

# Living Well 2020 Cross-Site Evaluation

## MISSOURI Living Well Grantee Profile



The [University of Missouri, Kansas City Institute for Human Development \(UMKC-IHD\)](#) 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

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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.

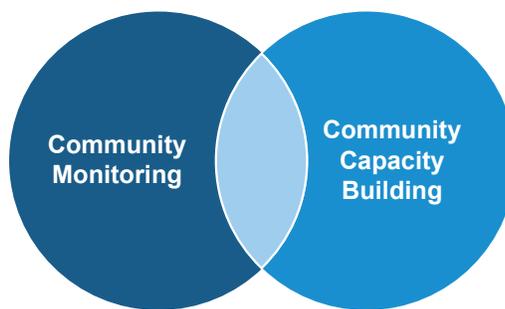
3 Office of Inspector General, Department of Health and Human Services. (2016). Massachusetts did not comply with federal and state requirements for critical incidents involving developmentally disabled Medicaid beneficiaries.

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>

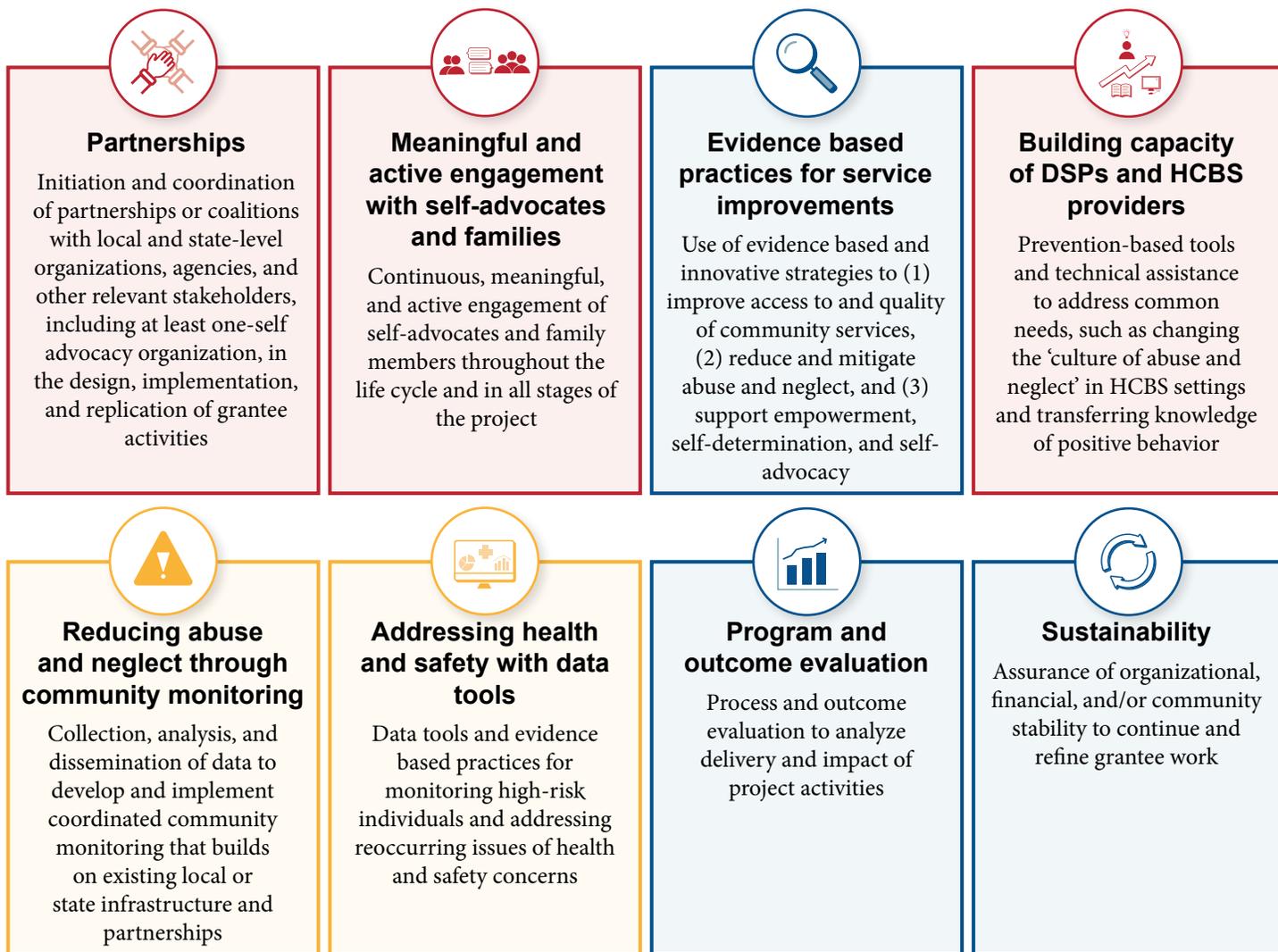
**Exhibit 1. Core Components of Living Well Models**



### C. Eight Key Features

Grantees incorporate eight key features into their Living Well models.

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



<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

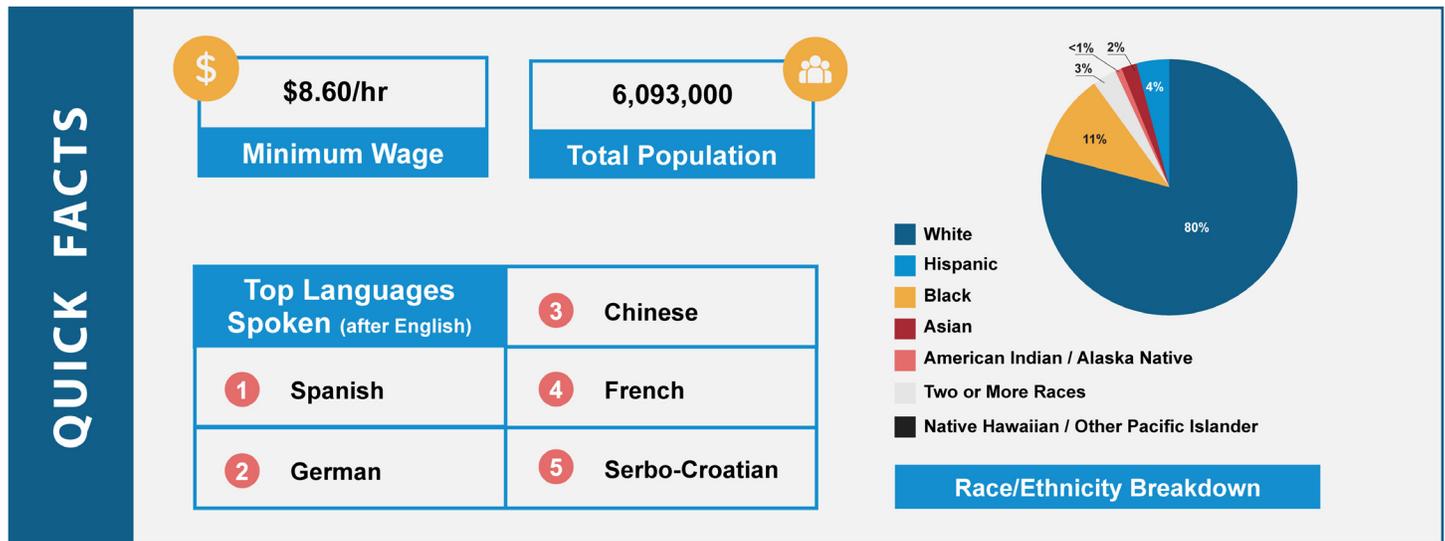
The UMKC-IHD is a University Center for Excellence in Developmental Disabilities Education, Research, and Service established in 1977 that works to promote self-determination among people with disabilities. The organization has an Advisory Leadership Team, comprised of adults with disabilities, family members, and leaders from the Missouri Division of Developmental Disabilities, Missouri Developmental Disabilities (DD) Council, Missouri Protection and Advocacy, Missouri Assistive Technology, Senate Bill 40 Boards, and other stakeholders that provides feedback on priorities and activities and participates in education efforts and coalition building.

The UMKC-IHD focuses on research and evaluation, program development, and training and technical assistance; they participate in and lead [projects](#) to promote the inclusion and well-being of individuals with disabilities in Missouri. These include the [iPad and iPhone Application for Prevention of Sexual Abuse](#), which involves the development of an app for people with disabilities to use for trainings and education; the [People First of Missouri Technical Assistance](#) project, an initiative to assist members of the state's People First coalition through ad hoc technical assistance; and the [Kansas City Hispanic Needs Assessment](#), a project developed to assess current conditions, assets, and needs of the Latinx population in the Greater Kansas City area. The UMKC-IHD also houses the [LifeCourse Nexus](#), a community of learning that brings people together to work towards transformational change within organizations, systems, and communities to support

“good lives for all people.” The LifeCourse Nexus both utilizes and continually refines the Charting the LifeCourse (CtLC) framework and tools to create a common language and philosophy for shaping and supporting innovation in policy, practice, procedure, and culture.

### III. Grantee Partnerships

The UMKC-IHD partners with key stakeholders on their Living Well grant (collectively, the Missouri Living Well team) including, but not limited to, Missouri Department of Mental Health Division of Developmental Disabilities (the Division), People First Missouri, the Missouri DD Council, Missouri Protection & Advocacy, the Missouri Association of County DD Services, the Marf (the Provider Association), and the Missouri Family-to-Family Resource Center. National partners include the Human Services Research Institute and the National Association of State Directors of Developmental Disabilities Services.



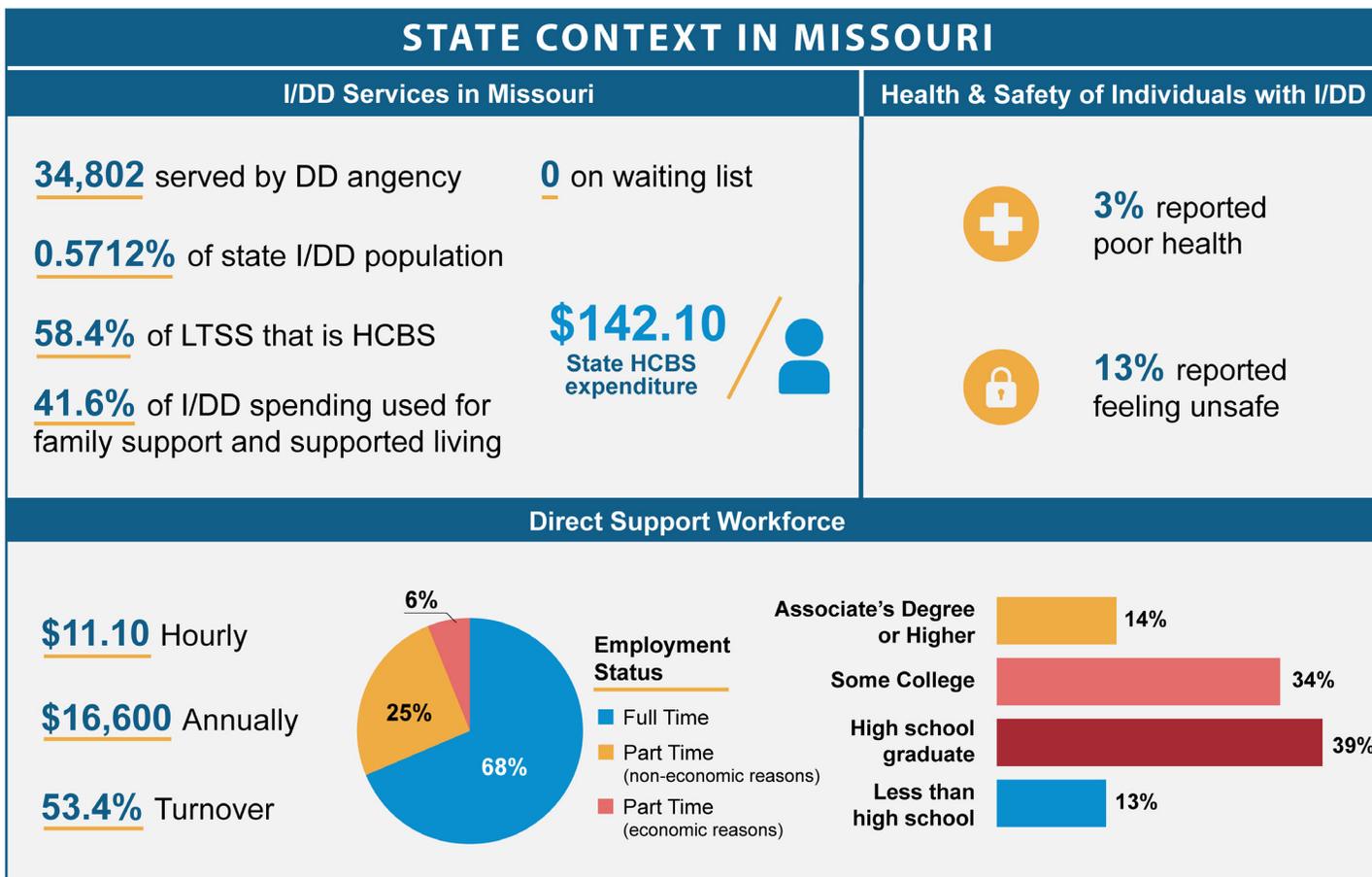
### IV. State Context

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 UMKC-IHD’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.

The UMKC-IHD continues to frequently convene stakeholders in Missouri, resulting in a strong collaboration across partners. The organization is engaged in disability-focused conversations and initiatives across the state. For example, UMKC-IHD conducts National Core Indicators (NCI) data collection. As a result, there is a longstanding partnership and consistent communications that facilitates awareness about what may be beneficial in the state, how to identify needs through Living Well grant work, and how to best align grant goals with other state initiatives. Additionally, the DD Council partnered with the Missouri Living Well team as part of their needs assessment for their next five-year plan.

The Division partners with UMKC-IHD through an annual contract, designed to support the division in its implementation of system wide enhancements to better support people with I/DD throughout the state. One result of this partnership are various capacity building curricula for multiple target audiences (including self-advocates, support coordinators, and community health workers). The Division also plans to implement the [Health Risk Screening Tool](#), a web-based tool designed to screen for health risks among vulnerable populations, particularly people with disabilities. The Missouri Living

Well team, in collaboration with the Division's leaders team is assessing what role the Living Well grant may play in the roll out and scaling of the identified and planned community monitoring and capacity building enhancement strategies of the Division. This may include using Living Well pilot sites, conducting evaluations, assisting with phased implementation, and making Missouri-specific modifications to the identified tools.



## V. Model and Objectives

The Missouri Living Well team is leading a diverse group of stakeholders to measure performance, develop a data visualization system, and build capacity through implementation of new tools and trainings. The team developed a levels of impact framework to organize their efforts and ensure that they are addressing the goals of their Living Well model at all levels of the DD system. The levels include self-advocate networks, family networks, support coordination entities, DD service provider organizations, the DD system, and cross-system organizations. The Missouri Living Well team is building on previous technical assistance experience and the CtLC framework, of which they were a lead developer. Their grant model contains both statewide activities and local engagement through county collaborative teams. These teams represent six of the state's 114 counties in the initial development phase, with plans to expand the county collaboratives to additional counties in future grant years.

The Missouri Living Well team's model objectives are:

1. To engage diverse partners in the design, implementation, and replication of the model;
2. Develop and implement a coordinated system for monitoring safety, health, and well-being of individuals with DD living in a variety of community settings; and,
3. To design, identify, and implement a range of evidence based practices and innovative strategies including training for direct service professionals and HCBS providers, designed to improve services 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 Missouri Living Well team during this evaluation period to address this core component:

#### Key Activity: Develop Virtual Data



- The Missouri Living Well team partnered with [Human Services Research Institute](#) to build a data dashboard to improve the accessibility and usefulness of data. The team engaged in a mapping exercise to identify data currently available to the team and data collected by project stakeholders. Through the CtLC Ambassador Series for Systems Transformation, county collaborative members recommended quality of life indicators for the dashboard and identified strengths and areas of improvement related to data collection and availability. This exercise identified data that are currently available and gaps that exist. The dashboard, which is still under development, currently includes NCI, Centers for Disease Control and Prevention, and census data. The dashboard will provide background information and case studies before displaying the actual data to provide context for users. The team is still collecting feedback on the dashboard and identifying additional data sources, such as critical incident data from the division.

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

#### Key Activity: Conduct CtLC Ambassador Series for System Transformation with County Collaborative Groups



- The Missouri Living Well team engaged and coached approximately 90 participants across six counties included in the pilot, including representatives from various levels of the DD system in each county, such as people who use services, providers, and county boards. Participants are using the CtLC Ambassador Series for Systems Transformation to discuss and identify their strengths and areas for growth in their role, their organization, and their community.
- County collaborative teams will develop and implement a strategic action plan to enhance capacity building or community monitoring in their local county, based on priorities identified throughout the series.
- The county collaborative teams piloted the Missouri Living Well team's new toolkit for system transformation. The toolkit is based on the CtLC framework and includes brainstorming and strategic planning resources. As the first pilot cohort wrapped up the series, the team evaluated the toolkit and process to identify areas for improvement. The team will make any changes to the series and is recruiting a new group of county collaborative teams to begin a second pilot group.

#### Key Activity: Establish Innovation Collaboratives



- The Missouri Living Well team established five innovation collaboratives to address specific topics of interest, such as data informed decision-making and person-centered support coordination. Each workgroup is currently led by members of the Missouri Living Well team and open to members of county collaborative groups from the first pilot cohort. Early workgroup members will form a steering committee for each workgroup and the Missouri Living Well team will expand the workgroups to the next cohort of county collaborative members once they complete training and coaching in CtLC (i.e., the Ambassador Series for Systems Transformation). The workgroups were launched in April

2020 and are in the early stage of development.

- The Missouri Living Well team is developing evaluation plans for each of the innovation workgroups. The evaluation plans will evaluate the goals, objectives, and activities of each workgroup in relation to the overall project outcomes.

### **Additional Activities:**

- **Conduct Training Using CtLC in Your Own Life Curriculum:** The Missouri Living Well team is conducting trainings for self-advocates through their 'Using CtLC in Your Own Life' to build self-advocate capacity.
- **Conduct CtLC Family Leadership Ambassador Series:** The Missouri Living Well team is also conducting capacity building training for family members of individuals with I/DD.
- **Partner with Station MD:** The Missouri Living Well team worked with the Division to bring Station MD to all recipients of the Division's Medicaid HCBS waivers. Station MD provides 24/7 access to an on-call emergency room physician who specializes in treating individuals with I/DD. The implementation of Station MD was accelerated by the COVID-19 pandemic. 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. Missouri Family-to-Family has supported the effort by using their platform to share information and tips about using Station MD.

## **VII. Analysis and Conclusion**

### **A. Contextual Factors**

The Missouri Living Well team is leveraging their levels of impact model and the CtLC framework to implement grant activities. The team is both strengthening existing partnerships and creating new partnerships to support their work. The Missouri Living Well team reports that their relationship with the Division is a significant advantage and is allowing them to integrate grant goals with the Division's strategic initiatives and the DD Councils next five-year state plan.

### **B. Model Design**

Missouri's Living Well model addresses grant objectives both locally and statewide. The levels of impact framework helps the Missouri Living Well team ensure that all levels of the DD system are targeted for improvement. The development, pilot, and evaluation of the new CtLC Ambassador Series for Systems Transformation is both driving positive changes in the communities participating in the pilot process and developing tools for future use.

### **C. Key Activities**

The Missouri Living Well team is developing new tools, implementing existing tools, and developing new and fostering existing partnerships through their Living Well grant. The Missouri Living Well team's multifaceted approach will lead to new tools and outputs that are sustainable beyond the grant funding period. Changes being identified and implemented at the county level will spur systems change in the coming years and the data dashboard will inform future decisions. The Missouri Living Well team intends to continue developing and implementing these tools, making modifications based on their internal evaluations and engaging new county collaborative teams in the final years of the grant. These finalized tools will then be ready for sustained use by other stakeholders in Missouri, as well as across the country.