Living Well 2020
Cross-Site Evaluation

Volume I
Introduction
I. Grant Context and Purpose

Between 1998 and 2016, the number of people with intellectual and developmental disabilities (I/DD) living in facility settings decreased 39 percent, while the number of people in small group settings of four to six people increased 80 percent. During the same period, the number of people with I/DD living in their own home increased 126 percent, and the number of people living in a host or foster home increased by 132 percent.1 People with I/DD who live in home and community-based service (HCBS) 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, and have a paid job in the community.2 Despite these positive outcomes, 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. A recent series of Office of Inspector General (OIG) reports identified significant gaps in the reporting of and response to critical incidents in group homes.3

To address these pressing needs, the Administration for Community Living (ACL)4 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 awarded eight five-year grants across two cohorts to identify, develop, and evaluate model approaches which address two interrelated core components by incorporating eight key features. ACL administers Living Well grants through the Projects of National Significance (PNS) program. Funded under Subtitle E in the Developmental Disabilities Assistance and Bill of Rights Act (DD Act), PNS create and enhance opportunities for people with developmental disabilities (DD) to contribute fully in all aspects of community life. Further, PNS support the development of national and state policies that promote independence, integration, and inclusion in community life.

In 2020, the COVID-19 pandemic exacerbated many of the challenges faced by individuals with I/DD living in HCBS settings and the systems that support them, including concerns about health and safety, abuse and neglect, and social isolation. While the COVID-19 pandemic was not anticipated when ACL awarded Living Well grants, the public health crisis magnified gaps in effective systems of community monitoring for individuals with I/DD and provided opportunities for grantees to rapidly respond to local and state needs.

II. Two Core Components

Grantees address two core components with their Living Well model(s).

- **Community Monitoring**: Development and implementation of a coordinated system utilizing multiple community and state level partners for monitoring the safety, health, and well-being of individuals with intellectual and developmental disabilities living in a variety of community settings. The purpose is to identify and eliminate the risk factors for tracking, redressing and preventing abuse, neglect and exploitation in community settings;

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4 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.
- **Community Capacity Building**: Application of evidence based practices and innovative strategies focusing on improving services that support people with developmental disabilities living in the community or those moving to the community from a more restrictive setting; access to and quality of community services through capacity building and scaling of evidence based and other promising practices; reducing and mitigating the incidence of and risk factors for abuse and neglect; and supporting empowerment, self-determination, self-advocacy, and an individual's independence, autonomy and right to live alongside their non-disabled neighbors.  

### III. Eight Key Features

Grantees incorporate eight key features into their Living Well models.

**Exhibit 2. Eight Key Features of Living Well Models**

<table>
<thead>
<tr>
<th>Partnerships</th>
<th>Meaningful and active engagement with self-advocates and families</th>
<th>Evidence based practices for service improvements</th>
<th>Building capacity of DSPs and HCBS providers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Initiation and coordination of partnerships or coalitions with local and state-level organizations, agencies, and other relevant stakeholders, including at least one self advocacy organization, in the design, implementation, and replication of grantee activities</td>
<td>Continuous, meaningful, and active engagement of self-advocates and family members throughout the life cycle and in all stages of the project</td>
<td>Use of evidence based and innovative strategies to (1) improve access to and quality of community services, (2) reduce and mitigate abuse and neglect, and (3) support empowerment, self-determination, and self-advocacy</td>
<td>Prevention-based tools and technical assistance to address common needs, such as changing the ‘culture of abuse and neglect’ in HCBS settings and transferring knowledge of positive behavior</td>
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<table>
<thead>
<tr>
<th>Reducing abuse and neglect through community monitoring</th>
<th>Addressing health and safety with data tools</th>
<th>Program and outcome evaluation</th>
<th>Sustainability</th>
</tr>
</thead>
<tbody>
<tr>
<td>Collection, analysis, and dissemination of data to develop and implement coordinated community monitoring that builds on existing local or state infrastructure and partnerships</td>
<td>Data tools and evidence based practices for monitoring high-risk individuals and addressing reoccurring issues of health and safety concerns</td>
<td>Process and outcome evaluation to analyze delivery and impact of project activities</td>
<td>Assurance of organizational, financial, and/or community stability to continue and refine grantee work</td>
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**IV. Grantees and Partnerships**

ACL awarded grants in two cohorts, with the first cohort of three grantees beginning in September 2017. The second cohort of five grantees began their five-year grants in September 2018.

![Exhibit 3. Living Well State Grantees by Cohort](image)

The grant requires partnerships among, at minimum:
- One Protection and Advocacy System, State Developmental Disabilities Council, or University Center for Excellence in Developmental Disabilities; and,
- At least one state agency (state I/DD agency, state Medicaid agency, self-advocacy organization, consumer-controlled organizations, or family-led organizations). Additional partnerships are strongly encouraged.

**V. About this Report**

This report is comprised of four volumes: (I) Introduction, (II) Grantee Profiles, (III) Cross-Site Analysis and Conclusion, and (IV) Methodology. Volume II reports grantee-specific data, including grantee background, state context data, and evaluation findings and analysis. Volume III provides cross-site analysis and discussion, comparing and contrasting grantee models by core components and key features.

The evaluation reports from grant year 2018-2019 are publicly available on the [Administration for Community Living’s website](https://www.acl.gov).