

Living Well Cross Site Evaluation

Volume II Findings



I. Overview of Findings

The evaluation team used the eight key features required for each grantee's Living Well model as a framework for collecting and analyzing data. Due to overlap in the grantees' implementation of the key features, the evaluation team organized key features into three categories (**Exhibit 1**).

Exhibit 1. Key Feature Categories



A. Capacity Building

Most grantee activities during this evaluation year focused on building capacity through stakeholder engagement and trainings.

Formation and growth of new and existing partnerships. All grantees (n=8) reported working with multiple partners on their projects, but varied in their approach to engaging partners and assigning responsibilities or roles. Each Living Well grantee is required to partner with a University Center for Excellence in Developmental Disabilities, Protection and Advocacy organization, or Developmental Disabilities Council, if not already represented by the grantee. Additional partners that the evaluation team noted include, but are not limited to, state and local government agencies, non-profit agencies, contracted partners, and providers. Specifically during this evaluation cycle, nearly all grantees (n=7) initiated new partnerships to obtain additional expertise or ensure a diversity of perspectives on their team.

Engagement of self-advocates and families alongside partners. All grantees (n=8) engaged self-advocates and family members through formal partnerships with non-profit groups or positions within the leadership team. Most grantees (n=7) engaged with self-advocates and families in separate settings to ensure their unique perspectives are represented.

Development and implementation of trainings. Grantees (n=6) introduced trainings for self-advocates and families on topics ranging from recognizing and reporting abuse and neglect to healthy relationships. All grantees offered trainings for direct support professionals (DSPs) and home and community-based settings (HCBS) providers to further professionalization and offer career advancement opportunities. Stakeholders in all states (n=8) expressed concern about the DSP workforce including, but not limited to, turnover, pay, cultural competency, pipeline shortages, training effectiveness, professional development opportunities, hiring and retention incentives, and resource dissemination. The most common grantee initiatives to address workforce concerns (n=5) were trainings developed and implemented for DSPs and other provider staff. Other grantee initiatives to address these concerns include technology and social media tools to support DSP training and communication as well as the evaluation of DSPs and provider agencies by individuals with intellectual and developmental disabilities (I/DD) and their families.

Grantees used varying strategies to address key features related to building capacity (**Exhibit 2**).

Exhibit 2. Grantee Activities: Capacity Building

Key Feature	Activity	Georgia	New Hampshire	Virginia	Alaska	Idaho	Indiana	Missouri	Wisconsin
		Cohort 1			Cohort 2				
Capacity Building	 Partnerships Engage new state partners Engage specialized partners	✓	✓			✓		✓	✓
		✓	✓	✓	✓	✓	✓		✓
		✓	✓	✓	✓				✓
	 Engagement and self-advocates and families Reach marginalized populations Improve supports for individuals with dual diagnoses and other disability types Develop and implement trainings for self-advocates and families		✓	✓	✓	✓		✓	
			✓	✓	✓	✓		✓	✓
			✓	✓	✓	✓		✓	✓
	 Building competencies of DSPs and HCBS Design and implement DSP trainings Use technology and social media Improve DSP recruitment and retention Solicit DSP and provider feedback	✓	✓	✓	✓	✓	✓	✓	✓
				✓	✓	✓		✓	✓
		✓	✓		✓	✓	✓	✓	
		✓	✓	✓	✓	✓	✓	✓	✓

B. Data Collection, Dissemination, and Monitoring

Whether in the planning or implementation stages, all state grantee teams (n=8) are pursuing initiatives related to the key features of addressing health and safety with data tools and reducing incidents of abuse and neglect through community monitoring. Nearly all grantee initiatives that address the reduction of abuse and neglect jointly address health and safety issues.

Examination of current incident reporting and community monitoring practices. All grantees (n=8) are working with stakeholders to determine and address issues with their critical incident reporting and monitoring systems. Many grantees (n=6) reported that their critical incident reporting and monitoring systems are not comprehensive enough to effectively address the issues that their communities are facing and that work is needed to improve these systems. For example, grantees are determining and addressing barriers to reporting, simplifying reporting structures, and expanding the scope of reporting systems to comprehensively monitor critical incidents. All grantees (n=8) are addressing issues of abuse, neglect, health, and safety in the development and dissemination of trainings to individuals with I/DD, family members, or providers. Training topics include general themes of recognizing and reporting abuse and neglect and specific topics such as medication administration, professionalism, and cultural competency for DSPs and provider staff. In some cases, grantees (n=2) identified existing trainings and other similar systems in their respective state to be improved.

Assessment of data collection, analysis, and use practices. Many grantees (n=5) shared similar concerns from their teams surrounding the data collection process. Examples of these concerns include data collection fatigue and not using collected data to its full potential. Grantees identified multiple barriers to data collection, including (1) the immense work of continuing data collection in line with pre-existing state practices, (2) the lack of knowledge on the value of specific data points, and, (3) lack of data sharing across stakeholders. Grantees are mindful of these concerns when adapting and developing initiatives under the Living Well grant. Grantees are collecting qualitative and quantitative measures to inform metrics, obtain an understanding of pressing concerns, and inform future initiatives. Half of the grantees (n=4) reported using specialized software tools such as Therap and Tableau, to collect, analyze, and capture data and trends from provider-reported, self-advocate-reported, and grantee-collected sources. Grantees (n=5) are also collecting data from self-advocates through tools such as surveys and focus groups.

Many grantees expressed their intent to deliberately select data collection points to accurately measure outcomes of value to the team in the future. Activities that support the key features related to data collection, dissemination, and monitoring are summarized in **Exhibit 3**.

Exhibit 3. Grantee Activities: Data Collection, Dissemination, and Monitoring

Key Feature	Activity	Georgia	New Hampshire	Virginia	Alaska	Idaho	Indiana	Missouri	Wisconsin
		Cohort 1			Cohort 2				
Data Collection, Dissemination, and Monitoring  Reducing abuse and neglect	Use software to collect and analyze data	✓	✓				✓		✓
	Monitor, certify, and improve group homes			✓		✓			
	Addressing health and safety 	Implement Medicaid waivers and statutes		✓		✓	✓	✓	

C. Implementation, Evaluation, and Sustainability

Compared to the other categories of key features, the evaluation team observed fewer activities focused on implementation of evidence based or innovative practices, evaluation, and sustainability during the first evaluation year. While this is likely due to the early stage that states are in, several common themes emerged.

Alignment of innovative and evidence based practices with existing practices. All grantees (n=8) are developing and implementing data-driven initiatives in their respective states to improve the lives of individuals with I/DD and their families. These innovative and evidence based initiatives include, but are not limited to, the integration of the Charting the LifeCourse (CtLC) framework, improvements to the incident reporting system, and increased information dissemination. State teams rely on the foundation built by earlier key features, such as partnerships and engagement of self-advocates to inform the execution of these initiatives.

Evaluation of progress. All grantees (n=8) reported being in the early stages of evaluation and working to gather baseline data, establish evaluation teams, and develop progress and outcome measures. State grantee teams plan to use this evaluation data to assess trainings implemented as part of the Living Well grant, as well as overall project progress. Furthermore, grantees plan to continually use this data to determine best practices for improving the lives of individuals with I/DD and their families.

Integration of grant initiatives into sustainable systems. Most of the grantees (n=6) noted that they are mindful of sustainability and scalability of their initiatives and products. While not yet a major focus, all grantees (n=8) are building on previously existing initiatives, including both grantee and partners' projects. Half of the grantees (n=4) are archiving education and training materials, such as the creation or maintenance of websites for information on the state grantee and resources developed. Grantees are also securing funding (n=4) through alternate federal or state sources or strategic partnerships with private funding sources.

The evaluation team acknowledges that implementation, evaluation, and sustainability require capacity building during the initial years of the grant. Key activities during year one are identified in **Exhibit 3**.

Exhibit 4. Grantee Activities: Implementation, Evaluation, and Sustainability

Key Feature	Activity	Georgia	New Hampshire	Virginia	Alaska	Idaho	Indiana	Missouri	Wisconsin	
		Cohort 1			Cohort 2					
Implementation, Evaluation, Sustainability	 Evidence based practices for service improvements	Improve incident reporting system	✓	✓	✓	✓	✓	✓	✓	✓
		Implement frameworks for culture change	✓	✓		✓	✓	✓	✓	✓
	 Program and outcome evaluation	Use tools to evaluate project outcomes	✓	✓	✓	✓	✓	✓	✓	✓
		 Sustainability	Leverage existing grants and initiatives	✓	✓	✓	✓	✓	✓	✓
	Secure funding			✓		✓	✓	✓	✓	✓

II. Emerging Practices by Key Feature

Grantees are using innovative strategies to address each of the key features. Emerging practices are documented for each key feature in **Appendix A**.

Appendix A

Emerging Practices by Key Feature

Partnerships



Grantees are required to have coordinated partnerships with at least one Developmental Disabilities (DD) Network agency and one state-wide agency. Other possible partnerships include local and state-level advocacy organizations, local government agencies, and provider agencies. Partners should be involved in the design, implementation, and replication of grantee activities.

Featured Practices

The Administration on Disabilities (AoD) awarded a five-year Living Well grant to the Wisconsin Board for People with Developmental Disabilities (BPDD) in 2018. A significant component of the state's strategy is its large number of partnerships with diverse organizations including many highly specialized subject area experts. The BPDD partners with state agencies, private advocacy organizations, and providers. These partnerships enable Wisconsin to obtain expertise in areas including, but not limited to, outreach and support to self-advocates and families, policy and practice recommendations, implementation of the Personal Outcomes Measurement tool, stakeholder input, evaluation processes, project dissemination, and access to relevant datasets. 

For example, the BPDD's partnership with People First Wisconsin, a state-wide self-advocacy organization for with intellectual or developmental disabilities, and The Arc Wisconsin, strengthens the voices of self-advocates and families in policy change and program initiatives. The partnership with InControl Wisconsin provides the state with expertise on improving and advancing meaningful connections in the community as well as integrated employment opportunities, outcomes, and services for people with disabilities. Partnering with InControl helps Wisconsin build strong partnerships within the state and create diverse labor solutions for employers to support positive life outcomes for individuals with disabilities. A central component of BPDD's Living Well initiative is six pilot sites that will be mentored and supported by the state's partnerships with Headwaters, Opportunity Development Centers, and Opportunity Inc., three organizations with extensive experience in person-centered operational improvements and service transformation. Through triannual meetings with these organizations and groups, Wisconsin is using their partnerships as a key component for success in their Living Well work.

Key Takeaways

- Wisconsin's variety of partners enhances their grant activities by ensuring that no voice is left out of the conversation and all views are included in each project initiative.
- Many of the advocacy organizations, provider organizations, and state agencies are highly specialized and offer authority on particular topics.

Meaningful and Active Engagement With Self-Advocates and Families



Grantees are required to have continuous, meaningful, and active engagement of self-advocates and family members throughout the life cycle and in all aspects of the project.

Featured Practices

The Administration on Disabilities (AoD) awarded a five-year Living Well grant to Virginia Commonwealth University (VCU) in 2017. The majority of the grant leadership team is composed of agency staff who are either individuals with intellectual and developmental disabilities (I/DD) or who have family members with I/DD. This involvement of self-advocates and family members ensures that the voices of self-advocates and their families are actively considered in all stages of the project development and implementation. Furthermore, the state is piloting an initiative to train self-advocates to serve as peer mentors and counselors. The Leadership for Empowerment & Abuse Prevention training is co-led by Virginia self-advocates, and it teaches individuals with I/DD about healthy relationships and abuse prevention.



AoD awarded a five-year Living Well grant to the Alaska Governor's Council on Disabilities and Special Education (DD Council) in 2018. As part of their efforts to increase family engagement, the Alaska Living Well team solicited input from family members of individuals with I/DD and self-advocates while developing multiple direct support professional (DSP) trainings. These individuals also supported planning and leading the annual state stakeholder summit. A leadership team comprised of four self-advocates ensured that the unique experiences of individuals with I/DD were heard throughout the discussions and breakout activities. To increase the accessibility of the information that was presented at the Summit to the attendees, a graphic facilitator created straightforward, image-based notes that captured the highlights of the discussion and were displayed on a large screen.



Key Takeaways

- Active engagement of self-advocates and family members is a crucial part of all Living Well grant work and both Alaska and Virginia include self-advocates and family members in all aspects of their initiatives.
- As co-trainers in Virginia, self-advocates ensure that their perspective is highlighted during trainings for DSPs.
- As grant team staff in Alaska and Virginia, family members of people with I/DD provide valuable insights and help direct and maintain each team's vision and goals.

Evidence Based Practices for Service Improvements



Grantees must design, identify and implement a range of evidence based practices or innovative strategies to support people with developmental disabilities living in the community. These practices should (1) improve access to and quality of community services, (2) reduce and mitigate abuse and neglect, and (3) support empowerment, self-determination, and self-advocacy.

Featured Practices

The Administration on Disabilities (AoD) awarded a five-year Living Well grant to the Wisconsin Board for People with Developmental Disabilities (BPDD) in 2018. Wisconsin is utilizing one of their projects, Building Full Lives, to expand best practices focused on providing individualized supports and services to help individuals with intellectual and developmental disabilities build skills, have meaningful contributions and connections to community, and secure employment. Wisconsin is incorporating their best practices into multiple Living Well project pilot sites. Wisconsin also has numerous partnerships with local agencies and various provider agencies that assist with developing and implementing evidence based practices such as learning collaboratives, comprehensive agency self-assessments, action plans, person-centered planning, development of peer networks, community conversations, and supported decision making that enable sites to achieve positive organizational and cultural change.



AoD awarded a five-year Living Well grant to the University of Missouri-Kansas City Institute for Human Development (UMKC-IHD) in 2018. UMKC-IHD is piloting their Living Well model with six county boards that were early adopters of the Charting the LifeCourse (CtLC) framework. CtLC is an evidence-informed approach based on the core belief that individuals of all abilities and ages should develop their vision of a good life and have the right to live, love, work, play, and pursue their dreams in their community. In collaboration with their pilot sites, the Missouri Living Well team is using the CtLC framework to guide their interpretation of data and capacity building activities. Statewide, Missouri is planning a pilot with Therap to test the ability to use electronic data collection systems to collect and track information about specific outcomes and how they are related to the Living Well framework in the state and how that impacts overall quality of health. Additionally, the team has created a guide to support self-advocates to avoid victimization.

Key Takeaways

- It is early in the process for grantees to identify and implement evidence based practices.
- Both Wisconsin and Missouri have looked to established projects to identify evidence based practices that they could use to promote success of their Living Well initiatives.
- Wisconsin partnered with experts to identify and guide evidence based practices.
- Missouri is effectively leveraging their existing relationships with stakeholders and have aligned the Living Well project initiatives with Standards of Practice for direct support professionals, support coordinators, and providers, as well as national survey instruments such as the National Core Indicators.

Building the Competencies and Capacities of DSPs and HCBS Providers



Prevention-based tools and technical assistance to address common needs of direct support professionals (DSPs) and provider agencies. Goals of trainings and other supports include eliminating the ‘culture of abuse and neglect’ in home and community-based services (HCBS) settings and transferring knowledge of positive behavior and alternate communication strategies.

Featured Practices

The Administration on Disabilities (AoD) awarded a five-year Living Well grant the University of Georgia Institute on Human Development and Disability (IHDD) in 2017. The grant team is using the College of Direct Support (CDS), a series of courses delivered through an online learning platform, to develop and provide trainings to DSPs and other HCBS provider staff. Examples of available course topics include Employment Supports, Person-Centered Planning, and Community Inclusion. Provider organization administrators are responsible for creating training modules, uploading in-house trainings, and assigning trainings for their staff. The platform allows for a balance between the state standards that courses are required to fulfill and the flexibility for provider agencies and DSPs to choose courses of best fit. Staff can access courses individually or as part of career paths designed for new hires, front line supervisors, and other provider agency positions. Learners can view content specialized to their current position or begin a new career path. The Georgia Living Well team intends to add more specialized paths, including employment supports and support of older adults.



Furthermore, all provider partners have memberships to the National Alliance for Direct Support Professionals, which gives access to additional trainings and resources, such as the annual Informed Decision-Making training. The IHDD also offers opportunities for DSPs to attend leadership promotion activities, conferences, and workshop trainings.

Key Takeaways

- Through the CDS platform, Georgia created access to a variety of options for DSPs to further their professional development.
- By making courses available online, giving flexibility in course selection to DSPs and providers, and providing opportunities to attend events, the Georgia Living Well grant team is encouraging each DSP to explore their own career advancement. DSPs are exposed to issues and topics that they may not typically see in their everyday environment and experiences of others in their field.

Reducing Abuse and Neglect through Community Monitoring



Grantees must work to develop and implement or improve a coordinated community monitoring system aimed at reducing abuse and neglect through the collection, analysis, and dissemination of data.

Featured Practices

The Administration on Disabilities (AoD) awarded a five-year Living Well grant to the **Virginia Commonwealth University (VCU)** Partnership for People with Disabilities in 2017. The grantee team is taking steps to improve the state's critical incident reporting process by refining the incident reporting platform, clarifying the process of reporting an incident for both individuals with intellectual and developmental disabilities (I/DD) and other community members, and improving the collection of incident reporting data. One of the state's partners, the disAbility Law Center, is conducting interviews with individuals with I/DD and using their experiences to guide the reporting process. 

 The AoD awarded a five-year Living Well grant to the **Center on Disabilities and Human Development** in 2018. Idaho's Living Well grant initiatives involves working with self-advocates of the Quality Assurance Workgroup and Mission Analytics in order to better quantify abuse, neglect, and exploitation. Using this information, the state is in the process of developing a person-friendly and accessible statewide reporting model and tool for critical incidents.

Key Takeaways

- Both Virginia and Idaho are increasing the monitoring of abuse and neglect by collecting and examining more data, though each state is taking a different approach.
- Virginia's approach to improve the reporting process focuses on the experiences of people with I/DD through targeted interviews.
- The Idaho Living Well team is building a statewide data reporting system for substantiated complaints of abuse and neglect against direct support professionals, which will improve statewide incident tracking and prevent future cases of abuse and neglect.

Addressing Health and Safety with Data Tools



Grantees are required to identify and address reoccurring health and safety concerns in home and community-based services using data tools and a coordinated system for community monitoring.

Featured Practices

The Administration on Disabilities (AoD) awarded a five-year Living Well grant to the **University of New Hampshire Institute on Disability (UNHIOD)** in 2017. One of the state's most pressing categories of critical incidents is medication administration errors that lead to health and safety incidents. UNHIOD determined that many of the direct support professionals (DSPs) who lost or are at risk of losing their medication administration privileges do not speak English as their native language, while medication administration training was provided only in English. In order to address this, New Hampshire is supporting efforts to improve the medication administration training by offering classes in Spanish, Nepali, and Dzongkha (Bhutanese). 

 The AoD awarded a five-year Living Well grant to the **Indiana Family and Social Services Administration (FSSA)** in 2018. FSSA is exploring options for using Tableau, a data visualization software, as a monitoring tool. The team will use Tableau to create diagrams and charts using data collected by case managers. Data will be broken into subsets such as by county, race/ethnicity, gender, and diagnosis. These data visualizations will be used by case managers and provider organizations to display clean, easily understandable data points during stakeholder meetings to better assess quality outcomes. The Indiana Living Well team is in the process of determining quality outcomes and goals to determine their intended data collection, analysis, and presentation methodology.

Key Takeaways

- Project initiatives from the New Hampshire and Indiana Living Well teams demonstrate approaches that are driven by goals to resolve and improve chronic, long-standing state-level issues.
- UNHIOD's initiative to offer medication administration trainings in common first languages of DSPs will help prevent medication errors thereby increasing health and safety of individuals receiving services.
- The Indiana Living Well team is using a specialized data visualization tool to collect and analyze data to help providers identify and address issues of health and safety.

Program and Outcome Evaluation



Grantees are expected to conduct process and outcome evaluations. The process evaluation should analyze initiative planning, development, and implementation to identify successful strategies as well as barriers. The summative outcomes evaluation should determine key initiatives driving the success of the model and how well the overall model is achieving the goals of the Living Well grant.

Featured Practices

The Administration on Disabilities (AoD) awarded a five-year Living Well grant to the University of Georgia Institute on Human Development and Disability (IHDD) in 2017. To evaluate progress, Georgia hired a dedicated evaluation director who developed a monitoring and evaluation Excel spreadsheet that tracks project outcomes and data points through multiple sources including interviews with provider agencies to evaluate progress. For each training conducted through the Living Well project, Georgia measured outcomes through experience surveys, tracking effectiveness and identifying areas for improvement. Georgia is also using the Therap Business Intelligence (BI) tool to track indicators over time, filter and analyze data, and produce real-time ad-hoc trend reports. The grant team developed two outcome measures within the Therap BI platform to refine the data that are collected.



The AoD awarded a five-year Living Well grant to the University of New Hampshire Institute on Disability (UNHIOD) in 2017. New Hampshire is developing a quality assessment tool with the potential to replicate in other states. UNHIOD worked with state partners to access quarterly satisfaction survey results and combine them with a statewide annual survey of direct support professionals. This allowed the grant team to assess provider capacity and competencies as well as project outcomes. The state aims to standardize and shift surveys to an electronic medium to facilitate consistency in future data analysis.



Key Takeaways

- Though both grantees are only in the second year of the grant, they are making noticeable progress on the evaluation component.
- The Georgia grant team's real-time evaluation of trainings enables the state to ensure training effectiveness and pursue modifications immediately.
- New Hampshire, like other grantees, recognized that there was a sizeable amount of already being collected in the state. Consequently, UNHIOD is working to gather and centralize these data sources.

Sustainability



It is expected that community monitoring and capacity building systems developed by grantees are sustainable beyond the term of the Living Well grant. Efforts to assure organizational, financial, or community stability to continue and refine grantee work should be considered during the course of the grant.

Featured Practices

The Administration on Disabilities (AoD) awarded a five-year Living Well grant to the Alaska Governor's Council on Disabilities and Special Education (DD Council) in 2018. To ensure financial sustainability once federal grant funding ends, Alaska is working closely with the Alaska Mental Health Trust Authority, a state organization that administers the Alaska Mental Health Trust, a perpetual trust to improve the lives of beneficiaries, which include Alaskans with developmental disabilities. The Council includes the Trust in their larger partner meetings with a goal of aligning initiatives and securing future funding opportunities. Alaska is also exploring options to enhance its website to include a permanent location for trainings developed as part of the Living Well grant work.



The AoD awarded a five-year Living Well grant to the University of New Hampshire Institute on Disability (UNHIOD) in 2017. The UNHIOD works closely with Community Support Network Inc. (CSNI), the association for the state's ten area agencies representing the majority of the state provider workforce. Parallel to the Living Well grant, CSNI engaged in a strategic planning process to identify strategies to address systemic issues faced by their members: expanding the workforce pipeline, increasing retention, establishing direct support professional (DSP) professionalization, and identifying promising incentives. In partnership with CSNI, New Hampshire's Living Well grant team builds DSP and home and community-based services provider capacity consistent with a statewide vision that will be sustained beyond the Living Well grant.



Key Takeaways

- While the Alaska DD Council and UNHIOD are in the initial years of their grant, both teams are making intentional efforts to consider sustainability partnerships with larger, more permanent organizations.
- Alaska is working closely with partners, such as the Mental Health Trust Authority, to integrate Living Well project work with existing projects and grants.
- Alaska is also finding a permanent home for the trainings created under the Living Well grant, so that they will continue to be available once the grant ends.
- New Hampshire is working to align their work with that of their partners to improve the state provider workforce and build a system that will continue to support the professionalization of DSPs after the end of the Living Well grant.