Agenda

1. Introduction
2. Living Well Grants
3. ACL DSP Prize Competition
4. Closing
Living Well – Model Approaches for Enhancing the Quality, Effectiveness and Monitoring of Home and Community-Based Services for Individuals with Developmental Disabilities

Living Well Grants – A Project of National Significance
Background and Structure
Background

There is a significant shift toward people with intellectual and developmental disabilities (I/DD) living in community settings:

- 80% increase in people with I/DD living in **small group settings** (i.e., 4-6 people)
- 126% increase in people with I/DD living in **their own home**
- 132% increase in people with I/DD living in **a host or foster home**
- 39% decrease in people with I/DD living in **facilities**

Background

People with I/DD living in community settings are more likely than people with I/DD living in institutional settings to:

- Make their own choices
- Have friends who are not paid staff
- Have a paid job in the community

Background

• Access to and quality of home and community-based services (HCBS) vary across the country

• Differences between demand and capacity for HCBS can place individuals’ health, safety, and well-being at risk

  – The Office of Inspector General (OIG) identified significant gaps in the reporting of and response to critical incidents in group homes in recent years, such as:
    • Direct support staff lacked adequate training
    • State agencies did not adequately safeguard individuals living in group homes
    • Policies and procedures did not establish clear definitions/provide examples of potential abuse/neglect to be reported

  – The infrastructure for monitoring institutional settings is more robust than that for community monitoring

• A coordinated, comprehensive system for monitoring health, safety, and well-being of individuals with I/DD is critical to quality community living

Purpose

• In 2017, the Administration on Disabilities (AoD) issued a funding opportunity announcement for *Living Well – Model Approaches for Enhancing the Quality, Effectiveness and Monitoring of Home and Community-Based Services for Individuals with Developmental Disabilities* (Living Well)

• By developing and testing one or more model approaches of a coordinated and comprehensive system, projects intend to:

  - Increase community integration and independence of individuals with developmental disabilities
  - Improve the quality of HCBS
Grant Design: Two Core Components

Each grantee designed one or more model approach including two interrelated core components for enhancing and assuring the independence, integration, safety, health, and well-being of individuals living in the community:

- **Community Monitoring** – Develop and implement a coordinated system with the incorporation of partnerships to monitor the safety, health, and well-being of individuals with I/DD living in the community, and identifying and eliminating risk factors for abuse, neglect, and exploitation.

- **Community Capacity Building** – Apply evidence-based practices and innovative strategies to support individuals with I/DD living in or moving to the community; improve access to and quality of community services; reduce and mitigate abuse and neglect; and support individuals’ empowerment, independence, and rights.
Grant Design: Eight Key Features

- Partnerships
- Meaningful & active engagement with self-advocates and families
- Evidence based practices for service improvements
- Reducing abuse and neglect through community monitoring:
- Building capacity of direct support professionals (DSP) and HCBS providers:
- Addressing healthy and safety with data tools:
- Sustainability
- Program and outcome evaluation:
Grantees

• AoD awarded eight five-year grants:
  – Cohort 1: Three grants awarded in 2017
  – Cohort 2: Five grants awarded in 2018

Cohort 1

- University of Georgia Institute on Human Development
- University of New Hampshire Institute on Disability
- Virginia Commonwealth University Partnership for People with Disabilities

Cohort 2

- Alaska Governor’s Council on Disabilities and Special Education
- University of Idaho Center on Disabilities and Human Development
- Indiana Family and Social Services Administration
- University of Missouri-Kansas City Institute for Human Development
- Wisconsin Board for People with Developmental Disabilities
Cross-Site Evaluation

• ACL contracted with the Lewin Group, as a subcontractor to New Editions Consulting, to conduct a cross-site evaluation of the Living Well grants starting in 2017. The purpose of the cross-site evaluation is to determine:
  – How the Living Well grants are being implemented across grantee sites
  – Whether Living Well grantees are meeting the goals of the project; and
  – Whether the models implemented across the sites impact the quality of life of individuals with I/DD

• The evaluation team collects data virtually via interviews, site visits, and materials review.

• Data are coded and analyzed to identify key themes in how grantees are progressing toward grant objectives for each of the core components, including state contextual factors.

• Annual reports are posted on ACL’s website:

  Access evaluation reports on ACL’s website

Ongoing Studies

- The Social Determinants of Health and ACL
- Older Americans Act Fidelity Evaluation
- Adult Protective Services Client Outcome Study
- Living Well (a Project of National Significance)
- Supporting Families Community of Practice Evaluation
Cross-Site Analysis
Overview of Cross-Site Analysis

- Model Design
- Activities
- Outputs and Outcomes
- Sustainability
Overview of Cross-Site Analysis

Model Design

Activities

Outputs and Outcomes

Sustainability
Model Design

Process
- Establish buy-in from stakeholders through collaborative planning (pre- and post-award)
- Capitalize on existing stakeholder groups or project structures
- Incorporate ongoing improvement and quality assurance processes into model design
- Anticipate and adapt barriers to implementation

Structure
- Adapt the project structure to meet evolving context and need
- Strategically engage stakeholders

Roles
- Employ a collaborative approach to leadership
- Formalize stakeholder roles
- Allow stakeholder roles to evolve

Context
- Plan for known contextual factors
- Anticipate and capitalize on unknown factors
- Leverage unique internal capabilities
Model Design

• Several model approaches to address Community Monitoring and Community Capacity Building have emerged; these are not mutually exclusive.

<table>
<thead>
<tr>
<th>Approach</th>
<th>Description</th>
<th>Grantee Examples</th>
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<tbody>
<tr>
<td>Align with established statewide systems change initiatives</td>
<td>Grantees using this model realized efficiencies and value from working with established stakeholder groups and a clearly articulated vision.</td>
<td>Alaska, Idaho</td>
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<tr>
<td>Leverage Living Well grants to convene partners and integrate discrete initiatives</td>
<td>Grantees using this model achieve synergy by convening stakeholders and integrating activities to holistically address the core components.</td>
<td>Indiana, Virginia, New Hampshire</td>
</tr>
<tr>
<td>Use a pilot or localized model to develop, implement, and test initiatives</td>
<td>Grantees using this model pilot and refine grant activities before scaling and finalizing.</td>
<td>Missouri, Georgia, Wisconsin</td>
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Overview of Cross-Site Analysis

Model Design

Activities

Outputs and Outcomes

Sustainability
Activities

Core Component: Community Monitoring

- Reducing abuse and neglect through community monitoring
- Addressing health and safety with data tools
- Partnerships

Core Component: Community Capacity Building

- Meaningful and Active Engagement with Self-Advocates and Families
- Building Capacity of DSPs and HCBS Providers
- Partnerships
Activities: Community Monitoring

Core Component: Community Monitoring
- Reducing abuse and neglect through community monitoring
- Addressing health and safety with data tools
- Partnerships

Core Component: Community Capacity Building
- Meaningful and Active Engagement with Self-Advocates and Families
- Building Capacity of DSPs and HCBS Providers
- Partnerships
Community Monitoring

Reducing abuse and neglect through community monitoring

- Assess current systems of community monitoring
- Advocate for improved tracking and reporting systems
- Enhance the quality of critical incident data through training

The **New Hampshire Living Well team** is planning statewide training for those responsible for data input on critical incident reports to increase accuracy and consistency of data reporting.

The **Idaho Living Well team** is working towards implementation of a statewide registry of abuse, neglect, and exploitation.
Community Monitoring: Assessing Systems

• All grantees worked with stakeholders to assess issues with their critical incident and monitoring systems; this effort is ongoing.

Themes identified by grantees through assessment include:
• Barriers to reporting
  • Uncertainty about what constitutes abuse or neglect
  • Cultural and linguistic barriers
  • Fear of retaliation (e.g., What if I report abuse and have to move out of my home?)
  • Unsure of how or where to report abuse or neglect
  • Lack of trust (e.g., lack of trust in anything happening if abuse/neglect is reported; or do not have a trusting person to ask for help)
Community Monitoring: Assessing Systems (cont’d)

- Complex and fragmented reporting structures
  - Systems have varying definitions of what constitutes a critical incident/abuse/neglect
  - Data systems do not talk to each other
- Lack of available or useful data
  - Some current data collection practices are labor intensive (e.g., paper reports)
  - Data are collected, but stakeholders are unsure of the value of specific data points
- Data overload – states collect a ton of data, but not in a format that is usable, or collect so much data no one knows what to do with them
- Data are not shared across systems or with stakeholders
Community Monitoring: Assessing Systems

• The Idaho Living Well team formed a workgroup with the goal 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. Strategies include:
  – Developing a logic model
  – Mapping all relevant stakeholders and processes related to community monitoring within the state and analyzing the system for gaps
  – Listening to the experiences of self-advocates and family members
  – Reviewing available training and resources
  – Identifying areas of further study
Community Monitoring

Addressing health and safety with data tools

✓ Integrate and analyze multiple sources of data
✓ Leverage existing data tools

The **Virginia Living Well team** is examining predictors and buffers of risk in the state by merging new datasets on abuse and exploitation crises with existing datasets, including the National Core Indicators (NCI).

The **Indiana Living Well team** triangulates data between their Medicaid HCBS waivers and the Person-Centered Individualized Support Plans (PCISPs) to audit quality and inform grant and steering group activities.
Community Monitoring

✓ Convene cross-agency partners
✓ Collaborate with external experts and peers

The Idaho Living Well Quality Assurance workgroup conducted a review of the state monitoring system for abuse and neglect reports, which included the court system and established subcommittees to develop training recommendations related to the monitoring of abuse and neglect.

The Wisconsin Living Well team reviewed the Wisconsin incident management system with stakeholders and shared a cross department recommendation report with the Wisconsin Department of Health Services.
Activities: Community Capacity Building

Core Component: Community Monitoring

- Reducing abuse and neglect through community monitoring
- Addressing health and safety with data tools
- Partnerships

Core Component: Community Capacity Building

- Meaningful and Active Engagement with Self-Advocates and Families
- Building Capacity of DSPs and HCBS Providers
- Partnerships
Community Capacity Building

Meaningful and Active Engagement with Self-Advocates and Families

- Build knowledge and advocacy skills among self-advocates and families
- Engage self-advocates and families as leaders, trainers, and advocates
- Solicit and act on feedback from self-advocates and families

Self-advocates and family members review, modify, and approve recommendations from each of the Idaho Living Well grant workgroups. This includes their Culturally Responsive Advisory Group, which focuses on policy recommendations that are culturally and linguistically relevant to the Latinx population.

Self-advocates serve as co-trainers for two trainings offered to HCBS providers through the Georgia Living Well grant: Supporting Informed Decision-Making training and Supporting Social Roles.
Community Capacity Building

Building Capacity of DSPs and HCBS Providers

- Develop and implement training to build HCBS provider capacity
- Establish growth opportunities for DSPs

The **New Hampshire Living Well team** worked with Community Support Network, Inc., the association of New Hampshire’s ten area agencies that provide services to people with DD, to develop the Care and Support program. The program provided high school students an introduction into the role of a DSP over the course of an 18-week multi-modal program. Upon completion of the program, the students have all of the necessary required training to apply for and become DSPs.
The **Georgia Living Well team** distributes an annual survey to the five providers participating in their grant to assess the type and nature of services provided, DSP participation in staff training, staff retention, and turnover rates. Data from this survey, Therap, and the College of Direct Support are used to conduct a comparative analysis to understand the impact of the trainings and interventions on each DSP by comparing CDS coursework and completed trainings against the number of critical incidents, staff survey results, and how individuals receiving support progress toward their goals.

The **Idaho Living Well team’s** bFair2DirectCare workgroup has developed a comprehensive list of required DSP competencies and developed a plan for necessary changes in Idaho policy related to provider qualifications, incentives, and training requirements. The workgroup also intends to develop a DSP code of ethics, evidence based knowledge and performance standards, an updated training plan, and statewide adoption of a new online training platform.
Community Capacity Building

- Align partnerships with existing goals and strategies
- Foster stakeholder engagement and ownership through concrete roles

Five county-based pilot sites participating in **Missouri’s Living Well grant** engaged in monthly strategic planning sessions. The planning informed material for Missouri’s Living Well product library to promote scaling and replication of emerging and promising practices across the state.
Overview of Cross-Site Analysis

- Model Design
- Activities
- Outputs and Outcomes
- Sustainability
Outputs & Outcomes: Community Monitoring

Grantees perform process and outcome evaluations to assess their progress toward outputs and outcomes, as well as sustainability across their grant activities.

Program and outcome evaluation:

Outputs most frequently reported by grantees (Community Monitoring):
- Aligning partner goals and activities
- Assessing/improving community monitoring reporting systems
- Developing and implementing data tools to address health and safety
- Designing and implementing program and outcome evaluation
- Sharing evaluation data and using evaluation data to inform activities
- Planning for sustainability

Outcomes most frequently reported by grantees (Community Monitoring):
- Enhanced health and safety for individuals with I/DD
- Improved incident reporting platforms
Outcomes: Community Monitoring

The Missouri Living Well team is evaluating the return on investment to determine the effectiveness (e.g., reduced emergency department visits) of the StationMD platform, a telehealth service for individuals with I/DD.

The Georgia Living Well team and their partners hosted vaccine events for individuals with I/DD. Through these efforts, 250 individuals with I/DD, staff, and caregivers were able to receive the COVID-19 vaccine.

The New Hampshire Living Well team integrated person-centered plans, the Health Risk Screening Tool (HRST), service agreement and amendment form, Supports Intensity Scale, Planning Process Acknowledgement Form, and satisfaction surveys into an online platform. They are incorporating a tool for sentinel events to track, trend, and analyze data in real-time for the Centers for Medicare & Medicaid Services (CMS) to produce performance measures.
Outputs & Outcomes: Community Capacity Building

Grantees perform process and outcome evaluations to assess their progress toward outputs and outcomes, as well as sustainability across their grant activities.

Outputs most frequently reported by grantees (Capacity Building):

- Aligning partner goals and activities
- Engaging with and training for self-advocates and families
- Building DSP/HCBS provider capacity through trainings and resources
- Designing and implementing program and outcome evaluation
- Planning for sustainability
- Creating durable products

Outcomes most frequently reported by grantees (Capacity Building):

- Increased knowledge and skill of self-advocates and family members
- Increased provider capacity
Outcomes: Community Capacity Building

The **Wisconsin Living Well team** developed the Safe and Free curriculum, which covers important for self-advocates to learn about rights, avoiding abuse, and having health relationships. Self-advocate leaders co-facilitated sessions. The Wisconsin Living Well Team also created accessible evaluation tools. Self-advocate feedback indicated that their confidence, knowledge, and skills increased since completing the curriculum.

The **Virginia Living Well team** supported training in person centered thinking and practices. Their evaluation found a statistically significant increase in knowledge of person-centered skill sets for participants who completed the training, including role-specific responsibilities, matching people with supports, communication style, analyzing issues using multiple perspectives, and steps for informing action.
Overview of Cross-Site Analysis

- Model Design
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Sustainability

Strategies for sustainability:

✓ Develop durable products
✓ Secure future funding
✓ Align partner goals

Durable Product Highlights

• Medication administration training (New Hampshire)
• Regional Quality Council recorded training modules (Virginia)
• Trainings and career tracks through College of Direct Support (Georgia)
• Healthy, Safe, and Connected COVID-19 toolkit (Wisconsin)
Mapping the Future: Sustaining A Vibrant DSP Workforce

ACL DSP Challenge Summary
The Collaborative for Citizen Directed Supports – New Jersey
HCBS Conference
9 December 2021
The Collaborative for Citizen Directed Supports - New Jersey

- focused on innovation in services, and in expanding and improving self-direction and disability supports in New Jersey.

- expanding opportunities for people with disabilities to fully participate in the design, delivery and evaluation of their services,

- with the support they need, from whom they want,

So that people and their families are supported in living lives of meaning, of their own choosing.
LEARN
how to confidently support people in whatever way is right for them.

PROMOTE
every person’s right to choose their services and lead their own journey.

JOIN
because together, we’re championing personal choice.

collaborate
verb • col·lab·o·rate • ˈkə-lə-bə-ˌrāt

to work with another person or group in order to achieve or do something
COMMUNITY INNOVATIONS GRANT SUPPORTING FAMILIES AND STAFF TOGETHER: INTERACTIVE MAP ENABLING PERSONALIZED CONNECTIONS FOR HEALTHY COMMUNITIES
“I always say that talent and capability is everywhere, all it needs is opportunity”.

-Katherine Switzer
The American Association on Intellectual and Developmental Disabilities (AAIDD) and the National Alliance for Direct Support Professionals (NADSP) contend that the approach to address the challenges needs to be comprehensive and include a variety of measures that address **livable wages**, **ongoing training and development**, and **access to available technologies**.

The Interactive Map addresses ALL of these measures!

Evidence Base: Trends

- **Social capitalism** …recognizes interdependence
- **Pace of digital acceleration** that compelled companies to adapt… companies and people will have to **embrace technology-enabled on-demand workforce models and platforms**
- **Use of an on-demand workforce** will increase as the economic impact of COVID-19 happens
- Industries will be forced to **reinvent their workforce with upskilling and reskilling** becoming a major priority

Community Stakeholder Input

We distributed an accessible survey so that service stakeholders have more effective and efficient means of providing feedback. We hosted Roundtable Feedback Sessions with stakeholders.

RESULTS & WHAT WE LEARNED:

- How to advertise the Interactive Map and open DSP positions in various capacities as suggested by self-advocates;
- Continuous Quality Improvement;
- Person-Centered learning component (per self-advocate input).
## The Interactive

<table>
<thead>
<tr>
<th></th>
<th>Size: Increase DSP Workforce</th>
<th>Stability: Improve DSP Stability</th>
<th>Capability: Improve DSP Capability</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Evidence</strong></td>
<td>• Technology enables access to the Sharing Economy</td>
<td>• Creates opportunities for freely chosen relationships</td>
<td>• Makes self and side by side learning accessible and readily available</td>
</tr>
<tr>
<td><strong>Partnerships</strong></td>
<td>• Requires cooperation through formal partnerships with organizations and allies</td>
<td>• Fosters outreach and effective marketing</td>
<td>• Invites continuous quality improvement</td>
</tr>
<tr>
<td><strong>Implementation</strong></td>
<td>• Increase visibility and access to the Interactive Map</td>
<td>• Provide opportunity for continuous feedback to help build effective relationships</td>
<td>• Increase access to professional training and shared learning opportunities</td>
</tr>
<tr>
<td><strong>Impact</strong></td>
<td>• 100% + increase in Map views during the Implementation Test Phase</td>
<td>• DSPs co-producing the Interactive Map per Roundtable sessions</td>
<td>• Learning and development opportunities available on the Interactive Map</td>
</tr>
</tbody>
</table>
Sustainability
Creating a Pathway to the Future
Google Says….

“When you build on the same infrastructure that serves billions of Google Maps’ users, you can count on a platform that will scale and flex as you do. On our secure, future-proof infrastructure, you can grow from prototype to planet-scale without having to think about capacity, reliability, or performance.”
Digital marketers encourage prospects along the path which takes them from awareness of an opportunity to a conversion action, "nurture."

The Interactive Map encourages prospective DSPs/SDEs to investigate the opportunities a career path as an SDE or DSP can deliver.

We cannot "market" our way out of this labor shortage. We need to understand what will attract people to this work and motivate them to see providing supports as a career option.

The Interactive Map is the pathway to that process.
For the SDE/DSP, it is a place to show off their accomplishments and "sell" themselves to those seeking service.
Implementation Plan

Building off the foundation that the ACL DSP Challenge has afforded The Collaborative.

- Year One: Refining the Interactive Map and building an effective support team.
- Year Two: Implementing and building proprietary content and geographical area expansion.
- Year Three: Expanding outreach to other markets and continually revising based on community feedback and technology innovations.
Financial Modeling
Scalability: The Sky is the Limit
Outside investment
Current Locations and Future Destinations
Thank you to the ACL!

The Collaborative is not only clear but confident that this is the time and we are the stakeholders to heed what the late great Representative John Lewis called us to do decades ago that relates to the ACL’s Innovative DSP Challenge:

‘If not now, then when? If not us, then who?’

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Thank you!