

Living Well 2020 Cross-Site Evaluation

ALASKA Living Well Grantee Profile



The Alaska [Governor's Council on Disabilities and Special Education](#) (the Council) received the five-year Living Well grant in 2018.

2018 – 2019	2019 – 2020	2020 – 2021	2021 – 2022	2022 – 2023
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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

1 Larson, S.A., Eschenbacher, H.J., Anderson, L.L., Taylor, B., Pettingell, S., Hewitt, A., Sowers, M., & Bourne, M.L. (2018). In-home and residential long-term supports and services for persons with intellectual or developmental disabilities: Status and trends through 2016. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

2 Human Services Research Institute (HSRI) and National Association of State Directors of Developmental Disabilities Services (NASDDDS). (2019). National Core Indicators In-Person Survey: 2017-2018 Final Report.

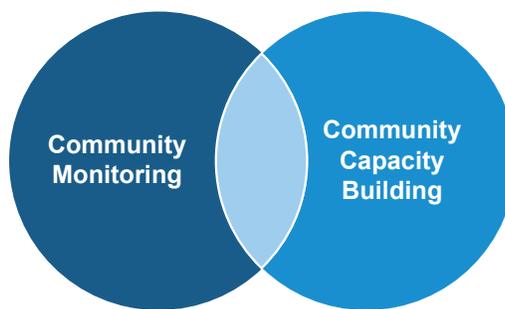
3 Office of Inspector General, Department of Health and Human Services. (2016). Massachusetts did not comply with federal and state requirements for critical incidents involving developmentally disabled Medicaid beneficiaries.

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.

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;

- **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.⁵

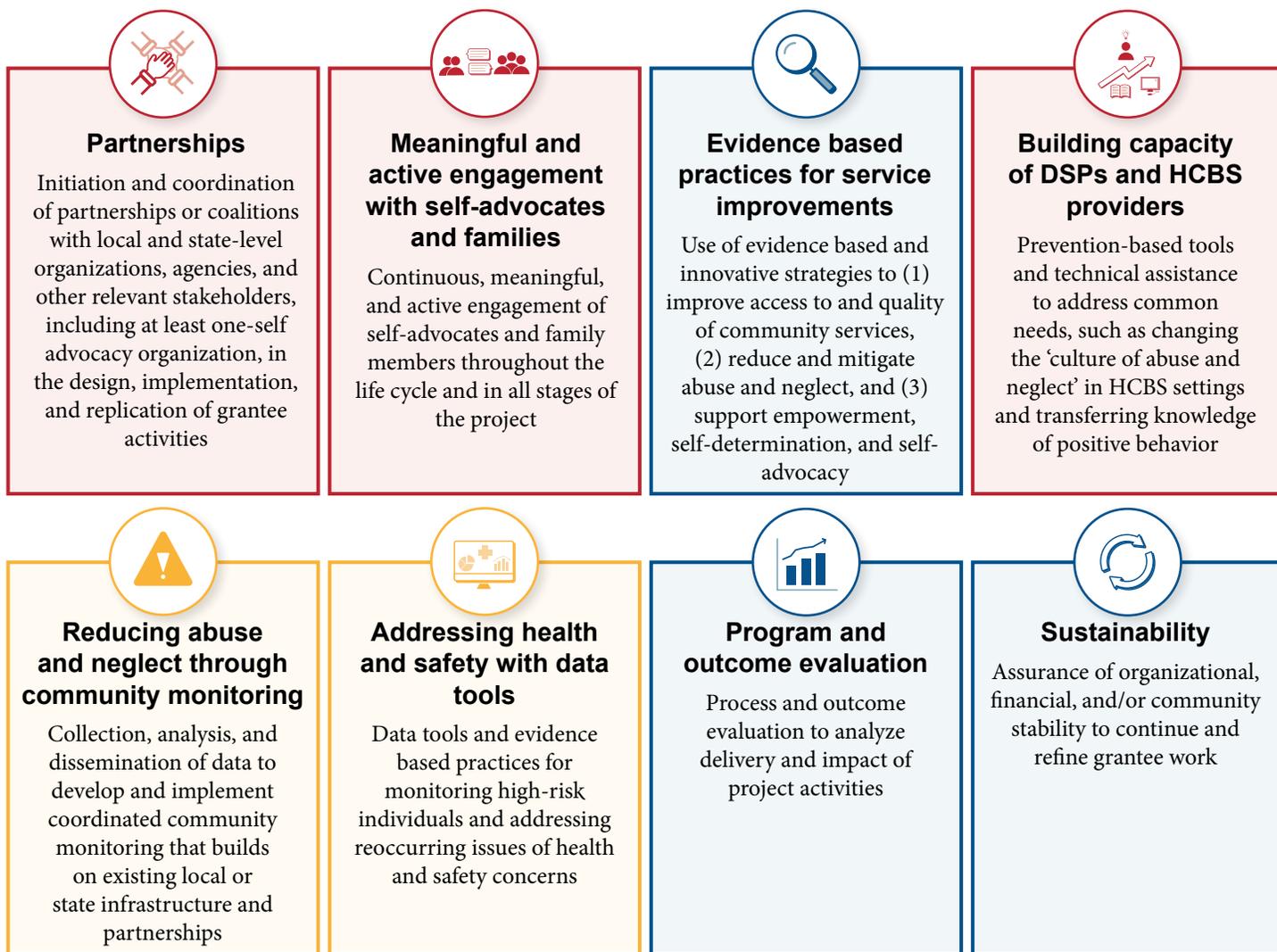
Exhibit 1. Core Components of Living Well Models



III. Eight Key Features

Grantees incorporate eight key features into their Living Well models.

Exhibit 2. Eight Key Features of Living Well Models



⁵ 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>

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

2017	1	Cohort 1	2018	2	Cohort 2
		University of Georgia Institute on Human Development			Alaska Governor's Council on Disabilities and Special Education
		University of New Hampshire Institute on Disability			University of Idaho Center on Disabilities and Human Development
		Virginia Commonwealth University Partnership for People with Disabilities			Indiana Family and Social Services Administration
					University of Missouri-Kansas City Institute for Human Development
					Wisconsin Board for People with Developmental Disabilities

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.

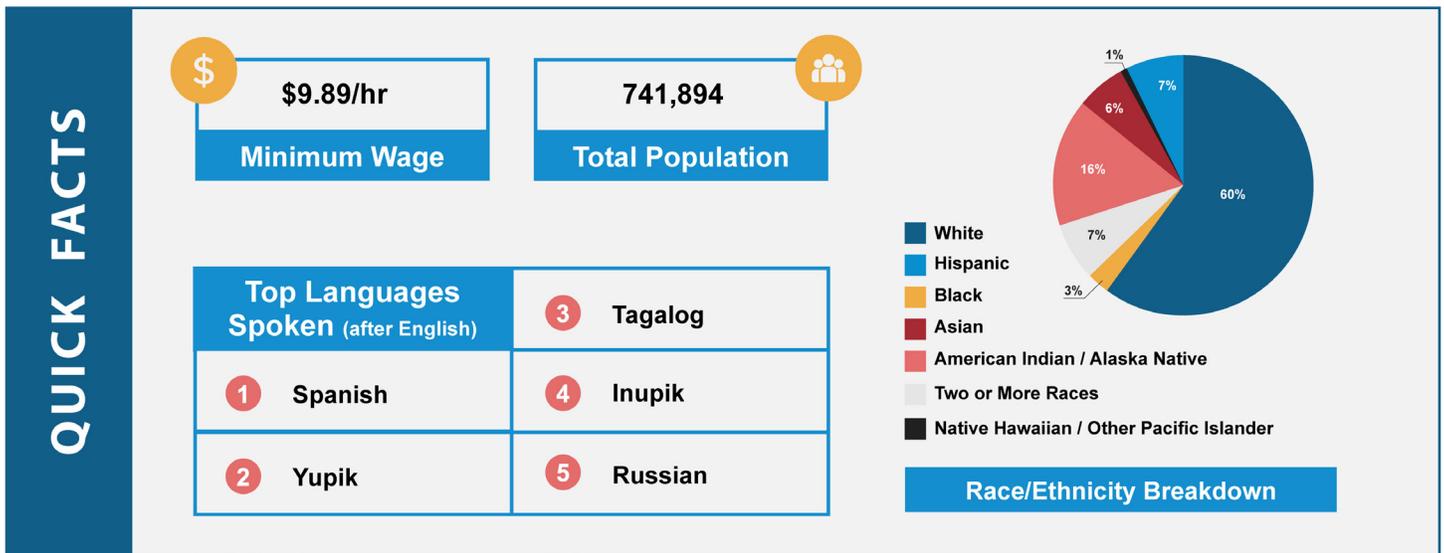
V. Grantee Information

The Council, started in 1975, comprises 26 members and serves a variety of state and federal roles. These 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 organization works towards systems change in areas including early intervention, independent living, inclusion in the community, education, employment, health, and self-directed lives with meaningful choices. The Council oversees a variety of initiatives in projects to improve the lives of people with disabilities in Alaska. These include emergency preparedness activities, including development and distribution of toolkits; supported decision-making agreements, which give people the help they need to make choices about their lives; and self-employment grants, which are available to qualifying people with disabilities.

VI. Grantee Partnerships

The Council partners with key stakeholders on their Living Well grant (collectively, the Alaska Living Well team) including, but not limited to, the Alaska Association on Developmental Disabilities, Disability Law Center of Alaska, State of Alaska Senior and Disability Services, and the University of Alaska Anchorage Center for Human Development.



VII. State Context

Variations in access to quality home and community-based services (HCBS) occur, in part, due to varying demographic, economic, political, and historical factors in each state. Key contextual factors are described here to better understand the Council's external conditions for their Living Well model. The COVID-19 pandemic rapidly evolved during the 2019-2020 evaluation cycle with significant impact on the delivery of HCBS and the health and safety of individuals with intellectual and developmental disabilities (I/DD). The pandemic response influenced both how and the extent to which grantees implemented grant activities as planned and the local and state context in which the grant is being implemented.

In Alaska, there are consistent challenges with the state budget, and budget uncertainty was exacerbated by COVID-19. The Alaska Living Well team anticipates more budget cuts, especially with the impact of COVID-19 on the tourism industry, which accounted for more than \$126 million in state revenues and \$88 million in municipal revenues in 2018.⁶ Revenue generated from tourism is used to fund services across the state, including services for people with disabilities. To mitigate this budget issue, the Alaska Living Well team continues to provide recommendations for cost savings to state agency leadership.

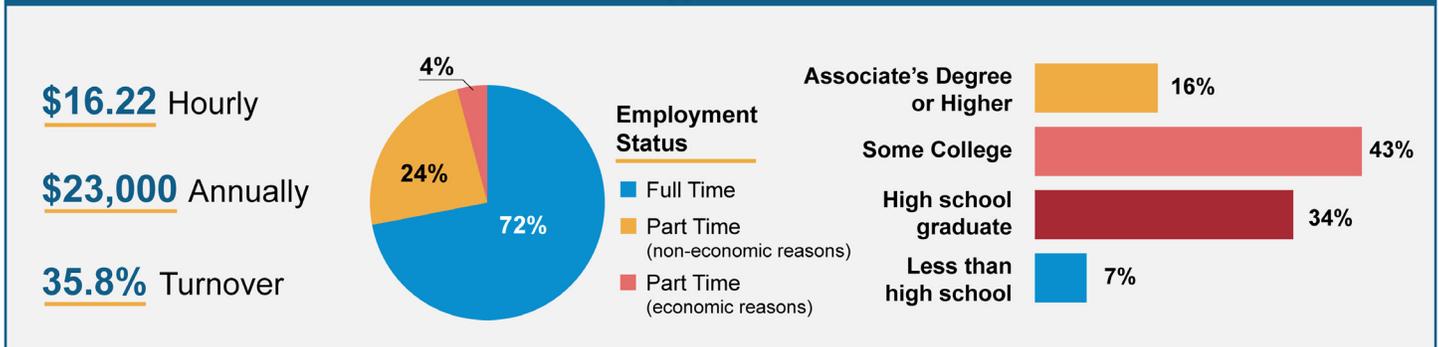
Several efforts to improve access to and quality of HCBS in Alaska are delayed. While implementation of some plans is delayed and impacted by budget cuts, Alaska Living Well staff are optimistic that a continued focus on person-centered care will increase awareness that individuals can direct their own plans.

⁶ Alaska Resource Development Center. (2020). *Alaska's Tourism Industry*. Retrieved from <https://www.akrdc.org/tourism>.

STATE CONTEXT IN ALASKA

I/DD Services in Alaska	Health & Safety of Individuals with I/DD
<p>2,636 served by DD agency 906 on waiting list</p> <p>0.3553% of state I/DD population</p> <p>64.1% of LTSS that is HCBS</p> <p>22.8% of I/DD spending used for family support and supported living</p> <p>\$258.42 State HCBS expenditure</p>	<p> N/A reported poor health</p> <p> N/A reported feeling unsafe</p>

Direct Support Workforce



VIII. Model and Objectives

The [Alaska DD Systems Collaborative](#), comprised of stakeholders from across the state, developed a shared vision statement for the DD system in Alaska: “Alaskans share a vision of a flexible system in which each person directs their own supports, based on their strengths and abilities, towards 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 aligned their Living Well objectives with the DD systems shared vision to most effectively impact change in parallel with other systems work. In order to build towards system alignment with the vision, the Alaska Living Well team is working with stakeholders to target three groups: individuals with I/DD and their families, service providers, and policymakers. These three groups provide valuable insight to inform best practices for systems alignment and priority setting.

The Alaska Living Well team’s model objectives are to:

1. Enhance the health and safety of individuals who experience developmental disabilities by increasing their independence, self-determination, community integration, employment, and participation;
2. Strengthen the knowledge and skills of direct support professionals (DSPs) to use evidence based and/or promising practices related to culturally and linguistically person-centered thinking and supported decision-making which may improve workforce stability, retention, and advancement;
3. 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; and
4. Enhance the effectiveness and coordination efforts by the state, the DD Act network and others to implement the HCBS settings rule and address rights violations in the HCBS delivery system for people with developmental disabilities.

IX. Key Activities by Core Components

A. Community Monitoring

Community Monitoring includes efforts to develop a comprehensive system to monitor the health and well-being of individuals with I/DD living in a variety of home and community-based settings. The following are key activities reported by the Alaska Living Well team during this evaluation period to address this core component:

Key Activity: Use National Core Indicators (NCI) Survey Data



- Alaska received approval to add questions to their NCI survey to gauge the person-centeredness or person-directedness of the existing emergency plans and ensure that emergency plans reflect the needs of individuals.
- The Alaska Living Well team is participating in a pilot from NCI to complete a remote version of the NCI survey to determine if remote administration of the survey is viable.

Key Activity: Conduct DD Systems Alignment Survey



- In collaboration with the Alaska University Center for Excellence in Developmental Disabilities, University of Alaska Anchorage Center for Human Development (Alaska UCEDD) and the DD Collaborative, the Alaska Living Well team developed a new survey designed to measure the state's overall DD systems alignment to the vision. One version of the survey is specific to individuals with I/DD and uses plain language; the other version is specific to family members, providers, and other stakeholders with more detailed language. Baseline data from the survey included responses from 48 self-advocates and 69 other stakeholders.

B. Community Capacity Building

Community Capacity Building includes efforts to increase the skills and knowledge of all individuals, families, and service providers in the HCBS system. The following are key activities reported by the Alaska Living Well team during this evaluation period to address this core component:

Key Activity: Participate in 2020 Key Campaign



- The Alaska Living Well team collaborated with self-advocates and other stakeholders to develop four documents for Alaskan legislators as part of the 2020 Key Campaign in Juneau. The Alaska Living Well team and other grant partners also produced a webinar series focused on supporting self-advocates ahead of the [Key Campaign](#) legislative visits 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.

Key Activity: Implement a Series of DSP Trainings and Capacity Building Activities



- The Alaska Living Well team continued to work with the Alaska UCEDD and the 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.
- The Alaska Living Well team and the Alaska UCEDD also developed and implemented an additional training module for DSPs and care coordinators. The training, which was also developed to be user-friendly for use by families, focuses on blending paid and unpaid supports for individuals strengthening their ability to live meaningful lives

through community integration. The training was delivered through three webinars, which each had an average of 92 registrants.

- The Alaska Living Well team partnered with the Alaska UCEDD to increase cultural and linguistic competence among Alaska's DSP workforce. The Alaska UCEDD contracted with the National Center on Linguistic and Cultural Competency to develop and deliver a four-part webinar series training. The training was designed to help Alaskan organizations and leaders identify ways to increase the cultural and linguistic competence of their services to individuals with I/DD and their families.

Key Activity: Implement Community Relationship Building Program Pilot



- The Alaska Living Well team collected feedback from the pilot cohort of the Community Relationship Building Program, a pilot funded by and existing within the Hope Community Resources, a provider agency. The pilot included training for all supervisors and DSPs at Hope Community Resources to understand the key concepts of support and how implementation supports meaningful lives. Pilot participants reported satisfaction with engagement and content.

Key Activity: Plan Supported Decision-Making Agreements Communication Pilot



- The Alaska Living Well team continued to plan the Supported Decision-Making Agreements (SDMA) Communication Pilot with Arc of Anchorage and Adult Protective Services, and ATLA, the assistive technology agency for the state, to improve first-person fact reporting to state agencies. The pilot design will assess the accuracy of receptive communication among individuals who use assistive technology or a supporter for communication. SDMAs outline a description of a supporter's assistance. The expected outcomes of the pilot are recommendations for policies, procedures, and training on effective communication with people who use supports and SDMAs.
- The Alaska Living Well team continued to share best practices around SDMAs nationally. As part of this effort, the team provided resources from Alaska's experiences. Alaska's work was highlighted in two American Bar Association Commission on Law and Aging reports.^{7,8}
- During this reporting period, there were 17 SDMAs in Alaska with five in the queue. The SDMAs are expected to live beyond the Living Well grant period, and the Alaska Living Well team is exploring ongoing funding strategies to continuing developing SDMAs. The Alaska Living Well team will develop a toolkit based on findings from the pilot, which will broadly support agencies communicating with people with disabilities.

Additional Activities:

- Partner with Peer Power Alaska: The Alaska Living Well team supported Peer Power Alaska, a statewide self-advocacy group, in facilitating monthly webinars with self-advocates and care coordinators and planning the annual Self-Advocacy Summit.
- Develop HCBS Plan of Care Training Framework: The Alaska Living Well team developed a training framework, which included person-centered emergency plans and goals around health, safety, and employment, to enhance the HCBS waiver plan of care process. The team offered four webinars online during summer 2020.
- Disseminate Employment Handbook: In partnership with the Division of Vocational Rehabilitation (DVR), the Alaska Living Well team disseminated 3,000 copies of the *Alaska Transition Handbook: Pathway to Adulthood and Employment* to all 54 school districts statewide.

7 American Bar Association (2020). *Supporting Decision-Supports Across the Age Spectrum: Final Report*. Retrieved from https://www.americanbar.org/content/dam/aba/administrative/law_aging/2020-supporting-decision-making-final-report.pdf.

8 American Bar Association (2020). *Supporting Decision-Supports Across the Age Spectrum: Supplemental Materials*. Retrieved from https://www.americanbar.org/content/dam/aba/administrative/law_aging/2020-decision-supports-forums-supplemental-materials.pdf.

X. Analysis and Conclusion

A. Contextual Factors

As with many other states, the impact of COVID-19 changed the way the Alaska Living Well team executed their Living Well activities. Alaska is a state consistently affected by budget cuts, and the pandemic presented even more competing priorities for state agency funding. The team's ability to remain proactive, partially due to their experience with budget restraints in the past, enabled them to efficiently provide recommendations for cost-savings in other areas to ensure critical services remain intact. These skills transcend the Living Well grant and offer promise for funding security even after the grant ends.

B. Model Design

The existing Alaska DD Systems Collaborative brings together a variety of key stakeholders; the Alaska Living Well team directly benefits from this group and may facilitate Living Well initiatives and goals through an existing infrastructure as opposed to creating a new one. In addition, the distinct focus on systems alignment via the shared vision serves as a direct mechanism for long-term impact. By focusing on engagement of individuals with I/DD and their families, service providers, and policymakers, the Alaska Living Well team maximizes the spread of information on Living Well grant activities, facilitates a platform to achieve grant objectives, and builds towards the agency alignment goal.

C. Key Activities

The Alaska Living Well team implements activities that are designed with person-centeredness and lived experience in mind, with consistent engagement of self-advocates and family members. The Alaska Living Well team facilitates systems change from the ground up by providing self-advocates a platform to share their goals and any areas of need with providers, care coordinators, and policymakers. The Alaska Living Well team also aims to lay the groundwork for long-term change, including through policy recommendations, resource development, and other capacity building efforts. To support scalability and sustainability, the team documents best practices and holds conversations with other agencies to secure additional funding post-Living Well grant. As a whole, the Alaska Living Well team implemented a variety of activities to measure progress, expedite cross-systems collaboration, and ultimately impact the HCBS system. These in turn influence key stakeholders' decisions and align outcomes with goals to support people with disabilities in achieving meaningful lives.