Living Well Cross-Site Evaluation
Volume II: Grantee Profiles

Access the full annual report and other evaluation materials here.
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Alaska: Living Well Grantee Profile

Grantee Information

The Alaska Governor’s Council on Disabilities and Special Education (the Council) received the five-year Living Well grant in 2018.

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The Council, started in 1975, comprises 26 members and serves a variety of state and federal roles. These include acting as the State Council on Developmental Disabilities (DD), the Interagency Coordinating Council for Infants and Toddlers with Disabilities, Alaska’s Special Education Advisory Panel, and as the governing board for the Special Education Services Agency. The Council is organized with multiple committees, each of which is chaired by a Council member.

The organization works towards systems change in areas including early intervention, independent living, inclusion in the community, education, employment, health, and self-directed lives with meaningful choices. The Council oversees a variety of project initiatives to improve the lives of people with disabilities in Alaska. These include emergency preparedness activities, including development and distribution of toolkits; supported decision-making agreements, which give people the help they need to make choices about their lives; and self-employment grants, which are available to qualifying people with disabilities.

Grantee Partnerships

The Council partners with key stakeholders on their Living Well grant (collectively, the Alaska Living Well team) including, but not limited to, the Alaska Association on Developmental Disabilities, Statewide Independent Living Council, Southeast Alaska Independent Living Center, Peer Power Alaska, Key Coalition of Alaska, Disability Law Center of Alaska, State of Alaska Senior and Disability Services, the Alaska Mental Health Trust Authority, the University of Alaska Anchorage Center for Human Development, and the Alaska DD Collaborative.
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 the Alaska team’s external conditions for their Living Well model.

The COVID-19 pandemic is significantly impacting the Alaska Living Well team’s grant activities. Alaska has a state budget deficit, which has been exacerbated by the COVID-19 pandemic. The Alaska Living Well team anticipates additional budget cuts and continues to provide recommendations for cost savings to state agency leadership as the state budget is set. Additionally, several efforts to improve access to and quality of HCBS in Alaska are delayed, though the
Living Well team remains optimistic that a continued focus on person-centered care will increase awareness that individuals can direct their own plans. The Alaska Living Well team also continues to explore which activities will be offered virtually, in-person, or through a hybrid approach.

**Model and Objectives**

The Alaska DD Systems Collaborative, comprised of stakeholders from across the state, developed a shared vision statement for the DD system in Alaska: “Alaskans share a vision of a flexible system in which each person directs their own supports, based on their strengths and abilities, towards a meaningful life in their home, their job and their community. Our vision includes supported families, professional staff and services available throughout the state now and into the future.”

The Alaska Living Well team aligned their Living Well objectives with the DD system’s shared vision to impact change most effectively in parallel with other systems work. To build system alignment with the vision, the Alaska Living Well team is working with stakeholders to target three groups: individuals with intellectual and developmental disabilities (I/DD) and their families, service providers, and policymakers. These three groups provide valuable insight to inform best practices for systems alignment and priority setting.

The Alaska Living Well team’s model objectives are to:

1. Enhance the health and safety of individuals who experience DD by increasing their independence, self-determination, community integration, employment, and participation;

2. Strengthen the knowledge and skills of direct support professionals to use evidence based and/or promising practices related to culturally and linguistically person-centered thinking and supported decision-making which may improve workforce stability, retention, and advancement;

3. Strengthen and elevate the leadership roles that self-advocacy organizations, Centers for Independent Living, and other peer support networks, working together with families and others, play in improving and assuring the quality of HCBS; and,

4. Enhance the effectiveness and coordination efforts by the state, the DD Act network and others to implement the HCBS settings rule and address rights violations in the HCBS delivery system for people with developmental disabilities.

**Key Activities by Core Components**

*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 Alaska Living Well team during this evaluation period to address this core component:
**Key Activity: Use of National Core Indicators (NCI) Survey Data**

The NCI program supports participating states to gather data on standard measures from individuals and families using state-funded DD services in order to track state performance over time and in comparison to other states. The Alaska Living Well team added questions to the NCI survey in Alaska to gauge the person-centeredness or person-directedness of the existing emergency plans and ensure that emergency plans reflect the needs of individuals. During the COVID-19 pandemic, statewide data have been collected virtually via the Zoom platform. The Alaska NCI team has employed and trained one self-advocate as a partner interviewer with lived experience to assist with the data collection.

**Key Activity: Conduct DD Alignment and Shared Vision Survey**

In collaboration with the Alaska University Center for Excellence in Developmental Disabilities, University of Alaska Anchorage Center for Human Development (Alaska UCEDD) and the DD Collaborative, the Alaska Living Well team developed a survey designed to measure the state's overall DD systems alignment to the shared vision. One version of the survey is specific to individuals with I/DD and uses plain language; the other version is specific to family members, providers, and other stakeholders with more detailed language. The second year of data collection is complete, with responses received from 100 family members, providers, and community members, and 32 responses received from self-advocates. The team analyzed the data and is tracking trends in responses across years.

**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 Alaska Living Well team during this evaluation period with the main goal of addressing this core component:

**Key Activity: Host Supported Decision-Making Agreement (SDMA) Symposium**

Supported decision-making is a way for individuals to make their own decisions with help from other people they trust; SDMAs document who will provide support and in what ways. The Alaska Living Well team hosted a three-day supported decision-making symposium via Zoom. The symposium included panels comprised of individuals with lived experiences using SDMAs, national experts discussing how to fund staff to develop and facilitate SDMAs, and professionals sharing how to use tools to promote choice in decision-making. Through their internal evaluation, the Alaska Living Well team found that the symposium was highly effective in increasing the participants’ knowledge of and comfort with SDMAs.

**Key Activity: Participate in Key Campaign 2021**

The Alaska Living Well team also partnered with Key Coalition of Alaska, a non-profit, statewide advocacy organization of people with disabilities and family members, to host the 2021 Key Campaign. Through the Key Campaign, 52 individuals, families, providers, and advocates
attended a self-advocacy training. The campaign included virtual legislative visits with Alaska’s representatives and senators over two weeks in February 2021 and culminated with a virtual unity luncheon with over 140 participants (including self-advocates, families, providers, and advocates) that focused on reemphasizing the DD shared vision.

**Key Activity: Update Environmental Modification (EMOD) Process**

Alaska’s EMOD program facilitates physical adaptations to an individual’s residence to promote greater independence or to meet accessibility needs. The Alaska Well Living Well team worked with their grant partner, Southeast Alaska Independent Living (SAIL), to update the EMOD process based on survey results of previous EMOD recipients and care coordinators. The EMOD process, which includes the application, review, approval, and modification steps, will also now include an assessment component. The assessment will help determine the specific environmental modification needed as well as what alternatives may exist. SAIL additionally continues to streamline processes for improving outreach, including developing a reference manual that outlines the application process and how individuals can sign up and receive payments.

**Additional Activities**

- **COVID-19 Resource Toolkit:** The Alaska Living Well team worked with their state Department of Health and Human Services to develop the COVID-19 Resource Toolkit: Information and Resources to Keep You Healthy, Safe, and Connected. This toolkit includes a number of resources for individuals with disabilities to stay connected, address social isolation, and learn about the COVID-19 vaccine.

- **I Have Rights Campaign:** The Alaska Living Well team launched the I Have Rights Campaign, and distributed the I Have Rights Guide, a resource detailing rights in access, choice, community, dignity and respect, privacy, safety, and work for Alaskans with disabilities.

- **Person-Centered Trainings:** The Alaska Living Well team worked with the Alaska UCEDD and the statewide DD service provider to develop person-centered trainings for the direct support professionals within the state. The trainings were co-led by self-advocates and were designed to be in alignment with the DD shared vision.
Georgia: Living Well Grantee Profile

Grantee Information

The University of Georgia Institute on Human Development and Disability (UGA IHDD) received the five-year Living Well grant in 2017.

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The UGA IHDD was established and has been a part of the University Centers for Excellence in Developmental Disabilities Education, Research and Service (UCEDD) network since 1969. The UGA IHDD works to create opportunities to improve the quality of life for people with disabilities and their families through education, research, and public service. Areas of focus include: assistive technology, employment, friendships and community membership, family support, human rights, and research and evaluation.

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.

The UGA IHDD provides a range of supports and services through various projects, including Living Well. Other projects include AgrAbility, which focuses on promoting independence for members of the agricultural community who have disabilities; Advancing Employment, which is dedicated to making Georgia a community for inclusive employment; Take a Look at Me™ and Welcome to My World™, which are interactive portfolios designed to engage individuals and/or family members as they identify strengths, interests, and preferences; and efforts to implement policy, including support of the HCBS Settings Rule.

Grantee Partnerships

The UGA IHDD partners with key stakeholders on their Living Well grant (collectively, the Georgia Living Well team) including, but not limited to, the Georgia Advocacy Organization, Georgia Council on Developmental Disabilities, Georgia Department of Behavioral Health and Developmental Disabilities, and Uniting For Change (a self-advocacy group that joined the advisory council after People First of GA disbanded in 2020).
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 the Georgia team’s external conditions for their Living Well model.

The COVID-19 pandemic caused the full or partial closure of the five provider partners in the Georgia Living Well grant between March and June 2020. Two of the provider partners also experienced a change in leadership, and all five providers experienced staffing shortages and significant turnover among direct support staff. As a result, providers could not implement all project activities or collect data as planned, and most in-person trainings were put on pause.

The state of Georgia is revising two of its Medicaid HCBS waivers for individuals with intellectual and developmental disabilities (I/DD). The proposed changes would cap certain services, and providers are concerned about the impact of such limits on their revenue. This is compounded by state budget constraints due to lost revenue during the COVID-19 pandemic.

<table>
<thead>
<tr>
<th>STATE CONTEXT IN GEORGIA</th>
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<tbody>
<tr>
<td>I/DD Services in Georgia</td>
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<tr>
<td>17,389 served by DD agency</td>
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<tr>
<td>0.1687% of state I/DD population</td>
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<tr>
<td>47.2% of LTSS that is HCBS</td>
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<tr>
<td>14.6% of I/DD spending used for family support and supported living</td>
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Direct Support Workforce

- $11.09 Hourly
- $19,100 Annualy
- 39.1% Turnover

Employment Status:
- Full Time: 6%
- Part Time (non-economic reasons): 18%
- Part Time (economic reasons): 76%

Associate’s Degree or Higher: 17%
Some College: 38%
High school graduate: 34%
Less than high school: 11%

Model and Objectives

The Georgia Living Well team is working to improve outcomes for individuals with I/DD receiving support by targeting interventions to the direct support workforce. In order to achieve this, the Georgia Living Well team partnered with five providers to implement training and monitoring using the College of Direct Support (CDS) and Therap platforms.
The Georgia Living Well team’s model objectives are to:

1. Increase staff knowledge and skill in supporting people with I/DD to be self-determined and included in the community through targeted training in Supporting Informed Decision-Making and Supporting Social Roles;

2. Create career paths through professional development for direct support staff to meet demand for services through the implementation of Direct Course’s CDS and engagement with the National Alliance for Direct Support Professionals;

3. Enhance monitoring using Therap’s electronic service tracking and reporting technologies including their Business Intelligence platform for data aggregation and trending; and,

4. Develop a replicable collaboration between HCBS stakeholders to enhance quality.

**Key Activities by Core Component**

**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 Georgia Living Well team during this evaluation period to address this core component:

**Key Activity: Collect and Analyze Data in Therap**

Therap is a secure, Health Insurance Portability and Accountability Act (HIPAA)-compliant, and comprehensive electronic monitoring system for HCBS providers. It allows for consistent and standardized documentation of incident reporting, medication management, goals, and outcomes. Each of the five provider organizations participating in Georgia’s Living Well grant use Therap to document individual outcomes, progress notes, and adverse incidents. Additionally, a portal was created to host resources for responding to COVID-19 and a means for tracking COVID-19 cases across the provider agencies. The Georgia Living Well team analyzes the data across all providers to identify trends and determine the impact of their interventions.

The Georgia Living Well team primarily uses two dashboards available in Therap for aggregating data. The Data Driven Outcomes dashboard allows for large-scale data aggregation and assessment of outcomes across two measurement types (Important To and Important For) and five domains: Safety, Health and Wellbeing, Social Connectedness and Relationships, Meaningful Activities, Person-Centered Planning, and Choice. The General Event Reporting dashboard, where incident reports and adverse incidents data are collected, allows for summary and longitudinal analyses of adverse incidents at all levels of organizations. The dashboard also has the capacity to input existing state level data to support comparative analyses. Providers enter day-to-day service data that are distributed to the internal quality assurance team. Raw data can be filtered and analyzed to look at incidents by program, the types of incidents occurring, and the number of incidents per individual. This information will help the Georgia Living Well team better understand how to allocate resources as well as identify which individuals in the system require special attention.
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 Georgia Living Well team during this evaluation period to address this core component:

**Key Activity: Use College of Direct Support (CDS) for Career Growth**

The CDS is an online training curriculum designed for the direct support workforce. The Georgia Living Well team is using CDS to develop sustainable career pathways and build capacity among direct support professionals (DSPs) and frontline supervisors. The Georgia Living Well team worked closely with five local provider agencies to develop three tracks in CDS for staff: new hire track, existing staff track, and the frontline supervisor track. To accompany these new tracks, the team created a new provider manual that cross-walked the Georgia Department of Behavioral Health and Developmental Disabilities (DBHDD) training requirements against the applicable CDS courses. In addition to the national CDS curriculum, providers can create and add their own training content. For example, the Georgia Living Well team developed a module on safety precautions during the COVID-19 pandemic, and provider partners developed content on person-centered planning, community inclusion, and crisis prevention.

**Key Activity: Conduct Annual DSP Staff Survey**

Each year, the Georgia Living Well team distributes a survey among the five provider partners that assesses the type and nature of services provided, participation in staff training, staff retention and turnover rates, and staff compensation, such as pay, bonuses, and incentives. Data are analyzed annually, and key trends are identified and shared with the provider agencies.

**Key Activity: Conduct Comparative Analysis**

The Georgia Living Well team uses data from their Annual DSP Staff Survey, Therap, and the CDS to conduct a comparative analysis. This analysis will allow the team to better understand the impact of the trainings and interventions on each individual DSP by comparing their CDS coursework and completed trainings against the number of incidents reported in Therap, their progress toward their goals, and their survey responses. These data will be used to illustrate if and how the Georgia Living Well model contributes to improving the quality of life for individuals with I/DD, inform and refine the Georgia Living Well team’s interventions, and will serve as the foundation for their community of practice.

**Additional Activities:**

- **Plan and Host COVID-19 Vaccination Event:** The Georgia Living Well team partnered with the Georgia Department of Public Health and Walgreens to host a one-day vaccine event for individuals with I/DD to receive the Johnson & Johnson single-dose vaccine. One provider partner hosted an additional vaccination event, and through these efforts, 250 individuals with I/DD, staff, and caregivers were able to receive the COVID-19 vaccine.
• **Implement Supporting Social Roles (SSR) Training**: The Georgia Living Well team updated and transitioned their SSR training to a virtual format. The SSR training focuses on what social roles are, how social roles can be supported by DSPs, and how social roles support community inclusion.

• **Implement Informed Decision-Making (IDM) Training**: The Georgia Living Well team updated and transitioned their IDM training to a virtual format. The purpose of these trainings is to increase staff knowledge and skills in supporting individuals with I/DD to be self-determined and included in the community. Through these trainings, staff of participating organizations learn how to support individuals with I/DD in achieving personal goals related to choice, independence, community integration, and productivity. At the end of each training, the team conducts an evaluation and then refines the training based on feedback. This process ensures that the training remains beneficial and relevant for the staff.
The University of Idaho Center on Disabilities and Human Development (CDHD) received the five-year Living Well grant in 2018.

The University of Idaho CDHD, a University Center for Excellence in Developmental Disabilities Education, Research, and Service, facilitates a variety of independent grant programs and provides training, services, technical assistance, research, and dissemination activities on a state and federal level to advance evidence based policy and practice for people with disabilities. The activities that CDHD participates in span five areas, including: interdisciplinary training and preparation of students, direct services and demonstration projects, community training and technical assistance, research, and dissemination of information and findings.

The University of Idaho CDHD’s includes projects such as Idaho Assistive Technology, a federally-funded program that aims to increase the availability of assistive technology devices and services for people with disabilities; IdahoSTARS, a statewide program designed to increase quality child care in inclusive settings through on-going training and technical assistance; the Idaho Training Clearinghouse, an initiative to compile all current special education-related trainings statewide to connect educators and parents with cross-agency training opportunities; Special Education Support and Technical Assistance Program funded through Idaho State Department of Education; and the federally funded Children and Youth with Deaf-Blindness Project—serving Idaho for almost 30 years. Other CDHD programs address the needs of people with autism spectrum disorder through clinical services, doctoral training, and an Act Early Idaho program, designed to provide awareness about Autism Spectrum Disorder-funded through the Centers for Disease Control and Prevention (CDC).

Grantee Partnerships

The CDHD partners with key stakeholders on their Living Well grant (collectively, the Idaho Living Well team) including, but not limited to, the Idaho Council on Developmental Disabilities, Disability Rights Idaho, and the Idaho Department of Health and Welfare.
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 the Idaho team’s external conditions for their Living Well model.

The physical distancing requirements put in place due to the COVID-19 pandemic required the Idaho Living Well team to shift to virtual delivery of their trainings and meetings. The pandemic also created new work and shifted priorities for project stakeholders. Further budget cuts to the Idaho Department of Health and Welfare’s services are expected to impact the Idaho Living Well team’s work in the future.
The K.W. vs. Armstrong lawsuit continues to be a factor that affects Idaho’s Living Well grant. The Idaho Living Well team remains in close contact with the state Medicaid agency and secured their ongoing commitment to Community Now! (CNOW!), regardless of the outcome of the lawsuit. The Idaho Living Well team must also be strategic about managing the agenda and priorities for CNOW!, which serves as the stakeholder body for both the Living Well grant and the K.W. lawsuit.

**Model and Objectives**

The CDHD’s Living Well grant objectives aligned with CNOW!’s recommendations, and the grant provided an opportunity to build on CNOW!’s momentum to advance the recommendations. The Idaho Living Well team, in partnership with CNOW! and other stakeholders, established a series of workgroups to implement key grant activities.

The Idaho Living Well project aims to build a self-advocate led monitoring system and build provider capacity through a training and incentive system that includes evidence based approaches to help individuals with I/DD advocate for their own lives. The Idaho Living Well team’s model objectives are to:

1. Develop a nationally relevant, replicable work plan via a continuous improvement process carried out through project workgroups and monitored by the project leadership team;

2. In partnership with people with disabilities, create a single, integrated, community-based reporting and monitoring system that reduces risk to people with disabilities who have experienced abuse, neglect and exploitation;

3. Develop a sustainable self-advocate train-the-trainer model to conduct statewide training on how and when to report abuse, neglect and exploitation, self-advocacy, individual rights, principles of person-centered thinking, self-determination, supported decision-making, post-secondary employment, education opportunities, and cultural competency;

4. Establish direct support professional qualifications, competencies, training requirements and propose a reimbursement model guided by evidence based practices and quality indicators identified by individuals with DD and family members. Deliver sustainable, accessible training for direct support staff taught by self advocates, family members and professionals guided by evidence based practices in person-centered thinking and planning, trauma informed care, supported decision-making, total and functional communication, and principles of positive behavioral intervention supports; and,

5. Develop a culturally and linguistically competent adult DD service system for the Latino community in Idaho.
Key Activities by Core Components

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

Key Activity: Analyze Abuse and Neglect Reporting System

As part of their broader Community NOW! efforts, the Idaho Living Well team formed the Quality Assurance Abuse and Neglect Reporting and Monitoring (QA) Workgroup with key stakeholders across the state. The goal of this workgroup is to protect individuals with disabilities from, and ultimately prevent, abuse, neglect, and exploitation by creating a self-advocate informed, integrated, community-based reporting and monitoring as a component of a larger quality assurance system.

To fully understand the abuse and neglect reporting system within Idaho, the QA workgroup mapped all relevant stakeholders and processes related to community monitoring within the state. The workgroup then analyzed the system for gaps and areas of overlap.

This year, the workgroup met with Idaho’s Region 2 Guardianship and Conservatorship Monitoring Coordinator to learn how the current guardianship system works as well as the process for reporting abuse, neglect, and exploitation. During this meeting, self-advocates and family members were given space to share their own personal stories of abuse and neglect and shared their experience navigating the current reporting system. From this meeting, the workgroup identified gaps in the system as well as areas in need of developing trainings for guardians and individuals under guardianship.

Key Activity: Conduct Studies on Abuse and Neglect

The Idaho Council on Developmental Disabilities, in conjunction with the QA workgroup, launched a three-part study with the Criminal Justice Department at Boise State University to better understand accountability structures to individuals with disabilities within the state agencies responsible for conducting the intake and investigation process. There is also emphasis in the studies to learn about outreach and accountability to unserved communities, specifically communities of color.

Each part of the study will focus on a specific group: individuals with developmental disabilities, individuals with physical disabilities, people who are Deaf, and older adults. Through these studies, the Idaho Living Well team intends to develop relevant trainings to address gaps in the system, provide evidence to advocate for legislative support, and use data to move toward a centralized reporting system.
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 Idaho Living Well team during this evaluation period to address this core component:

**Key Activity: Develop Recommendations to Retain a Quality Direct Support Workforce**

The Idaho Living Well team formed the bFair 2Direct Care Workgroup, which brings together service providers, direct support workers, self-advocates, parent advocates, and representatives from the Idaho Department of Health and Welfare to develop a series of recommendations to increase the retention, skills, and knowledge of the direct support workforce. Discussion topics include required training and competencies of direct support workers, code of ethics, wages and benefits, career pathways, and direct support worker evaluations.

The bFair 2Direct Care workgroup continues to refine recommendations for DSP trainings and incentive programs. The workgroup ensures that the recommendations align with evidence based practice and are designed to recruit and retain quality individuals into the DSP workforce. The workgroup also reviewed a training matrix that includes DSP training topics, associated competencies, level of training for each topic, and sources of existing training material that match specific competencies from specific vendors. The bFair 2Direct Care workgroup is in the process of recommending a training platform for DSP trainings and has worked with multiple vendors for platform demonstrations to ensure that the vendor meets all necessary training requirements.

**Key Activity: Promote Diversity, Inclusion, and Cultural Competency**

The Idaho Living Well team formed the Culturally Responsive Advisory Group (CRAG) with self-advocates and parents from the Latino community to represent the needs of the Latino I/DD community. Members of the CRAG continue to play an active role in shaping policy recommendations that are culturally and linguistically relevant to the Latino population. Additionally, the CRAG provided input on the proposed DSP competencies and shared how DSPs could become more culturally competent.

The Idaho Living Well team adapted the one-day cultural competency training by the National Center for Cultural Competence at Georgetown University into a five-part webinar series. The webinar series aims to create a greater understanding of cultural differences within the current service system. A total of 76 people attended one or more webinars, and post-event satisfaction rates for the participants ranged from 95% to 100%.

The Idaho Living Well team, in partnership with Support Development Associates, conducted two six-session trainings on Person Centered Thinking (PCT) with people with disabilities, family members, and service coordinators. The team currently has two bilingual trainers, fluent in both English and Spanish, and intends to recruit additional bilingual PCT trainers to provide trainings to the Latino I/DD community.
The Indiana Family and Social Services Administration (FSSA) Division of Disability and Rehabilitative Services (DDRS) received the five-year Living Well grant in 2018.

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The Indiana FSSA 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 FSSA, DDRS manages the delivery of services to children and adults with intellectual and developmental disabilities (I/DD).

Within DDRS, the Bureau of Quality Improvement Services (BQIS) 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, BQIS assists in the distribution of multiple resources, quality-related trainings, and technical assistance. Further, the Bureau of Developmental Disabilities Services (BDDS) provides services for individuals with I/DD that enable them to live as independently as possible in their communities. As part of these efforts, BDDS 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.

**Grantee Partnerships**

The DDRS partners with key stakeholders on their Living Well grant (collectively, the Indiana Living Well team) including, but not limited to, self-advocates, families, providers, the Indiana Institute on Disability and Community (IIDC), Indiana Universities University Center for Excellent on Developmental Disabilities (UCEDD), the National Association of State Directors of Developmental Disabilities Services (NASDDDS) Culture of Quality, Indiana Disability Rights (IDR), the Indiana Association of Rehabilitative Facilities (INARF), The Arc of Indiana, Liberty Healthcare Corporation of Indiana (Liberty), and Charting the LifeCourse (CtLC) Nexus Chapter through the University of Missouri Kansas City (UMKC).
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 the Indiana team’s external conditions for their Living Well model.

A comprehensive systems change effort is ongoing in Indiana; it includes the redesign of HCBS waivers administered by BDDS, as well as ongoing participation in the Supporting Families and Cultural Competency communities of practice. As a whole, the Indiana Living Well team is working to integrate their Living Well grant activities into these broader systems change efforts.
Indiana DDRS is the only state agency among the eight Living Well grantees. As a state agency, building trust among stakeholders can be difficult. The team is working to build a grassroots movement, though this can be difficult when stakeholders also look to the state for direction. The Indiana team must also manage 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 and access to data that can inform decision-making.

**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 intellectual and developmental disabilities (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.

**Key Activities by Core Components**

*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 Systems and Strategies**

State systems of community monitoring and reporting are siloed. The Indiana Living Well team is addressing this challenge by determining which data are being collected and exploring potential data collection systems. The Indiana Living Well team added questions to the National Core Indicators (NCI) survey, a voluntary effort by state DD systems to measure performance, that reflect the goals of the Living Well project. The team will begin piloting a rubric to evaluate the quality of Person Centered Individualized Service Plans (PCISPs). Through these data collection points, the Indiana Living Well team will triangulate the data to identify consumers, understand consumer perspectives, and demonstrate how individual goals align with the PCISPs.

**Key Activity: Quality Indicators and Surveys**

Recognizing the need to gather data on Indiana’s current culture around waiver supports and service delivery, the Indiana Living Well team conducted a series of key informant interviews and extensively reviewed literature and state policy. The team developed and administered a survey to case managers, providers, and DSPs with the intention of identifying quality indicators to inform a shift in culture and performance for DDRS and develop innovative strategies to support systems change. The survey, developed in partnership with Indiana University, gathers data on expectations that individuals receiving supports and their families, providers, and other key stakeholders have for the state, as well as their perceived priorities of the state. The team successfully established baseline data from this survey and additional qualitative data collected through a series of meetings with key stakeholders.

The team employs the Plan-Do-Study-Act approach as another quality indicator through their partnership with NASDDDS Culture of Quality. The Culture of Quality work will lead to a better understanding of the model for improvement for both state employees and key stakeholders. The intention is that the Culture of Quality will spread and tools like Plan-Do-Study-Act will bring improvements to current and future processes.

**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 has a subsect of members that form the Partners in Transformation (PIT) workgroup. The PIT workgroup completed the CtLC Ambassador series to build knowledge of CtLC principles and a shared understanding of the goals and vision for the state. To inform a collective impact approach to align state initiatives with broader systems change efforts, the Indiana Living Well team additionally engaged key stakeholders in the state with partners in NASDDDS Culture of Quality and the CtLC Nexus through UMKC. The strong collaboration between the PIT workgroup, the CtLC Nexus, and the Culture of Quality provides the
Indiana Living Well team various perspectives and a collective impact approach to align initiatives within the state, allowing the team to utilize resources and partnerships efficiently to work toward grant goals and objectives.

**Key Activity: Conduct Trainings and Events**

The Indiana Living Well team along with PIT workgroup members administered the CtLC Leadership Ambassador series six times. The CtLC Ambassador series provides an overview of foundational principles of the CtLC framework and associated tools; the series can be adapted for specific audiences. Two sessions targeted each of the following audiences: providers and case managers, self-advocates and supporters, and family leaders.

- The series for providers and case managers aimed to provide professional development for case managers, providers, and support coordinators and aid in understanding and utilizing the CtLC framework.

- The series for self-advocates and supporters aimed to support self-advocates to understand and utilize the CtLC framework in their own lives and is structured so that self-advocates can choose one of their own supporters to assist them in completing the series.

- The series for family leaders aimed to support family members of individuals with I/DD to understand and grow their advocacy and family leadership skills, as well as connect with and build family peer networks within the CtLC framework.

In addition to these series, BDDS and BQIS have also been developing and implementing trainings on risk assessments for providers to ensure that they have a full and complete understanding of risk assessments and how they are utilized. Indiana has also partnered with Liberty on trainings and technical assistance for providers, individuals, and their families that are intentionally focused on person-centeredness and advocacy.
Missouri: Living Well Grantee Profile

Grantee Information

The University of Missouri, Kansas City Institute for Human Development (UMKC-IHD) received the five-year Living Well grant in 2018.


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.
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.

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 the Missouri team’s external conditions for their Living Well model.

The Missouri Living Well team 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 for the state. As a result, there is a longstanding partnership and consistent communication 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. 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 intellectual and developmental disabilities (I/DD) throughout the state. The Missouri Living Well team, in collaboration with the Division’s leadership team, is assessing what role the Living Well grant may play in the roll out and scaling of 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.
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. To 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.
Key Activities by Core Components

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: Build Virtual Data Dashboard
The Missouri Living Well team partnered with the Human Services Research Institute to build a data dashboard to improve the accessibility and usefulness of the data collected within the state. 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 (a structured introduction to CtLC principles and tools) 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 Bureau data. The dashboard will provide background information and case studies before displaying the actual data to provide context for users. The team is collecting feedback on the dashboard and identifying additional data sources, such as critical incident data from the state.

Additional crosswalks of community monitoring and needs assessment tools using the Charting the LifeCourse Life domains were also completed and have provided insight on relevant indicators to be included in the data dashboard as it is being developed.

Key Activity: Utilize Therap
The Missouri Living Well team is planning to begin using the Therap platform for a pilot project. The team is selecting providers that currently use Therap to go through a CtLC Ambassador series as they work to identify and map person-centered outcomes and provider quality measures through Therap's Data Driven Outcomes dashboard. The team is hoping to use this pilot to develop person-centered outcome provider quality measures.

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 Charting the LifeCourse for Systems Transformation Pilot

To guide their efforts to creating a replicable model, the Missouri Living Well team utilizes the Charting the LifeCourse framework, a system comprised of various quality improvement models, methodologies, and best practices in the field to establish a modality for driving systems change to improve quality of life for individuals with I/DD and their communities.

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.

Through this Ambassador series, county collaborative teams developed and are now implementing 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 systems transformation as part of the new Ambassador series. The toolkit is based on the CtLC framework and includes several brainstorming and strategic planning resources. As the first pilot cohort wrapped up the series, the team evaluated the toolkit and processes to identify areas for improvement.

The Missouri Living Well project team supported county sites in piloting the Charting the LifeCourse Supported Decision-Making in Healthcare workshop series virtually in March 2021. This series is a side-by-side training model on the topic of supported decision-making as it relates to healthcare and having effective medical appointments.

Key Activity: Launch Innovation Collaboratives

The Missouri Living Well team, in partnership with Missouri Association of Rehabilitation Facilities (MARF) and the Missouri Association of County Developmental Disabilities Services (MACDDS), the respective provider and support coordination entities in Missouri, and Charting the LifeCourse Nexus, launched the Innovation Collaboratives. This collection of collaborative workgroups will result in replicable, scalable models of policies, practices, and procedures that implement and integrate the Charting the LifeCourse framework.

Key Activity: Implement and Assess StationMD

The Missouri Living Well team assisted their state with a rapid implementation of StationMD during the COVID-19 pandemic. StationMD is telemedicine platform for individuals with I/DD aimed at reducing emergency department visits. Now, the Missouri Living Well team is conducting a return on investment (ROI) evaluation to determine the effectiveness of the platform in the state and whether the state should continue to make the platform available.
New Hampshire: Grantee Profile

Grantee Information

The University of New Hampshire Institute on Disability (UNH IOD) received the five-year Living Well grant in 2017.

|--------|-------------|-------------|-------------|-------------|-------------|

The UNH IOD was established in 1987 and is the state’s University Center for Excellence in Developmental Disabilities Education, Research, and Service. The UNH IOD builds local, state, and national capacity to serve the needs of people with disabilities and their families through research, academic, service, and dissemination initiatives. These initiatives focus on various areas, including assistive technology, community living and employment, inclusive early care and education, and health and genetics.

New Hampshire’s IOD is involved in related projects that address disability topics across the lifespan. These include the New Hampshire Disability and Public Health Project, which aims to improve the health and quality of life of people with disabilities in the state; and Disability Statistics and Demographics Rehabilitation Research and Training Center, a center that works to alleviate gaps between producers and end users of disability statistics in order to support better data collection, more effective programs, and better lives for people with disabilities.

Grantee Partnerships

The UNH IOD partners with key stakeholders on their Living Well grant (collectively, the New Hampshire Living Well team) including, but not limited to, the Council on Developmental Disabilities, the New Hampshire Department of Health and Human Services Bureau of Developmental Services, Community Support Network, Inc., ABLE New Hampshire, People First of New Hampshire, and the Disability Rights Center of New Hampshire.
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 the New Hampshire team’s external conditions for their Living Well model.

While the COVID-19 pandemic created challenges, particularly around in-person training, the New Hampshire Living Well team quickly adapted to continue working toward their goals. For instance, training on the direct support workforce for seniors at local technical high schools relationships with stakeholders as a key contextual factor contributing to their success. The UNH IOD partners with the New Hampshire Department of Health and Human Services Bureau of Developmental Services on numerous projects, which fosters trust and insight into shared goals between the two organizations. Additionally, the New Hampshire Living Well team cites stability in their stakeholders over the course of the grant as a facilitator of their success.

<table>
<thead>
<tr>
<th>STATE CONTEXT IN NEW HAMPSHIRE</th>
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<tbody>
<tr>
<td>Health and Safety</td>
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<tr>
<td>I/DD Services in New Hampshire</td>
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<tr>
<td>5,235 served by DD agency</td>
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<tr>
<td>0.3922% of state I/DD population</td>
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<tr>
<td>47.7% of LTSS that is HCBS</td>
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<tr>
<td>3.7% of I/DD spending used for family support and supported living</td>
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<tr>
<td>105 on waiting list</td>
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<tr>
<td>$174.14 State HCBS expenditure</td>
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<tr>
<td>N/A reported poor health</td>
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<td>N/A reported feeling unsafe</td>
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Direct Support Workforce

<table>
<thead>
<tr>
<th>Employment Status</th>
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<tr>
<td>Full Time</td>
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<td>Part Time (non-economic reasons)</td>
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<tr>
<td>Part Time (economic reasons)</td>
<td>36%</td>
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<tr>
<td>Less than high school</td>
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</tbody>
</table>

Model and Objectives

The New Hampshire Developmental Services Quality Council provides leadership for the consistent review and improvement of the quality of services for individuals with intellectual and developmental disabilities (I/DD) within the system. The Quality Council acts as an advisory group to the New Hampshire Living Well project, titled the New Hampshire Quality Framework.
The objectives of the New Hampshire Quality Framework are as follows:

1. Self-advocates, family members, developmental disability (DD) network members, and other stakeholders will actively engage in the full implementation of the project;

2. The New Hampshire Quality Framework will demonstrate a comprehensive system to improve services for individuals living in the community;

3. Direct support professionals (DSPs) and other HCBS providers will demonstrate improved competencies to improve access to and quality of HCBS services to individuals in the community;

4. The community monitoring system in New Hampshire will demonstrate an increase in tools, training and other strategies to address all types of abuse, neglect, and exploitation;

5. DSPs and other HCBS providers will demonstrate increased understanding and follow through on health issues and the supports needed;

6. The project evaluation process will measure and report on activity progress, barriers, and areas of improvement; and,

7. The New Hampshire Quality Framework will demonstrate a sustainability plan that reflects organizational, financial, and community sustainability.

The New Hampshire Living Well team is supporting the way that providers across the state collect and analyze data. The team strategically leverages their strong, long-lasting partnerships across the state to implement evidence-based practices to improve the health and safety of individuals with disabilities. The New Hampshire Living Well team encourages collaboration within the state, and their involvement of other partners in the development of trainings and key activities have resulted in vetted and effective resources.

**Key Activities by Core Components**

**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 New Hampshire Living Well team during this evaluation period with the main goal of addressing this core component:

**Key Activity: Expand and Refine Data Collection Using the Health Risk Screening (HRS) Platform**

The New Hampshire Living Well team partnered with IntelectAbility Inc., formerly Health Risk Screening, Inc., to use the HRS Platform to improve the community monitoring system in New Hampshire and move from paper-based to electronic data collection and documentation methods. The HRS Platform is used statewide to integrate person-centered planning documentation and to host the Health Risk Screening Tool (HRST), New Hampshire Service
Agreement, Supports Intensity Scale, Planning Process Acknowledgement Form, Service Agreement Amendment Form, and the Quarterly Satisfaction Surveys.

The New Hampshire Living Well team is working closely with the New Hampshire Bureau of Developmental Services and the Bureau of Quality to use the HRS platform for the state’s Sentinel Event Reporting, a tool that electronically tracks sentinel events and mortality reporting. The tool will be able to track, trend, and analyze data in real-time, and will be used to provide information for Centers for Medicare & Medicaid Services (CMS) to produce performance measures. The New Hampshire Living Well team is now working with stakeholders to enhance the quality of data being collected.

**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 New Hampshire Living Well team during this evaluation period with the main goal of addressing this core component:

**Key Activity: Update and Deliver Medication Administration Training**

New Hampshire’s Bureau of Developmental Services requires all DSPs and home providers to participate in a medication administration training. The eight-hour, in-person training was only provided in English and had not been updated in twelve years. The New Hampshire Living Well team determined that the outdated information and inconsistency in presentation impacted DSP success and resulted in DSP attrition. Additionally, many staff administering medication do not speak English as their first language. The New Hampshire Living Well team updated and translated the training to the top languages spoken by staff, Spanish and Nepalese.

At the onset of the COVID-19 pandemic, the Bureau of Developmental Services requested help from the New Hampshire Living Well team to offer this training virtually. The New Hampshire Living Well team was able to give the updated training to the state so that there would be virtual access. Once it was safe to do so, demonstration videos were developed using self-advocates, a nurse, and a home provider. The training also includes four tests to assess competency.

**Key Activity: Launch Care and Support DSP Pilot with Technical High School**

The New Hampshire Living Well team partnered with Gateways Community Services, the PLUS Company, Community Support Network Inc, New Hampshire service providers, and Alvirne High School to launch the Care and Support pilot program. The Care and Support program provided 11 high school students an introduction into the role of a DSP. Through this 18-week multi-modal program, students completed coursework and experiential trainings that mirrors mandatory training for new DSPs.

The curriculum is comprised of a mix of courses available in the online platform RELIAS, the training series created by Dr. Teresa Bolick, for Gateways Community Services including direct interaction with direct support professionals and individuals served, role play, and hands-on
experiential learning. Through the completion of the curriculum, students become qualified to apply for and become a DSP upon their high school graduation having already completed the initial training required.

The pilot program was deemed a success, with students expressing high satisfaction with their overall experience. Of the 11 students that completed the program, two students have already begun working with families to provide respite care, one student is seeking volunteer opportunities with Gateways, and one student is seeking employment as a direct support professional.

Due to the success of the pilot, Gateways Community Services plans to share the DSP training model and curriculum with additional career and technical schools to continue to implement the program with the intention of building capacity of the DSP workforce.

**Key Activity: Implement Dream Big: Tools for Supporting Individual Choice and Robust Community-Based Life for DSPs**

The New Hampshire Living Well team supported the New Hampshire Council on Developmental Disabilities, ABLE NH, and People First of New Hampshire to provide the Dream Big DSP training, which focuses on supporting individual choice and robust community-based life. Seven three-hour virtual trainings have been administered to 117 individuals, with high satisfaction expressed through post-event surveys. The participants shared that this training helped raise their awareness around ableism and how to properly support individuals with disabilities in their personal choice in achieving their dreams.

**Additional Activities**

- **Support Performance Measures for HCBS Waivers:** The New Hampshire Living Well team is working closely with the Bureau of Developmental Services to renew the CMS In-Home Supports for Adults with Developmental Disabilities, Developmental Disabilities, and Acquired Brain Disorders waivers. The team supported BDS by developing informative presentations, conducting listening sessions for stakeholder feedback prior to the revision of the waiver, coordinating public comment sessions, and capturing performance measures and quality monitoring.

- **Sponsor Supported Decision-Making Training with Disability Rights Center:** The New Hampshire Living Well team partnered with Disability Rights Center New Hampshire to sponsor a supported decision-making training that included a panel of individuals with disabilities and their family members with lived experience. Additionally, the New Hampshire Living Well team advocated for supported decision-making legislation, which was recently passed in the state.
Grantee Information

The Virginia Commonwealth University (VCU) Partnership for People with Disabilities (the Partnership) received the five-year Living Well grant in 2017.

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The Partnership, Virginia’s University Center for Excellence in Developmental Disabilities, works to promote inclusion of people with intellectual and developmental disabilities (I/DD) within their communities. The Partnership was founded in 1985 and has four main content areas that encompass the work they do: community supports/living, early intervention and early childhood, education, and health.

The Partnership’s community supports/living projects that intersect with Project Living Well (PLW) include the Family to Family Network of Virginia, which provides support to diverse families across Virginia to navigate services and systems and helps to coordinate the state developmental disability (DD) agency’s Individual & Family Support Program regional council; Leadership for Empowerment and Abuse Prevention project, which provides training by and for people with I/DD about prevention of abuse by establishing healthy relationships; Cost and Outcomes for People with I/DD Who Use Services in Virginia, a project that involves research on the relationship between cost and outcomes for people with I/DD who use home and community-based services (HCBS) in Virginia; Positive Behavior Support (PBS) Facilitation, which prepares practitioners to become endorsed PBS facilitators; and Person Centered Practices, which promotes effective practices in person centeredness through training and activities.

Grantee Partnerships

The Partnership collaborates with key stakeholders on their Living Well grant, collectively, the Virginia PLW leadership team, including, but not limited to the Virginia Departments of Medical Assistance Services (DMAS) and Behavioral Health & Developmental Services (DBHDS), the Virginia Board for People with Disabilities, disAbility Law Center of Virginia, Arc of Virginia, Richmond Resources for Independent Living, the VCU Center on Transition Innovations, and community-based provider organizations across Virginia.
State Context

Variations in access to quality 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 the Virginia team’s external conditions for their Living Well model.

Leadership changes at the state and regional level and shifting priorities continue to be key contextual factors for the Virginia PLW leadership team. Bringing the United States Department of Justice (DOJ) settlement agreement to a close is a focus in Virginia, as well as community-based provider compliance with the Centers for Medicare & Medicaid Services (CMS) Final Settings Rule. The COVID-19 pandemic put further stress on a challenged system. While the Virginia DBHDS remains engaged with the Virginia PLW leadership team, exiting the settlement agreement continues to be a primary focus of the agency.
Model and Objectives

The Virginia Living Well team’s model objectives are:

1. A replicable and sustainable model process for system change implementation is in place for collaboration among diverse stakeholders, to manage systems capacity building, and to monitor individual, regional, and systems’ outcomes and impact;

2. A coordinated model of evidence based and informed interventions managed through the Regional Leadership Team comprised of diverse stakeholders will a) expand knowledge and skills of people with I/DD and those who support them; b) generate innovative and responsive policy that encourages independence and full engagement in community life; and, c) produce process data and outcomes that will serve as a national model for integrated, effective I/DD supports and services; and,

3. A multiagency, multi-tiered system of HCBS and community monitoring managed through a diverse leadership team will coordinate and augment disparate monitoring and quality initiatives in Virginia to serve as a national model for a) improving and increasing identification of health and safety risks for people with I/DD who use, and those waiting for, HCBS services; b) using varied data points gathered from multiple organizational and agency partners to develop high quality data rich analysis and reporting; and, c) documenting process and outcome data that facilitate continuous quality improvement in community programs.

Key Activities by Core Components

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 Virginia Living Well team during this evaluation period with the main goal of addressing this core component:

Key Activity: Analysis of Medicaid Claims, Supports Intensity Scale (SIS), and National Core Indicators (NCI)

As part of their mission to use data to drive decision-making, the Virginia Living Well team is analyzing data from Medicaid claims, SIS, and NCI. This data provides insight into service utilization, support needs, and outcomes. The analysis will enhance the team’s understanding of community participation and wellness outcomes in Virginia. Statistical models have shown that greater support needs are predictive of less community participation and choice. Questions have been added to Virginia’s NCI to more effectively monitor unplanned hospitalizations and conditions associated with preventable injury and death, such as falls, seizures, and constipation. Annually, the Virginia Living Well team shares findings from the analysis with the Quality Improvement Council, comprised of stakeholders within the disability community, and discuss how the data can help them address needs and disparities in Virginia.
Key Activity: Produce Trend Reports

The Virginia Board for People with Disabilities (VBPD) has continued to create trend reports on key issues such as employment, early intervention, education, health, and housing. These reports are intended to be a quick reference for self-advocates, legislators, and others to influence policy change based on trend results that outline how topical service systems are doing. In addition to the detailed trend publications, the VBPD is developing plain language reports.

Key Activity: Support Coalition for Community Safety

As part of PLW, the disAbility Law Center of Virginia (dLCV) routinely reviews critical incident reporting in Virginia to identify trends and convenes the Coalition for Community Safety to develop system solutions to mitigate risk.

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 Virginia Living Well team during this evaluation period with the main goal of addressing this core component:

Key Activity: Develop and Implement Regional Quality Council (RQC) Training Modules

As part of their settlement agreement, the U.S. DOJ requires Regional Quality Councils (RQCs) in Virginia to receive formal quality improvement and assurance training. To meet the DOJ training requirements, the Virginia Living Well team worked with the technical assistance provider for the Living Well grant, Mission Analytics, and their subcontractor, Human Services Research Institute (HSRI), to develop a webinar series for the RQCs around quality improvement. Through this collaboration, the Virginia Living Well team identified presenters and developed content material for three webinar training sessions: (1) Introduction to Quality Improvement, (2) Quality Improvement Tools and Facilitation, and (3) Making the Most of Quality Improvement Data. In addition to the three live webinars, the team developed a series of modules to address topics such as the history and purpose of Regional Quality Councils, supporting people with disabilities and their families as partners in quality improvement, understanding data, and quality improvement planning and tools. The Virginia Living Well team continues to support the RQCs to make decisions based on data, identify trends, and address barriers through technical assistance with RQC leads and annual RQC Summits.

Key Activity: Conduct Leadership for Empowerment and Abuse Prevention (LEAP) Trainings

The Virginia Living Well team, in partnership with the LEAP Project, provides trainings to adults with I/DD on healthy relationships and preventing abuse. Adults with I/DD who participated in LEAP training completed pre- and post-test measures. Participants watched and responded to video vignettes before and after the training intervention to identify the difference between healthy and unhealthy relationships. The LEAP curriculum is now adapted to a single 90-minute virtual training session. The Virginia Living Well team also collaborated with four young adults.
from Florida to pilot a LEAP curriculum tailored to adolescents. The adolescent-specific LEAP curriculum will be piloted in the Fall of 2021.

**Key Activity: Expand and Administer Person Centered Thinking © (PCT) Trainings**

As part of their efforts to build a quality, person-focused system within the state, the Virginia Living Well team continued to administer the PCT curriculum. PCT is a national, train-the-trainer model for offering training in person-centered thinking and practices. Originally instructed in person, the trainings were adapted to virtual instruction during the COVID-19 pandemic. The team offered 22 virtual trainings to over 350 individuals. Through their internal evaluation, the team found a statistically significant increase in knowledge of person-centered skill sets for participants that completed the training. Skills and strategies included in the evaluation include, but are not limited to, role-specific responsibilities, matching people with supports, communication style, analyzing issues using multiple perspectives, and steps for informing action. The Virginia Living Well team and the Department for Aging and Rehabilitative Services are collaborating to certify four PCT trainers.

**Additional Activities**

- **Administer Discovering ME!:** Discovering ME! is a program that promotes career discovery for students with complex disabilities beginning in middle school and continuing through high school, providing employment training in the home, school, and community to improve the likelihood of employment upon graduation.

- **Transition PBS Trainings to Virtual Format:** The PBS Trainings, aimed at increasing a person’s competence in community-based settings through the application of behavioral techniques, were intended to be held in-person but have been transformed to a virtual format.

- **Conduct Communication and Health Advocacy Trainings (CHAT):** VCU provides health literacy trainings to adults with disabilities and the individuals who support them. A prototype is currently being developed to transform the training into an educational board game.

- **Provide Support to Families:** The Family to Family Network of Virginia provides one-to-one emotional, informational, and systems navigational support to families of children and adults with I/DD as they navigate life with a disability and the services and systems that support them.
Wisconsin: Living Well Grantee Profile

Grantee Information

The Wisconsin Board for People with Developmental Disabilities (BPDD) received the five-year Living Well grant in 2018.

The Wisconsin BPDD was established in 1970 through the national Developmental Disabilities Act of the same year and serves as the state’s developmental disabilities (DD) council. The Governor appoints BPDD’s board members, 60 percent of whom are people with intellectual and developmental disabilities (I/DD) and family members. The organization conducts outreach, funds local initiatives, and provides information and training to educate citizens about issues affecting people with disabilities. More than 70 percent of BPDD’s funds go to local projects and to advocate for better programs. At large, BPDD focuses on advocacy, capacity building, and systems change to improve self-determination, independence, productivity, and integration and inclusion for people with disabilities. The Wisconsin BPDD supports initiatives related to the well-being of people with disabilities. These include administration of grants, including Employment First Partner and SPARKS grants; trainings on various topics, such as how to advocate for policies; self-advocate spotlights and leadership forums; conferences, including the Self-Determination Conference; and distribution of family navigators to provide intensive case management for tribal and Latinx families.

Grantee Partnerships

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

The Wisconsin Living Well team provided recommendations for the Governor’s budget for 2021-2023, including on the American Recovery Act and the Federal Medical Assistance Percentages. The recommendations emphasized strengthening community monitoring and reporting, including investing in a statewide reporting system. The Wisconsin state biennial budget passed with no additional funding to strengthen these systems. The Wisconsin Living Well team's recommendations focused on:

- Strengthening community monitoring and reporting
- Investing in a statewide reporting system

**State Context in Wisconsin**

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<thead>
<tr>
<th>I/DD Services in Wisconsin</th>
<th>Health and Safety</th>
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<tbody>
<tr>
<td>41,007 served by DD agency</td>
<td>6% reported poor health</td>
</tr>
<tr>
<td>0.7096% of state I/DD population</td>
<td>19% reported feeling unsafe</td>
</tr>
<tr>
<td>66.3% of LTSS that is HCBS</td>
<td></td>
</tr>
<tr>
<td>31.3% of I/DD spending used for family support and supported living</td>
<td></td>
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</tbody>
</table>

**Direct Support Workforce**

- **Hourly Pay:** $12.28
- **Annual Pay:** $18,600
- **Turnover:** N/A

**Employment Status**

- 62% Full Time
- 34% Part Time
- 4% Part Time (non-economic reasons)

**Associate’s Degree or Higher**

- 18%

**Some College**

- 40%

**High school Graduate**

- 34%

**Less than high school**

- 7%
Well team continues to look for opportunities for change, with and without fiscal implications. The I/DD abuse and neglect reporting service system in Wisconsin is county-based, which makes coordination, reporting, and incentivizing outcomes improvement difficult. In addition, Wisconsin long-term care managed care organizations have responsibility for oversight, training and accountability for safety and monitoring for a substantial number of people in the state. These considerations, combined with the fiscally conservative budget, are important contextual factors in understanding the Wisconsin Living Well team’s grant activities.

Model and Objectives

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

A group of pilot sites are equipping individuals with I/DD, families, and direct support professionals (DSPs) with skills and trainings to address health and safety needs identified through self-assessments conducted in partnership with Wisconsin Living Well team coaching staff. Each site is working with up to 20 individuals on this project. During this grant year, the mentor sites have come on board as full participants in the grant.

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

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

Key Activities by Core Components

**Community Monitoring**

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

**Key Activity: Advocacy and Policy Recommendations for Expanded Reporting**

The Wisconsin Living Well team formed a policy team that includes the Living Well project manager, coordinator, principal investigator, evaluator, lead coach, and representatives from the UCEDD, Disability Rights Wisconsin, and the Arc of Wisconsin. This Living Well Policy team advocates for policies to create systemic change in the Wisconsin abuse and neglect reporting system, expand state budget, and address COVID-19-related issues within the I/DD community.

The policy team’s COVID-19-related policy priorities are protecting rights for people with disabilities during the COVID-19 pandemic, combating increased social isolation, and increasing COVID-19 vaccine eligibility and access to vaccinations. The team advocated for both teens and adults using Medicaid HCBS waivers to be eligible to receive the COVID-19 vaccine in group 1b (as designated by the state’s vaccine plan), for COVID-19 infection, hospitalization, and mortality rates data to be publicly shared, and for the collection of vaccination rates within long-term services and supports.

The Wisconsin Living Well policy team is working with legislators on statutory language changes that would require Adult Protective Services (APS) to investigate all reports of abuse and neglect cases of adults with disabilities. Investigation of all abuse and neglect cases is only required by law for cases involving seniors in Wisconsin. Reports of abuse and neglect involving adults with I/DD are not currently required by law to be investigated. Currently, the standalone bill is working its way through the legislative process as the budget motion was not adopted.

**Key Activity: Reporting Systems Review and Recommendations**

The Wisconsin Living Well team continued their ongoing research of the state’s reporting system, which led them to the 2019 Centers for Medicare & Medicaid Services (CMS) presentation on Incident Management 101. The presentation was based on findings from a review of state systems by the Office of Inspector General (OIG), Government Accountability Office (GOA), and CMS. The presentation described key elements of a comprehensive incident management system. The Wisconsin Living Well team adapted this into a framework that was used to review managed care organizations, self-directed agencies, and Wisconsin DHS on whether these practices and policies in place in Wisconsin.

The Wisconsin Living Well team reviewed the Wisconsin Incident Management System with their stakeholders and developed a cross-department recommendation report that has been shared with multiple divisions at the Department of Health Services including the Division of Long-Term Care, State Adult Protective Services, Division of Quality Assurance, and Department of Justice. The recommendations include:

- Invest in technology and infrastructure for a statewide Incident Management System to better facilitate communication between all abuse and neglect reporting systems in
Wisconsin to allow state agencies, managed care organizations, independent consultant agencies, and services providers greater access to information;

- Expand the requirements of the Memorandum of Understanding required between County adult protective services and our long-term care agencies to allow for more detailed information sharing to these agencies;

- Review each Managed Care Organization’s Incident Management Systems for uniformity. After review, revise the requirements to include the best practices determined from each system;

- The long-term care agencies should develop a service provider/member portal for reporting abuse and neglect as an additional tool for reporting; and,

- Invest recovery funds to expand the state DOJ Elder Abuse Hotline to include adults at risk.

As part of their strategy for these policy changes in the state’s community monitoring system, the Wisconsin Living Well team is advocating with the Governor’s office and the Department of Health Services to use a portion of their American Rescue Plan Act funds and Federal Medicaid Assistance Percentage increase to implement the recommendations in the cross-department report.

**Community Capacity Building**

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

**Key Activity: Safe and Free Curriculum**

The Wisconsin Living Well team developed the Safe and Free Curriculum, in partnership with Wisconsin People First, to be implemented at the Living Well pilot sites. The curriculum covers topics important for self-advocates to learn about their rights, how to avoid abuse, and how to have healthy relationships. The leadership team helped pilot sites connect with or recruit self-advocate leaders to deliver the Safe and Free Curriculum trainings.

The Wisconsin Living Well team partnered with self-advocate leaders to co-facilitate the Safe and Free curriculum and develop greater roles as self-advocate leaders. The self-advocate leaders provided feedback on the modules of the curriculum and created new materials to make it more accessible to all people. The self-advocates also provided input to the Wisconsin Living Well team on how to best communicate changes and what new materials should be added to the training. The team created and distributed an updated virtual curriculum guide for self-advocate leaders. The Wisconsin Living Well team and self-advocates worked together to modify the Safe and Free curriculum to a virtual format when the COVID-19 pandemic caused the temporary closure of in-person services.
The Wisconsin Living Well team created accessible evaluation tools based on what stakeholders want to learn from the pilot testing of the curriculum. Some of the tools were created for participant completion after the training. Other tools include a protocol to debrief the self-advocate trainers after each class. The Wisconsin Living Well evaluation team adapted the tools to fit the new virtual format of the curriculum. The debrief forms help inform changes to the curriculum content and the delivery of the curriculum. Throughout the COVID-19 pandemic, the Safe and Free Curriculum was administered to over 87 people through their six pilot sites. Feedback from self-advocates indicated that their confidence, knowledge, and skills have increased since completing the curriculum. Two self-advocates are now working with People First Wisconsin to organize an entirely peer-to-peer version of the curriculum.

**Key Activity: COVID-19 Toolkit and Living Well Wednesdays**

The Wisconsin Living Well team was in the process of creating an abuse and neglect reporting toolkit before the COVID-19 pandemic. The team took this initial document and developed a full toolkit to meet the needs of people with disabilities during the pandemic. The Healthy, Safe, and Connected toolkit was an identified long-term goal of the grant. The Wisconsin Living Well team worked with self-advocates and other stakeholders to put together a plain language toolkit for use during the pandemic. The toolkit also led to the creation of several rights documents including rights during the pandemic, employment rights, and re-opening rights.

The [COVID-19 toolkit](#) is a pre-cursor to the eventual grant final deliverable of an overall toolkit focused on improving the health, safety, and connectedness of people with I/DD using long-term services and supports. The initial distribution of the COVID-19 toolkit included social media postings, virtual trainings via Zoom and Facebook Live, and power mail through the Board for People with Developmental Disabilities (BPDD) databank to more than 8000 individuals and organizations. The toolkit was piloted by 150 individuals across seven pilot sites, People First Wisconsin, managed care organizations, and one self-direction agency. The pilot included an evaluation component, which was used to compile detailed recommendations to improve the toolkit before a general version is developed.

The Wisconsin Living Well team companioned the toolkit with live presentations, called Living Well Wednesdays, via Zoom and Facebook Live to provide information to a larger audience on ways to stay healthy, safe, and connected. The team began broadcasting in early April 2020 every Wednesday on COVID-19 related topics and other topics of interest including employment, voting, and racial equity with an overall focus on rights. These presentations were also uploaded to the BPDD YouTube Channel for additional viewing. The self-advocate leaders created plain language videos for the BPDD Self-Determination YouTube Channel to inform people with I/DD about the toolkit in a more accessible format and have presented alongside professionals and the Wisconsin Living Well team during Living Well Wednesdays.

**Key Activity: Pilot Sites and Intervention Plans**

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

This year, the three sites that were recruited as mentor sites were invited to join the original pilot sites as full participants in the grant. The Wisconsin Living Well team saw an opportunity for the mentor sites to continuously work to improve their own service provision by participating in the full grant intervention package implementation. This requires the mentor sites to recruit participants, complete the self-assessment, create an action plan, and complete the evaluation package. The grant manager and coach met with each of the sites to review their action plans and reorient them to the intervention packages. Through this work, the team supported each site’s delivery of the Safe and Free curriculum, the COVID-19 toolkit, training opportunities with staff, policy and practice changes, and work with self-advocate leaders.