I. Introduction

A. Model Design

Living Well grantees are tasked with “developing and testing one or more model approaches of a coordinated and comprehensive system that includes two interrelated core components for enhancing and assuring the independence, integration, safety, health, and well-being of individuals living in the community.” The two core components are: (1) Community Monitoring and (2) Community Capacity Building. Each grantee is using a detailed work plan to guide progress toward specific goals and objectives. As grantees achieve milestones indicated in their work plans, their Living Well models are taking shape in varied ways in response to the context in which they are being designed and implemented. Additionally, the models are evolving as grantees evaluate their activities and respond to new challenges.

Several model approaches are emerging, which are not mutually exclusive. One approach is to align with established statewide systems change initiatives. Grantees using this approach (e.g., teams in Alaska and Idaho) benefit from existing stakeholder groups and a clearly articulated vision or set of goals to which the Living Well grant is aligned. Other grantees (e.g., those in Indiana, Virginia, and New Hampshire) are leveraging their Living Well grants to convene partners and integrate discrete initiatives to holistically address the core components. Finally, several grant teams (e.g., teams in Missouri, Georgia, and Wisconsin) are using a pilot model approach to develop, implement, test, and revise initiatives on a local level before planning to scale and finalize their outputs.

B. Contextual Factors

The evaluation team identified several contextual factors influencing grant implementation. Several grantees reported state budget deficits prior to the COVID-19 pandemic. At the conclusion of this evaluation cycle, many grantees expressed concern about future budget cuts due to the economic impact of the pandemic on state budgets. Even when they do not directly affect grant activities, budget deficits can divert the attention of grantees or the stakeholders with whom they partner. In some cases, budget cuts are associated with state leadership changes, which shift priorities. The needs of individuals with intellectual and developmental disabilities (I/DD) vary across and within states, and grant models must respond to these culturally and linguistically diverse needs. Grantees must account for diverse, geographically widespread, and often under-represented populations in their models (e.g., offering materials and events in multiple languages, deliberately engaging culturally diverse stakeholders). While the specific impact on grantees varied, the COVID-19 pandemic is a significant factor in interpreting these findings.

Impact of COVID-19

The COVID-19 pandemic affected all grantees during this evaluation cycle. All grantees adapted to conducting grant activities in a virtual environment. Some grantees pivoted to more rapidly implement planned activities. For example, the New Hampshire Living Well team quickly deployed their medication administration training in a virtual format. Some grantees produced resources in response to the pandemic. The Wisconsin Living Well team developed a COVID-19 toolkit with information and resources. Grantees’ responses to the COVID-19 pandemic are evolving and emerging practices are highlighted in a separate brief.

2 Throughout this document, the New Hampshire Living Well team refers to the lead agency for the Living Well grant in New Hampshire, the University of New Hampshire Institute on Disability.
3 Throughout this document, the Wisconsin Living Well team refers to the lead agency for the Living Well grant in Wisconsin, the Wisconsin Board for People with Developmental Disabilities.
II. Grant Implementation and Progress Toward Goals: Cross-Site Analysis

Evaluators collected data from grantees through virtual interviews, an online reporting tool, and virtual stakeholder meetings. Evaluators analyzed data by core component on how grantees are progressing toward their goals and identified key themes within each core component. A discussion of these themes follows. A full discussion of the methodology is found in Volume IV.

A. Community Monitoring

Community Monitoring refers to the development and implementation of a coordinated system to monitor the health and safety of individuals with I/DD living in community settings. A 2018 report by the U.S Department of Health and Human Services Office of Inspector General documenting findings from a review of four states revealed significant gaps in compliance with state and federal requirements for reporting and monitoring critical incidents. For example, state agencies did not ensure that critical incidents were appropriately reported, recorded, and addressed. Responding to these gaps is challenging; states often have complex and fragmented systems for community monitoring that include multiple agencies with responsibility for receiving and responding to reports of suspected abuse. States may also face vulnerabilities in clearly defining incidents, balancing risk with health and safety, designing community monitoring systems that reflect the cultural diversity of the state, and implementing effective incident management systems. Grantees engaged in cross-system collaboration, data collection and analysis, and policy recommendations to improve systems of community monitoring.

Community Monitoring: Collaborating with Strategic State Partners

Grantees are addressing systems of community monitoring that are complex and often function in siloes. Grantees collaborated with partners across these systems to assess statewide community monitoring efforts and collect and analyze data related to the health and well-being of individuals with I/DD using home and community-based services (HCBS).

Forming cross-system partnerships to improve reporting and data collection. To improve incident reporting and data collection, grantees are forming cross-system collaborations within and across states. Through these partnerships, grantees gain access to knowledge and expertise that accelerate their efforts to improve community monitoring. For example, the Wisconsin Living Well team is working with the Wisconsin Department of Justice to expand its new elder abuse hotline to vulnerable adults across the state. The Idaho Living Well team and Community NOW! (CNOW!), an advocacy collaborative, sought advice from the Arizona Developmental Disabilities Planning Council on their approach to updating their abuse and neglect reporting system. The Indiana Living Well team is exploring how the Indiana Division of Long Term Care’s data collection system might inform their efforts to improve their own reporting system, given the Division’s reputation in the state for having a model system.

Developing partnerships to drive statewide systems change. Addressing complex systems of community monitoring often requires changes to policies and practices across multiple agencies. Living Well grantees are partnering with key stakeholders to achieve systems change. These strategies allow for alignment across systems. For example, the Idaho Living Well team attempted to map their incident reporting systems, but their limited research has shown that: The abuse and neglect reporting system in Idaho is fragmented, lacks transparency, and is parceled out to multiple state agencies that do not communicate, share data, investigate, or share results with one another.

The Indiana Living Well team is leveraging its state’s Partners in Transformation group to advance a common vision for systems change in the state. Using Charting the LifeCourse (CtLC) as an organizing framework, the Partners

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6 Throughout this document, the Idaho Living Well team refers to the lead agency for the Living Well grant in Idaho, the Idaho Center on Disabilities and Human Development.

7 Throughout this document, the Indiana Living Well team refers to the lead agency for the Living Well grant in Indiana, the Indiana Division of Disability and Rehabilitative Services.
in Transformation group brings together key stakeholders, including individuals with I/DD, families, providers, state agencies, and other community organizations, to address overlapping initiatives such as the Living Well grant, redesign of Medicaid HCBS waivers for individuals with I/DD, supporting families and cultural and linguistic competency communities of practice, and supported decision making.

Community Monitoring: Collecting and Analyzing Data

Effective use of data is integral to community monitoring. Collecting and analyzing data can help stakeholders understand the HCBS system's strengths and weaknesses and where improvements are necessary. Early in their grants, many grantees identified available data sources and explored how data could be analyzed, presented, and used. During this evaluation cycle, grantees reported using tools to collect primary data and to integrate and interpret data from multiple existing sources.

Leveraging data tools to drive action. One challenge facing grantees is having access to appropriate data to inform their decisions. Several grantees implemented tools in their state to collect data needed to drive their models. The Wisconsin Living Well team uses data from an agency self-assessment tool they created, as well as The Council on Quality and Leaderships Personal Outcome Measures® (POM) interviews as baseline evaluation data for pilot participants, which will help inform pilot sites on specific areas of improvement. The Georgia Living Well team's five pilot sites are using Therap to collect and monitor data on individuals receiving services through those providers and identify trends where interventions may be needed.

Integrating and interpreting data to facilitate access and use. Another challenge facing grantees is an abundance of data that are difficult to access or use. Some grantees identified data sources that already existed in their state but were not being fully utilized. These grantees are working to increase access to existing data by integrating them into user-friendly platforms. Over the duration of the grant, the Missouri Living Well team is developing a data dashboard with Verity Analytics to share and contextualize data to inform stakeholder decision-making and identify if individuals with disabilities have similar life experiences and outcomes as the general population in order to further define the concept of quality. The dashboard uses data from multiple sources including the National Core Indicators (NCI) survey, as well as population data from the Centers for Disease Control and Prevention and the U.S. Census Bureau to make these connections between life experiences across and beyond the disability system. Grantees also engaged in mapping activities to identify data from multiple sources and determine how they might access that data in the future.

As part of their Quality Framework, the New Hampshire Living Well team conducted a crosswalk of various data points, their purpose, and the systems requirements that they fulfill in order to assess compliance of quality, effectiveness, and monitoring of data within the state. These data points include, but are not limited to, Office of Inspector General requirements, sub-assurance monitoring requirements, regulation requirements, file review audits, HCBS compliance monitoring, and the re-designation process. This crosswalk informed the changes New Hampshire is making to the Health Risk Screening platform, which will integrate these multiple data points and enable easier analysis and use.

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8 Throughout this document, the Georgia Living Well team refers to the lead agency for the Living Well grant in Georgia, the University of Georgia, Institute on Human Development and Disability.
9 Throughout this document, the Missouri Living Well team refers to the lead agency for the Living Well grant in Missouri, the University of Missouri-Kansas City Institute for Human Development.
Spotlight on the National Core Indicators Survey

The NCI is a collaboration of participating states, Human Services Research Institute, and National Association of State Directors of Developmental Disabilities Services (NASDDDS) to measure and track public developmental disabilities agencies’ performance. The core indicators, which address areas of concern such as employment, rights, community inclusion, and health and safety, are standard measures used across states. The measures aim to assess the outcomes of services provided to individuals and families, and are used by all eight Living Well states. Many of the grantees use the data from the NCI survey to inform their grant activities. For example, the Indiana Living Well team identified three domains from the CtLC framework on which to focus their efforts and analyzed NCI data associated with those domains. The Alaska Living Well team worked with the state to add several questions to the survey regarding COVID-19. The Missouri Living Well team is sharing data from the NCI on their new data dashboard, as well as creating a series of short videos to highlight and build capacity around key indicator areas. The Georgia Living Well team used NCI data to inform the indicators they are using to measure direct support professional demand and capacity at their provider partners. The NCI provides important data to Living Well grantees to help inform and drive community monitoring efforts.

Community Monitoring: Recognizing the Importance of Policy

Some of the key components of effective systems of community monitoring (e.g., defining abuse and neglect, reporting and responding to incidents) can only be addressed through state policy change. While state policy change can be arduous, it is necessary and ensures sustainability of improvements to systems of community monitoring. Living Well grantees used two key strategies to advance systems change: advocacy and research.

Advancing state policy through advocacy and awareness. Raising awareness of issues related to abuse and neglect is foundational to achieving policy change. Several grantees are working with their local legislators to advocate for stronger policies to improve the health and safety of individuals with I/DD. The Alaska Living Well team collaborated with self-advocates and other stakeholders to meet with and develop four documents for Alaskan legislators as part of the 2020 Key Campaign in Juneau, which advocates for state policies supporting HCBS for individuals with I/DD. The Key Campaign offers an opportunity for self-advocates and other stakeholders to demonstrate the importance of certain policies for supporting the livelihoods of individuals with I/DD and allows legislators to ask questions and better understand the needs of the community.

The Idaho Living Well team worked with CNOW! to advocate for mandatory reporting and improved systems coordination to enhance the effectiveness of efforts by the state to reduce abuse, neglect, and other rights violations in HCBS. As part of their monitoring and reporting efforts, the CNOW! team is developing a caregiver misconduct registry. This registry would act as a single repository that contains all reports of abuse within Medicaid providers. As part of this process, the team is working on standardizing legal terminology and codes for abuse across the state and intends to use this work to enact legislative change for the state monitoring and reporting system.

Researching and making policy recommendations. Other grantees are using their expertise to conduct research and develop specific policy recommendations for their state governments. By request, the Wisconsin Living Well team provided input on the biennial Governor’s budget based on their expertise. The Wisconsin Living Well team also researched centralized reporting systems in other states and is collecting input from their stakeholders to refine their recommendations to the state. These policy recommendations aim to serve as the basis for a new statewide community monitoring system, and allow the team to explicitly identify areas of need for the budget that will in turn apply the principles of Living Well on a longer-term basis.

The New Hampshire Living Well team is participating on a workgroup with New Hampshire’s Department of Health and Human Services to update state administrative code, He-M 310: The Rights of Persons Receiving Developmental Services or Acquired Brain Disorder Services in the Community. In addition, they have updated the required

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11 Throughout this document, the Alaska Living Well team refers to the lead agency for the Living Well grant in Alaska, the Alaska Governor’s Council on Disabilities and Special Education.
medication administration training in order to enhance compliance with He-M 1201, Medication Administration and Healthcare Coordination. The engagement of Living Well teams in informing policies and other recommendations is an indication of other agencies’ commitment to cross-systems coordination and trust in Living Well staff expertise, a relationship that may continue throughout and after the grant.

B. Community Capacity Building

Community Capacity Building refers to efforts to support, develop, and build knowledge among individuals with I/DD and the people and systems that support them in the community. Nationally, most people with I/DD live in community settings. Among people with I/DD who use Medicaid-funded services, a majority (92%) receive HCBS12. While living in HCBS settings is associated with positive outcomes related to choice, relationships, and employment, barriers to full inclusion remain; people with I/DD experience low rates of integrated employment and often do not fully exercise choice and control in their lives.13 The workforce of direct support professionals who play a key role in facilitating health, well-being, and community inclusion of individuals with I/DD experience high turnover (51.3% weighted average), due in part to low wages, few benefits, and limited training, which leads to poorer outcomes for individuals receiving support.14,15 Grantee efforts focused on knowledge and capacity building among individuals with I/DD, their families, and HCBS providers through training, partnerships, and empowerment.

Community Capacity Building: Building Capacity of Individuals with I/DD

All grantees worked to build the capacity of individuals with I/DD through their Living Well models. Grantees targeted their efforts toward increasing individual knowledge, such as identifying and reporting abuse and neglect, and empowering self-advocates as leaders.

Implementing trainings to build knowledge and awareness of well-being and rights. One strategy for reducing incidents of abuse and neglect is increasing awareness of risk factors, indicators, and methods for reporting among people with I/DD. Grantees implemented trainings designed to build knowledge and capacity among people with I/DD on topics such as identifying safe and healthy relationships and guiding one’s own choices. The Wisconsin Living Well team worked closely with self-advocates to develop and lead their Safe and Free curriculum. The Missouri Living Well team is providing their “Using Charting the LifeCourse in Your Own Life” training to individuals with I/DD, as well as piloting a side-by-side guide for Abuse, Neglect, and Exploitation prevention (in partnership with the MO DD Council), and the Virginia Living Well team16 is supporting Leadership for Empowerment and Abuse Prevention training.

Supporting self-advocates as leaders, trainers, and peer-advocates. In addition to educating individuals with I/DD about abuse and neglect, grantees are building capacity by supporting and engaging self-advocates as leaders. Grantees are empowering self-advocates through leadership roles in their projects, as co-trainers delivering trainings to providers, and as peer-advocates, working with other individuals with I/DD to build peer leadership networks. For example, the Alaska Living Well team works with Peer Power to hold their self-advocacy summit and includes self-advocates on the grant leadership committee. In Idaho, CNOW! carefully ensures self-advocates have a prominent role in guiding the coalition and responding to issues brought to the group for discussion. The Wisconsin Living Well team engaged self-advocates to lead training using the Safe and Free curriculum developed by the Wisconsin Living

16 Throughout this document, the Virginia Living Well team refers to the lead agency for the Living Well grant in Virginia, the Virginia Commonwealth University (VCU) Partnership for People with Disabilities.
Well team and asked self-advocates to review the Healthy, Safe and Connected COVID-19 Toolkit and other project materials. Additionally, self-advocates are supported to create informational videos on key topics related to health, safety, and self-advocacy for the Wisconsin Living Well lead agency’s Self-Determination YouTube Channel.

Community Capacity Building: Building the Capacity of HCBS Providers

Grantees are building the capacity of HCBS providers in their respective states with a particular focus on direct service professionals (DSPs). A stable, qualified workforce is central to delivering high quality services to individuals with I/DD in the community. Two themes emerged as grantees develop and implement trainings and other capacity-building activities, highlighted below.

Developing DSP careers. Developing the careers of DSPs is critical to building the capacity of providers across the HCBS system. Beyond improving the quality of services provided by DSPs, providing continual development opportunities can also support the stability of the workforce as a whole. In addition to the mandatory trainings that DSPs generally receive upon entering the workforce, Living Well grantees invested in expanded career development opportunities for DSPs that support their retention and growth. For example, the Georgia Living Well team’s career track trainings through the College of Direct Support provide continuing training to DSPs and allow them to gain more skills and progress in their field. To meet the needs of the culturally diverse DSP workforce in New Hampshire, the New Hampshire Living Well team updated and translated the medication administration training to the top three languages spoken by DSPs aside from English. This update provides improved training curricula for DSPs, increases the safety of those they serve, and improves retention of existing DSPs in the workforce by maintaining their medication administration privileges. The Idaho Living Well team’s cultural competency training and bFair 2Direct Care workgroup seeks to support and maintain DSP careers. This workgroup developed a series of recommendations and trainings to improve and standardize the core competencies of DSPs, the code of ethics, and the performance review process.

Addressing state-specific training needs by utilizing and adapting existing curricula. Grantees identified training areas based on their state-specific needs. In many cases, grantees found that their needs could be met by using or adapting existing training materials or models rather than developing entirely new curricula, offering an efficient and scalable strategy for training implementation. Some examples include the Indiana Living Well team’s use of the CtLC framework to help organize and encourage participation in their stakeholder group and the Alaska Living Well team’s partnership with the state’s UCEDD and I/DD service provider organization to deliver capacity building trainings to DSPs. In addition to these trainings, grantees also identified needs for which there were no readily available or up-to-date training materials. In order to address these needs, grantees are developing, testing, and refining new trainings. The New Hampshire Living Well team refined and updated New Hampshire’s medication administration training curriculum to ensure consistency and availability in other languages, while the Georgia Living Well team used the established College of Direct Support platform and worked with their partners to build new training modules within the platform. The Idaho Living Well team is continuing to pilot its Supported Decision Making training to self-advocates, family members, and education professionals.

Spotlight on Charting the LifeCourse Framework

The CtLC Nexus is a community of learning that brings people together to work toward transformational change within organizations, systems, and communities to support “good lives for all people” using the CtLC framework. The framework and supporting tools were developed by the University of Missouri-Kansas City with input from stakeholders. Several Living Well grantees are using or have used tools from the CtLC framework to support and organize their work. Notably, the Missouri Living Well team is developing a new set of tools within the framework aimed at systems change and the Indiana Living Well team is using the CtLC framework to organize and strategize with their stakeholders. The CtLC principles and related tools can support stakeholders in organizing and developing a person-centered HCBS system.

Community Capacity Building: Developing and Sustaining Strategic Partnerships

Grantees built capacity within their service systems by fostering collaboration across agencies. This collaboration unified partners around common goals and leveraged the skills and capabilities of partner organizations.

Building state partnerships to pilot innovative practices. Grantees are utilizing their Living Well grants to connect and build relationships with strategic partners to pilot activities within the state. Grantees are developing important partnerships that will help accomplish specific goals of their projects. For example, the Alaska Living Well team partnered with Adult Protective Services and the Arc of Anchorage for the Supported Decision Making Agreement (SDMA) pilot. The pilot aims to improve first-person fact reporting to state agencies among individuals with I/DD. While the pilot is aimed at improving SDMAs, the Alaska Living Well team believes that the best practices identified by the pilot could extend to other Alaska state agencies and beyond. The Missouri Living Well team recognized from prior work that having champions across the state in local communities helps advance their work and push their model forward. The Missouri Living Well team partnered with local county collaborative groups to pilot their new CtLC for Systems Transformation framework. The Wisconsin Living Well team has stakeholders from state agencies, managed care organizations, the Include, Respect, I Self-Direct consulting agencies, providers, independent living centers, pilot and mentor sites, and self-advocate leaders convene in a consortium three times a year to share progress updates and ideas that influence Living Well work.

Leveraging national expertise to build state capacity. Beyond their own states, some grantees are seeking strategic partnerships across state lines or with national partners. These professional relationships and partnerships can help grantees identify best practices to build capacity of both individuals with I/DD as well as the HCBS system. The Indiana Living Well team partnered with NASDDDS to integrate their Living Well activities with NASDDDS’ Culture of Quality initiative. The Missouri Living Well team worked with the state Division of Developmental Disabilities to contact with Station MD, a company that provides 24/7 access to an on-call emergency room physician who specializes in treating individuals with I/DD. Additionally, both the Missouri and the Indiana Living Well team used CtLC to provide a framework for their grant activities. The Georgia Living Well team partnered with the National Alliance for Direct Support Professionals (NADSP) to develop a Code of Ethics training to guide DSPs as they support individuals with I/DD to be active members of their communities.

III. Conclusion

The purpose of Living Well grants “is to increase community integration and independence of individuals with developmental disabilities and to improve the quality of HCBS.” Grantees are making progress toward this purpose by developing and testing models that address the overlapping core components of Community Monitoring and Community Capacity Building. As grantees complete their second or third years of the five-year Living Well grants, they are achieving outputs and progressing toward grant outcomes. Through this, their models are taking shape within their unique state context. The fluidity of model activities and outcomes is a part of the nature of the Living Well grant, and reflects the various state contextual factors.

Living Well states were particularly impacted by COVID-19 this year. The pandemic induced unanticipated changes from shifting state budget priorities to physical distancing requirements, which challenged grant teams to modify programming in response. The COVID-19 pandemic also exposed vulnerabilities in systems that support the health, safety, and well-being of individuals with I/DD; grantees are adapting and retooling their resources to continue to build quality HCBS networks for individuals with I/DD living in a variety of community settings in light of this changing context.

Findings from the first year of the evaluation indicated that grantees focused on building capacity through stakeholder engagement and training. Efforts to address health and safety with data tools and reduce incidents of abuse and neglect focused on assessing current practices and available data. Activities related to implementation, evaluation, and sustainability included alignment with existing state initiatives or practices. Findings in year two build on these early achievements. Stakeholder engagement is leading to measurable outputs, and grantees’ evaluation of initial training efforts enabled them to refine their approaches. Grantees are collecting and using data informed by earlier exploration.

Findings in year two of the evaluation also demonstrate more integrated project models. While each core component is
distinct, they overlap. To address Community Monitoring, grantees focused on coordinating data collection strategies across stakeholders and partners, utilizing various data tools for accessible and effective use, and recommending and implementing policy to improve HCBS quality. Within Community Capacity Building, grantees focused on supporting self-advocates through trainings and leadership opportunities, building DSP capacity, and developing thoughtful state and national partnerships. These components, while different, cannot be understood apart from one another. For example, it is essential to both build the quality and capacity of the HCBS provider system and states’ capacity for community monitoring. Further, in order to effectively use data collection tools and strategies, DSPs must have adequate access and training to support implementation across the system.

The activities related to each component, while distinct in execution, ultimately serve a common goal to sustainably improve the HCBS system for individuals with I/DD. Grantees demonstrated progress during this evaluation cycle and generated learning about how they can continue to refine their approaches and shape their models. Next year, grantees intend to advance their models by continuing key activities, launching data tools and dashboards, and producing materials (e.g., toolkits) based on their experiences. While the response to the COVID-19 pandemic may be less intense and urgent in the coming year, grantees anticipate they will continue to support their states’ efforts and adapt their models as the pandemic evolves.