



Strategies for Using Data Tools for Monitoring and Decision-Making

Living Well Grant Background

This brief focuses on how grantees are utilizing data tools to address community monitoring challenges and make data-driven decisions.

Variations in access to and quality of home and community-based services (HCBS) across the country can put the wellbeing 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) issued Living Well-Model Approaches for Enhancing the Quality, Effectiveness and Monitoring of HCBS for Individuals with I/DD (Living Well) grants, with two key goals:

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

ACL administers Living Well grants through the Projects of National Significance program. 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. Grantees are located in the following states: 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.¹

Each Living Well grantee is developing and implementing data tools and evidence-based practices to monitor and address the health and safety of individuals with developmental disabilities at increased risk.² This brief focuses on how grantees are utilizing data tools to address community monitoring challenges and make data-driven decisions. Throughout this brief, the recipients of Living Well grants and their respective project teams are referred to as “grantees.”

Background: The Need for Data Tools

State systems of community monitoring are complex and typically require coordination across multiple state agencies. Within a state, there are often multiple reporting channels, each with its own processes and requirements (e.g., type of incident, age of individual involved, mandated reporters). States typically require significant documentation of incident reporting and response, but may face challenges analyzing, interpreting, and acting on the data.³ Addressing these challenges requires states to integrate data from multiple sources, reduce burden on individuals and providers, and analyze data to identify trends and take action.

¹ For more detailed information on the Living Well grant, grantees, and full evaluation findings, evaluation reports can be found here: <https://acl.gov/programs/program-evaluations-and-reports>

² Living Well-Model Approaches for Enhancing the Quality, Effectiveness and Monitoring of Home and Community Based Services for Individuals with Developmental Disabilities; HHS-2017-ACL-AOD-DNIQ-0221. <https://acl.gov/grants/living-well-model-approaches-enhancing-quality-effectiveness-and-monitoring-home-and-1>

³ Bourne, M.L., Sowers, M., & Vegas, L. (2017). Health and Welfare Review: Report and Self-Assessment. National Association of State Directors of Developmental Disabilities Services.

Data Tools



Grantees are using data tools, both nationally available and custom built, to address challenges associated with aggregating and utilizing data to their full potential. This brief describes the data tools, provides an example of how each tool is being utilized in Living Well grant initiatives, and discusses the intended impact of each tool.

Therap

Tool Overview

[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. Data can then be aggregated at the individual, program, provider, and project level through the use of Therap's Business Intelligence platform to assess the impact of project activities on individuals' outcomes.

Example: Georgia



The Georgia Living Well team is using Therap with the five provider agencies participating in their pilot. The Georgia Living Well team uses two dashboards available in the Therap Business Intelligence platform that aggregate data entered by providers. 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.

Intended Outcomes

The Georgia Living Well team expects to use these data to make decisions about allocating resources and identifying individuals who are at risk of abuse, neglect, or other adverse outcomes. The Georgia Living Well team anticipates improved outcomes including increased achievement of personal goals by people with I/DD who are receiving supports. The Therap reporting tool and dashboards allow staff to see progress in the system (e.g., decreased critical incidents) and quickly assess performance against established benchmarks and domains based on individualized service data. The performance metrics allow the Georgia Living Well team and provider agencies to better target interventions to improve the quality of services provided.

Health Risk Screening (HRS) Platform

Tool Overview

The Health Risk Screening Tool (HRST) is a validated web-based screening tool for individuals with disabilities. The HRST assigns scores to 22 health and behavioral rated items to detect health risks and destabilization early. Health care information is entered into the HRST monthly and whenever a significant event occurs. When the screening is complete, the HRST provides an overall Health Care Level (HCL) showing an individual's risk intensity and considerations for action to address risks.⁴

Example: New Hampshire



The New Hampshire Living Well team partnered with [IntellectAbility 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 HRST diagnoses are auto-populated into the service agreement to avoid duplication of effort for service coordinators and to eliminate errors.

The platform will track critical events and mortality reports in addition to hosting health care information, service agreements, and satisfaction survey results. The team is meeting with various stakeholders to assess and improve the quality of the data being entered into the system and ensure that the state can easily pull reports to support Medicaid HCBS waiver requirements and renewals.

Intended Outcomes

The New Hampshire Living Well team is aiming to use the HRS platform to track both sentinel events (i.e., critical incidents), as well as data to calculate performance measures for Centers for Medicare & Medicaid Services (CMS) reporting. This will allow the state to track and analyze data in real time and identify immediate action steps when a problem is identified. The development and use of this tool is supporting improved community monitoring for abuse, neglect, exploitation in New Hampshire, one of the Living Well team's project goals.

⁴ Health Risk Screening Tool. IntellectAbility. (2021). Retrieved September 13, 2021, from <https://replacingrisk.com/health-risk-screening-tool/>.

Custom Tools

Tool Overview

In some cases, grantees are developing their own data tools to analyze data in new ways to support community monitoring and decision-making in their states. While commercially available tools are easily available, grantees can design custom tools to collect and aggregate data from multiple sources and display it in a way that best meets their needs.

Example: Missouri



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 state and national data. The team engaged in a mapping exercise to identify data currently available to the team and data collected by project stakeholders. Through the Charting the LifeCourse (CtLC) Ambassador Series (a structured introduction to CtLC principles and tools) for Systems Transformation, members of county-based pilot sites 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 as well as gaps in available data. The dashboard, which is still under development, currently includes National Core Indicators, 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.

Intended Outcomes

The Missouri Living Well team is aiming to use their custom data dashboard to present a wide range of data to help stakeholders better understand the real-world meaning of a specific data point and use it to support decision making. Goals include being able to evaluate quality of life across individuals with and without I/DD to better benchmark quality standards. The team hopes that this information will drive improved outcomes across HCBS and I/DD supports in Missouri.

Conclusion

Living Well grantees are using a variety of data tools to support progress toward their goals and improved individual outcomes by:

- Increase providers' ability to collect and analyze data to identify areas for growth through Therap and the Business Intelligence dashboards;

- Improve community monitoring and drive service improvements by tracking and analyzing data in a centralized system such as the HRS platform;
- Support the use of data from multiple sources to inform decisions and better understand quality.

This use of data tools in Living Well grants is supporting decisions that will lead to higher quality supports and HCBS for individuals with I/DD. This in turn will lead to improved outcomes including more individuals achieving their goals and leading to a higher quality of life.