

# Living Well 2020 Cross-Site Evaluation

## INDIANA Living Well Grantee Profile



The [Indiana Family and Social Services Administration Division of Disability and Rehabilitative Services](#) (DDRS) received the five-year Living Well grant in 2018.

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

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.

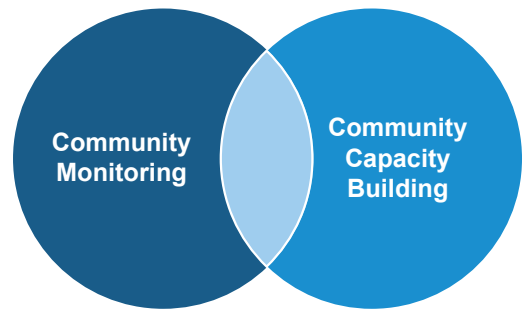
3 Office of Inspector General, Department of Health and Human Services. (2016). Massachusetts did not comply with federal and state requirements for critical incidents involving developmentally disabled Medicaid beneficiaries.

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.

developmental disabilities living in a variety of community settings. The purpose is to identify and eliminate the risk 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**









 <p><b>Partnerships</b></p> <p>Initiation and coordination of partnerships or coalitions with local and state-level organizations, agencies, and other relevant stakeholders, including at least one self-advocacy organization, in the design, implementation, and replication of grantee activities</p>	 <p><b>Meaningful and active engagement with self-advocates and families</b></p> <p>Continuous, meaningful, and active engagement of self-advocates and family members throughout the life cycle and in all stages of the project</p>	 <p><b>Evidence based practices for service improvements</b></p> <p>Use of evidence based and innovative strategies to (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</p>	 <p><b>Building capacity of DSPs and HCBS providers</b></p> <p>Prevention-based tools and technical assistance to address common needs, such as changing the 'culture of abuse and neglect' in HCBS settings and transferring knowledge of positive behavior</p>
 <p><b>Reducing abuse and neglect through community monitoring</b></p> <p>Collection, analysis, and dissemination of data to develop and implement coordinated community monitoring that builds on existing local or state infrastructure and partnerships</p>	 <p><b>Addressing health and safety with data tools</b></p> <p>Data tools and evidence based practices for monitoring high-risk individuals and addressing reoccurring issues of health and safety concerns</p>	 <p><b>Program and outcome evaluation</b></p> <p>Process and outcome evaluation to analyze delivery and impact of project activities</p>	 <p><b>Sustainability</b></p> <p>Assurance of organizational, financial, and/or community stability to continue and refine grantee work</p>

<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.

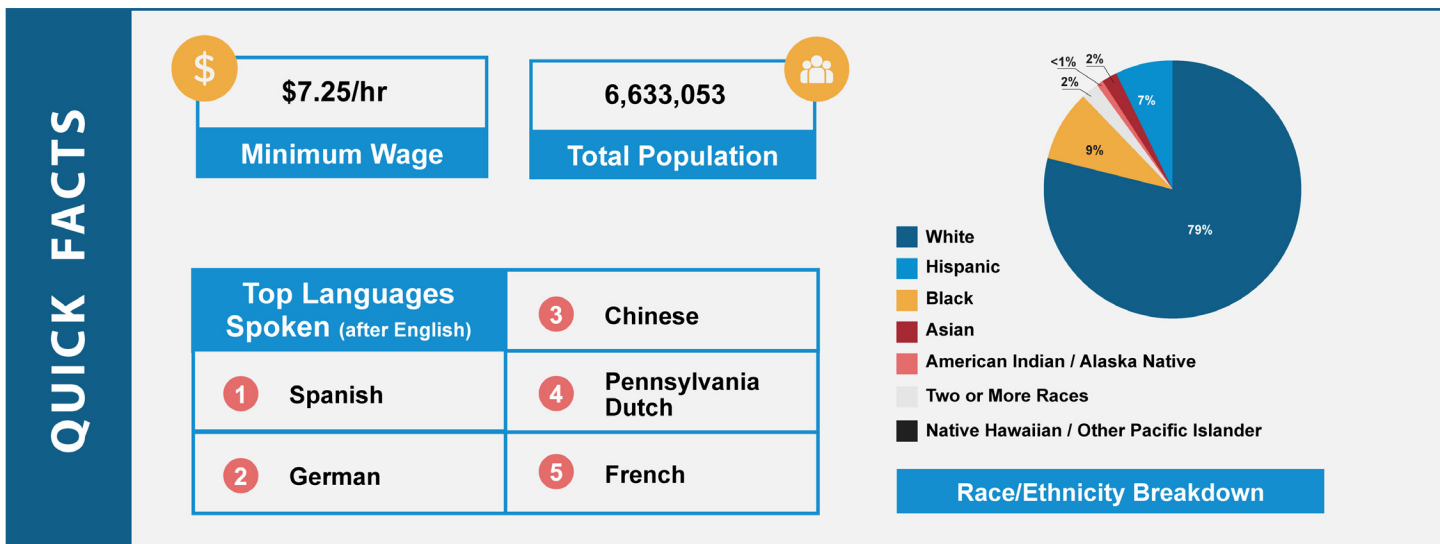
## II. Grantee Information

The Indiana Family and Social Services Administration was established by the Indiana General Assembly in 1991 and is a health care and social services state agency with six care divisions. Within the Family and Social Services Administration, DDRS manages the delivery of services to children and adults with developmental disabilities (DD).

Within DDRS, the [Bureau of Quality Improvement Services](#) monitors the quality of HCBS waiver services for individuals with DD and the organizations and providers who are approved to provide those services. They oversee the approval and enrollment of new providers, provider recertification, case record reviews, incident management, community monitoring and complaints. In addition, the [Bureau of Quality Improvement Services](#) assists in the distribution of multiple resources, quality-related trainings, and technical assistance. Further, the [Bureau of Developmental Disabilities Services](#) provides services for individuals with DD that enable them to live as independently as possible in their communities. As part of these efforts, the [Bureau of Developmental Disabilities Services](#) assists individuals in receiving community supports and residential services using a person-centered plan to help determine which services are needed and who can best provide them.

### III. Grantee Partnerships

The DDRS partners with key stakeholders on their Living Well grant (collectively, the Indiana Living Well team) including, but not limited to including self-advocates, families, providers, the National Association of State Directors of Developmental Disabilities Services (NASDDDS) Culture of Quality, and Charting the LifeCourse (CtLC) Nexus Chapter through the University of Missouri Kansas City.




### IV. State Context

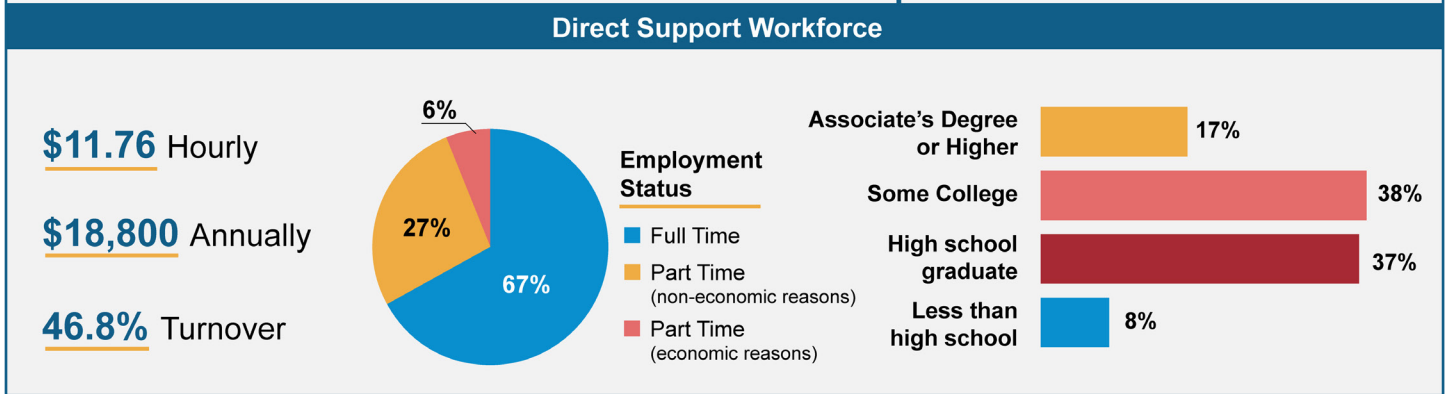
Variations in access to quality home and community-based settings (HCBS) occur, in part, due to varying demographic, economic, political, and historical factors in each state. Key contextual factors are described here to better understand DDRS's external conditions for their Living Well model. The COVID-19 pandemic rapidly evolved during the 2019-2020 evaluation cycle with significant impact on the delivery of HCBS and the health and safety of individuals with intellectual and developmental disabilities (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.

Indiana DDRS oversees the Partners in Transformation stakeholder group, which maintains a common vision and set of goals to align systems change efforts; this includes engaging local and statewide stakeholders, defining quality metrics and service outcomes, providing education to system partners to help people achieve a “good life,” and supporting providers and case managers. Collectively, these activities work towards a system that supports the individual as the primary driver of their own life and the system as a whole using CtLC as an organizing framework. Systems change efforts in Indiana include the redesign of HCBS waivers administered by the [Bureau of Developmental Disabilities Services](#) and ongoing participation in the Supporting Families and Cultural Competency communities of practice. As a whole, DDRS is integrating their Living Well grant activities into broader systems change efforts.

Indiana DDRS is the only state agency among the eight Living Well grantees. As a state agency, building trust can be difficult. The team is working to build a grassroots movement, but is sometimes constrained by DDRS' competing priorities, such as their response to the COVID-19 pandemic. At the same time, DDRS' role as a state agency can facilitate grant activities, such as alignment with other systems change initiatives.

# STATE CONTEXT IN INDIANA

I/DD Services in Indiana	Health & Safety of Individuals with I/DD
<p><b>29,948</b> served by DD agency      <b>1495</b> on waiting list</p> <p><b>0.4515%</b> of state I/DD population</p> <p><b>31.9%</b> of LTSS that is HCBS</p> <p><b>31.6%</b> of I/DD spending used for family support and supported living</p>	<p><b>3%</b> reported poor health</p> <p><b>9%</b> reported feeling unsafe</p>
<p><b>\$148.44</b> State HCBS expenditure</p> 	



## V. Model and Objectives

The Indiana Living Well grant model focuses on using the CtLC organizing principles and framework. The Indiana Living Well team began by working to include self-advocates, families, direct support professionals (DSPs), and other key stakeholders. In concert with these stakeholders, the Indiana Living Well team is working to develop, and eventually implement, a new integrated proactive community monitoring system by examining the current system through the lens of the CtLC framework. The Indiana Living Well team and stakeholders are developing and disseminating toolkits using CtLC principles to support HCBS.

The Indiana Living Well team's model objectives are:

1. Collaborate with and empower self-advocates, families, and key stakeholders throughout this project, ensuring full involvement in the development of practices, policies, and procedures to elevate HCBS;
2. Develop and implement an improved process for analyzing data from HCBS providers to influence practices, policies, and procedures for increasing quality of and access to services that improve positive outcomes for individuals with I/DD;
3. Develop and test toolkits for providers, individuals, and their families to improve monitoring of safety, health, and well-being of individuals with I/DD as well as reduce risk factors for abuse, neglect, and exploitation; and
4. Identify, develop, and implement an innovative approach to build the capacity of community supports for individuals with I/DD, bolstering paid and non-paid community services and supports.

## 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 Indiana Living Well team during this evaluation period to address this core component:

#### Key Activity: Explore Data Collection Strategies and Systems



- The Indiana Living Well team continued addressing the challenge of community monitoring and reporting occurring in silos by examining what data are being collected and exploring potential data collection systems. The Indiana State Department of Health Division of Long Term Care, which oversees licensing and certification for long term care facilities, has a robust data collection system. The Indiana Living Well team will meet with representatives from the Division of Long Term Care to discuss strategies for data collection and integration.

#### Key Activity: Identify Quality Indicators and Conduct Surveys



- The Indiana Living Well team conducted an extensive review of literature, review of state policies, and interviews to identify quality indicators to inform a shift in culture and performance for DDRS and develop innovative strategies that impact Indiana's systems change efforts. The Indiana Living Well team aligned strategies with the CtLC framework. Through this process, the team recognized a need to disseminate a survey to case managers, providers, and DSPs. The survey, developed in partnership with Indiana University, is for case managers, DSPs, and management of provider organizations. The goal of the survey is to gauge the priorities of respondents based on the direction they believe that the state agency has set.
- The Indiana Living Well team also began development of a survey to gather baseline data focused on expectations that individuals receiving supports and their families, providers, and other key stakeholders have for the state. The survey aims to capture what the perceived priorities of the state are compared to what the key stakeholders believe priorities should be.

#### Key Activity: Revise Needs Assessment and Evaluation Plan



- The Indiana Living Well team continued to revise the ongoing needs assessment and evaluation plan based on the project's activities and focus. Part of these efforts included analysis of Indiana's National Core Indicators (NCI) from 2015-2018. Staff shared results from the analysis at the NCI Annual Meeting.
- The Indiana Living Well team discussed efforts to link NCI data, portal data, and Medicaid reimbursement data to gain a stronger understanding of what data gaps exist. The team also began discussions on what questions to add to the NCI survey to support understanding of three CtLC domains and waiver redesign. In order to avoid redundancy, Indiana Living Well team members planned to review three existing data sources first.

### 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 Indiana Living Well team during this evaluation to address this core component:

#### Key Activity: Align Efforts Across Systems



- The Indiana Living Well team engaged key stakeholders in the state with partners in NASDDDS Culture of Quality

and the CtLC Nexus through University of Missouri-Kansas City to inform a collective impact approach to align state initiatives with broader systems change efforts. For example, the Indiana Living Well team initiated efforts to align their work in the Community of Practice for Cultural and Linguistic Competency in Developmental Disabilities with the CtLC framework and the Living Well grant work to ensure adequate consideration of people's backgrounds and cultures. The team shared this goal with stakeholders at a meeting in January 2020. Additionally, the Indiana Living Well team used Culture of Quality resources to develop a weekly residential provider check-in process via phone call, in response to COVID-19. This process enabled the Indiana Living Well team to support providers with key challenges in a timely, collaborative manner. Based on the results and feedback from this process, the team is exploring how to leverage this approach into its broader community monitoring approach. As a result, staff recorded detailed steps of the process and progress, including how they trained staff and analyzed data, to inform future Living Well and other related efforts.

### Key Activity: Conduct a Series of Trainings and Events for Self-Advocates, Families, and Providers



- The Indiana Living Well team worked to ensure self-advocates and families have equal footing with other stakeholders. The [CtLC Ambassador Series](#) included self-advocates, and the team reserved several other Ambassador Series' targeted at different stakeholder groups (e.g., self-advocates, families, providers, and case managers) to build leadership and encourage participation.
- A subset of the larger grant team was developed to serve as the leadership group. The group includes self-advocates, families, providers, and other system stakeholders, including the Governor's Council and Protection & Advocacy representatives, who are also self-advocates. The leadership group participated in a policy-focused Ambassador Series to support team development and improve information-sharing.
- The Indiana Living Well team began development of a series of provider trainings on the CtLC framework, as well as partnerships to provide on-the-ground support to self-advocates. The provider trainings aim to ensure that providers can facilitate self-advocate leadership opportunities in the future.

## VII. Analysis and Conclusion

### A. Contextual Factors

The Indiana Living Well team is uniquely positioned within a state agency, and leverages this role by capitalizing on existing partnerships, access to key stakeholders, and rapport built across systems since the agency's inception. As a result, the Indiana Living Well team works closely with leadership across partner agencies to integrate Living Well goals, philosophies, and activities for short- and long-term support. While there is some apprehension among individuals about DDRS' ability to impact true systems change as an agency tied to fluctuating priorities, such as COVID-19, the Indiana Living Well team built strong partnerships with other agencies early on, allowing the team to disseminate Living Well project information widely and generate enthusiasm around the project across systems. The Indiana Living Well team also has a unique opportunity to engage with other related grants in which DDRS is involved, such as an advocacy grant with the Arc of Indiana, and braid Living Well goals to those existing opportunities.

### B. Model Design

The Indiana Living Well team utilizes a variety of strategies to build on existing structures in the state while updating or creating new tools to promote Living Well activities. Notably, the state focuses on how to embed the CtLC framework in a range of initiatives, which supports alignment across their work. Through integration of the framework, the Indiana Living Well team strengthened stakeholder engagement and improved person-centered thinking among agency leadership. In tandem, key partnerships, such as with NASDDDS, support transformational change in the way HCBS are implemented in the state. Indiana's Living Well objectives include areas of focus across a wide range of stakeholders, from self-advocates and families to policymakers, in order to affect change on a systems-level and offer effective, scalable, and sustainable products that will continue even after the grant ends.



### **C. Key Activities**

The Indiana Living Well team works to create opportunities for self-advocates and family members to serve in leadership roles and trains providers to create similar opportunities, which also serves as a strategy to uphold Living Well philosophies once the grant ends. In order to sustain and scale data collection and evaluation tools, the Indiana Living Well team developed metrics to assess progress. These include creating surveys and working with quality managers to review data collection methods and use, update provider reviews and examine provider-level outcomes, and build provider capacity based on incident reporting. All of these activities provide critical information on gaps that may exist and other areas of need to better inform and drive the conversation on the trajectory of the Living Well project, including as it relates to sustainability. Overall, the Indiana Living Well team capitalizes on existing systems change momentum to integrate Living Well goals and achieve desired outcomes through hands-on activities with self-advocates, families, community members, providers, care coordinators, and other state agencies.