

Strategies for Improving Community Monitoring

Living Well Grant

Variations in access to and quality of home and community-based services (HCBS) across the country can put the well-being of people with intellectual and developmental disabilities (I/DD) living in their communities at risk. To address these pressing needs, the Administration for Community Living (ACL)¹ issued Living Well-Model Approaches for Enhancing the Quality, Effectiveness and Monitoring of HCBS for Individuals with I/DD (Living Well) grants, with two key goals:

- Increase community integration and independence of individuals with I/DD; and,
- Improve the quality of HCBS.

The ACL administers Living Well grants through the Projects of National Significance program. The ACL awarded eight five-year grants across two cohorts in 2017 and 2018 to identify, develop, and evaluate model approaches that address the two goals. The Living Well grantees are: Alaska, Georgia, Idaho, Indiana, Missouri, New Hampshire, Virginia, and Wisconsin. ACL contracted with the Lewin Group, as a sub-contractor to New Editions Consulting, to conduct a cross-site evaluation of the eight grants.²

Community Monitoring is a core component of the Living Well grants. **This brief focuses on how several grantees have developed innovative or promising practices using various data tools to address community monitoring challenges.** Throughout this brief, the recipients of Living Well grants and their respective project teams are referred to as “grantees.”

Background

Challenges to Community Monitoring

States face many challenges to utilizing and sustaining a comprehensive community monitoring system. During the first two years of the cross-site evaluation of Living Well grantees, several common themes emerged from the challenges reported by grantees.

- **Reliance on paper-based methods:** Paper-based data collection methods can make data collection and analysis more challenging and less available to people within and outside of the collecting agency. This limits how effectively data can be used in decision-making by all stakeholders in the state.
- **Lack of consistency in how incidents of abuse and neglect are defined, reported, and tracked:** State reporting systems may collect slightly or entirely different data sets through different means and varying definitions of terms, which can make cross-state comparisons difficult or impossible. If cross-site or cross-region analysis is prevented by incompatible data and any issues cannot be fully understood, solutions will be more difficult to identify.
- **Budget or funding issues for sustaining data tools:** Many grantees are facing budget shortfalls. In some cases, this led to cuts at the agencies that provide services to individuals with I/DD. In other cases, monitoring or reporting

1 The Administration on Intellectual and Developmental Disabilities (AIDD) oversaw the Living Well grants when they were awarded in 2017 and 2018. The Administration on Disabilities (AoD) now provides oversight to the grants within ACL.

2 Evaluation reports can be found here: <https://acl.gov/programs/program-evaluations-and-reports>

upgrades or data collection may be disrupted by budget cuts.

- **Stakeholder compliance with reporting requirements:** Fragmented systems and complex reporting processes can prevent or make it difficult for stakeholders to consistently collect and report certain data to the correct system. This may limit the quality of data that a state or system stakeholder receives, analyzes, and uses to make decisions about services.

Innovations in Community Monitoring

Grantees are addressing these challenges in unique ways to effectively monitor the health and safety of individuals with I/DD living in the community. This brief highlights three innovations to improve community monitoring by Living Well grantees.

Grantee Spotlight: University of Georgia Institute on Human Development and Disability

Background

To enhance community monitoring efforts across the state, the Georgia Living Well team³ partnered with Therap. Therap is a web-based, electronic documentation and communication system for human service providers that is secure and HIPAA compliant. The Therap platform has been used in Georgia for several years and is used by providers across the nation. The five provider agency pilot sites participating in the Georgia Living Well grant use this tool on a daily basis to input data on incident reporting, medication management, goals, and outcomes for individuals they support.



Overview of Tool

Therap provides a platform for providers to capture their documentation in a web-based system that is easily accessible with any internet-ready device. The data can then be aggregated at the individual, program, provider, and project level through the use of Therap's Business Intelligence platform to assess impact of project activities on outcomes for individuals.

The Business Intelligence platform has multiple dashboards that can produce nearly real time, ad-hoc reports. The Georgia Living Well team primarily uses two dashboards in the Business Intelligence platform: Data Driven Outcomes and General Event Reporting.

The Data Driven Outcomes dashboard allows for large scale data aggregation and assessment of outcomes across measurement types that were identified and implemented by project participants - Important To and Important For within five domains: Safety, Health and Wellbeing, Social Connectedness and Relationships, Meaningful Activities, Person-Centered Planning, and Choice. The concept of assessing what is Important To and Important For an individual is foundational to person-centered practices and has been incorporated into this dashboard as such.

The General Event Reporting dashboard, where incident reports and adverse incident data are collected, allows for summary and longitudinal analyses of adverse incidents at all levels of organizations. Providers enter day-to-day service data that are distributed to the internal grant 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. In response to COVID-19, Therap identified several new indicators to add to the platform for providers to report data regarding COVID-19.

Intended Outcomes

The use of Therap is intended to address the fragmented monitoring within the state by aggregating data across domains, analyzing individual progress toward goals over time, and tracking trends hindering the quality of HCBS. Having all of the

³ Throughout this document, the Georgia Living Well team refers to the lead agency for the Living Well grant in Georgia, the [University of Georgia Institute on Human Development and Disability](#).

data in one system allows for the identification of trends in the data and analysis of the impact of different interventions within the program.

The adoption of the Therap tool allows for the consistent and standardized documentation of incident reporting, medication management, goals, and outcomes. This information will help the Georgia Living Well team better understand how to allocate resources and identify individuals receiving services who are at risk or require special attention.

Grantee Spotlight: University of Missouri - Kansas City Institute on Human Development

Background

The Missouri Living Well team⁴ is developing a virtual data dashboard with Human Services Research Institute (HSRI) to improve the accessibility and usefulness of data available in Missouri. The Missouri Living Well team noted state and national data sources available to their team that were not being used to their full potential. In order to make these data sources more useful, the Missouri Living Well team is working with HSRI to develop a tool to analyze, present, and contextualize the data.



Overview of Tool

The dashboard utilizes the Verity Analytics platform. The dashboard will provide background information and case studies in addition to displaying the actual data to provide context for users. The Missouri Living Well team engaged in a mapping exercise to identify data currently available to the team as well as data collected by project stakeholders. The Missouri Living Well team began with the National Core Indicator (NCI) Survey data that is collected annually in Missouri and added data from the Centers for Disease Control and Prevention (CDC) and the Census Bureau. Through the Charting the LifeCourse Ambassador Series for Systems Transformation, county collaborative members recommended quality of life indicators for the dashboard and identified strengths and areas of improvement related to data collection and availability. This exercise identified data that are currently available and highlighted existing gaps. The team is still identifying possible data sources, such as de-identified critical incident data and Health Risk Screening Tool data from the state Division of Developmental Disabilities, and determining how to access that data and include it on the dashboard.

Intended Outcomes

The dashboard is intended help users utilize the data that are available to them to make informed decisions. The Missouri Living Well team is working to contextualize all of the information and help users examine the data within the state and national context. For instance, the current beta version of the dashboard shows how HCBS have changed over time using trends from the NCI data. With side-by-side indicators, users can compare key data points for the general population with the CDC's Healthy People 2020 goals.

Grantee Spotlight: University of New Hampshire Institute on Disability

Background

The New Hampshire Living Well team⁵ is changing the way that providers across the state collect, report, and analyze data. Previously, data collection within the state occurred primarily through paper-based methods. The reliance on paper-based data collection and the lack of a standardized reporting and monitoring system within the state led the team to adopt the Health Risk Screening (HRS) platform to integrate data collection from multiple sources. The HRS platform is used statewide for person-centered planning documentation and



4 Throughout this document, the Missouri Living Well team refers to the lead agency for the Living Well grant in Missouri, the [University of Missouri-Kansas City Institute for Human Development](#).

5 Throughout this document, the New Hampshire Living Well team refers to the lead agency for the Living Well grant in New Hampshire, the [University of New Hampshire Institute on Disability](#).

hosts the Health Risk Screening Tool, the New Hampshire Service Agreement, the Supports Intensity Scale, the Planning Process Acknowledgement Form, the Service Agreement Amendment Form, and the Quarterly Satisfaction Surveys. While planning the HRS platform, the New Hampshire team conducted a crosswalk of various data points, their purpose, and the systems requirements that they fulfill in order to assess compliance of quality, effectiveness, and monitoring of data within the state. These data points include, but are not limited to, Office of Inspector General requirements, sub-assurance monitoring requirements, regulation requirements, file review audits, HCBS compliance monitoring, and the re-designation process. This crosswalk informed the changes New Hampshire made to the Health Risk Screening platform, which integrates these multiple data points and enable easier analysis and use.

Overview of Tool

The Health Risk Screening Tool is a web-based tool used to detect health risks and destabilization early in vulnerable populations. The Health Risk Screening Tool user (e.g., service coordinator) assigns scores to 22 health and behavioral-related items using a series of objective questions. The total points result in a Health Care Level (HCL) with an associated degree of health risk. The HCLs can range from one through six with Level 1 being the lowest risk for health concerns and Level 6 being the highest risk for health care concerns. The data are input in the system by a service coordinator, and the Health Risk Screening Tool is redone whenever an event occurs (e.g., if an individual falls or their medical condition changes). Whenever an individual's HCL changes, the HRS platform sends an automatic notification to their nurse to ensure that health conditions are not overlooked by an individual's team, who are often responsible for capturing health related data on a regular basis. Additionally, the Health Risk Screening Tool will include functionality that identifies through the embedded service agreement if there are any opportunities for trainings that the staff members could receive in relation to the specific health issues.

Intended Outcomes

By moving to an electronic-based platform, the New Hampshire Living Well team is improving data collection and streamlining crucial elements of the community monitoring system for all stakeholders. The team's inclusion of stakeholders throughout the development of the data points to be captured both strengthens existing partnerships and ensures the final product is relevant, appropriate, and best serves the needs of the community. Having one platform used across the system will result in more comprehensive, up-to-date data collection that can be easily accessed to run reports and identify trends in a more timely manner.

Further, the Living Well Grant will support the state's enhancement of the role of managed care organizations (MCOs) by notifying them when an individual's HCL is three or above. The MCO will then take advanced measures to work with the individual and their team to address health care issues, ideally preventing the HCL from increasing. The additional information and forms captured in the HRS platform will support regional and statewide quality monitoring efforts.

Summary

Living Well teams in Georgia, Missouri, and New Hampshire are all taking innovative steps to collect and use data to improve community monitoring in their states. Each of these Living Well grantees are using specialized and customizable data tools to collect, aggregate, analyze, and share data in new ways. This will support stakeholders, within and beyond the Living Well grant teams, to more effectively use data to drive decisions and support higher quality HCBS for individuals with I/DD throughout their states.