlight: Idaho Center on Disabilities and Human Development

The Idaho Living Well team⁸ works closely with the Culturally Responsive Advisory Group (CRAG), which includes five self-advocates and five parent advocates from the Latinx community. As grant stakeholder meetings transitioned to a virtual format in response to the COVID-19 pandemic, the Idaho Living Well team worked diligently with CRAG to maintain their inclusion in team meetings, share Spanish language materials and resources, and disseminate other tools to support their participation in virtual settings. The CRAG also informed strategies to improve access to technology, which became increasingly important as a result of the



6 The Alaska Living Well team refers to the lead agency for the Living Well grant in Alaska, the [Alaska Governor's Council on Disabilities and Special Education](#).

7 The Georgia Living Well team refers to the lead agency for the Living Well grant in Georgia, the [University of Georgia Institute on Human Development and Disability](#).

8 The Idaho Living Well team refers to the lead agency for the Living Well grant in Idaho, the [Idaho Center on Disabilities and Human Development](#).

pandemic. This included efforts to ensure virtual platforms, such as Zoom, were accessible to all individuals and families, particularly Spanish-speaking families. The Idaho Living Well team is focused on the inclusion and design of products to match what individuals with I/DD want and need most during this time.

Grantee Spotlight: Indiana Division of Disability and Rehabilitative Services

Throughout the pandemic, the Indiana Living Well team⁹ continued using Culture of Quality resources through the National Association of State Directors of Developmental Disabilities Services (NASDDDS). In response to the pandemic, the team developed a weekly residential provider check-in process via phone call, during which access to and use of personal protective equipment as well as staffing issues were immediate topics. Due to the success of these check-ins, the team began adding additional questions throughout the summer to discuss more topics beyond COVID-19. The Indiana Living Well team kept track of their process, including how they trained staff and analyzed data, to inform future efforts related to their Living Well goals.



Grantee Spotlight: University of Missouri - Kansas City Institute for Human Development

Over the course of the Living Well grant, the Missouri Living Well team¹⁰ worked with Station MD, a company that provides 24/7 access to an on-call emergency room physician who specialize in treating individuals with I/DD. In HCBS settings, DSPs can consult with a physician prior to visiting the hospital, which reduces unnecessary emergency room visits. If medical care is required, Station MD physicians can consult with the individual's providers to ensure quality care. When national telehealth regulations were relaxed due to COVID-19, the Missouri Living Well team was poised to support the state Division of Developmental Disabilities to quickly implement a contract with Station MD, as well as to provide outreach to people with I/DD and their families, given their strong relationship with both partners and with the Missouri Family to Family Health Information Resource Center.



Grantee Spotlight: University of New Hampshire Institute on Disability

In response to the pandemic, the New Hampshire Living Well team¹¹ partnered with Easter Seals New Hampshire to issue a weekly resource guide for DSPs within the state. This partnership included work with a licensed recreational therapist from Easter Seals to develop specific, needs-based, creative activities for virtual engagement. Additionally, the team was able to provide the in-person medication administration to the BDS to be uploaded to Relias, an online training platform, for staff to continue to be trained during COVID-19. Due to the work already completed on the medication training, the state was able to have an on-line version up and running in a short amount of time eliminating the expiration of DSP medication administration privileges.



9 The Indiana Living Well team refers to the lead agency for the Living Well grant in Indiana, the [Indiana Division of Disability and Rehabilitative Services](#).

10 The Missouri Living Well team refers to the lead agency for the Living Well grant in Missouri, the [University of Missouri-Kansas City Institute for Human Development](#).

11 The New Hampshire Living Well team refers to the lead agency for the Living Well grant in New Hampshire, the [University of New Hampshire Institute on Disability](#).

Grantee Spotlight: Virginia Commonwealth University Partnership for People with Disabilities

The Virginia Living Well team,¹² in collaboration with UCEDD staff, developed a [COVID-19 toolkit](#) by and for individuals with disabilities and their families to support them during the pandemic. This toolkit contains information and resources on COVID-19 prevention, rights of individuals with I/DD, treatment options, and employment and benefits. Additionally, the disAbility Law Center Virginia (dLCV) reviewed and logged every Computerized Human Rights Information System report that mentions COVID-19. Once a COVID-19 report is identified, dLCV sends a questionnaire to the provider identified by the report for data collection to identify inequities in services and treatment as well as potential solutions.



Grantee Spotlight: Wisconsin Board for People with Developmental Disabilities

In response to COVID-19, the Wisconsin Living Well team¹³ is conducting an evaluation of virtual services being offered across 15 sites within the state. Providers developed a wide range of virtual services and the team is identifying related best practices in order to make recommendations to the state Department of Human Services. The Wisconsin Living Well team also quickly pivoted a planned abuse and reporting toolkit to meet the needs of people with I/DD specifically during the pandemic. The plain-language [toolkit](#) includes *My Safe at Home Plan*, a health form, a Frequently Asked Questions document, and several rights documents. The toolkit was shared through various presentations via Zoom and Facebook Live. Self-advocate leaders also created videos about the toolkit to share on the People First Self-Determination [YouTube channel](#).



Summary

COVID-19 pushed Living Well grantees to think creatively and engage stakeholders in unprecedented ways. The grantees experienced setbacks to their grant activities, but still found ways to mitigate these challenges and continue working towards Living Well goals. As the pandemic continues to impact how individuals with I/DD achieve well-being in all aspects of life, the grantees' responses thus far indicate signs of a promising "new normal" with renewed enthusiasm for the Living Well charge.

COVID-19 Resources

The ACL published resources to on health, safety, and virtual engagement to a new [COVID-19](#) page.

The **Virginia Living Well team** developed a [COVID-19 Resource Toolkit](#) on treatment and prevention, I/DD rights, and employment and benefits information.

The **Wisconsin Living Well team** created a [COVID-19 Resource Toolkit](#) on health, safety, and rights as they specifically relate to the pandemic.

¹² The Virginia Living Well team refers to the lead agency for the Living Well grant in Virginia, the [Virginia Commonwealth University Partnership for People with Disabilities](#).

¹³ The Wisconsin Living Well team refers to the lead agency for the Living Well grant in Wisconsin, the [Wisconsin Board for People with Developmental Disabilities](#).