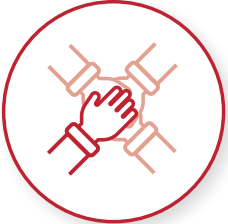


# Living Well 2020 Cross-Site Evaluation

## WISCONSIN Living Well Grantee Profile



2018 – 2019	2019 – 2020	2020 – 2021	2021 – 2022	2022 – 2023
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## I. Grant Background

### A. Grant Context and Purpose

Between 1998 and 2016, the number of people with intellectual and developmental disabilities (I/DD) living in facility settings decreased 39 percent, while the number of people in small group settings of four to six people increased 80 percent. During the same period, the number of people with I/DD living in their own home increased 126 percent, and the number of people living in a host or foster home increased by 132 percent.<sup>1</sup> People with I/DD who live in home and community-based service (HCBS) settings are more likely than people with I/DD living in institutional settings to make their own choices, have friends who are not paid staff, and have a paid job in the community.<sup>2</sup> Despite these positive outcomes, variations in access to and quality of HCBS across the country can put the well-being of people with I/DD living in their communities at risk. A recent series of Office of Inspector General (OIG) reports identified significant gaps in the reporting of and response to critical incidents in group homes.<sup>3</sup>

To address these pressing needs, the Administration for Community Living (ACL)<sup>4</sup> 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.

ACL awarded eight five-year grants across two cohorts to identify, develop, and evaluate model approaches which address two interrelated core components by incorporating eight key features. ACL administers Living Well grants through the Projects of National Significance (PNS) program. Funded under Subtitle E in the Developmental Disabilities Assistance and Bill of Rights Act (DD Act), PNS create and enhance opportunities for people with developmental disabilities (DD) to contribute fully in all aspects of community life. Further, PNS support the development of national and state policies that promote independence, integration, and inclusion in community life.

In 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. 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 rapidly respond to local and state needs.

### B. Two Core Components

Grantees address two core components with their Living Well model(s).

- **Community Monitoring:** Development and implementation of a coordinated system utilizing multiple community and state level partners for monitoring the safety, health, and well-being of individuals with intellectual and developmental disabilities living in a variety of community settings. The purpose is to identify and eliminate the risk

1 Larson, S.A., Eschenbacher, H.J., Anderson, L.L., Taylor, B., Pettingell, S., Hewitt, A., Sowers, M., & Bourne, M.L. (2018). In-home and residential long-term supports and services for persons with intellectual or developmental disabilities: Status and trends through 2016. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

2 Human Services Research Institute (HSRI) and National Association of State Directors of Developmental Disabilities Services (NASDDDS). (2019). National Core Indicators In-Person Survey: 2017-2018 Final Report.

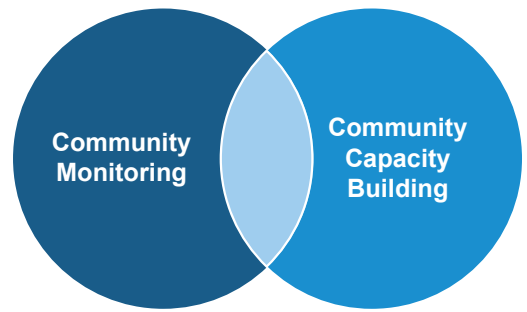
3 Office of Inspector General, Department of Health and Human Services. (2016). Massachusetts did not comply with federal and state requirements for critical incidents involving developmentally disabled Medicaid beneficiaries.

4 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.

factors for tracking, redressing and preventing abuse, neglect and exploitation in community settings;

- **Community Capacity Building:** Application of evidence based practices and innovative strategies focusing on improving services that support people with developmental disabilities living in the community or those moving to the community from a more restrictive setting; access to and quality of community services through capacity building and scaling of evidence based and other promising practices; reducing and mitigating the incidence of and risk factors for abuse and neglect; and supporting empowerment, self-determination, self-advocacy, and an individual’s independence, autonomy and right to live alongside their non-disabled neighbors.<sup>5</sup>

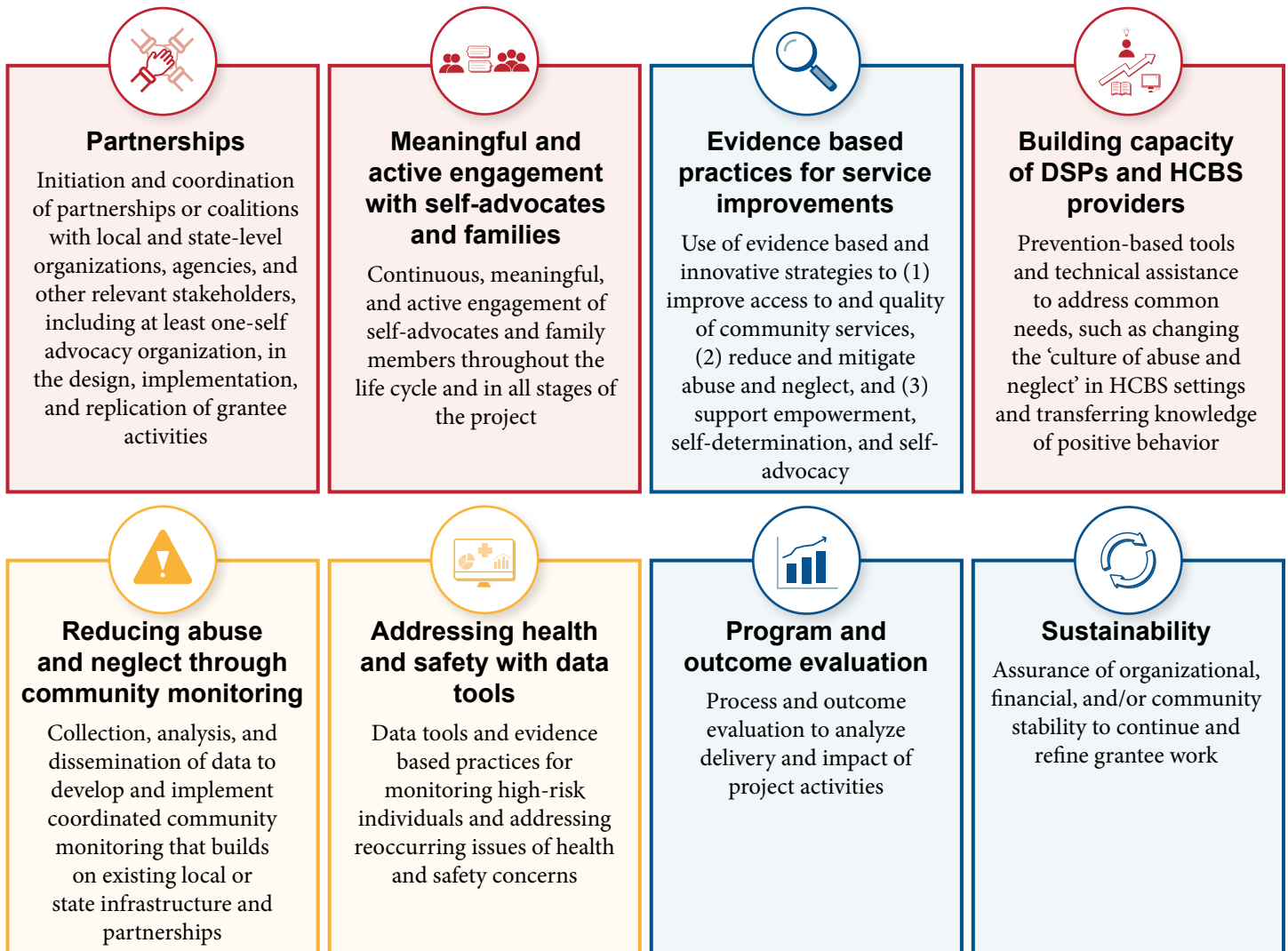
**Exhibit 1. Core Components of Living Well Models**



**C. Eight Key Features**

Grantees incorporate eight key features into their Living Well models.

**Exhibit 2. Eight Key Features of Living Well Models**











<sup>5</sup> Living Well-Model Approaches for Enhancing the Quality, Effectiveness and Monitoring of Home and Community Based Services for Individuals with Developmental Disabilities; HHS-2017-ACL-AOD-DNIQ-0221. <https://acl.gov/grants/living-well-model-approaches-enhancing-quality-effectiveness-and-monitoring-home-and-1>

## D. Grantees and Partnerships

ACL awarded grants in two cohorts, with the first cohort of three grantees beginning in September 2017. The second cohort of five grantees began their five-year grants in September 2018.

**Exhibit 3. Living Well State Grantees by Cohort**

2017	1	Cohort 1	2018	2	Cohort 2
		University of Georgia Institute on Human Development			Alaska Governor's Council on Disabilities and Special Education
		University of New Hampshire Institute on Disability			University of Idaho Center on Disabilities and Human Development
		Virginia Commonwealth University Partnership for People with Disabilities			Indiana Family and Social Services Administration
					University of Missouri-Kansas City Institute for Human Development
					Wisconsin Board for People with Developmental Disabilities

The grant requires partnerships among, at minimum:

- One Protection and Advocacy System, State Developmental Disabilities Council, or University Center for Excellence in Developmental Disabilities; and,
- At least one state agency (state I/DD agency, state Medicaid agency, self-advocacy organization, consumer-controlled organizations, or family-led organizations). Additional partnerships are strongly encouraged.

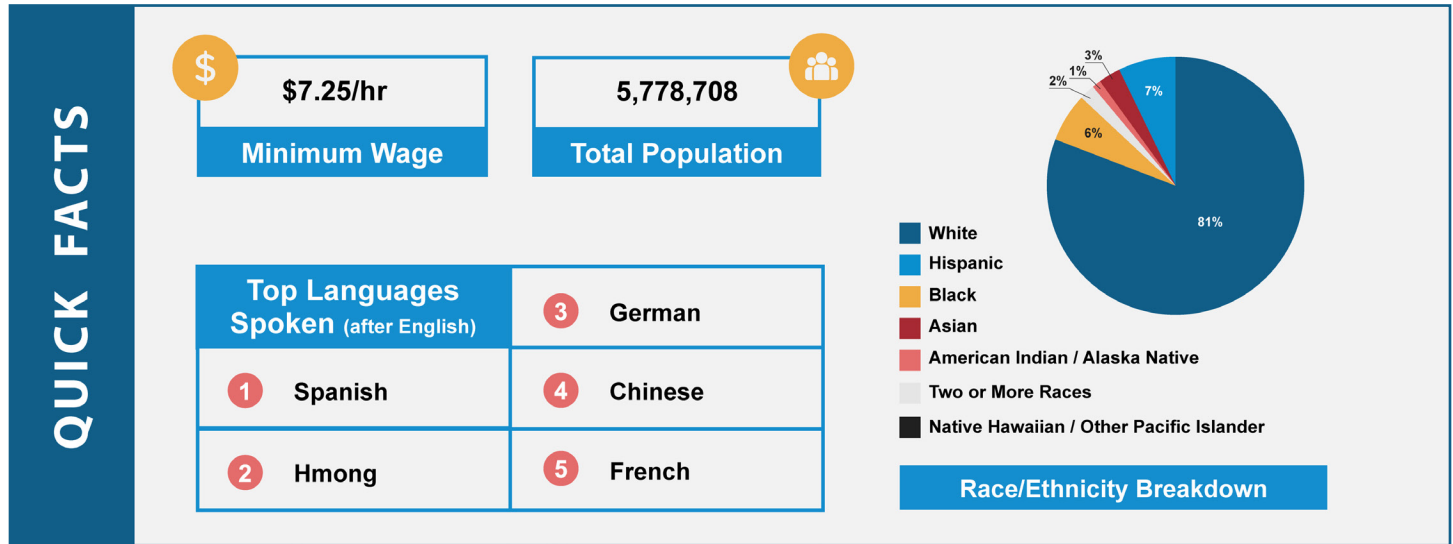
## II. Grantee Information

The Wisconsin BPDD was established in 1970 through the national Developmental Disabilities Act of the same year and serves as the state's developmental disabilities (DD) council. The Governor appoints BPDD's board members, 60 percent of whom are people with intellectual and developmental disabilities (I/DD) and family members. The organization conducts outreach, funds local initiatives, and provides information and training to educate citizens about issues affecting people with disabilities. More than 70 percent of BPDD's funds go to local projects and to advocate for better programs. At large, BPDD focuses on advocacy, capacity building, and systems change to improve self-determination, independence, productivity, and integration and inclusion for people with disabilities.

The Wisconsin BPDD supports [initiatives](#) related to the well-being of people with disabilities. These include administration of grants, including Employment First Partner and [SPARKS grants](#); trainings on various topics, such as how to advocate for policies; self-advocate spotlights and leadership forums; conferences, including the Self-Determination Conference; and distribution of family navigators to provide intensive case management for tribal and Latinx families.

### III. Grantee Partnerships

The Wisconsin BPDD partners with key stakeholders on their Living Well grant (collectively, the Wisconsin Living Well team) including, but not limited to, the Waisman Center, Disability Rights Wisconsin, the Arc Wisconsin, InControl Wisconsin, the Council on Quality and Leadership, People First Wisconsin, the state Department of Health Services (DHS), Adult Protective Services, Wisconsin Department of Justice (DOJ), managed care organizations, and Self-Directed Support Consultant Agencies.



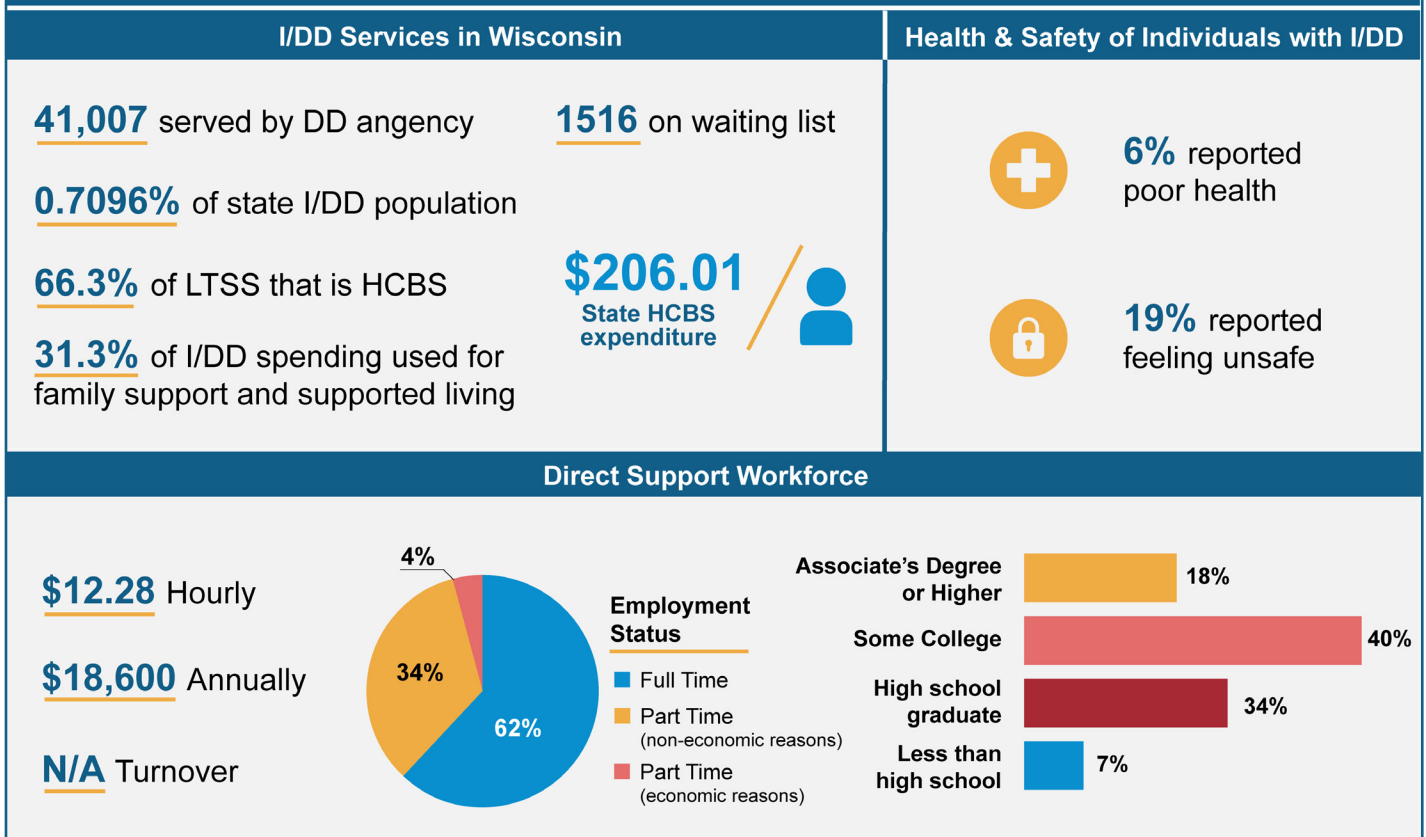
### IV. State Context

Variations in access to quality home and community-based services (HCBS) occur, in part, due to varying demographic, economic, political, and historical factors in each state. Key contextual factors are described here to better understand BPDD’s external conditions for their Living Well model. The COVID-19 pandemic rapidly evolved during the 2019-2020 evaluation cycle with significant impact on the delivery of in-person HCBS and the health and safety of individuals with I/DD. The pandemic response influenced both how and the extent to which grantees implemented grant activities as planned and the local and state context in which the grant is being implemented.

The Wisconsin Governor previously expressed interest in reducing abuse, neglect, and exploitation among people with disabilities and older adults. This interest provides an opportunity for the Wisconsin Living Well team to influence budgets and priorities; for example, the team provided recommendations for the Governor’s budget for 2021-2023. The recommendations include an emphasis on strengthening reporting and monitoring. The Wisconsin Living Well team anticipates COVID-19 will change the biennial budget significantly because of drastic tax shortfalls and added expenses. The Wisconsin Living Well team continues to look for opportunities for change without fiscal implications.

The Wisconsin Living Well team recently initiated a unique partnership with the Wisconsin DOJ. The Wisconsin DOJ launched a number of initiatives to address abuse and neglect, including obtaining grant funding for a hotline to report elder abuse. Wisconsin Living Well team members met with the Wisconsin Attorney General to share goals for the Living Well project and discuss strategies for reducing abuse, neglect, and exploitation. Future discussions will aim to hone in on opportunities for further collaboration, including expanding the hotline for vulnerable adults ages 18-65 and identifying and mapping the current incident response system across the state.

## STATE CONTEXT IN WISCONSIN



## V. Model and Objectives

The Wisconsin Living Well model uses a multi-level approach: The Wisconsin Living Well team is leading statewide policy recommendations and advocacy while providing coaching and leadership to the stakeholder group and local pilot and mentor sites. The team is also developing a peer self-advocate leadership network to advise project activities and goals and serve as the training team on the project using the Safe and Free self-advocacy curriculum. The grant formed a consortium of stakeholders that meets three times a year to assist in the development of a sustainable models of capacity building and community monitoring. The consortium participants receive project updates from the pilot and mentor sites, self-advocates, and state agencies and are given the opportunity to share back information gathered around the project objectives.

A group of pilot and mentor sites are equipping individuals with I/DD, families, and direct support professionals (DSPs) with skills and trainings to address health and safety needs identified through self-assessments conducted in partnership with Wisconsin Living Well team coaching staff. Each site is working with up to 20 individuals on this project. In addition, the mentor sites are participating in a learning collaborative with the pilot sites to provide insights and expertise.

The Wisconsin Living Well team's model objectives are to:

1. Implement an intervention package in five pilot providers across the state;
2. Provide coaching to pilots to ensure full implementation and fidelity;
3. Create policy and practice recommendations based on pilot findings;
4. Develop a statewide peer leadership network to maximize independence and conduct health and safety monitoring; and
5. Determine a sustainable model of capacity building and community monitoring to benefit individuals with I/DD living in the community.



## VI. Key Activities by Core Components

### A. Community Monitoring

Community Monitoring includes efforts to develop a comprehensive system to monitor the health and well-being of individuals with I/DD living in a variety of home and community-based settings. The following are key activities reported by the Wisconsin Living Well team during this evaluation period with the main goal of addressing this core component:

#### Key Activity: Develop Policy Recommendations



- The Wisconsin Living Well team established a policy team, which includes grant team members and representatives from stakeholders, to develop the policy recommendations to improve the health, well-being of people, and right of people with I/DD in Wisconsin. The team includes grant staff and grant partner representatives. The policy team conducted an environmental scan including reviewing other states' approaches to abuse and neglect monitoring and reporting. Based on their research, the Wisconsin Living Well team is now working on policy recommendations to support a central reporting system, including statutory changes and new contractual language in the State long-term care contracts. The Wisconsin Living Well team is working to narrow these recommendations and determine which to forward to the Wisconsin DHS for inclusion in the state biennial budget.
- The policy team met with the Wisconsin Attorney General and DOJ to discuss their new hotline for reporting elder abuse and neglect. The Wisconsin Living Well team is working with the DOJ to expand the service to include reporting for abuse and neglect of vulnerable adults under age 59.
- A core component of Wisconsin's Living Well project is the statewide consortium. The Wisconsin Living Well team holds three consortium meetings per year with project staff, project partners, community members and representatives from each of the pilot sites, including the self-advocate leaders implementing the Safe and Free curriculum. The events allow for community conversations to take place on a range of topics including abuse and neglect systems in Wisconsin. Feedback during one meeting provided concrete actions steps to improve our systems in Wisconsin, ways to break down the silos between systems, and possible policy recommendations.

### B. Community Capacity Building

Community Capacity Building includes efforts to increase the skills and knowledge of all individuals, families, and service providers in the HCBS system. The following are key activities reported by the Wisconsin Living Well team during this evaluation period with the main goal of addressing this core component:

#### Key Activity: Engage Pilot Sites and Implement Intervention Plans



- The Wisconsin Living Well team recruited five pilot sites from across the state, most of which have recruited between 10 and 20 participants, who are individuals with I/DD, each. The grant coach worked with the pilot sites to complete self-assessments about their organizations. The majority of participants completed Personal Outcome Measures interviews which the leadership team then analyzed. The Wisconsin Living Well team staff used this information to work with the pilot sites to develop and begin to implement intervention packages to begin addressing team-recommended activities as well as their self-identified areas of need. The intervention packages include trainings for staff as well as individuals with I/DD. The leadership team held bi-monthly Learning Collaborative calls to connect pilot sites with mentor sites.

#### Key Activity: Develop the Safe and Free Curriculum



- The Safe and Free Curriculum is being developed by the Wisconsin Living Well team and implemented at the Living Well pilot sites. The curriculum covers topics important for self-advocates to learn about their rights, how to avoid abuse, and how to have healthy relationships. The leadership team helped pilot sites connect with or recruit self-

advocate leaders to deliver the Safe and Free Curriculum trainings.

- The Wisconsin Living Well team's grant coach worked with People First Wisconsin and the self-advocate leaders to modify the curriculum for virtual training. The self-advocate leaders provided feedback on the modules of the curriculum and created new materials to make it more accessible to all people. The self-advocates also provided input to the Wisconsin Living Well team on how to best communicate changes and what new materials should be added to the training. The team created and distributed an updated virtual curriculum guide for self-advocate leaders.
- The Wisconsin Living Well team and self-advocates worked together to modify the Safe and Free curriculum to a virtual format once COVID-19 stopped in person services. The Wisconsin Living Well team has further developed the role of the self-advocate leaders and included them in additional activities through the Self-Determination Channel and Living Well Wednesday presentations.
- The Wisconsin Living Well team created accessible evaluation tools based on what stakeholders want to learn from the pilot testing of the curriculum. Some of the tools were created to be completed by participants after the training. Other tools include a protocol to debrief the self-advocate trainers after each class. The Wisconsin Living Well evaluation team adapted the tools to fit the new virtual format of the curriculum.

### Key Activity: Create and Distribute COVID-19 Toolkit and Host Living Well Wednesdays



- The Wisconsin Living Well team was in the process of creating an abuse and neglect reporting toolkit before COVID-19. The team took this initial document and developed a full toolkit to meet the needs of people with disabilities during COVID-19. The healthy, safe, and connected toolkit was an identified long-term goal of the grant outcomes. The Wisconsin Living Well team worked with self-advocates and other stakeholders to put together a plain language toolkit for use during COVID-19. The toolkit also led to the creation of several rights documents including rights during COVID-19, employment rights, and re-opening rights.
- The Wisconsin Living Well team companioned the toolkit with live presentations, called Living Well Wednesdays, via Zoom and Facebook Live to provide information to a larger audience on ways to stay healthy, safe, and connected. The team began broadcasting in early April every Wednesday on COVID-19 related topics and other topics of interest including employment, voting, and racial equity with an overall focus on rights.
- The self-advocate leaders created plain language videos for the People First Self-Determination YouTube Channel to inform people with I/DD about the toolkit in a more accessible format and have presented alongside professionals and the Wisconsin Living Well team during Living Well Wednesdays.

### Key Activity: Conduct Virtual Services Evaluation



- The Wisconsin Living Well team is conducting an evaluation of virtual services being offered in response to COVID-19 changes. The evaluation period ran from May to August and took place across 10 providers. Information was reported directly from provider agencies about what services were available, how the agencies were adapting and developing the services, and feedback the agencies were receiving about how the virtual services. While not all services can be delivered virtually, the Wisconsin Living Well team recognizes the important role of virtual services in the future. The evaluation will help identify best practices and the extent of the role of virtual services in the future. A final report will be shared with the DHS to be considered as part of a State telehealth policy on HCBS.
- This evaluation focuses on defining effectiveness for virtual services and implementing effective practices. The evaluation includes the full range of virtual programming offered by providers. For example, some providers are holding virtual programming sessions on specific topics once or twice a week while others are conducting activities on defined topics at a set time once a week, and still other providers are holding general social hours. Preliminary data from the virtual services evaluation indicated a positive participant response (506 end of session responses; includes duplicate participants): 99 percent are satisfied with the session and 98 percent report they learned more about the topics covered in the virtual service in which they participated. Another important element is that participants experience increased independence in the use of virtual service technology over time. Two-thirds of participants report using the technology to connect to others outside of the virtual service sessions.



## **VII. Analysis and Conclusion**

### **A. Contextual Factors**

A lack of a statewide centralized reporting system in Wisconsin led the Wisconsin Living Well team to study and identify best practices and make recommendations to the state for policies and budget considerations. The Wisconsin Living Well team is also looking to take advantage of executive branch interest in reducing abuse and neglect to build a partnership with the Wisconsin DOJ. This relationship between the BPDD and DOJ will allow the Wisconsin Living Well team to ensure that work on reducing abuse and neglect continues beyond the grant period.

### **B. Model Design**

The Wisconsin Living Well team's work is tiered, working with pilot sites to build, test, and implement action plans at a local level and various statewide partners to make policy recommendations for systems change at a statewide level. While policy updates and systems change take time, the Wisconsin Living Well team has used their grant to begin setting these processes in motion. In addition to these systems changes, the Wisconsin Living Well team and grant coach are working with pilot sites to enact immediate changes to build capacity among individuals with I/DD and the systems that serve them.

### **C. Key Activities**

The Wisconsin Living Well team is utilizing five provider partners as pilot sites to identify needs and implement action plans that address common goals as well as goals that meet their needs. This model supports disability service providers and those they serve to build capacity by focusing on their local areas of need. The partnership with several other providers to serve as mentor sites and develop a learning collaborative has the potential to be a sustainable best practice if the mentor sites stay engaged and continue to learn and improve their services as well.

Overall, improvements in service quality that pilot sites make by implementing their action plans should be sustainable beyond the life of the grant. In addition, relationships between providers (both mentor and pilot sites) should continue beyond the grant as the Wisconsin Living Well team is working to build a sustainable community of practice. The Wisconsin Living Well team is working to build and develop tools that will support providers beyond the life of the grant and the support of the grant coach.