

Strategies for Self-Advocate Engagement

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

This issue brief focuses on how grantees across the eight states awarded the Living Well grant engaged self-advocates throughout their grant activities and model development. Throughout this brief, the recipients of Living Well grants and their respective project teams are referred to as “grantees.”

Background

Self-Advocacy in the Living Well Model

It is the vision of ACL “for all people, regardless of age and disability, to live with dignity, make their own choices, and fully participate in society.”³ As such, self-advocacy is a prominent feature in the Living Well grants. ACL seeks to promote empowerment, self-determination, and independence of individuals with I/DD living in the community. For individuals to successfully carry out these critical leadership roles and responsibilities, they must be valued and well supported in their efforts. The Living Well models elevate the leadership role that self-advocates play in order to be effective advocates for themselves and others. It is expected that self-advocates and family members will be fully and meaningfully engaged throughout the life cycle of Living Well grants. Grantees reported providing support outside of meetings to self-advocates to help understand materials and meeting objectives as well as ensuring self-advocates or families led project activities.

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>

3 <https://acl.gov/about-acl>

Innovations in Engaging Self-Advocates

This document highlights Alaska and Idaho's Living Well models, both of which use robust, multifaceted approaches to meaningfully engage self-advocates. These models reflect a commitment to recognizing and supporting self-advocates as leaders that is foundational to all other grant activities.

Grantee Spotlight: Alaska Governor's Council on Disabilities and Special Education

Background

The Alaska Living Well grant is held by the Governor's Council on Disabilities and Special Education (the Council) which was formed in 1975, comprises 26 members, and serves a variety of state and federal roles. These roles 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 Council works closely on the Living Well grant with the [Alaska DD Systems Collaborative](#). In the Collaborative, all of the project team work is co-led by self-advocates and includes an advocate advisory team to oversee the work. The advocate advisory team is serving as part of the advisory board for the Living Well grant, in partnership with staff from The Council.

The Collaborative developed the Shared Vision statement for the DD system in Alaska, which was passed into state statute in 2018: "Alaskans share a vision of a flexible system in which each person directs their own supports, based on their strengths and abilities, toward 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, including the self-advocate advisory team leaders, aligned their Living Well objectives with the Shared Vision to most effectively impact change in parallel with other systems work.

Overview

Self-advocates play a significant role in the leadership of the Alaska Living Well team. In addition to these leadership roles on the grant team, self-advocates are also involved in the implementation of the Alaska Living Well team's model.

The Alaska Living Well team is working with [Peer Power Alaska](#), a self-advocacy organization that engages and empowers individuals with I/DD as self-advocates, to organize and hold annual self-advocacy summits. The 2019 Peer Power Summit brought in people from more than 20 communities from across Alaska. The 2020 summit planning has been complicated by COVID-19 and the Peer Power Board is assessing the current situation. In the interim, the Alaska Living Well team is planning to assist, as needed, to hold the summit virtually. In addition to the summits, Peer Power established a YouTube channel to share information with self-advocates across Alaska. The Alaska Living Well team is supporting Peer Power and the channel with the creation of several webinars on self-determination featuring self-advocates.

In addition to their partnership with Peer Power, the Alaska Living Well team is also supporting the Key Campaign, an advocacy event at the state legislature hosted by the [Key Coalition of Alaska](#). For the 2020 Key Campaign, the Alaska Living Well team collaborated with self-advocates and other stakeholders to develop four documents for Alaskan legislators to create discussion on the [DD Shared Vision](#), [supported decision-making agreements](#), the [cost-savings of HCBS](#), and [ideas to create efficiencies in HCBS](#). The Alaska Living Well team also produced a webinar series focused on supporting self-advocates and ensuring an in-depth understanding of the DD shared vision. Following the webinar series, and as part of the Key Campaign, self-advocates created a DD shared vision brochure for dissemination to policymakers.

The Alaska Living Well team is also working to implement a series of trainings for direct service professionals (DSPs). The team is working with the Alaska University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDD) and the state statewide DD service provider organization on capacity building efforts with Alaska's DD providers and their DSPs. The Alaska UCEDD has expertise in innovative training delivery models focused on reaching rural and remote regions of the state, which is valuable to the grant team as they seek to share vital information rapidly statewide during the pandemic. As part of these efforts, the teams will implement trainings that will be aligned with the DD shared vision and co-led by self-advocates.

Intended Outcomes

One of the Alaska Living Well team's grant objectives is to "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." The Alaska Living Well team includes self-advocates in leadership roles, both as grant team staff and leaders of project activities. Beyond engaging self-advocates as leaders and advisors in their grant work, the team supports several activities as part of their model that seek to expand and connect the self-advocate network across Alaska, including the Key Campaign and Peer Power Self-Advocacy Summits. These events will also drive sustainability by supporting policies and statutes that will outlast the Living Well grant. The team is also working to build the capacity of the HCBS system in Alaska by supporting and implementing new trainings for DSPs, co-led by self-advocates. Through these trainings, the team hopes to build the skills of DSPs related to person-centered practices and supported decision-making to improve health and safety and increase independence and self-determination of individuals who experience I/DD.

Grantee Spotlight: Idaho Center on Disabilities and Human Development

Background

The Idaho Living Well grant is held by the University of Idaho Center on Disabilities and Human Development. The Idaho Living Well team puts the voices and needs of people with disabilities at the forefront of all their project activities. The Idaho Living Well project aims to empower individuals with disabilities through the contribution of self-advocates in leadership positions and their involvement in all decision-making activities.



The Living Well team leveraged and aligned with the efforts of the self-advocate led statewide Community NOW! (CNOW!) stakeholder group. The group initially was formed in response to a [class-action lawsuit](#) (K.W. vs. Armstrong) that sought to increase the transparency of the Medicaid resource allocation tool for individuals with disabilities and improve the quality of HCBS within the state. CNOW! utilizes the leadership of self-advocates and the active participation of family members, direct support professionals, providers, and state representatives to develop a number of trainings and topic-specific workgroups.

Overview

Through CNOW!, a number of topic-specific workgroups were born. The Self-Advocacy Training Workgroup meets monthly to build the framework for a self-advocacy training program. This group developed a description of the self-advocate training model, a job description for the training coordinator, the self-advocate trainer job description, interview questions, and a self-advocate trainer application. One purpose of the training is to help individuals learn about the person-centered planning process, build skills to advocate for their goals and preferences, and become more active in developing and implementing their individual service plans.

The Quality Assurance Abuse and Neglect Reporting and Monitoring Workgroup, a workgroup under the CNOW! stakeholder group, aims to prevent abuse, neglect, and exploitation by creating self-advocate informed community-based reporting and monitoring as a component of a larger quality assurance system. The workgroup provided a platform for individuals with I/DD to share their experiences and concerns with the reporting and monitoring system within the state, and works with these individuals to change the system in a manner that most justly serves them.

The Advocate Advisory Committee, a group comprised of self-advocates and family members, reviews and provides feedback on all resources and recommendations produced by these workgroups to ensure that recommended process and systems changes clearly benefit those using HCBS.

The Idaho Living Well team additionally collaborates with the Culturally Responsive Action Group (CRAG), a workgroup of self-advocates and family members from the Latinx community, to ensure that the service systems recommended are culturally and linguistically competent. Members of the CRAG have provided valuable input into the proposed criteria for becoming a person-centered plan facilitator.

Intended Outcomes

The Idaho Living Well team demonstrates their commitment to supporting and empowering individuals with I/DD across their grant activities. As self-advocates hold leadership positions and provide guidance and feedback throughout each stage of grant activity, the team is able to ensure the voices of self-advocates are heard and their needs addressed. Through their workgroups, the team convenes self-advocates and key stakeholders to collaborate and work toward specific goals.

The objectives of the Self-Advocacy Training group are to deliver sustainable, accessible trainings for DSPs taught by self-advocates, family members, and professionals and 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. By working with the CRAG, the team increased the level of cultural awareness and created a more accessible and culturally competent environment for those with diverse backgrounds interacting within the service system. The creation of a self-advocate led, community-based reporting and monitoring system that reduces the risk of abuse and neglect to people with disabilities, improve capabilities of direct support staff through self-advocate led trainings, and the development of culturally competent and person-centered resources and tools.

Summary

Alaska's and Idaho's Living Well teams both created unique models to support individuals with I/DD within their respective states. Similarities between these models include the engagement of self-advocates in leadership positions, inclusion of cultural competency and person-centered practices, and the development of trainings to support self-advocacy. The Alaska and Idaho Living Well teams' initiatives, in their individual and comparative capacities, promote ACL's vision for a self-empowered life for individuals with I/DD.