Moving Forward

FINAL REPORT | **MARCH 2025**

Evaluation of the
Hawaii Developmental Disabilities Division

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Contents

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Gratitude

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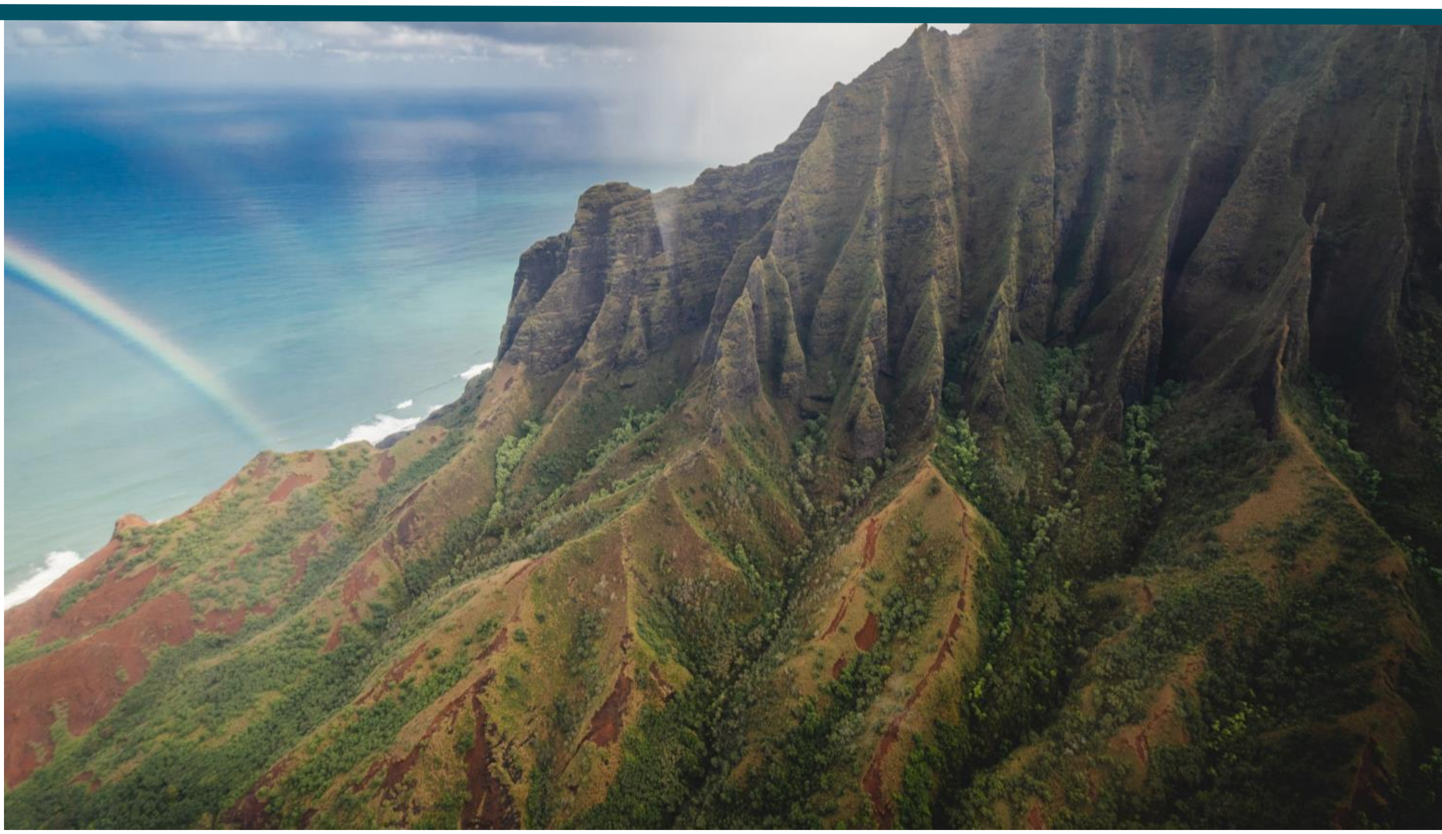

Executive Summary

The Hawaii Department of Health’s Developmental Disabilities Division (DDD) has undertaken a series of initiatives since 2015 to enhance services for individuals with intellectual and developmental disabilities (IDD). These efforts aimed to improve service delivery, increase person-centered approaches, and optimize operational efficiency. DDD contracted the Human Services Research Institute (HSRI), in collaboration with Burns & Associates (a division of Health Management Associates) and the Center on Disability Studies at the University of Hawaiʻi Mānoa, to evaluate the effectiveness of these initiatives and identify opportunities for future improvements.

Background and System Overview

DDD is responsible for administering a statewide system of services for individuals with IDD. These services are primarily delivered through a Medicaid Section 1915(c) home and community-based services (HCBS) waiver. The evaluation focused on understanding the factors driving system changes, assessing their impact, and identifying areas for further development.

Guiding Questions

DDD supplied a list of questions to guide the evaluation. Our research activities centered around answering these questions in ways that revealed the extent to which DDD had achieved desired outcomes.

- How well is DDD meeting the requirements of the federal Centers for Medicare and Medicaid Services (CMS) mandate for increased community integration?
- How has the quality of service plans and the service planning process changed?
- What has been the impact of changes on service utilization and utilization patterns?
- What impact have new payment rates and rate structures had?
- How has service quality changed?
- How well and what impacts have there been in relation to implementation of the Supports Intensity Scale - Adult (SIS-A) assessments and individual supports budgets?
- What are the outcomes for DDD participants?
- How well have intended goals of the initiatives been achieved?

In addition to the list above, the research team also posed the following question for further analysis:

- To what extent are engagement activities, communications, and strategies effective?

Strengths and Challenges

The evaluation identified a number of strengths that played a role in supporting forward momentum.

Dedicated Leadership. The core DDD leadership team — including members of the DDD Administration, Case Management Branch, Community Resources Branch, Outcomes and Compliance Branch, and Hospital & Community Dental Services Branch — led the changes to the IDD HCBS waiver alongside other aligned initiatives. They were guided by a strategic vision, a commitment to progress, and building accountability across the system. Many members of the DDD leadership with whom we spoke have

Expert Assistance. DDD has been successful in securing additional resources through contracting and other opportunities to receive guidance and technical assistance from experts in the IDD field. These resources helped to support the state staff to plan and implement processes to align with regulatory requirements and best practices.

Collective Care as a Cultural Value. Embedded in the culture in Hawaii is a recognition of the importance of the collective well-being of family and community. The service system has embraced supporting people with IDD to live with immediate family, extended relatives, or in family home-like settings.

We also found that DDD faced significant challenges.

Staffing Shortages. DDD has encountered significant staffing shortages. At one point, DDD reported to have about a 30 percent vacancy rate among state staff. Staffing shortages and staff turnover at times constrained DDD’s ability to prioritize systems change.

Enduring Emergencies. The COVID-19 pandemic greatly impacted the DDD system. Particularly during the first year of the pandemic, health and safety protocols evolved rapidly to protect participants, families, and the provider network, and to comply with public health mandates. While this evaluation was being conducted, in August 2023, Hawaii suffered another emergency with the Maui wildfires, which caused extensive destruction. Efforts to recover from the Maui wildfires continue to this day.

Changing Expectations. What constitutes best practice in supports and services for people with IDD are shaped in part from the ground up, by the demands from people with disabilities and their families, and from the top down, including regulations issued in 2014 by CMS regarding home and community-based settings through the Settings Rule. These expectations stem from the assertion that people with IDD have the right to live a life like anyone else as valued members of communities. However, the realities of the pace and effort required to institute new policies and practices that support these changing expectations may have contributed to a sense of resistance to change among various communities.

Key Takeaways

The information collected during this evaluation revealed a few key takeaways:

- Recognizing the unique landscape and cultural values in the state is critical to understanding the past and future of supports for people with IDD and their families in Hawaii.
- Improving system operations to efficiently allocate resources across the waiver program and design adequate rates of reimbursement through a comprehensive rate study resulted in major system improvements including productive deliberations with the Hawaii State Legislature about funding levels necessary to sustain and improve the supports and services available to people with IDD and their families, which supported an infusion of resources into the system.
- Embarking on an ambitious path to address several parts of the system simultaneously required focused effort, detailed policy decisions, and frequent reprioritization to manage.
- Pursuing this level of systems transformation felt challenging for some within DDD including case managers as well as the larger IDD community such as providers, caregivers, family members, and participants due to the pace and complexity of the initiatives involved.

Initiatives and Findings

We worked with DDD to identify 16 key initiatives to be included in this study. The list of initiatives was organized under five major headings: (1) community engagement, (2) community access and person-centered practices, (3) services and provider network, (4) system operations and oversight, and (5) modernization and innovation. The project team created these larger categories to group similar initiatives and better support the depiction of the findings and recommendations.

This evaluation also considered initiatives funded through the federal American Rescue Plan Act (ARPA) designed to support economic recovery during and following the COVID-19 pandemic. Section 9817 of ARPA provided a temporary increase in federal funding to enhance, expand, or strengthen home and community-based services. DDD's plan for these funds was developed through a collaborative process involving the IDD community. The resulting plan included 14 initiatives grouped into five priority areas shown below. This offered a unique opportunity for DDD to build on the work already underway to make further improvements to the system on an expedited timeline.

Priority 1: Supports for Participants and Families

- Option for Individuals with Behavioral Challenges
- Family-to-Family Peer Mentoring Service
- Host Participant and Family Forums

Priority 2: Strengthen Provider Capacities and System Infrastructure

- Increase Provider Payment Rates
- Invest in Quality Management
- Support Community Integration
- Advance Competitive Integrated Employment (CIE)
- Support Community Navigator Practice Development

Priority 3: Workforce Development

- Develop the Direct Support Professional Workforce

Priority 4: Improve Protections for Health, Safety and Well-being

- Positive Approaches for Challenging Behaviors
- Improve Critical Incident Response through Analytics

Priority 5: Strengthen System Infrastructure and Accountability

- Conduct System Evaluation
- Strengthen Provider Monitoring
- Implement the Spending Plan

The following presents a brief description of the evaluation findings and opportunities for DDD to consider. Appendix A provides a summary table of this information.

Community Engagement

The overall intent behind DDD's engagement initiatives was to ensure that people were informed about changes that were happening, understood how the changes would impact them, and had opportunities to provide feedback to DDD along the way. In this section we sought to answer the question: *To what extent were engagement activities, communications, and strategies effective?*

We found that there were several ways that DDD shared information with the community and received feedback, particularly related to large-scale changes like the HCBS Settings Rule. In general, this is an area where states recognize that outreach and engagement require ongoing commitment and improvement.

Summary Findings:

- ► Successful engagement was noted around systems change activities among advisory groups and those with an established connection with DDD.
- ► Ongoing communications will require consistency in methods and messaging.

Based on these findings we offer several strategies for enhancing communication:

- Establishing consistent communication with case managers,
- Working alongside the advocacy community,
- Employing people with lived experience to design inclusive communications, and
- Building partnerships with agencies or communities that are not currently connected with DDD.

Community Access and Person-Centered Practices

DDD endeavored to adopt person-centered approaches at every level including leadership, case management, and service provision. In 2014, the federal Centers for Medicare and Medicaid Services (CMS) issued new regulations to enhance the quality of services and provide additional protections for individuals receiving home and community-based services through the HCBS Settings Rule. DDD sought to align services with the HCBS Settings Rule and emphasize person-centered approaches. In this section we studied DDD's activities around the HCBS Settings Rule, person-centered planning initiatives, and the addition of the Community Learning Service to support community access. Our research activities in this section centered on answering the following questions: *How well is DDD meeting the requirements of the federal CMS mandate for increased community integration? How has quality of service plans and the service planning process changed?*

Summary Findings:

- ► Technical requirements of the HCBS Settings Rule were successfully met but work with the community is still needed to promote participant choice and control.
- ► Commitment to person-centered principles was evident but will require consistent effort.

Based on these findings we offer these opportunities for consideration:

- Enhance methods to support community access through strategies such as community asset-mapping, and
- Bolster person-centered practices through ongoing training for case managers, service providers, participants, and families on person-centered practices and Charting the LifeCourse principles for planning and problem-solving.

Services and Provider Network

DDD made significant changes during the 2016 reauthorization of the IDD waiver to support community integration, strengthen employment supports, and ensure the rights of waiver participants particularly through eliminating the use of seclusion. DDD used this opportunity to stabilize the service network to improve the quality and accessibility of IDD services. In this section we studied waiver service array and rates and payment structures to answer the following questions: *What has the impact of changes been on service utilization and utilization patterns? What impact have new payment rates and rate structures had? How has service quality changed?*

Summary Findings:

- ► Changes to the service array have supported a significant level of access to the community.
- ► Updates to the rates were well received among the provider community. The provider network remained stable throughout the evaluation period, although there are a limited number of providers outside of Oahu.
- ► The wages of direct support professionals increased markedly in recent years, which contributed to reduced turnover rates.

Based on these findings we offer the following ideas to continue to support community access and the provider network:

- Reevaluate the intended purpose of Community Learning Services and provide training and education as needed,
- Continue to ensure adequacy of provider payment rates,
- Implement the DSP certification framework that is in development, and
- Consider additional services like shared living and family to family networking

System Operations and Oversight

DDD has invested in expanding access to home and community-based services for individuals with IDD, streamlining eligibility processes, and enhancing service delivery systems. Included in this section are those initiatives closely aligned with enhancing system operations such as assessment processes, managing distribution of resources through individual supports budgets, managing exceptions and utilization review processes, supporting quality assurance/quality improvement plans, and streamlining eligibility and enrollment processes.

In this section we explored the question: *How well and what impacts have there been in relation to implementation of the Supports Intensity Scale – Adult (SIS-A) assessments and individual supports budgets?*

Summary Findings:

- ► New methods for assessments, allocating resources, and managing exceptions were successfully implemented.
- ► Certain policies and practices need refinement and support with ongoing communication.

Based on what we learned, we offer the following considerations:

- Increase assessment capacity by identifying additional local SIS-A assessors, refreshing scheduling protocols, and continuing to monitor assessor quality,
- Refine the individual supports budget process to include sharing information about the supports budget with participants and families, and clarifying policies and procedures around budget exceptions, and
- Reset the quality assurance and improvement plan to align with the initial process and strategy.

Modernization and Innovation

Some initiatives were aimed at supporting modernization through technology, engagement with national consultants, and research into best practices employed by other states to shift expectations and increase choice and control for people with IDD. In this section we reviewed the development of the INSPIRE IT solution, and employment first activities. We sought to answer the question: *What are the outcomes for DDD participants?*

Summary Findings:

- ► New IT solution (INSPIRE) created efficiencies in case management practices, and data collection and reporting.
- ► Efforts to promote employment have promise but have yet to show significant gains in people using employment services or having community jobs.

Based on these findings we offer the following for consideration:

- Continue data-informed practices to prepare for the upcoming HCBS ACCESS Rule requirements, and
- Scale up promising practices learned through the ARPA employment initiative to support employment goals.

In addition to laying out the findings of this evaluation based on an exploration of qualitative and quantitative data, we hope to tell the story of the evolution of this system over the past several years. Behind all these efforts are the people who are committed to pushing the system forward to better support people with IDD and their families to have full lives in their communities. Continuing the forward momentum will require striving to maintain the balance between pursuing system advancements and ensuring meaningful dialogue with the community including people with IDD, family members, service providers, and others in ways that feel supportive and aligned with common goals.

Background

The Hawaii Department of Health's Developmental Disabilities Division (DDD) implemented a series of initiatives starting in 2015 to modernize the system of support for people with intellectual and developmental disabilities (IDD) and to improve the experience of those who rely on these supports. The Human Services Research Institute (HSRI), in collaboration with Burns & Associates (a division of Health Management Associates) and the Center on Disability Studies at the University of Hawaiʻi Mānoa, were contracted to evaluate the effectiveness of these reforms and describe opportunities for DDD to consider.

We used a data-driven mixed-methods approach, combining quantitative and qualitative methods, to analyze the impacts of the initiatives undertaken from 2015 through 2024. This included a review of the system's strengths, assets, limitations, and challenges. Our purpose was to gauge the impacts of initiatives undertaken by DDD — including activities funded through the federal American Rescue Plan Act (ARPA).

We began by studying the basic elements of Hawaii's system of support for people with IDD and the impetuses for the changes pursued by DDD. This section provides an overview of the key elements of the service system, summary statistics, policy intentions, and the initiatives undertaken from 2015-2024 to modernize the system, and the questions that DDD sought to answer with this evaluation.

Overview of the DDD Service System

DDD is charged with establishing a system and conditions for the provision of services for people with a developmental or intellectual disability (§11-88.1-1, HAR). Stemming from its statutory charge, DDD's mission is to administer a statewide comprehensive system of services for persons with IDD based on the principles of self-determination, quality of life and person-centered planning.[1] DDD carries out its mission:

- as the operating agency for the state's Medicaid Section 1915(c) Home and Community-Based Services Waiver (HCBS) for individuals with IDD;
- through the operation of a Neurotrauma Program that provides education on neurotrauma, assists individuals and families to identify and obtain access to services, and maintains a neurotrauma registry through the Neurotrauma Special Fund; and
- through the provision of Hospital and Community Dental services for populations with

Policy decisions over time have shaped the nature and availability of service options for people with IDD. In 1999, Hawaii was among the first 10 states in the nation to close its state-operated institution for people with IDD (the Waimano Training School and Hospital). Most Waimano residents relocated to adult foster homes and licensed group homes, also called developmental disability domiciliary homes. During our interviews, we learned that many of these homes were, and continue to be, operated by staff who formerly worked at the Waimano Training School and Hospital. While the institution's closure predates the period under review in this evaluation, it is a significant reference point because it impacted the HCBS system that was established.

Around 2014, a new organizational structure was established within DDD with four distinct branches: Case Management, Community Resources, Outcomes and Compliance, and Hospital and Community Dental Services. Many of the initiatives included in this evaluation were spearheaded by the DDD administrator and the DDD leadership team, which included branch chiefs and other key staff members. This evaluation considers only the 1915(c) HCBS waiver,[2] which DDD operates through a memorandum of agreement with the Hawaii State Department of Human Services, Med-QUEST Division (MQD; the Hawaii State Medicaid agency).

For people with IDD who meet specific level of care criteria, waiver services are available. To be eligible for waiver services, a person must meet all of the following:

1. Have a diagnosis of intellectual disability or a related condition before the age of 22.
2. Have substantial deficits in at least three areas of adaptive functioning.

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[1] STATE OF HAWAII

[2] HI HCB Services for People with Intellectual and Developmental Disabilities (I/DD) (0013.R08.00) | Medicaid

3. Their impairment cannot be primarily from dementia, mental illness, emotional disorders, substance abuse, sensory impairment, learning disabilities, attention deficit hyperactivity disorder, spinal cord injuries, or neuromuscular disorders.[3]

All individuals enrolled in the waiver receive case management services to establish individual service plans, authorize services, and connect individuals to available resources provided by DDD. DDD currently has approximately 80 case managers assigned to one of 15 regionally based case management units (CMUs), including eight CMUs on Oahu, three on the Big Island, and one each for Maui, Lanai (covered under Maui), Molokai, and Kauai. While caseloads may fluctuate, the average caseload is approximately 35 participants per case manager. According to a national study completed in 2019, this is slightly above the mean of 31 individuals as reported by IDD service directors who responded to a survey.[4] In that same study IDD service directors reported that the optimal caseload size would be around 24.

Figure 1: Map of Hawaii

Participants receiving DDD services represent many ethnic groups and cultures. As just one indication of Hawaii's diversity, the DOH/DDD's list of common languages in the state includes Ilocano, Japanese, Korean, English, Tagalog, Chinese, Spanish, Vietnamese, Marshallese, Hawaiian, Samoan, Laotian, Micronesian (Pohnpeian), Trukese (Chuukese), Tongan: Fakatokanga'i, and Bisayan (Cebuano). In light of this diversity, throughout the evaluation we looked for potential variability in circumstances, resources, and experiences that may exist across the islands and may be due to

What follows is a review of selected summary statistics within three categories: (1) trends in service users and spending from FY15 to FY23, (2), living arrangement options, (3) and day services and competitive employment services.

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[3] https://health.hawaii.gov/ddd/files/2014/12/HAR-88-1.pdf

[4] Bogenschutz MD, Dinora PA, Johnson KR. Case Management Workforce Supporting People With Intellectual and Developmental Disabilities: Indications of a New Frontier of the Workforce Crisis. Intellect Dev Disabil. 2019 Dec;57(6):499-511. doi: 10.1352/1934-9556-57.6.499. PMID: 31751173.

Summary Statistics

The number of service users generally trended upward from FY15 through FY20. The COVID-19 pandemic resulted in an 8 percent decrease in service users in FY21, with Adult Day Health (ADH), Community Learning Service – Group (CLS-G), and employment services being the most impacted. As of FY23, the number of service users had yet to recover to pre-pandemic levels.

DDD does not have a waitlist for waiver services. The service system experiences an average increase of 35 participants per year; on average, about 120 participants stop receiving services annually while approximately 155 participants start receiving services. This number does not tie to enrollee figures as some participants are shown as enrolled but did not have any services during a year.

Total spending increased substantially between FY15 and FY23, from $102 million to $160 million, an average growth rate of 5.8 percent per year. These increases were driven primarily by rate increases; however, caseload and utilization growth also had an effect.

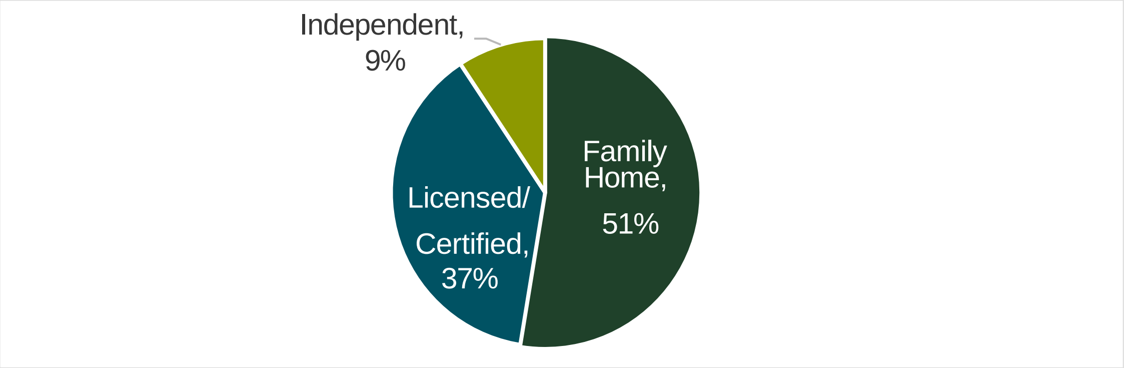
Table 1: Number of Total Service Users and Total Spending from FY15 to FY23

	FY15	FY16	FY17	FY18	FY19	FY20	FY21	FY22	FY23
Total Service Users	2,719	2,746	2,852	2,839	2,830	2,842	2,610	2,660	2,688
Total Spending (Million)	$102	$107	$111	$124	$141	$~~130~~	$130	$144	$160

As shown in Figure 2, in FY23 approximately half (51 percent) of participants with IDD live with family. The advisory group assembled for this project shared that the cultural values in the state include an expansive view of family and collective care. Ohana, or family, often includes the concept of extended family. There is also a sense of caring for one another as both a privilege and a responsibility. The lines between formal and informal supports at times appear to blend. For example, a person with IDD who lives in an adult foster home setting may use terms like “aunty” and “uncle” to refer to their caregivers even if they are not related.

> “It isn’t just related to your blood relatives. Ohana is the potential for interrelatedness. Anyone within the community can become part of Ohana.”
>
> —Advisory Group Member

Figure 2: Percent of Waiver Participants by Living Arrangement in FY23[5]



Day Services and Employment Supports

Table 2 provides an overall view of the number of DDD participants using day services and employment services compared with the United States as a whole. These data, the most recent available, were gathered in 2022 through the National Survey of State IDD Agency Day and Employment Services.[6] In Hawaii, 5 percent of participants receive integrated employment services, compared with 24 percent nationally.

Table 2: Day Service and Employment Services Use in Hawaii and Nationally (FY22)

	Hawaii		U.S.	
	Number	Percent	Number	Percent
Total in day and employment services	2,453		598,303	
Total in integrated employment services	110	5%	140,521	24%
Total funding for day and employment services	$70,755,498		$10,727,527,261	
Total funding for integrated employment services	$1,268,480	1.8%	$1,004,686,749	9.4%

Comparisons of the use of employment supports across states can be complicated for a number of factors, including differences in how states classify services. For example, DDD has reported that some providers are offering employment supports as allowable under the Community Learning

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[5] Approximately 3 percent did not have a living arrangement identified in the data.
[6] State Snapshots | Think Work

Service-Individual (CLS-I), which would not be reported in the employment count. Nonetheless, this data demonstrates that Hawaii underperforms in supporting individuals with IDD to work.

DDD Policy Intentions and Initiatives

Early in the evaluation, interviewees shared that after the closing of the state institution and the establishment of the community-based service system, small incremental changes were introduced through the HCBS waiver renewal process, but major system reforms were uncommon. However, over the past decade, internal and external factors emerged that required more significant retooling of the system. These factors included the opportunity to make substantial changes to the waiver during the 5-year reauthorization in 2016, the federal Centers for Medicare and Medicaid Services (CMS) HCBS Settings Rule,[7] the direct support professional (DSP) workforce shortage, and a commitment on behalf of DDD leadership to achieve efficiencies in operations and service delivery to meet the needs and expectations of participants and their families. DDD needed to make changes to its programs and service delivery infrastructure to respond with urgency while remaining thoughtful and planful to ensure the system is efficient, sustainable, and person- and family-centered.

DDD leadership sought to change the trajectory of the system and undertook a series of initiatives since 2015 — in great measure to achieve two primary policy intentions:

1. To increase and enhance opportunities for people with IDD to control their lives while also participating in and contributing to their communities. These included actions meant to promote person-centered approaches to service delivery while expanding opportunities to live an enhanced community life.
2. To improve system operations in support of achieving this first goal by focusing on systems modernization, updating IT systems, promoting equitable distribution of resources, and achieving other efficiencies.

The 16 initiatives under review are aligned with these two goals to produce better outcomes for the people they serve and to enhance system operations. During the initial phases of this evaluation, we worked with DDD staff and leadership to expand and define the initiatives to be included in this review. A final list of initiatives was organized under five major headings: (1) community engagement, (2) community access and person-centered practices, (3) services and provider network, (4) system operations and oversight, and (5) modernization and innovation. The project team created these larger categories to group similar initiatives and better support the depiction of the findings and recommendations.

Community Engagement

1. Enhance community engagement to provide feedback and advise policy

Community Access and Person Centered-Practices

2. Align with the intentions of the HCBS Settings Rule to increase access to community

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[7] Home & Community Based Services Final Regulation | Medicaid

3. Emphasize person-centered approaches to building individual service plans and guide service delivery
4. Better understand how people were using services to access the community

Services and Provider Network

5. Add new or modify existing services to enhance the array of services available and increase community integration
6. Enhance service standards to clarify expectations for waiver services and achieve quality outcomes
7. Adjust service reimbursement rates and payment structures based on the results of a comprehensive rate study

System Operations and Oversight

8. Improve on practices to enhance individual assessment of support needs
9. Establish individual supports budgets for participants based on assessed support need
10. Establish exceptions and utilization reviews to meet the needs of participants with extraordinary support needs
11. Enhance DDD's quality assurance and improvement program
12. Streamline access to waiver services through improved processes

Modernization and Innovation

13. Develop the INSPIRE Case Management System to increase efficiencies
14. Plan and implement an Employment First Initiative to increase the availability of supports for people with IDD to explore and gain employment
15. Promote improved dental health services for people with IDD
16. Promote initiatives related to DDD's neurotrauma program

These initiatives are consistent with DDD's 2018-2020 Strategic Plan entitled *Possibilities Now!* The plan broadly reinforces DDD's intentions to partner with individuals and families to promote greater opportunities for participants to control their lives, receive the supports they need in the community, and enhance system operations overall.[8] Specifically, the plan included the following objectives:

- Building partnerships with individuals and families
- Promoting community integration for people with IDD
- Promoting employment opportunity for people with IDD through greater emphasis on Employment First initiatives

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[8] Possibilities Now! Developmental Disabilities Division. Strategic Plan. Fiscal Years 2018-2020. https://health.hawaii.gov/ddd/files/2017/11/DDD-Strategic-Plan-2018-2020.pdf

- Achieving preferred personal outcomes through more effective service delivery
- Providing effective leadership and accountability related to strategic intents
- Greater efficiency in the use and application of Information Technology
- Improved dental health access for people with IDD

In 2021, Congress enacted the American Rescue Plan Act (ARPA) to support economic recovery during and following the COVID-19 pandemic. Section 9817 temporarily increased the federal funding to enhance, expand, or strengthen Medicaid HCBS. DDD's ARPA spending plan, which totaled over $30 million,[9] was developed through a collaborative process that involved the IDD community. It outlined the following five priority areas and 14 associated initiatives.

Priority 1: Supports for Participants and Families

- Option for Individuals with Behavioral Challenges
- Family-to-Family Peer Mentoring Service
- Host Participant and Family Forums

Priority 2: Strengthen Provider Capacities and System Infrastructure

- Increase Provider Payment Rates
- Invest in Quality Management
- Support Community Integration
- Advance Competitive Integrated Employment (CIE)
- Support Community Navigator Practice Development

Priority 3: Workforce Development

- Develop the DSP Workforce

Priority 4: Improve Protections for Health, Safety and Well-being

- Positive Approaches for Challenging Behaviors
- Improve Critical Incident Response through Analytics

Priority 5: Strengthen System Infrastructure and Accountability

- Conduct System Evaluation
- Strengthen Provider Monitoring
- Implement the Spending Plan

The ARPA initiatives offered a unique opportunity for DDD to build on the work already underway to further improve the system. DDD was well-positioned to act quickly to take advantage of this historic

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[9] https://www.medicaid.gov/sites/default/files/2021-10/hi-spending-plan-for-implementation.pdf

investment in HCBS. Due to the timing of this study, the outcomes of the ARPA initiatives would not necessarily be reflected in our findings. However, we include the progress to date because the nature of the service system is ever evolving and documenting current efforts will be helpful for ongoing evaluation.

Timeline of Initiatives

The following timeline shows when major activities associated with the initiatives or notable events occurred between 2014 to 2023. Although the timeline depicts the start date, many of these initiatives required sustained effort over several years, which resulted in overlapping efforts across many workstreams. The timeline shows the breadth of activities necessary to meet federal requirements, such as the HCBS Settings Rule, as well as those initiated within DDD to address internal priorities and develop system infrastructure.

Major Initiatives & Key Dates

2014
(July) CMS Final Rule regulations introduced

2015
Hawaii receives Employment First Leadership Mentoring Program Technical Assistance grant

2016
Burns & Associates rate study; Hawaii joins National Community of Practice for Supporting Families; **(July)** Medicaid HCBS waiver reauthorization introduced Community Learning Services, changed employment services, raised rates, added new policies for restrictive procedures, abolished use of seclusion. Established Administrative Claiming Special Fund (creating fund for key system infrastructure improvements)

2017
(May) Supporting Families Across the LifeCourse kickoff events **(June)** Medicaid HCBS waiver amendment

2018
(March) CMS granted initial approval of statewide Transition Plan; **(April)** LifeCourse framework built into INSPIRE case management system; **(June)** Medicaid HCBS waiver amendment introduced individual supports budgets and exceptions & utilization review process established **(October)** HCBS waiver service standards updated

2019
(February) INSPIRE case management IT system goes live; **(July)** Medicaid HCBS waiver amendment

2020
Updated rates study, Burns & Associates; **(March)** 1st confirmed COVID-19 case in Hawaii, HCBS waiver Appendix K

2021
(June) Updates to HCBS waiver service standards; **(July)** Medicaid HCBS waiver renewal; **(September)** Hawaii receives partial CMS approval for ARPA Spend Plan (14 initiatives)

2022
(February) Updates to HCBS waiver service standards; **(April)** Medicaid HCBS waiver amendment; **(July)** Adverse Event Reporting (AER) launched in INSPIRE

2023
(March) CMS Final Rule compliance deadline; **(August)** Maui wildfires

Guiding Questions

DDD supplied a list of questions to guide the evaluation. Our research activities centered around answering these questions in ways that revealed the extent to which DDD had achieved desired outcomes.

- How well is DDD meeting the requirements of the federal Centers for Medicare and Medicaid Services (CMS) mandate for increased community integration?
- How has the quality of service plans and the service planning process changed?
- What has been the impact of changes on service utilization and utilization patterns?
- What impact have new payment rates and rate structures had?
- How has service quality changed?
- How well and what impacts have there been in relation to implementation of the Supports Intensity Scale-Adult (SIS-A) assessments and individual supports budgets?
- What are the outcomes for DDD participants?
- How well have intended goals of the initiatives been achieved?

In addition to the list above, the research team also posed the following question for further analysis:

- To what extent are engagement activities, communications, and strategies effective?

Through our evaluation methods, we explored the results of the changes to the system; however, it is worth noting that changes to infrastructure can take several years to show in the data. The outputs we observed to evaluate the system included aggregate system performance metrics, and how people access, use, and experience services.

Strengths and Challenges

Throughout this process we identified strengths that played an important role in supporting forward momentum.

- ► **Dedicated Leadership.** The core DDD leadership team — including members of the DDD Administration, Case Management Branch, Community Resources Branch, Outcomes and Compliance Branch, and Hospital & Community Dental Services Branch — led the changes to the IDD HCBS waiver alongside other aligned initiatives. They were guided by a strategic vision, a commitment to progress, and building accountability across the system. Many members of the DDD leadership with whom we spoke have been with DDD for many years and have witnessed the system transform over time.
- ► **Expert Assistance.** DDD has been successful in securing additional resources through contracting and other opportunities to receive guidance and technical assistance from

experts in the IDD field. These resources helped to support the state staff to plan and implement processes to align with regulatory requirements and best practices.

- **Collective Care as a Cultural Value**. Embedded in the culture in Hawaii is a recognition of the importance of the collective well-being of family and community. The system has embraced supporting people with IDD to live with immediate family, or extended relatives, or in family home-like settings.

We also found that DDD has faced significant challenges.

- **Staffing Shortages.** DDD has encountered significant staffing shortages in state staff positions. At one point, DDD reported to have about a 30 percent vacancy rate among state staff. Staffing shortages and staff turnover required frequent shifting of attention and reprioritization of the many initiatives that were operating concurrently. During the interviews, a few DDD staff members said the loss of internal positions was hindering their ability to effectively manage the workload and expressed a need to return to adequate staffing levels in each branch. Even so, this collective team focused on building accountability into the system through changes to the IDD HCBS waiver and related initiatives.
- **Enduring Emergencies.** The COVID-19 pandemic greatly impacted the DDD system. Particularly during the first year of the pandemic, health and safety protocols evolved rapidly to protect participants, families, and the provider network, and to comply with public health mandates. Due to the remote nature of the islands, the state's economic reliance on tourism, and other factors, the state enacted strict policies to help protect its citizens. While this evaluation was being conducted, in August 2023, Hawaii suffered another emergency with the Maui wildfires, which caused extensive destruction. Efforts to recover from the Maui wildfires continue to this day.
- **Changing Expectations.** What constitutes best practice in supports and services for people with IDD are shaped in part from the ground up, by the demands from people with disabilities and their families, and from the top down, including regulations issued in 2014 by CMS regarding home and community-based settings through the Settings Rule. These expectations stem from the assertion that people with intellectual disabilities have the right to live a life like anyone else as valued members of communities. However, the realities of the pace and effort required to institute new policies and practices that support these changing expectations may have contributed to a sense of resistance to change among various communities.

Overview of the Report

In the following sections, we report our findings under five major headings: (1) community engagement, (2) community access and person-centered practices, (3) services and provider network, (4) system operations and oversight, and (5) modernization and innovation.

Within these sections we briefly describe the intentions — the *why* behind what led DDD to pursue a certain strategy — and the processes involved to implement the initiatives, including any ARPA-funded efforts. We convey what we learned about successes and challenges that were encountered when implementing the initiatives. Documenting the intention and implementation of each initiative was an important part of understanding the level of effort that was involved. We conclude each section with our evaluation findings based on review of the quantitative and qualitative data and present opportunities for consideration. Wherever possible we point to current actions that DDD is pursuing that align with the opportunities.

Community Engagement

Effective community engagement is a core element of operating an HCBS service system. One of DDD's stated goals in its strategic plan (FY18-FY20) is that individuals with IDD and their families are active participants at all levels of the DDD.[10] "Nothing about us without us" is the motto of the self-advocacy movement. Therefore, we sought to answer the question: **To what extent were engagement activities, communications, and strategies effective?**

We discuss the variety of initiatives specifically aimed at engaging communities who have an interest in shaping the IDD service system — including self-advocates, families, providers, advocacy organizations, legislators, and other policymakers. The overall intent behind these engagement initiatives was to inform people about changes happening at DDD, to make sure people understood how the changes would impact them, and to provide opportunities for people to submit feedback to DDD along the way.

There are several ways that DDD shares information with the community and gets feedback, particularly related to large-scale changes like the HCBS Settings Rule. In general, this is an area

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[10] https://health.hawaii.gov/ddd/files/2017/11/DDD-Strategic-Plan-2018-2020.pdf

where states commonly recognize there is always more to be done around outreach and engagement.

Engagement strategies

These strategies were intended to share information broadly related to initiatives underway at DDD, provide operational detail for different audiences, and get feedback from the IDD community. Those operating in an advisory capacity had opportunities to meaningfully contribute to the discussion and decision-making process. Strategies such as providing accessible materials ahead of meetings helped make sure that advisory group members were prepared and could offer relevant feedback. During COVID-19 many of the advisory committees and other engagement activities quickly shifted to virtual formats to maintain involvement.

DDD also recognized the importance of supporting families of people with IDD and moving from family engagement to family partnerships. These partnerships enhanced DDD's ability to design service modalities to support the whole family. Strategies to build these types of partnerships were central to DDD's involvement in the National Community of Practice on Supporting Families of Individuals with Intellectual and Developmental Disabilities.

Implementation

During our initial interviews with DDD staff, we documented DDD's multipronged approach to communicating and engaging with community groups. Examples such as those shown in the table included redesigning the DDD website, publishing a family newsletter, distributing information such as FAQs, providing periodic memorandums on selected topics, convening advisory groups, and hosting events such as the "Santa Summit" to gather information about priorities.

Below are examples of the types of communication and engagement strategies, including advisory groups, that DDD has convened over the past several years.

Table 3: DDD Communication and Engagement Strategies

Communication Materials	Audience	Content/Purpose
Website Redesign	General public, specific areas on the site for participants, families, and providers	Share mission, vision of DDD as well as specific information for targeted audiences
DDD Family Newsletter	Families, participants	Share stories and information about DDD
Countdown to Compliance Newsletter	Providers	Bimonthly e-newsletter regarding the transition process for the HCBS Settings Rule
FAQ Documents	Participants, families, case managers	Provide information in an accessible format

Memos/Letters	Participants, families, providers, DDD staff, case managers	Provide detailed content regarding operations, changes, policies and procedures

Advisory Groups	**Audience**	**Content/Purpose**
My Choice My Way Advisory Group	Representatives from various groups	Advise on the development of the statewide transition plan to comply with the HCBS Settings Rule
Waiver Policy Advisory Council	Representatives from various groups	Advise DDD on development of 1915(c) waiver services
Peer to Peer Family Membership Advisory Group	Families, other advocates	Advise on the development of peer-to-peer mentoring

Engagement Strategies	**Audience**	**Content/Purpose**
Community of Practice on Supporting Families	Families, participants, advocates, DDD staff	Connect with other states using Charting the LifeCourse and develop supports for families
Santa Summit	Representatives from various groups	Contribute to the priorities of DDD and engage with broad range of people
Hawaii Waiver Provider Association	Representatives from provider organizations that deliver waiver services	Connect with the provider network
Virtual Open Houses	Provider network	Technical assistance sessions on the HCBS Settings Rule

Over the period included in this study, some of these communication efforts were maintained and others were ended (e.g., discontinuation of the family newsletter). Our findings revealed that communication efforts were largely tied to new initiatives or major changes to the service system such as waiver changes, HCBS Appendix K flexibilities to respond to the COVID-19 pandemic and Maui wildfires, and ARPA initiatives. For example, the priorities included in the ARPA spend plan were developed with input from the community through various means including a survey, focus groups, and town hall style meetings.

In addition to these DDD actions, the Hawaii Waiver Provider Association (HWPA), which represents service providers across the state, and DDD worked to increase collaboration and sought to build an increasingly positive and productive relationship. This rapport was strengthened by DDD’s efforts to stabilize and enhance the HCBS infrastructure including the provider network.

Findings

The following presents the high-level summary of our findings in this section.

Summary Findings:

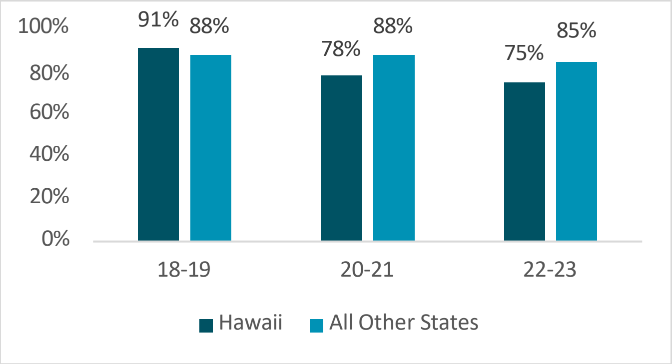
- Successful engagement was noted around systems change activities among advisory groups and those with an established connection with DDD.
- Ongoing communications will require consistency in methods and messaging.

What follows are our detailed findings related to the question: **To what extent were engagement activities, communications, and strategies effective?** We found that one of the strongest forms of engagement was convening advisory groups. Interviewees spoke about how advisory groups such as the My Choice My Way Advisory Group, Waiver Policy Advisory Council, and Peer-to-Peer Family Membership Advisory Council create the opportunity to meaningfully contribute to discussions and decision-making processes. Advisory groups helped to foster relationships between DDD and community groups. We noted that some people served on more than one of the advisory groups and workgroups, which reflects the relatively small and connected IDD network in the state.

In general, we found that those with connections or established relationships with DDD staff reported good communication with the Division. They felt that there was good communication, and that staff were responsive to their ideas and concerns. This was particularly true during the COVID-19 pandemic. One interviewee commented that even when DDD staff did not have an immediate answer to a question, they would acknowledge that they were working to find the answer.

However, others felt disconnected with DDD and expressed concerns regarding communication. Case managers reported that at times they received information after participants or agencies and pointed to a breakdown in communication from administrative levels. Caregivers and some service providers struggled to access information and support, especially during times of policy changes such as changes made to adhere to the HCBS Settings Rule. One limitation noted was that communications were often single events rather than ongoing. Stand-alone communication events may have contributed to the feeling voiced by some participants and families that they received information not as a situation develops but when “there is something new to report.” This lack of clarity added pressure on both caregivers and case managers. Further, concerns were raised about the focus on certain regions such as Oahu and less focus for neighbor islands, indicating a lack of inclusivity in information sharing.

Figure 3: Can Contact Case Manager



Participants and family members also shared that they typically received communication directly through case managers and the agencies that provide services. Because case managers and agencies that provide services are a primary source of information, we turned to National Core Indicators (NCI) survey data to learn about people's perceptions of access to their case manager. Figure 3 illustrates that the percentage of Hawaii participants who reported that they can contact their case manager when they want to fluctuated between 91 percent and 75 percent, with a statistically significant difference between 2018-19 (91 percent) and 2022-23 (75 percent). The 2018-19 data point appears to be an outlier for Hawaii and subsequent years seem to be trending down slightly. Based on statistical testing, the difference between Hawaii and other NCI states was not significant.

Opportunities for Consideration

Overall, the feedback indicates there is room to build on successful communication efforts as well as to enhance structures that can support more direct and ongoing communication with the broader community that includes participants, their families, caregivers, and service providers. When channels for communication are established and strong, information can be shared in a way that nurtures partnerships and supports a shared vision and interest. To build meaningful partnerships, a foundation of trust and understanding is important to facilitate mutual sharing of ideas. Creating this foundation often means meeting groups "where they are at" and meeting consistently over time. Within groups, individuals may have different levels of understanding of a subject and different experiences. This increases the complexity of crafting messages that are both specific and clear, and points to the kinds of resources that are needed to support communication and partnerships.

Even when established, communication channels must be maintained to bring groups along as information and circumstances evolve. Identifying the key distributors of information and developing communication channels between an information source and key distributors can help increase the clarity and consistency of messaging. In this example, building a direct line of communication between leadership and case managers could reduce confusion.

Based on the evaluation findings we offer the following recommendations for consideration.

Enhance Communications

DDD may want to consider additional methods to set consistent expectations and communication with case managers across CMUs. Case managers play an important role in conveying information to participants and families. Therefore, it is optimal that they have access to timely information in preparation for any upcoming changes to policies or procedures. Establishing written directives would help to make sure that consistent messages are conveyed, rather than relying on messages passed verbally.

It is beneficial to build opportunities to work alongside the advocacy community to raise expectations about what is possible for people with disabilities. Hearing directly from people with disabilities about what they want for the future of services and supports will help to set the barometer for where the system should head. We understand that DDD has been successful in partnering with members of the Self-Advocacy Advisory Council and we would encourage DDD to continue that avenue.

We encourage DDD to consider employing people with lived experience to help design inclusive communication, or hire a communications consultant who has experience with disabilities.

Build Partnerships

DDD may focus on building relationships with other entities like the health plans, Vocational Rehabilitation, and Department of Education. While there are some existing mechanisms for collaboration among agencies, DDD might consider establishing more formal and routine ways for these partnerships to flourish and achieve common goals and create a seamless experience for people whose needs may cut across agencies. Interviews conducted as part of this evaluation with leadership from sister agencies affirm, they are supportive of working collaboratively to solve common issues.

More might be done to build trusting partnerships particularly with communities that have more barriers and may not already have strong connections with DDD. This can include establishing methods for personal outreach to neighbor islands, proactively translating materials into different languages, and connecting with local community guides, or those who have personal ties to the communities and can help facilitate communication with DDD.

Recent Activity:

In line with these recommendations, DDD has already begun to institute some new methods for supporting ongoing communication with providers and case managers including:

- ✓ **DDD Provider "News to Use" Newsletter.** This is intended to be a regular newsletter issued to the provider network to share current and relevant information. The inaugural newsletter in July 2024 states, "Our common aim to support individuals with intellectual and developmental disabilities (IDD) to have good lives calls for open and collaborative communication strategies."[11]
- ✓ **Case Management Memos.** The Case Management Branch has started issuing memos to all case managers when there is a need to communicate new or updated policies and procedures. The intent behind the memos is to make sure that consistent messages and expectations are distributed to case managers, who in turn share information with participants and families.

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[11] DDD provider news to use. A periodic newsletter for Hawai'i DDD HCBS Providers, Welcome to News to Use! Issue 01. July 2024

Community Access and Person-Centered Practices

DDD endeavored to adopt person-centered approaches at every level, including leadership, case management, and service provision. One long-tenured DDD staff member characterized this shift to person-centered practices — and supporting the whole person beyond a label or diagnosis — as one of the most transformational shifts within the culture at DDD.

Aligned with person-centered approaches, CMS issued the HCBS Settings Rule in 2014; the rule's requirements are designed to enhance the quality of HCBS and provide additional protections for individuals receiving HCBS. The purpose of the Settings Rule was to maximize opportunities for people receiving services to access the benefits of community living, including receiving services in the most integrated settings. The rule defined the qualities of, and set expectations for, what is and is not considered a community-based setting. This represented a shift to a more outcome-oriented definition of HCBS settings.

Under the rule, an HCBS setting:

- *Is integrated in and supports access to the greater community*
- *Provides opportunities to seek employment and work in competitive integrated settings, engage in community life, and control personal resources*

- *Ensures the individual receives services in the community to the same degree of access as individuals not receiving HCBS*
- *Is selected by the individual from among setting options, including non-disability specific settings and an option for a private unit in a residential setting*
    - *Person-centered service plans document the options based on the individual's needs, preferences; and for residential settings, the individual's resources*
- *Ensures an individual's rights of privacy, dignity, respect, and freedom from coercion and restraint*
- *Optimizes individual initiative, autonomy, and independence in making life choices*
- *Facilitates individual choice regarding services and supports, and who provides them*[12]

The rule also set specific requirements for provider-owned or -operated residential settings and included provisions for person-centered planning. Any modifications to the additional requirements for provider-owned or -controlled residential settings must be supported by a specific assessed need and justified and documented in the person-centered service plan.[13]

Initially when the rule launched in 2014, states had a 5-year transition period, and the original deadline for compliance was March 2019. The deadline was extended several times, but a final deadline was established as March 2023.

Because of the substantial nature of the Settings Rule, many of the subsequent initiatives were driven by the requirements to comply. The following describes the process evaluation findings regarding the initiatives that relate to HCBS Settings Rule activities, person-centered approaches, and the focus on services that promoted access to community. We were interested in exploring the following questions:

- **How well is DDD meeting the requirements of the federal CMS mandate for increased community integration?**
- **How has quality of service plans and the service planning process changed?**

We found that DDD diligently worked with the provider community to reach compliance with the HCBS Settings Rule. In addition, DDD developed or updated policies and procedures to codify the rule operationally and support ongoing monitoring.

That said, the evaluation's focus group and interview findings revealed that there may still be work to do to engage with providers and case managers to enhance person-centered practices, beyond meeting the letter of compliance.

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[12] https://acl.gov/programs/hcbs-settings-rule

[13] https://www.medicaid.gov/medicaid/home-community-based-services/downloads/final-rule-slides-01292014.pdf

HCBS Settings Rule Activities

DDD's intention was to align policies and practices with the aims of the HCBS Settings Rule — to maximize opportunities for people receiving services to access the benefits of community living, including receiving services in the most integrated settings.[14] To meet the intentions of the rule, DDD established new processes to educate providers and make sure they knew how to achieve compliance.

Implementation

To assess the current state of HCBS against the Settings Rule requirements and develop a plan to achieve compliance, DDD contributed to the development of Hawaii's statewide transition plan, *My Choice My Way.*[15] The transition plan outlined how information about settings would primarily be collected through onsite visits, provider self-assessments, and participant surveys. To assess provider compliance, four categories were established:

Category 1 – Yes, meets requirements

Category 2 – Not yet, can meet with remediation

Category 3 – No, cannot meet requirements

Category 4 – Not yet, presumed not HCBS but State will require heightened scrutiny

After assessing the provider community, DDD then had to work with all providers, residential and non-residential, to get to Category 1. DDD oversees certification for adult foster homes that serve IDD waiver participants and had to modify the certification process and tools used to monitor settings. The monitoring tool included all the requirements that adult foster home providers had to meet. For example, the updated tool included questions related to the Settings Rule such as:[16]

- *Does each adult with IDD have a current residency agreement signed by the adult with IDD (or the legal guardian, if applicable) and certified caregiver?*
- *Can each participant access food of their choosing at any time, without restrictions (e.g., without limitations on where food can be consumed, or offering substitute meal options in residential settings)?*
- *Based on the adult with IDD's Individualized Service Plan (ISP), how is the participant supported to exercise their choice of activities in the home and broader community?*
- *Does the adult with IDD have opportunities to engage in activities of their individual preferences such as shop, dine, vote, and volunteer, with people without disabilities?*

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[14] Fact Sheet: Summary of Key Provisions of the Home and Community-Based Services (HCBS) Settings Final Rule (CMS 2249-F/2296-F). https://www.medicaid.gov/sites/default/files/2019-12/hcbs-setting-fact-sheet.pdf
[15] My Choice My Way, Hawaii Statewide Transition Plan
[16] DDD Adult Foster Home Inspection Report.

- *Does the setting provide a comfortable private place for each participant to meet with visitors?*
- *Does each adult with IDD have the freedom and support to control their own schedule and activities?*
- *Is each adult with IDD supported to explore and pursue competitive integrated employment in the community if they choose to do so?*

The Outcomes and Compliance Branch (OCB) was responsible for overseeing this process. OCB staff conducted onsite reviews and worked with providers to explain the new requirements and enacted processes to help them come into compliance.

The Community Resources Branch (CRB) also developed tools and processes for measuring compliance with the Settings Rule. CRB engaged in processes to assist residential and non-residential providers to understand what was required to comply with the rule. Additional templates were created to track different required data elements. For example, the evidence template for providers was developed to demonstrate compliance. These tools were instrumental to operationalizing the intent of the Settings Rule and creating mechanisms for ongoing monitoring.

The State also developed the Hawaii HCBS Rights Modification Policy to standardize the approach to any modifications. The policy specifies which rights and freedoms may be modified, and which may not; it also specifies the circumstances in which those modifications can be added to the Individualized Service Plan.

American Rescue Plan Act (ARPA) Initiatives

Technical Assistance on Community Integration. Through this initiative, DDD continued work with providers to achieve and maintain compliance with the HCBS Settings Rule and to improve service delivery and access to community-integrated services and supports. Technical assistance was provided through DDD as well as a contractor with expertise in this area. This initiative helped DDD identify the support that providers needed to create and carry out policies for the ongoing implementation of the Settings Rule. Several tracking and documentation tools were developed and refined through this initiative for providers as well as case managers since case managers had opportunities to gather information from participants about their experiences relative to the intent of rule. Lessons learned from these activities helped DDD design customized technical assistance to meet providers' needs. At times, the level of technical assistance provided included intensive one-on-one support to ensure providers had a good understanding of the requirements and could maintain compliance.

Strengthen Provider Monitoring. Through this initiative, DDD is developing a process for provider monitoring and looking into methods for sharing performance data. DDD will seek a consultant to assist with this process. This initiative was still in the process of getting started during this evaluation period.

Person-Centered Approaches

Person-centered practices focus on the person with a disability and helping them achieve the life they want. The HCBS Settings Rule provided a further impetus to build a culture of person-centeredness in the planning and delivery of services and supports. The rule included specific provisions for person-centered planning, including that participants will:

- Be in the lead when planning their supports as much as possible.
- Choose where, when, and who will go to their planning meeting.
- Get information in a way that is easy to understand.
- Choose how they want to be supported and who provides support.
- Get a copy of their support plan.
- Have opportunity to discuss friendships and relationships, accessing community, and employment.

DDD's intention was to ensure that Individualized Service Plans (ISPs) were of high quality and developed using person-centered principles and practices and aligned with what was set forth in the rule.

Implementation

Putting person-centered principles into practice is often an ongoing process. It requires training, person-centered policies and procedures, and monitoring across several points in the system — including when engaging with participants and families, creating the ISP, delivering services, and handling exceptions. To address this, DDD offered a myriad of trainings and supportive experiences tailored for different groups. Examples included:

- Charting the LifeCourse Framework[17] planning tools workshops
- Framework Fridays drop-in series for DDD case managers on the Charting the LifeCourse framework
- Person-Centered Organizations training, a joint effort with the Med-QUEST Division and provided by Support Development Associates (SDA)
- DDD First Tuesday Training Series on topics such as person-centered planning
- Case Management Trainings
- Service Provider Trainings

Although the content of these trainings aligned with the goal to promote person-centered principles, we found that they were not offered steadily over time. This was due in part to staff turnover. During

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[17] Charting the LifeCourse Framework LifeCourse Nexus Training and Technical Assistance Center: https://www.lifecoursetools.com/

the time of this study, we noted that the DDD training coordinator position was vacant for more than one year.

American Rescue Plan Act (ARPA) Initiatives

Positive Approaches for Challenging Behaviors. This initiative represents a shift in approach to supporting people who exhibit challenging behaviors. Rather than trying to “fix” the individual, this initiative promoted more person-centered strategies that account for the whole person and their environment. While work in this area had been underway, it was identified as a priority to carry forward with the ARPA investment. This initiative grew out of the recognition that there was a gap in access for people with IDD who also experience mental health issues. The positive approaches that DDD is exploring with this initiative seek to better understand the expressions of “behavior” in terms of potential medical, environmental, and/or situational causes.

The intent is to change the mindset within DDD toward people with IDD who exhibit challenging behaviors and ask questions such as:

- What might be occurring in this person’s environment?
- Has the person experienced past trauma that might be influencing their current reactions?
- How can we improve their environment and supports?
- Is there an underlying medical cause?

DDD is interested in developing mechanisms to assess for root causes of challenging behaviors. For example, ruling out physiological reasons that may be contributing to behaviors by first conducting medical tests such as an MRI of the brain, a CT of the abdomen, or blood tests. The results of these tests may indicate that the person has an underlying physical condition that may be causing physical symptoms, and they could be expressing discomfort by engaging in challenging behaviors. Therefore, treating the condition may help to alleviate some of the behaviors.

Currently common interventions for challenging behaviors may include medications, more intensive staffing, and/or restrictions, and DDD was interested in offering person-centered and supportive solutions that focus on the whole person. During events hosted through this initiative it was noted that expansion to others in the medical community and providers on neighbor islands would be of value. Responding to the Maui wildfires provided an opportunity to put positive approaches into

The initiative centers on providing multiple opportunities for training, conferences, and workshops for DDD providers and others on the impacts of trauma, alternative positive approaches through trauma-informed care, and how to make sustainable and person-centered organizational change. National experts in this area were hired to provide the trainings. This initiative also included a community of practice among 14 provider agencies.

The groundwork laid through this initiative was aimed at supporting a cultural shift to seek to better understand people with IDD and expressions of “behavior” and frustrations. DDD staff expressed that by working on this initiative they learned what was required to implement positive approaches through an organizational change model.

Community Services

DDD leadership was interested in responding to the requirements of the HCBS Settings Rule and shaping the system going forward. DDD specifically intended to build out services that were meant to help participants be involved in their communities and enhance DDD's ability to better track information about service utilization and understand when and how participants were accessing the community.

Implementation

Prior to 2016, the most widely used services were Personal Assistance/Habilitation (PAB) and Adult Day Health (ADH). Because the PAB service supported participants at home and in the community, service utilization data, which is commonly used to identify service use patterns, would not show the percent of the time participants received services in the community. To distinguish between settings and to pay higher rates for services provided in the community, the 2016 waiver renewal added a new service — Community Learning Services (CLS) — for one-to-one and group supports provided in the community. Because CLS represented a significant shift in service planning and billing, new service definitions, provider qualifications, and training on the intent of the service had to be developed.

According to the service definition:

> *Community Learning Services (CLS) assist the participant to maintain, learn, or improve skills; develop social roles valued by non-disabled members of the community; use community resources; pursue leisure skills and hobbies; and exercise civil rights and self-advocacy skills required for active community participation. Services will meet the participant's needs and preferences for community participation, including the participant's choice whether to do the activity individually or with a small group of others who share that interest. The intended outcome of CLS is to support the participant to access the community in a manner that best meets their choices and interests. CLS includes assistance and supervision for community activities to maintain current skills, as well as training that may lead to greater independence in their chosen community activities.*[18]

The definition also specifies that while personal care/assistance may be part of this service it should not comprise the entirety of the service. As CLS became available, DDD was interested in making sure the service was delivered according to the intended goals.

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[18] Hawaii. 2023. HCB Services for People with Intellectual and Developmental Disabilities (I/DD Waiver). HI0013R0807

Findings

The following presents the high-level summary of our findings in this section.

Summary Findings:

- Technical requirements of the HCBS Settings Rule were successfully met but work with the community is still needed to promote choice and control.
- Commitment to person-centered principles was evident but will require consistent effort.

Next, we present our detailed findings related to the following question: **How well is DDD meeting the requirements of the federal CMS mandate for increased community integration?**

Initial assessment data regarding the Settings Rule compliance found that no providers were considered Category 1 (Yes, meets requirements) or Category 3 (No, cannot meet compliance). Most providers were determined to be Category 2 (Not yet, can meet with remediation) and a few were considered Category 4 (Not yet, presumed not HCBS but State will require heightened scrutiny) due to proximity to settings not considered HCBS. Leading up to the deadline, DDD worked with the provider community and was successful in assisting residential and non-residential providers to reach compliance.

In focus groups, service providers discussed the challenges and advantages they faced in complying with the Settings Rule. Efforts were made to maintain person-centered care and accommodate participant preferences; however, some providers felt that certain aspects of the rule were too restrictive. One provider reported that they engaged families and participants in decision-making processes but faced criticism during site reviews for perceived shortcomings in compliance. Balancing participant choice with health and safety considerations was a recurring challenge voiced by service providers in implementing the Settings Rule.

When asked about where and how to find information about available community activities, interview participants mentioned relying on their personal networks and agency resources. Case managers mentioned that networks and knowledge of community were accumulated over years of work and service in the field; therefore, the knowledge of community resources that are accessible for people with disabilities could vary among case managers. Families referred to connections at church programs, Special Olympics, or to their networks established during their child's time in school. Direct support professionals mentioned that they receive information from agencies but that they rely on their personal social network, social media groups, and colleagues.

The idea of a community map was mentioned by an advocate who reflected on their efforts in gathering community activities for staff and waiver participants. They stated, “I think that would be, or will be, a really fabulous resource if they are able to get the funding and really allow someone, a DSW or somebody, to do some community mapping and figure it out, because I think there are a lot of resources that they aren't fully accessing” (Advocate, 2023).

Interview participants expressed various challenges and experiences related to transportation. They discussed issues with reliability, scheduling, and accessibility of transportation. Funding limitations affected the distances covered by transportation services. At least one service provider highlighted the use of public transportation, which provides waiver participants with a sense of agency and independence. Of the waiver participants we talked to, only one used public transit.

To ensure community activities had a purposeful outcome with learning experiences and skill development, service providers referenced goals identified in the ISP. “So, any service that I provide that takes the participant out in the community is going to be because they have community goals written into their ISP” (Direct Support Professional, 2023). Other adult day health providers offered waiver participants choices in their daily activities through their programs.

To see how well the system supports the goals of the Settings Rule and impacts the lives of people with IDD, we reviewed NCI items that measure choice and control and access to community. While we cannot make a direct link between activities to comply with the Settings Rule and the NCI survey data, it is helpful to give an impression of where DDD might be doing well or need improvement. NCI is also helpful as a point of comparison with other states.

If activities to advance the aims of the rule were successful, we would expect to see an increase in the indicators related to choice and control about living arrangement and daily routines and engagement in community activities. The figures show selected NCI indicators for Hawaii compared to other states that participate in NCI. For some, we noticed positive increases over time across the selected indicators; however, Hawaii was typically below the NCI average.

Figure 4: Choose Where You Live

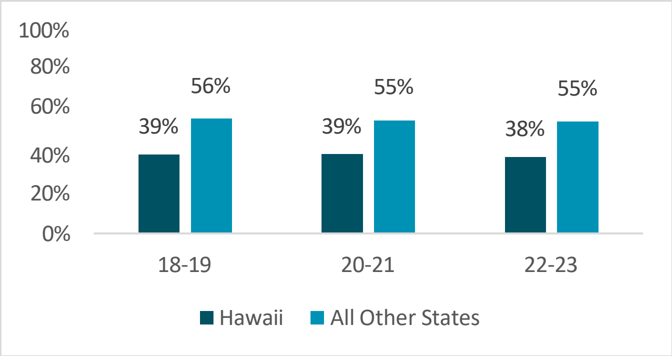

Figure 4 shows that Hawaii’s measure remained significantly lower than the other states through 2022-23 regarding choice of where one lives. Members of the advisory group for this evaluation pondered whether the lower incidence of choice of living setting compared with other states might not be unique to people with IDD and could be due to general circumstances that impact housing choices in Hawaii.

Figure 5: Decide Daily Schedule

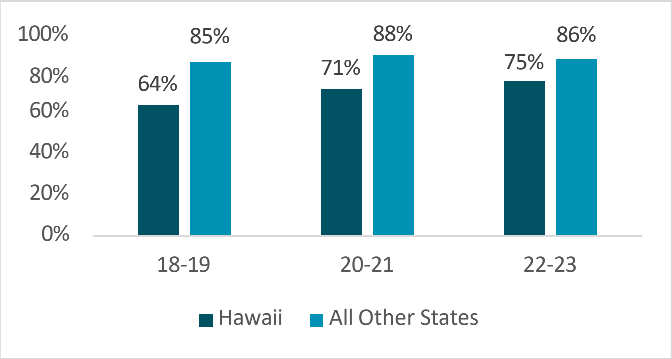

Figure 5 shows that 2022-23, Hawaii had significantly increased to 75 percent regarding the item on deciding one’s daily schedule. However, the Hawaii measure remained significantly lower than the other states throughout the three years.

Figure 6: Decide How to Spend Free Time

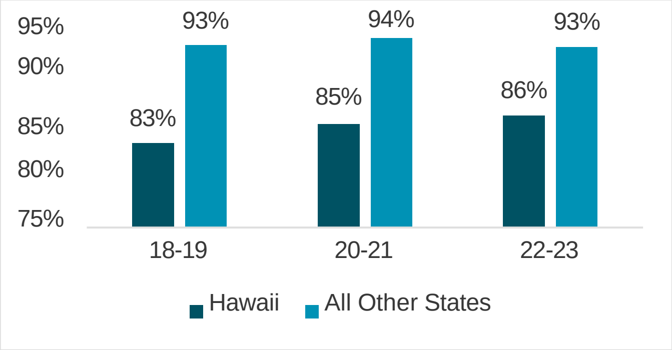

Figure 6 shows that the Hawaii measure regarding decisions over free time increased over the three-year period but remained lower than the other NCI states across all years included. Viewing these types of differences against the NCI average may offer DDD a place to start with taking a closer look at how participants are supported to make decisions about their day and how they spend their free time.

In this section we also explored results related to the question: **How has quality of service plans and the service planning process changed?**

These initiatives intended to shift expectations to focusing on the person with IDD and helping them achieve the life they want. One interviewee noted, that, "The individual needs to be in the lead along with their family members in planning." Several interviewees noted the implementation of the Charting the LifeCourse framework as contributing to the new approaches for developing plans that assist a participant in setting goals to achieve their good life; again, aligned with the final rule. The Charting the LifeCourse framework is a way of thinking and a set of planning and problem-solving tools that "help individuals and families of all abilities and ages develop a vision for a good life, think about what they need to know and do, identify how to find or develop supports, and discover what it takes to live the lives they want."[19] Key informants noted that the LifeCourse tools offer a way to be more consistent with support planning if used routinely.

> "Adopting the LifeCourse was really important and changed the conversation."
> —Interview Participant

A common issue highlighted in focus groups regarding the ISP meetings was the parental or guardian influence, at times overshadowing the participant's voice and preferences. There was a call for greater focus on the participant's desires and needs during ISP meetings, emphasizing their autonomy and participation in decision-making processes. Additionally, resistance to change and deference to parental input were identified as barriers.

Service providers shared instances in which waiver participants have kept the same goals for many years. This could be due in part to challenges such as turnover among case managers, a lack of clarity regarding goal setting, and inadequate data collection to inform future planning.

Case managers and service providers mentioned that participants still bring different understandings about person-centered planning to the ISP meeting. Waiver participants who were interviewed

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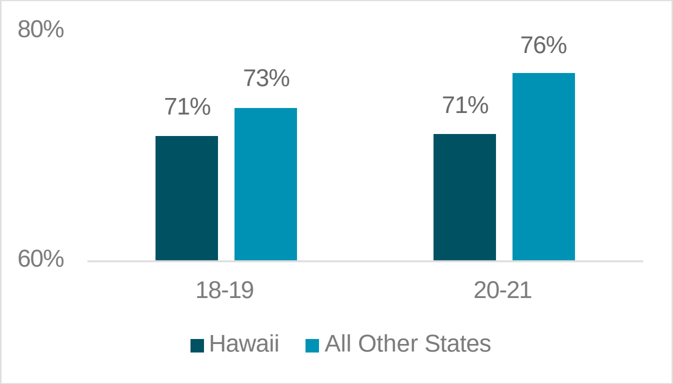
[19] LifeCourse Framework – LifeCourse Nexus (lifecoursetools.com)

emphasized the importance of maintaining independence and making decisions for themselves, expressing discomfort with overprotection and control from caregivers or agencies. They advocated for a balance between support and autonomy, emphasizing the need for agencies to understand and respect their desire for independence.

Figure 7: Chooses Services in Plan



To gain understanding of the alignment of support plans with person-centered principles, we turned to NCI items that relate to choices about the services in the plan. Figure 7 shows that for this measure Hawaii was 71 percent in 2018-19 and remained at that level through 2020-21, which was slightly lower than other NCI averages for this measure. This measure was changed in 2022-23 and therefore excluded for comparison.

Opportunities for Consideration

Enhance Methods to Support Community Access

While DDD continues to promote access to community and align with the intentions of the Settings Rule, there are additional opportunities to enhance the skills of case managers, service providers, and others to broker connections with community for people with IDD and their families.

- As one example — and a previously mentioned suggestion from a focus group participant — planning teams could integrate community-asset mapping into their practices. Community-asset maps would help planning teams learn about available resources, and sharing this information may help participants explore new options and make connections. While the Community Navigator service can also be leveraged for assistance in this area as a service authorized in the ISP, there may be shared goals among those with responsibilities for assisting participants to connect with community. Toward this aim, DDD might consider mutual training or learning opportunities on how to map local resources.

Bolster Person-Centered Practices

Promoting person-centered principles requires consistent effort. Eventually the goal is for person-centered strategies to become second nature and for people with disabilities to drive the planning process to arrive at the services and supports they need.

Based on what we learned, we would offer the following areas of opportunities for consideration.

- Provide ongoing training to case managers, service providers, participants and families on person-centered practices and skills to inform the service planning process. Access to basic training will ensure that those who are new to the system understand person-centered concepts. It is also helpful to offer training for those who are more experienced and need to enhance their skills in this area to achieve advanced levels of person-centered competencies. The *Five Competency Domains for Person-Centered Planning*[20] offers a framework for developing PCP competencies. It includes a list of associated competencies under the following domains:

  - Strengths-based, culturally informed, whole person focused
  - Cultivating connections inside the system and out
  - Rights, choice, and control
  - Partnership, teamwork, communication, and facilitation
  - Documentation, implementation, and monitoring

- Enhance the use of Charting the LifeCourse principles and tools within the planning process. The CtLC tools are already available in the INSPIRE platform and our review of a sample of ISPs revealed that most plans have at least some information recorded in those tools. For CtLC tools to be most impactful, it helps to have clear processes and examples that show how the framework can shape support plans. CtLC tools can help planning teams think creatively and problem-solve in ways that are most supportive for the participant to live a good life as they define it. When sharing information about CtLC principles with participants and families, it helps to share examples that draw from the local culture and experience; that way, the content is relatable and culturally competent. Concepts presented in person-centered approaches like CtLC might need to be adjusted to fit with social models that value collective care.

In alignment with these ideas, DDD is already pursuing some ways to promote person-centered service planning.

Recent Activity:

- ✓ **Person-Centered Planning Training.** DDD is implementing a renewed approach to training. New person-centered trainings are under development and will be offered by DDD staff. The trainings will include a focus on DDD person-centered policies and procedures to keep a focus on putting person-centered principles into action across the service system.
- ✓ **Charting the LifeCourse (CtLC) Ambassadors.**[21] DDD is providing opportunities for some case managers to become CtLC Ambassadors. The Ambassador course provides in-depth instruction on the CtLC principles and how to apply them. The course also offers opportunities for trainees to connect with other CtLC Ambassadors. CtLC principles closely align with person-centered approaches; having additional CtLC Ambassadors on staff will promote the use and application of the CtLC tools, which are imbedded in the INSPIRE system as part of the planning documents.

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[20] Tondora, J., Croft, B., Kardell, Y., Camacho-Gonsalves, T., and Kwak, M. (2022). Five Competency Domains for Person-Centered Planning. Cambridge, MA: National Center on Advancing Person-Centered Practices and Systems.

[21] https://www.lifecoursetools.com/lifecourse-learning/ambassador-series/

- ✓ **Online learning platform**. DDD is contracting with an online learning platform to provide access to Division-vetted and -approved person-centered trainings.
- ✓ **Participant experience survey**. This annual survey will gather participant perspectives on freedom of choice and rights. This information will help DDD understand what is working well for participants and what may need improvement in planning for supports and services.

Services and Provider Network

Over the past decade, DDD has refined service definitions to more clearly articulate the expectations of each service, added several new services targeted at specific needs, and made significant investments in provider payment rates. These initiatives have considered input from community partners as well as best practices across the country. Goals for these changes included complying with federal requirements, supporting employment services and community integration, and strengthening the provider network and the direct support professionals they employ.

In this section we sought to answer the following questions:

- **What has the impact of changes been on service utilization and utilization patterns?**
- **What impact have new payment rates and rate structures had?**
- **How has service quality changed?**

In general, we found that updates to the rates were well received among the provider community as rates had not been updated in approximately 12 years. The results of the rate study led to rate increases for several services and allowed DDD to leverage and apply the ARPA funds effectively.

Waiver Service Array

DDD made significant changes to system infrastructure to support community integration starting with the 2016 reauthorization of the HCBS waiver. DDD's intention was to modify existing services and add new services to create a better defined and more comprehensive service array. Given the expectations of the federal HCBS Settings Rule, promoting community access and including integrated employment opportunities were of particular interest. DDD incorporated these changes in the 2016 and 2021 renewals of the HCBS waiver as well as several amendments in the intervening years.

Prior to the 2016 waiver renewal, the list of available services included typical services such as Personal Assistance/Habilitation (PAB), Adult Day Health (ADH), Prevocational Services, and Respite. With broad service definitions that covered a wide array of activities, two services – PAB and ADH – accounted for more than 90 percent of waiver spending, providing little insight into the types of supports provided or the location of supports.

With each renewal and amendment of the HCBS waiver, DDD also developed progressively more detailed and robust service standards.[22] These changes resulted from a concerted effort by DDD staff to redesign the service standards into an accessible resource that could be utilized and referenced by those implementing waiver services. The latest version includes a section related to quality management and requirements including quality of care assurances for waiver providers in three required areas including service plans, provider qualifications, and health and welfare[23].

Implementation

DDD successfully used the renewal and amendment processes to plan for and reach agreement with CMS for the resulting service array. Adding the new services required thoughtful planning, prioritization, and sequencing — both to ensure the waiver contained all the required elements and for communicating the changes to service providers, participants, and families.

The process of redesigning service standards included identification of best practices from other states and engagement with a range of partners within the IDD system including case managers and other DDD staff, service providers, and system advocates to evaluate changes that reflect the needs of Hawaii. The collaborative redesign process included discussions of system strengths and challenges. DDD staff reported they intentionally designed the structure of the waiver standards so that they could continue to evolve with future iterations of the waiver. With each substantive revision to the service standards, DDD offered training to the provider community.

Figure 8 below illustrates the evolution of changes made through the renewal and amendment cycles starting with the 2016 waiver renewal.

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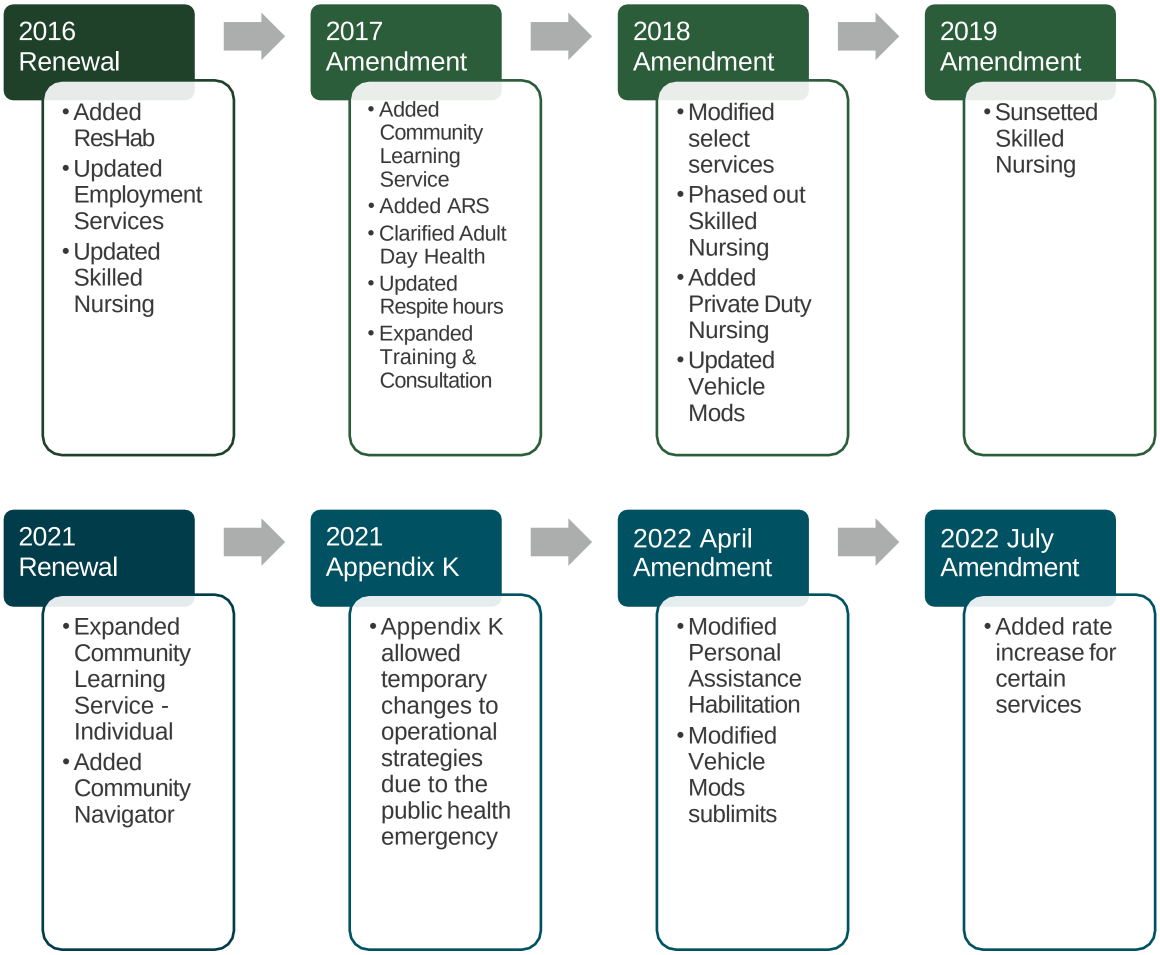
[22] https://health.hawaii.gov/ddd/files/2021/06/Waiver-Standards-Manual-July2021.pdf

[23] https://health.hawaii.gov/ddd/files/2023/10/2023-10-02-Waiver-Standards-Manual-Version-B.pdf

Figure 8: Summary of Waiver Renewals and Amendments by Year



2016 Renewal
- Added ResHab
- Updated Employment Services
- Updated Skilled Nursing

2017 Amendment
- Added Community Learning Service
- Added ARS
- Clarified Adult Day Health
- Updated Respite hours
- Expanded Training & Consultation

2018 Amendment
- Modified select services
- Phased out Skilled Nursing
- Added Private Duty Nursing
- Updated Vehicle Mods

2019 Amendment
- Sunsetted Skilled Nursing

2021 Renewal
- Expanded Community Learning Service - Individual
- Added Community Navigator

2021 Appendix K
- Appendix K allowed temporary changes to operational strategies due to the public health emergency

2022 April Amendment
- Modified Personal Assistance Habilitation
- Modified Vehicle Mods sublimits

2022 July Amendment
- Added rate increase for certain services

IDD 1915(c) HCBS Medicaid Waiver Renewal 2016

Approved on July 1, 2016, the HCBS waiver renewal incorporated many substantial changes, including:

- Adding language throughout the waiver to reflect the expectations of full community integration and person-centered planning in line with the HCBS Settings Rule.
- Restoring a specific Residential Habilitation (ResHab) service. ResHab had previously been a waiver service but had been combined with Personal Assistance/Habilitation in the 2011 waiver renewal. Creating a standalone ResHab service allowed for the creation of a service definition that recognized the differing requirements and expectations of providers delivering full-time residential care in an adult foster home or group home compared to providing intermittent supports in individuals' own homes or family homes.
- Updating employment services (previously called prevocational services) in two primary ways. Language prohibiting the service for people not expected to join the general workforce

in one year was removed. Additionally, the service was expanded to enable participants to use it to explore potential areas of employment that interest them if they want to change careers, to revise an existing career plan, or to work on general skills needed for advancing their chosen career.

- Revising the Skilled Nursing service to clarify terms.

IDD 1915(c) HCBS Medicaid Waiver Amendment 2017

The 2017 technical waiver amendment went into effect on June 1, 2017. A primary purpose of this amendment was the inclusion of a multi-year phase-in of the Supports Intensity Scale for Adults (SIS-A) into Individualized Service Plans (ISPs). Additionally, the amendment included several significant changes related to the service array, including:

- Adding Community Learning Services (CLS) to cover supports delivered in the community either to a group of individuals or on a one-to-one basis. These supports were previously included in PAB and ADH, but the creation of separate services allowed for more targeted service definitions and the payment of higher rates for community-based services.
- Transitioning Adult Day Health rates to 15-minute billing to better facilitate individual choice, including the receipt of different services during a day (such as both ADH and CLS-Group).
- Creating Additional Residential Supports for individuals who require more support than incorporated in their ResHab rates.
- Clarifying waiver emergency services and renaming Crisis Shelter to Out-of-Home Stabilization to better align with the services offered.
- Establishing limits to daily respite provided in licensed or certified residential homes to change how Respite services were reported and billed. The amount of Respite hours was capped at 760 hours annually and an exception process was established.
- Expanding provider qualifications for Training and Consultation to include clinicians that specialize in working with families and licensed registered nurses for nurse delegation.

Increasing the cost limits for Environmental Accessibility Adaptations and Vehicular Modifications to account for market costs.

IDD 1915(c) HCBS Medicaid Waiver Amendment 2018

This amendment established a methodology to provide service recipients an individualized supports budget based on their assessed support need to offer participants greater choice, flexibility, and control over their services. Changes to the service array included:

- Modifying service specifications for Adult Day Health, Assistive Technology, Community Learning Services, and Environmental Accessibility Adaptations (EAA).
- Phasing out Skilled Nursing as these supports transitioned to individuals' health plans.

- Adding Private Duty Nursing (PDN) for individuals with complex medical needs who require more long-term nursing service than available through Skilled Nursing.
- Expanding Vehicular Modifications to cover repairs to adaptive equipment to ensure safe, operational lift systems for vehicles.

IDD 1915(c) HCBS Medicaid Waiver Amendment 2019

This technical amendment addressed the Skilled Nursing service that sunsetted on June 30, 2019. Considering this change, participants were informed of their right to be notified in advance of change in services, their right to request an informal review by DOH, and their right to request an administrative hearing before a DOH/DDD Hearing Officer or a DHS/MQD Hearing Officer.

IDD 1915(c) HCBS Medicaid Waiver Renewal 2021

Although not as dramatic as the changes made in the 2016 waiver renewal, the 2021 waiver renewal incorporated several major changes to waiver services, including:

- Broadening the service definition for Community Living Service-Individual to expand the ways the service can be used, reinforce CLS-I in work settings, and provide flexibility to support ongoing community engagement without the expectation of fading.
- Expanding Training and Consultation (T&C) to include telehealth as a service delivery method and to allow for concurrent billing for professionals and paraprofessionals.
- Revising service limits for three services. The limitations on Adult Day Health (ADH) and Community Learning Services-Group (CLS-G) related to Individual Supports Budgets were removed. The service limit for Individual Employment Services (IES) was increased to 80 hours per year and the limit of three months was removed.
- Adding a new Community Navigator service to support participants by connecting them with natural supports and building relationships in the community through volunteer opportunities, sports teams, clubs, and other strategies.
- Expanding provider qualifications for Environmental Accessibility Adaptations to include licensed general contractors and licensed specialty contractors.

A number of general updates were made throughout the waiver. Changes were made to provide information on the *My Choice My Way* transition plan towards compliance with the HCBS Settings Rule; enhance performance measures around the Quality Improvement Strategy; add staff qualifications to applicable service definitions in line with CMS requirements; include statutory language to the criminal background check requirements to specify the types of disqualifying offenses; clarify staff training requirements by consumer-directed employers for their workers; remove requirements for independent audits by individual providers; and add language related to independent audits performed by the State Office of the Auditor.

IDD 1915(c) HCBS Medicaid Waiver Appendix K

Like nearly every state, DDD submitted an Appendix K to enact temporary measures to address the COVID-19 pandemic. Appendix K allows states to operate aspects of their 1915(c) waivers with temporary flexibilities during a declared national emergency.

The COVID-19 pandemic presented multiple challenges around the delivery of waiver services. DDD utilized Appendix K to adjust to arising circumstances:

- The initial Appendix K application allowed for modifications to prior authorization and exceptions reviews, suspended certain service limits, expanded allowable purchases to include personal protective equipment when not otherwise covered in the Medicaid state plan, created exceptions to individual budget limits, suspended certain staff qualification requirements and minimum staff ratios, allowed for telehealth in some circumstances, and provided for retainer payments.
- The second amendment added Medical Respite, modified Private Duty Nursing and Specialized Medical Equipment and Supplies, temporarily allowed payment for certain waiver services provided to participants who are in a hospital or other short-term facility such as a nursing facility (excluding ICF/IID), further defined retainer payments, and expanded provider qualifications to include any provider agencies contracted with the Hawaii Department of Education performing similar work.
- The third amendment extended timeframes for federal reporting and data collection.
- The fourth amendment updated the terms of retainer payments.
- The fifth amendment increased rates for selected services to help cover fixed costs as well as increased costs due to the pandemic.
- The sixth amendment adjusted the anticipated end date to six months after the end of the public health emergency.
- The seventh amendment temporarily increased payment rates for select services.

IDD Medicaid HCBS Waiver Amendment April 2022

This amendment:

- Modified the service definition for PAB to cover supports provided to participants when hospitalized to foster communication, to provide intensive personal care, to maintain participants’ functional abilities, and to support participants as they transition back to the community.
- Revised the service definition for Vehicle Modifications to add an exception review, enabling DDD to remove the sublimit for vehicle shipping costs. This change was made to improve access to this service for participants due to unique issues in Hawaii around vehicle availability and market fluctuations for shipping vehicles to and from the mainland.

IDD 1915(c) HCBS Medicaid Waiver Amendment July 2022

This amendment implemented rate increases for waiver services recommended by the 2020 rate study. DDD relied on funds made available through section 9817 of ARPA to implement these rate increases.

American Rescue Plan Act (ARPA) Initiatives

Option for Individuals with Behavioral Challenges. This initiative is exploring the addition of a new waiver service that would be provided in a licensed home setting. The aim would be to offer the type of support necessary for those with increased behavioral support needs by an interdisciplinary team and skilled staff. The service will have a focus on community integration, family engagement, and trauma-informed care, and will leverage the learning from the previously described Positive Approaches initiative. The preliminary brainstorming for this service has begun; however, as of the writing of this report, it is still in early development stages. DDD is in the process of working through the design, standards, and training that would be required for this service to be successful.

Community Navigator Service Practice Development. As mentioned, the new Community Navigator service was added in 2021. This service emphasizes, promotes, and coordinates the use of community resources and natural supports to address the participant's needs in addition to paid services. This initiative grew out of the recognition that service providers would benefit from training and technical assistance to grow the necessary skills and toolsets to offer this service. The training offered through this initiative included a multi-method approach that included modules, training materials, on-demand videos, and mentoring and coaching. It also included a train-the-trainer model to sustain the availability of this training and continue to support growth of the community navigator service. An important component that was built into this training was the ability to collect data regarding how this service may be assisting participants to achieve valued roles in their community and increase a sense of belonging. This initiative was completed in 2023.

Exploration of Family-to-Family Mentoring Service. DDD used this initiative to explore the possibility of adding a new waiver service that would provide information, resources, guidance, and support from a mentor to help families navigate the service system, the person-centered planning process, and other community resources. This initiative is still underway; DDD is working with the community on its design and is assessing the feasibility of adding it to an upcoming waiver renewal or amendment.

Invest in Quality Management. As part of the new service standards, DDD has required provider agencies to phase in the development of internal quality management structures and practices. This initiative aimed to provide peer support, training, and technical assistance from contractors who have expertise in designing quality management systems. Service providers could opt in for this technical assistance to help them with their quality management plans. Those providers that did partake in this opportunity reacted positively to the technical assistance they received.

Rates and Payment Structures

Adequate provider payment rates are integral to maintaining a provider network that offers choice to individuals and supports a high-quality workforce. However, although the federal government expects states to conduct a comprehensive review of provider payment rates at least every five years, prior to the initiation of a rate study in 2016, rates had not been substantially altered for 12 years.

DDD sought the development of a payment rate methodology that complies with federal requirements, including transparency and community engagement; aligns payments rates with service requirements and DDD's policy intentions; and produces payments that reflect providers' costs.

Implementation

DDD contracted with Burns & Associates (now a division of Health Management Associates, HMA-Burns) to develop rate models that meet the requirements of Medicaid waivers. The rate models that HMA-Burns developed were designed to account for the reasonable costs providers incur to deliver services consistent with state requirements and participants' service plans.

As detailed in Appendix I-2-a of the IDD waiver, the rate study included the following key activities:

- A series of meetings with a Provider Advisory Group comprised of a diverse cross-section of providers in terms of services delivered, size, and location.
- Development and administration of a provider survey related to service design and costs. All providers were sent the survey and given an opportunity to participate.
- Identification of benchmark data, such as cross-industry wage data from the Bureau of Labor Statistics.
- Development of rate models for each service that include specific assumptions related to the various costs associated with delivering each service, including direct care worker wages, benefits, and 'productivity' (i.e., billable time); staffing ratios; mileage; facility expenses; and agency program support and administration.
- A public comment process through which proposed rate models were emailed to providers and other community members and posted online. Interested parties were given several weeks to submit written comments. DDD prepared written responses to all comments received and revised the rates as appropriate.

Major features of the resulting rates, included:

- Creating rates to support the division of services described earlier in this section, such as pulling Residential Habilitation out of Personal Assistance/Habilitation and Community Learning Service-Group out of Adult Day Health.

- Establishing higher rates for services delivered on the Big Island to accommodate the rural landscape and costs of transportation.
- Supporting a tiered rate structure for certain services that pays higher rates for services provided to individuals with greater assessed needs developed in conjunction with the support needs framework based on assessed support needs discussed in more detail in the System Operations and Oversight section.

Due to the need to complete assessments for individuals receiving services that would move to a tiered rate structure, the rate changes were phased-in across three cohorts of the service population:[24]

- Cohort 1: Participants living in certified or licensed settings
- Cohort 2: Participants living independently, in family homes, or non-certified or non-licensed settings AND receiving Adult Day Health
- Cohort 3: Participants living independently, in family homes, or non-certified or non-licensed settings and NOT receiving Adult Day Health

HMA-Burns completed additional rate studies in 2020 and 2024. The July 2022 waiver amendment included rate increases for several waiver services equal to one-half of the difference between the rates at the time and those recommended by the 2020 rate study.

DDD used ARPA funds to continue to implement the recommended rate increases based on the rate study. Rate models were adjusted in October 2022 to account for an increase in Hawaii's minimum wage. At the time of this evaluation, the state is considering funding the rate increases recommended by the 2024 rate study as part of the overall state budget.

American Rescue Plan Act (ARPA) Initiatives

Develop the Direct Support Professional (DSP) Workforce. This initiative aimed to develop a career path for the direct support workforce. DDD focused on identifying and securing access to relevant curricula and certification that could form the basis for competencies and explore mechanisms to administer pay differentials for DSPs. DDD has developed a certification framework and begun to pilot it with a small group of providers. At the time of this evaluation, DDD had launched the Workforce Development Training Incentive Program (WDTIP) and opened applications for provider agencies to apply to receive funding. The goal is to offer certified training to achieve National Association of Direct Support Professionals (NADSP) Level 1 Certification.

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[24] Phase-in Timing for New Rates, by Services and 'Cohort' prepared for Developmental Disabilities Division. https://health.hawaii.gov/ddd/files/2017/11/Timing-for-New-Rates-by-Service-and-Cohort.pdf

Findings

While new and modified services added to the IDD waiver service array had to be available statewide as of the effective date of federal approval, DDD knew that it may take time for participants to begin utilizing the new services. DDD aimed to introduce new services through the waiver and then work to support the service provider community to offer the new services. Similarly, it takes time for providers to build service capacity in response to rate increases. Our findings in this section illustrate the trends in service utilization over the years included in this evaluation.

Summary Findings:

- Changes to the service array have supported a significant level of access to the community.
- Updates to the rates were well received among the provider community. The provider network remained stable throughout the evaluation period, although there are a limited number of providers outside of Oahu.
- The wages of direct support professionals increased markedly in recent years, which contributed to reduced turnover rates.

In this section, we present detailed results to answer the question: **What has the impact of changes been on service utilization and utilization patterns?**

As part of this evaluation, we analyzed service payments between 2015 and 2023. In the data that follows, the total users reflect the number of participants who received one or more services during the year. At the service level, there have been some significant changes in service definitions and billing codes that impact these analyses:

- Prior to the 2016 waiver reauthorization, the Personal Assistance/Habilitation (PAB) service covered residential care (i.e., group homes and foster homes) as well as one-to-one supports in the community that are now billed as Community Learning Service – Individual (CLS-I).
- With the 2016 waiver reauthorization, Adult Day Health services were divided between facility-based supports (which continue to be called ADH) and CLS-G. Additionally, billing transitioned from daily units of service to hourly units.
- Beginning in 2022, separate billing codes were established for licensed homes and adult foster homes.

Table 4 reports the number of individuals who used a given service or category of service between fiscal years 2015 and 2023.

Table 4: Number of Service Users by Service or Service Group, FY15-FY23

	FY15	FY16	FY17	FY18	FY19	FY20	FY21	FY22	FY23
Any Service	**2,719**	**2,746**	**2,852**	**2,839**	**2,830**	**2,842**	**2,610**	**2,660**	**2,688**
Personal Assist./Habilitation	2,008	2,053	2,100	2,023	774	761	744	698	685
Residential Habilitation				652	781	772	776	770	780
Comm. Learn. Svc.-Indiv.				1,284	1,598	1,595	1,513	1,475	1,502
Adult Day Health	1,417	1,421	1,445	1,465	1,415	1,395	713	920	1,058
Comm. Learn. Svc.-Group				1,073	1,308	1,264	370	629	862
Respite	129	137	124	151	195	196	189	184	175
Employment	30	46	59	75	118	133	88	92	110
Self-Directed PAB	514	477	548	535	453	449	513	519	543
Self-Directed CLS-I				13	383	427	452	492	529
Self-Directed Respite	314	291	391	375	365	348	364	391	386
Clinical	208	182	185	251	377	348	342	404	452
All Other	75	65	59	71	71	76	308	177	210

A noticeable drop in PAB users occurs in fiscal year 2019 due to the transition to other services described above. Since that time, though, the number of users has continued to decline modestly, which may indicate that individuals are receiving more supports in the community (through CLS-I) rather than in their homes.

About 30 percent of total service users receive full-time residential supports (ResHab) in licensed homes and adult foster homes and ResHab services currently account for approximately one-quarter of waiver spending. Based on the number of paid units of service, about 60 percent of individuals receiving ResHab supports are in an adult foster home with the remaining individuals residing in a licensed home.

CLS-I represents the single largest service in terms of both users and spending. As with other services, CLS-I utilization decreased during the pandemic; however, these declines were much more modest than with other services, and a greater proportion of CLS-I services have recovered since the pandemic. The proportion of individuals who use CLS-I and the typical amount they use has remained fairly consistent, meaning there does not appear to be an ongoing shift to more CLS-I.

The pandemic reduced the use of shared day program supports and utilization of these services remains substantially less than pre-pandemic levels. In fiscal years 2019 and 2020, about 1,400 individuals received ADH; in fiscal year 2023, there were 1,058 users. The reduction in CLS-G is even greater. In fiscal years 2019 and 2020, about 1,300 individuals received CLS-G; in fiscal year 2023, there were 862 users. Shared day supports continue to be primarily facility-based as billed units for ADH remain about three times greater than CLS-G units, a ratio that has remained consistent since separate billing units were established.

Use of employment supports is very low, accounting for only one percent of total spending. That said, some employment supports are authorized and billed as other services (e.g., CLS-I). Only about one percent of individuals receive Job Coaching in any year. There is greater use of Discovery and Career Planning: approximately three percent of individuals receive this service. However, this does not seem to translate to increases in Job Coaching, suggesting that individuals either are not progressing to employment or are able to secure jobs where they do not need paid supports.

The use of consumer-directed services has grown since fiscal year 2015. Nearly three-in-ten individuals (29 percent) who received waiver services self-directed one or more services in FY23 and approximately 18 percent of all spending in that year occurred through a self-directed model. Individuals who self-direct tend to use more supports than those who do not (for example, individuals who self-direct CLS-I use an average of 15.1 hours per week compared to individuals with traditional providers who use an average of 13.7 hours per week).

The popularity of consumer-directed services was echoed in the focus groups. They shared that consumer-directed support offered them the opportunity to create a support system, especially in situations where traditional agency-provided services were lacking or inadequate. Opting for consumer-directed services enabled families to customize care plans, ensure tailored support, and increase flexibility in hiring trusted staff. Despite administrative challenges, this approach offered families greater autonomy and increased flexibility to ensure consistent care and support for their loved ones. Focus group participants mentioned Acumen – the financial management services (FMS) vendor that processes timesheets, issues payments to workers, withholds payroll taxes, and performs other similar financial functions – provided a helpful and easy-to-use tool to manage their budget. One family member disclosed that some families feel challenged in finding reliable staff.

There is little utilization of other services. That includes Skilled Nursing, which was phased-out of the waiver and transitioned to the health plan for children. The increase in Training & Consultation by a registered nurse reflects a policy change related to nurse delegation, which is being unwound.

We also explored results related to the question: **What impact have new payment rates and rate structures had?**

The providers we spoke with as part of the key informant interviews generally expressed appreciation for DDD's efforts to update service reimbursement rates. One interviewee expressed that size may have been a factor that influenced a provider's ability to easily adapt to new payment structures such as breaking ResHab and CLS-I out of PAB or billing separately for ADH and CLS-G on a 15-minute basis. For example, a larger provider operating several residential homes may have an easier time implementing a new rate model than a smaller provider with less administrative infrastructure and capabilities.

77% of service providers active in 2015 were still delivering services in 2023

Another indicator of the impact of adequate reimbursement rates would be that providers are able to sustain their business. In Hawaii, the provider network has been remarkably stable. Of the 56 providers delivering services in FY15, 43 (77 percent) were still delivering services in FY23. The 13 providers that exited had a median waiver revenue in FY15 of only $40,000, meaning they were very small organizations or organizations that primarily operate programs other than waiver services.

About two thirds of the providers that have remained in the system have increased their revenues over time, with a median increase of 87 percent.

In any given year, providers that leave the system account for less than half a percent of total spending and less than 1 percent of total users. There was one significant departure in fiscal year 2016-17, but most of that business shifted to a related organization.

For the most part, the impact on participants when providers have exited has been minimal; most participants were able to switch to other providers for their services.

However, there was a notable exception in FY21 when a provider delivering employment supports on Oahu ceased providing services. Of the 24 individuals who had been receiving employment supports, only four transitioned to employment services with another provider, reflecting the limited availability of employment supports generally.

There are 14 providers that did not deliver services in FY15 but did deliver services in FY23 (there are also a few providers that started after FY15 but exited before FY23). Some of these providers have remained small, but others have grown quickly. Five of these 14 providers billed more than $500,000 in FY23.

Given the larger population base on Oahu, there are substantially more providers there than on the neighbor islands and they generate more revenue as shown in Table 5:

Table 5: Counts of Providers for Major Service Groups by Island, FY23

	Oahu	Big Island	Maui/Lanai/ Molokai	Kauai	Total
All Providers	**46**	**22**	**16**	**11**	**58**
ResHab	14	2	2	4	**19**
PAB	33	16	14	5	**47**
CLS-I	36	15	12	5	**47**
ADH/CLS-G	22	7	4	4	**30**
Employment	7	3	3	2	**11**
Median Revenue	$1,000,000	$350,000	$300,000	$100,000	**$1,250,000**

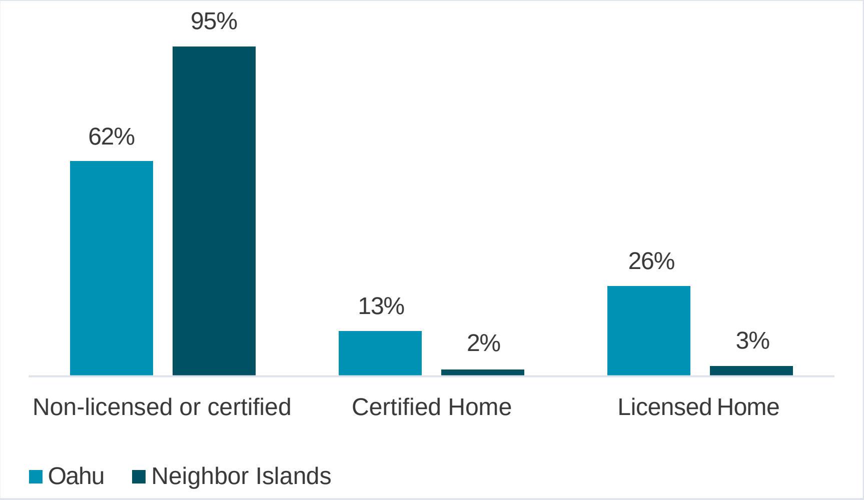
As with the statewide count, provider counts by island in 2023 are nearly the same as they were in FY15. Oahu has at least twice as many providers (46) as any other island and these providers bill a median of $1,000,000 to island residents. In contrast, median annual provider revenues for services delivered to individuals on the neighbor islands are only $100,000 to $300,000.

Due to the lower service volumes on the neighbor islands, about two-thirds of services on the neighbor islands are delivered by providers that also have operations on Oahu. Half of the providers operating on Oahu (23 providers) only operate on Oahu; the other half (23) also provide services on one or more neighbor islands. Smaller proportions of providers operate on only a single neighbor island: five providers operate only on the Big Island, five providers operate only on Maui/Lanai/Molokai, and one provider operates only on Kauai. There are no providers that operate on multiple neighbor islands, but not Oahu.

Of the 58 providers that delivered services in FY23, the largest numbers – 46 agencies – delivered PAB and CLS-I with smaller providers of residential, day program, or employment services. As the table demonstrates, there are few residential or day program providers on the neighbor islands: between two and four ResHab providers per island and between four and seven ADH and CLS-G providers.

Full-time residential use is higher among those living on Oahu than on neighbor islands. In Figure 9, certified settings are adult foster homes that are certified by DDD, and licensed settings are licensed by the Office of Health Care Assurance, State Licensing Section. All other living arrangements are categorized as non-licensed/certified. As illustrated, use of certified (13 percent) and licensed homes (26 percent) is higher on Oahu than neighbor islands (2 percent and 3 percent respectively).

Figure 9: Full-time Residential Use Is Higher on Oahu (FY23)



In addition to understanding the impacts at the provider agency level, it is also helpful to look at how the DSP workforce is faring as a result of the rate increases and other initiatives focused on those who provide day-to-day supports to people with IDD. As part of a temporary, conditional rate increase using ARPA funds (which was later made permanent with state dollars), DDD required providers to report key metrics related to their DSP workforce between July 2021 and September 2023. During this period, the reported average hourly base wage for DSPs increased from $16.13 to $19.42 and the turnover rate fell from 26 percent to 16 percent. However, despite these improvements, the total number of reported DSPs was effectively unchanged during this period and the overtime rate increased from four percent of worked hours to five percent, demonstrating ongoing recruitment and retention challenges.

Hawaii participates in the NCI State of the Workforce Survey, which can be used to examine the key measures and benchmarks pertaining to the direct support workforce. Results of the 2022 survey show that compared with the other 29 states that participated in the survey that year, Hawaii demonstrates strong support for the DSP workforce. Compared to all participating states, providers in Hawaii that responded to the survey report had:[25]

- Lower DSP turnover rates (30.1 percent versus 40.9 percent)
- Higher tenure among DSPs (53.4 percent with 36+ months of employment versus 36.7 percent)
- Lower vacancy rates for full-time DSPs (13.9 percent versus 15.3 percent)
- Slightly higher average starting DSP wages ($15.45 versus $15.13)

In this section we explored results related to the question: **How has service quality changed?**

Figure 10: Feels Staff Has Right Training

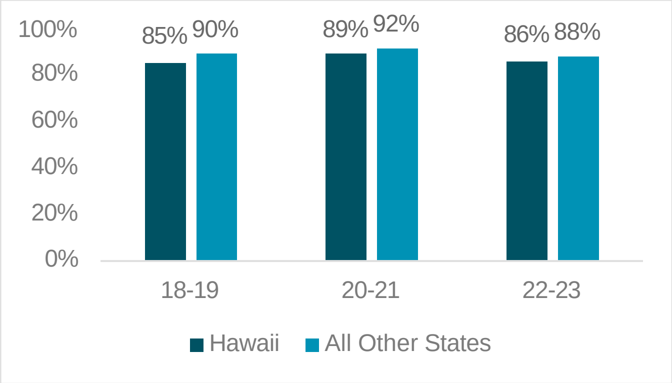
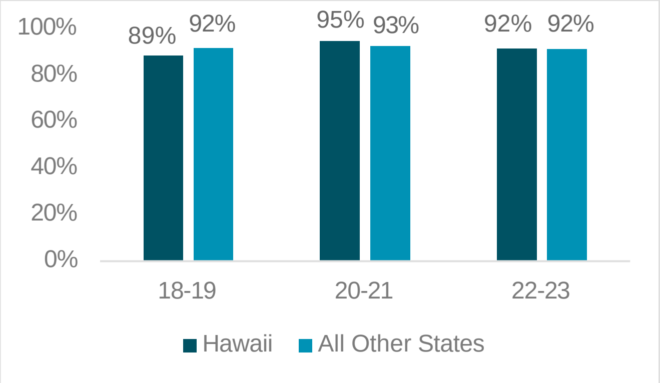


Figure 11: Services Help Live Good Life



There are a multitude of factors that can impact service quality, including the capabilities of individual providers and the expectations of participants and families. Most of what we learned regarding service quality changes was gathered through interviews, focus groups, and NCI measures of overall satisfaction with quality of staff and services.

In Figure 10, the percentage of Hawaii participants who felt their staff had the right training to meet their needs fluctuated between 85% and 89%, with no statistically significant differences across years.

Across the NCI periods evaluated, a large majority of participants (generally more than 90 percent) reported that the services and supports help them live a good life, equivalent to the results for other NCI states.

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[25] National Core Indicators Intellectual and Developmental Disabilities. (2023). National Core Indicators Intellectual and Developmental Disabilities State of the Workforce in 2022 Survey Report. https://idd.nationalcoreindicators.org/survey-reports-insights/

Some family members, but also service providers and case managers, mentioned the discrepancy in the quality of community activities provided by agencies or staff. More than once, interview participants raised concerns about engagement in meaningful activities. Interview participants stated that, in some instances, individuals may be “present in” the community but not “part of” the community. That is, there was some belief that Community Learning Services may be provided in the community but do not reach the intent of the service to offer meaningful and personalized opportunities for community integration.

We conclude that the initiatives aimed at enhancing the HCBS service array and supporting the provider network have been successful in establishing the infrastructure to support service delivery. However, based on direct feedback from participants and family members, case managers, providers, and others, there are opportunities to ensure that the results of these efforts reach the end-users of services and supports. With that in mind, we offer the following ideas for consideration.

Opportunities for Consideration

Consider the Intended Purpose of CLS and Provide Training for the Community

As described above, DDD added CLS to the waiver in 2017 to provide higher payments for community-based supports and to have a clearer view of how participants are served. CLS-I has since become the most utilized service within the IDD waiver. The service definition included in the waiver includes:

> *Community Learning Services (CLS) assist the participant to maintain, learn, or improve skills; develop social roles valued by non-disabled members of the community; use community resources; pursue leisure skills and hobbies; and exercise civil rights and self-advocacy skills required for active community participation.*

Rather than emphasizing the types of activities and opportunities described in the waiver definition, some interview participants believe that the focus of some supports has become merely the location of the service rather than promoting true integration.

As a next step, DDD should consider whether being in the community is a necessary but insufficient condition for defining a support as CLS. That is, the service may be defined as simply delivering support in the community or it may be defined as requiring meaningful integration in the community. Regardless of this decision, DDD should provide training or a communication to the IDD community defining purpose of CLS and the requirements for billing the service so that there is a shared understanding across the community.

Continue to Ensure the Adequacy of Provider Payment Rates

Prompted in part by federal requirements, DDD has emphasized the importance of a thorough, data-informed methodology for establishing provider payment rates. During the evaluation period, three comprehensive rate studies have been conducted, resulting in significant increases in waiver spending. This has helped to maintain a stable and durable provider network.

DDD should continue to regularly evaluate the appropriateness of payment structures and the adequacy of payment rates, particularly as Hawaii's minimum wage increases, putting pressure on DSP wages.

Continue to Support the Direct Support Workforce

DDD should continue to expand the promising practices discovered through its ongoing workforce development initiative to establish a DSP certification process. A significant amount of work has been done through the ARPA-funded initiatives to build ways to better support the workforce such as enhanced trainings, certifications, and pay differentials or other methods that support a career trajectory in this field. We encourage DDD to continue to pursue the direction that has been laid out through that work and prioritize ways to support direct support professionals.

Additionally, the broader IDD community should consider strategies to recognize DSPs for their role and expertise. For example, DDD could consider ways to promote or showcase the good work that DSPs do and highlight mentoring opportunities.

Consider Additional Services

While the IDD waiver covers a comprehensive service array, if DDD is interested in establishing additional services that might enhance service offerings, there are a few that are worth considering, such as:

- **Shared living.** Currently, participants seeking to leave their family home have few options other than a certified or licensed setting controlled by the service provider. On the neighbor islands, even these options are often unavailable. To expand the options available to families and participants, Hawaii could consider shared living models intended to cultivate and maximize a mutually supportive relationship between the caregiver and the person(s) receiving supports who have chosen to share a residence. This type of arrangement is becoming an increasingly popular HCBS option because it allows for integrated support to be provided while offering additional opportunity for natural community connections and greater independence. DDD should review similar services nationally to identify promising practices such as matching processes, ongoing training, and other support offered to both the caregiver/mentors and the person(s) supported to achieve successful, long-lasting shared living relationships. After preliminary review, DDD could initiate discussions with the community about the feasibility of this model.
- **Family-to-family networking service.** Given the significant role that families play in the lives of people with IDD, particularly in Hawaii, it would be worthwhile to invest in service models that directly support family members. The preliminary brainstorming for what is required to offer this type of service is already underway. Based on a review of the information to date, it appears as though DDD is crafting this service to offer peer support tied to specific aspects of navigating the system that families and participants with which often need guidance such as service planning and self-direction.

Recent Activity:

✓ **Partnership with National Association to embrace a Culture of Quality.** DDD is working with the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the Council on Quality and Leadership (CQL) to assist with training HCBS providers on the principles and practices of continuous quality improvement.

System Operations and Oversight

DDD has invested in expanding access to HCBS for individuals with IDD, streamlining eligibility processes, and enhancing service delivery systems. Specific initiatives include improving system operations such as assessment processes, resource distribution through individual supports budgets, exceptions and utilization review processes, quality assurance and improvement plans, and streamlining of eligibility and enrollment processes.

In this section we explored the question: **How well and what impacts have there been in relation to implementation of the Supports Intensity Scale – Adult (SIS-A) assessments and individual supports budgets?**

We found that new methods for assessments, allocating resources, and managing exceptions were successfully implemented. However, certain policies and practices need refinement and support with ongoing communication.

Assessment Processes

Individuals with IDD have a range of needs. Adopting standardized processes to identify individual needs consistently and objectively was a key priority for DDD during the time period covered by this evaluation. DDD began piloting the Supports Intensity Scale for Adults (SIS-A), developed by the American Association on Intellectual and Developmental Disabilities (AAIDD) years prior to 2014, though the use of the assessment was inconsistent. DDD did not commit to using the SIS-A as an official assessment tool until its planned use as the instrument aligned with the supports budget framework. This was the point that DDD implemented solid processes for administering the tool to everyone served on the waiver according to AAIDD recommended practices to maintain validity and reliability.

Implementation

The move to administer SIS-A assessments across the waiver population represented a significant undertaking. DDD had to develop the necessary infrastructure to support the assessment process including creating a SIS manager position; a cadre of assessors trained and endorsed by AAIDD; and developing assessment interview protocols, scheduling procedures, and other policies and procedures.

A group of case managers were selected to become SIS-A assessors. To be recognized as a SIS-A assessor, they had to complete a robust training program provided by AAIDD and at least four practice interviews, as well as pass an Interviewer Reliability Qualifications Review (IRQR). AAIDD also recommends that assessors receive training refreshers from an AAIDD-endorsed trainer and pass the IRQR annually to demonstrate adherence to quality standards and best practices as an assessor.[26]

Individuals receive a SIS-A assessment every three years. To conduct the initial assessments, DDD created three cohorts of individuals as discussed in the Services and Provider Network section. Based on the number of participants in each cohort DDD had to plan for approximately 65 assessments per month in 2017, 80 per month in 2018, and 85 per month in 2019. The scheduling unit developed a mechanism to identify when a participant would need a SIS-A assessment in relation to their service planning meeting. To support the scheduling process, the SIS manager sent templates to the case management units to populate with appropriate information for all participants with an upcoming assessment.

Around 2017, DDD had approximately 13 SIS-A assessors and the number of assessments that each assessor completed varied. However, during the COVID-19 emergency, the number of SIS assessors waned for a variety of reasons. As of the writing of this report, DDD only has five local SIS assessors. Because SIS assessors are also case managers and have responsibilities associated with that role, the local assessors generally conduct only about 20 to 25 assessments per month, which is less than half the total that need to be completed. As a result, in recent years, DDD has contracted with AAIDD assessors from out-of-state to supplement local assessors.

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[26] https://www.aaidd.org/sis/training/overview

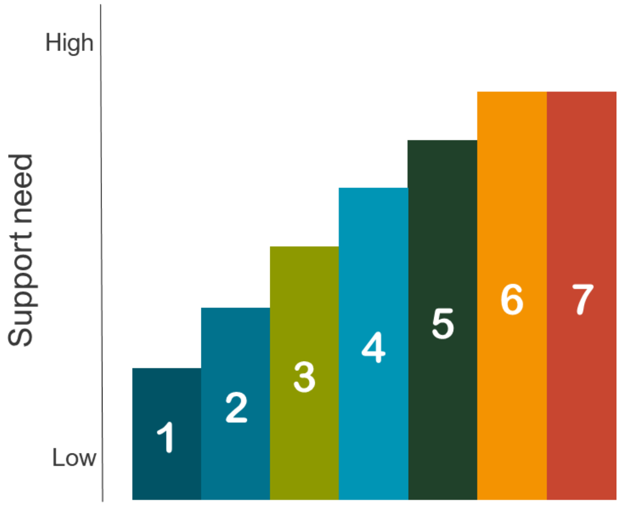
Individual Supports Budgets

A “supports budget” is an individually based, prospectively determined amount of funds that is made available to waiver participants to plan for the services and supports they need. DDD’s implementation of a supports budget framework was intended to create a system of allocating resources that is fair, efficient, person-centered, and flexible. Ideally, participants are made aware of the amount of their supports budget before planning for supports for the upcoming year, providing them the opportunity to make choices about their services. The framework also offers increased predictability of overall system spending, as well as greater understanding of the service population.

Implementation

DDD embarked on a substantial effort to design and implement a support level framework for adults. The framework is based on a participant’s support needs, as measured by the SIS-A, and their type of residence (e.g., adult foster home, living with family). Assessment results were used to assign participants to one of seven levels, related to their support needs. Figure 16 illustrates these levels. Levels 1, 2, 4 and 5 include participants from less to more general support need, while Levels 3, 6 and 7 include participants with modest behavioral challenges (3), extraordinary medical needs (6) and extraordinary behavioral needs (7).

Figure 12: Support Needs Framework



To establish budgets, DDD analyzed past service use among each group to create service mixes that reflect the types and amounts of service appropriate to meet the needs of most individuals in each group. The services were then priced using the rates per service to arrive at the individual supports budget for each support level and living arrangement.

A complementing set of policies and procedures was developed to support the operations of the supports budget framework. Additionally, a calculator tool was developed to support planning teams to use while planning for services within the budget amount. As service hours were entered into the tool the annualized amounts would be auto-calculated.

The supports budget framework was phased-in over three years according to the three cohorts of the population discussed above. This phase-in process allowed time for participants to be assessed and for planning teams to prepare for using a supports budget as one piece of information in the service planning process.

Exceptions and Utilization Reviews

As part of the implementation of individual supports budgets, it was necessary to develop an exceptions and utilization review process for circumstances when support teams felt that a participant required supports beyond what was available within their individual supports budget.

DDD sought to establish a comprehensive and uniform review process for exception requests to ensure participants have the support they need.

Implementation

DDD established policies and procedures that defined the circumstances that support an approval. When a participant requests additional supports, the Exceptions Review Committee has 30 days to review and provide a response. The team also streamlined operations for exceptions cases seeking enhanced staffing ratios, which also require the review and approval of the Clinical Interdisciplinary Team (CIT); combining meetings, the Exceptions Review Committee and CIT reviewed these requests together.

A byproduct of implementing this process is that it helped to clarify the range of decisions that could be made by case management supervisors and those that required a review by DDD. This increased DDD's involvement and ability to determine the type of circumstances around exceptional needs. The Exceptions Review Committee collects data regarding the number and type of requests, participants' support levels and supports budget amounts, and request decisions. These trends can be viewed over time and provide information about how well the supports budget framework is working.

Quality Assurance and Improvement Program

Both DDD and CMS in recent years have emphasized the development of quality assurance structures and performance improvement. DDD's Quality Assurance and Improvement Program (QAIP) was established in 2012. It uses a steering committee and subcommittee structure to review data and reports related to incident reporting, mortality reviews, and provider monitoring tools. The three subcommittees include Quality Services and Care, Safety and Well-Being, and Service Provision. The QAIP process uses a work plan with performance measures to track progress. The QAIP Steering Committee can also make recommendations to the DDD Management Team regarding quality improvements.

Some of the quality assurance processes aimed to improve relationships with providers by proactively establishing expectations. This promoted a shift from a compliance focus to methods that encouraged agencies to track performance data and make improvements based on a continuous quality improvement (CQI) approach.

Implementation

Previously the legislature removed funding for the position that oversees the QAIP, but it was restored last year. When the process is fully functional a report would be produced annually to evaluate performance measures. However, because DDD did not have the staffing capacity to fully implement this process as originally envisioned, an annual report has not been released in recent years.

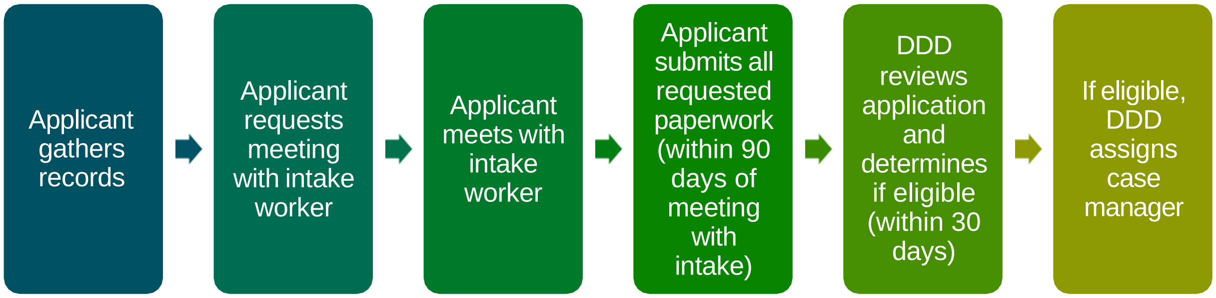
HCBS Waiver Access

To receive waiver services, an applicant must meet the functional requirements specified in the waiver (that is, they must meet institutional level of care) and additionally be approved for Medicaid through Med-QUEST (for example, by meeting income and asset requirements).

DDD’s intention is to streamline this process to the extent possible and create a smooth transition into DDD services once a person is deemed eligible.

Each step in the eligibility process has its own timeline requirements. CIT ultimately reviews all the documentation and determines waiver eligibility. The applicant must also go through a separate Medicaid approval process through Med-QUEST before they are ready to receive waiver services.

Figure 13: DDD Eligibility Process



DDD contracts with psychologists for the required psychological assessments; however, an applicant may choose to obtain a psychological evaluation by a psychologist independently. The availability of professionals to conduct the necessary psychological assessments is limited, and this results in delays. Part of the current initiative is aimed at expanding the number of providers qualified to render this assessment through outreach and engagement.

Implementation

This initiative involved efforts to study and improve the front-end eligibility and intake process. A review of the process identified several areas for improvement; these included updating policies and procedures to include periodic communication and information sharing with applicants, being clearer about additional documentation requests from both DDD and waiver eligibility through Med-QUEST, use of features in the INSPIRE IT system for communication and document organization, and integration of data reporting into intake team meetings.

Findings

The following presents our high-level summary of our findings for this section.

Summary Findings

- ► New methods for assessments, allocating resources, and managing exceptions were successfully implemented.
- ► Certain policies and practices need refinement and support with ongoing communication.

In this section we explore: **How well and what impacts have there been in relation to implementation of SIS-A assessments and individual supports budgets?**

To answer this question, we analyzed data on spending in relation to what would be expected given the parameters established with individual supports budgets. We also include reflections from focus groups and interviews about the assessment and supports budget process.

Support Needs Assessment Process

While the SIS-A assessment aimed to provide a comprehensive understanding of support needs, waiver participants, families, and caregivers interviewed as part of this evaluation voiced concerns. In particular, some individuals feel there is inconsistent scoring and interpretation among assessors that results in unfairness in the assessment process. Moreover, the lengthy and sometimes repetitive nature of the assessment was seen as burdensome, potentially leading to fatigue, reduced engagement, and dissatisfaction with the process.

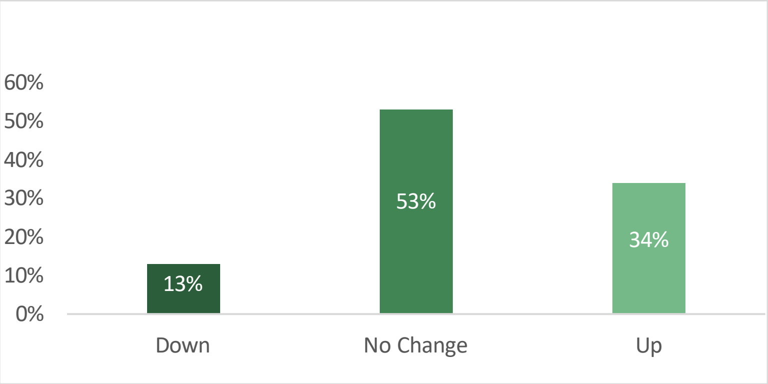
Case managers cautioned that some participants and families struggled to understand the nuances in the assessment procedure. Some case managers expressed their own concerns, including:

- The weight of the assessment in determining individual supports budgets.
- The assessment not accounting for the participant's living situation.
- A lack of understanding of the local culture among some out-of-state assessors.
- An inability of the SIS-A to measure preventative or behavioral support work carried out by caregivers and family members thereby understating individuals’ actual support needs.

There was also some discussion among focus group participants about the fluctuation in support levels as a result of a new SIS-A assessment that may lead to differences in supports budget amounts.

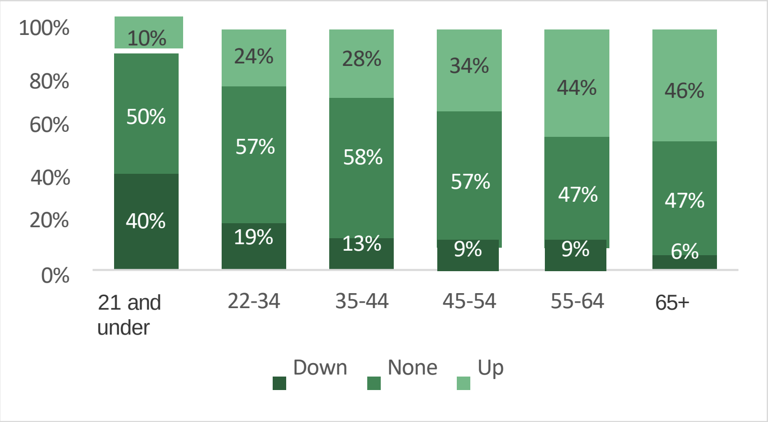
To quantify this consideration, we looked at support level change over time.

Figure 14: Support Level Change from First Assessment to Last Assessment



Of the 1,838 participants that have had more than one assessment, Figure 14 shows that about half had no change in support level from the first assessment to the last assessment. Thirteen percent had a decrease in support level and 34 percent had an increase in support level. This is showing the change in support level; however, this does not account for change in an individual supports budget. Depending on the type of living arrangement, a change in support level does not necessarily mean a change to the individualized supports budget.

Figure 15: Support Level Change by Age from First Assessment to Second Assessment



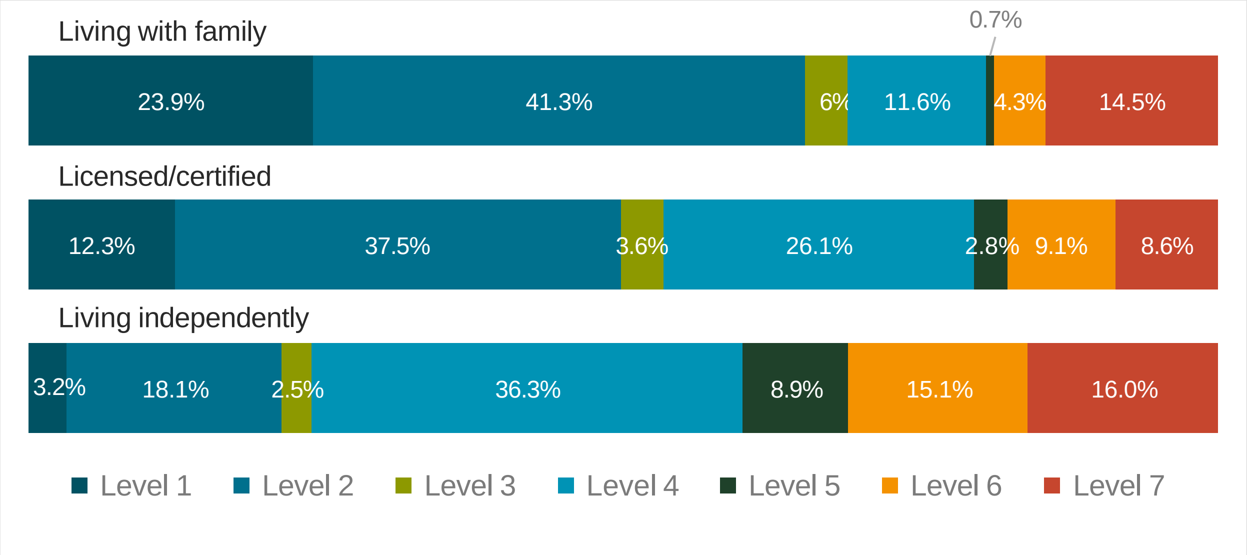
We also examined changes in support levels by age. Figure 15 shows that participants in older age categories were more likely to see an increase in support level from the first assessment to the second assessment, which might be partly explained by an increase in support need due to aging. The number of participants in the 21 and under category is relatively small as in Hawaii the SIS-A assessment is only administered to those 18 and above.

Per-Person Spending (measured as per-member, per-month)

A participant's living arrangement is the most significant predictor of the cost of supporting an individual. In fiscal year 2023, the average monthly cost of supporting an individual in a licensed or certified setting was $6,703 compared to $4,609 for those living with family and $9,402 for those living independently.

Participants in licensed and certified settings have higher average costs because they are receiving 24-hour care 365 days per year. Additionally, participants in these settings tend to have higher assessed needs, as shown in Figure 16. The very high average for those living independently is due to individuals in higher assessment levels receiving individualized budgets with large amounts of approved hours; if participants in Levels 4-7 are excluded, the average monthly cost for those living independently is $4,419.

Figure 16: Support Level Distribution by Living Arrangement



There are significant differences in per-person spending across the islands, even after accounting for differences in the distribution of living arrangements. Table 6 shows however, there is no consistent pattern. For example, on the Big Island, average spending for individuals living with family is considerably higher than the statewide average (some premium would be expected due to the higher rates paid on the Big Island), but average spending is lower for those in licensed and certified settings and those living independently. It is noted, though, that these figures may be skewed due to low population counts on the neighbor islands.

Table 6: Per Member Per Month Spending as a Percentage of Statewide Average by Living Arrangement and Island

	Oahu	Big Island	Maui/ Lanai/ Molokai	Kauai
Licensed/certified	101%	87%	78%	104%
Living with family	88%	133%	105%	115%
Living independently	82%	84%	165%	81%

Participants with more significant assessed needs have higher costs due to a higher likelihood of receiving 24-hour care, greater service utilization, and higher rates for tiered services:

Table 7: Average Costs Per Member Per Month by Support Level

Support Level	Level 1	Level 2	Level 3	Level 4	Level 5	Level 6	Level 7
Average PMPM	$2,870	$3,579	$4,698	$5,656	$6,895	$7,219	$10,875

Authorizations, Individual Supports Budgets, and Exceptions

In FY23, there were notable numbers of participants with service authorizations who did not use any of the authorized service:

- ADH: 16 percent of participants with an authorization did not access the service
- CLS-G: 22 percent of participants with an authorization did not access the service
- CLS-I: 10 percent of participants with an authorization did not access the service
- PAB: 9 percent of participants with an authorization did not access the service
- Respite-Hourly: 33 percent of participants with an authorization did not access the service
- Discovery and Career Planning: 30 percent of participants with an authorization did not access the service

The reasons for this may require further investigation; however, focus group participants and interviewees mentioned the challenge of finding suitable staff. They also mentioned this led to frustration when services were not available despite being authorized.

Participants living independently are much more likely to have an authorization for PAB (75 percent with an authorization for agency services and 21 percent with an authorization for self-directed services) than those living with family (34 percent and 28 percent, respectively). They also have larger authorizations, 36 hours per week for agency services and 28 hours for self-directed services compared to 21 hours and 25 hours, respectively.

There are notable differences in authorizations and usage of day program services based on individuals’ living arrangement:

- Participants in licensed and certified settings are much more likely to have an authorization for ADH (73 percent compared to 40 percent of those living with family and 20 percent of those living independently). The average number of authorized hours, utilized hours, and the utilization rate (percentage of authorizations used) is somewhat higher among those in licensed and certified settings.
- Participants in licensed and certified settings are also more likely to have an authorization for CLS-G (60 percent compared to 38 percent of those living with family and 18 percent of

those living independently). Authorized amounts are much lower than ADH and are similar across arrangements at about five to seven hours per week.

- Participants who live independently are most likely to have an authorization for CLS-I (85 percent compared to 63 percent of those in licensed and certified settings and 59 percent of those living with family). They also tend to use a greater number of hours (19 hours per week compared to 11 hours for those in licensed and certified settings and 15 hours for those living with family).

More than half of those in licensed and certified settings have an authorization for Training and Consultation by an RN, compared to 13 percent of those living with family and 29 percent of those living independently.

The overall percentage of individuals with needs that are greater than their individual supports budget (ISB) is generally consistent with expected exception rates. However, the number of overages somewhat exceeds the number of approved exceptions. We learned from DDD staff that there are a few scenarios that can lead to this circumstance (where a participant has been authorized for services that exceed the ISB amount without an approved exception) — and these are mainly related to procedural challenges. For example:

- To maintain continuation of services, the ISP will be authorized, even though the plan exceeds the supports budget, while the case manager sends the formal request through the exceptions process and awaits the decision.
- The ISB might also appear to be exceeded if an exceptions request was reviewed and approved but for a timeframe less than the full plan year.
- In some cases, if a participant has a new SIS-A assessment prior to the end of the plan year that results in a lower support level; this will also result in a reduction to their supports budget amount.

Table 8: Percent with Overages by Living Arrangement and Support Level

	Level 1	Level 2	Level 3	Level 4	Level 5	Level 6	Level 7	Total
Licensed/certified	5 (26%)	16 (15%)	3 (17%)	26 (11%)	3 (6%)	7 (9%)	29 (26%)	89 (14%)
Living with family	12 (6%)	27 (4%)	4 (8%)	31 (7%)	6 (13%)	8 (5%)	29 (22%)	117 (7%)
Living independently	3 (9%)	13 (22%)	0 (0%)					16 (16%)

The primary drivers of authorizations that exceed ISBs are:

- **Licensed/certified homes:** Almost two thirds of overages are primarily due to CLS-I authorizations that exceed the model service mix assumptions, and another third are primarily due to combined congregate service hours (ADH and CLS-G) that exceed the model service mix assumptions.
- **Living with family:** 57 percent of overages are primarily due to CLS-I authorizations that exceed the model service mix assumptions and 29 percent are primarily due to combined PAB and CLS-I hours that exceed the model service mix assumptions.
- **Living independently:** 56 percent of overages are primarily due to CLS-I authorizations that exceed the model service mix assumptions and 44 percent are primarily due to combined PAB and CLS-I hours that exceed the model service mix assumptions.

Overall, about 7 percent of individuals requested an exception and about 80 percent of exceptions were approved. The percentage of individuals with an approved exception is no higher than 4 percent for those assigned to Levels 1-6, but 28 percent of those assigned to Level 7 have an approved exception.

In terms of the reasons for exceptions:

- About 20 percent (28 individuals) of exceptions are for individuals living independently assigned to Levels 4-7 for which there are no ISBs (meaning they automatically require an exception).
- The largest group (37 percent, 51 individuals) is individuals with behavioral needs. Most of these individuals are already assigned to Level 7 (the extraordinary behavioral needs group).
- Only 6 percent (9 individuals) relate to medical needs.
- The remaining exceptions are for “situational” (20 percent, 28 individuals) and “other” (17 percent, 23 individuals) reasons.

Excluding individuals living independently and assigned to Levels 4-7 (who always require an exception), the exception rates are similar across living arrangements. In terms of the services for which exceptions were granted:

- The largest number of approved exceptions are for CLS-I.
- For individuals living with family, the number of exceptions for PAB were almost as great as those for CLS-I. The next most frequently approved service was Respite.

Exception rates are similar across islands.

Some case managers described the exceptions procedure as inefficient, while others felt it ensured that waiver participants received adequate services. Because the needs of participants with disabilities do not change greatly from year to year, case managers questioned why the exceptions process had to be repeated yearly or every 6 months in some cases. Though some case managers we talked to had been rather successful in their exception applications, they expressed frustration with having to compile and organize large numbers of documents for review. One case manager expressed gratitude that the Exceptions Review Committee had been tasked with handling the determination of additional support, while others felt that their expertise was being called into question.

Overall, while we observed established policies and procedures that support and implement the needs assessment processes, individual supports budgets, and the exceptions processes, it appears that some areas could use further refinement to ensure the process is running as smoothly as possible.

Opportunities for Consideration

Increase Assessment Capacity

We would recommend building capacity to conduct SIS-A assessments. Information from the focus groups and interviews revealed a preference for local assessors who are familiar with the population. The optimal arrangement is for DDD to have between 10-15 case managers who are also SIS assessors to manage caseloads and maintain a consistent assessment schedule.

It would be beneficial to revisit the scheduling protocols and administrative processes to ensure they are working efficiently to address the backlog of assessments that have accumulated over time. It is imperative that the CMUs submit their templates with participant information in a timely fashion to keep the scheduling on track.

DDD should continue monitoring assessor quality through training and IRQR processes as recommended by AAIDD. It is important to provide ongoing monitoring of SIS-A assessors. It is beneficial to periodically conduct a review of assessor data that includes indicators such as average number of assessments completed per CMU, average range of scores and resulting support levels, and any other qualitative information that is collected from assessment respondents.

In line with these recommendations, DDD has already taken several steps to build the assessment capacity through the activities listed below.

Recent Activity:

- ✓ **Train-the-trainer Assessment Contract.** DDD has engaged AAIDD to support a train-the-trainer model to build capacity among a cadre of local assessors. This will provide the ability for DDD staff to offer training to new case managers to become SIS-A assessors.
- ✓ **Assessment Requirements in Job Positions.** DDD now requires new hires in specific staff roles to be SIS assessors as part of their job responsibilities.

Improve Supports Budget Processes

To make the best use of the individual supports budgets, case managers can share information about the budget amount in advance of the planning meeting. The hallmark of the ISB is the transparency it offers to participants and their planning team. Having information about the budget in advance of or during the planning meeting is intended to increase the amount of control participants and their families have over the services and supports they choose to receive. Participants would also benefit from materials that explain the services available to them based on their ISB, not just its dollar amount. It is best if the information is communicated ahead of time, thoroughly explained during the planning meeting, and demonstrated using the calculator tool to show how the budget is being spent.

In the case that a new SIS-A assessment is administered on the typical reassessment cycle (i.e., approximately every 3 years) and the scoring results in a new support level that is lower than the participant’s current level, we would recommend planning for that reduction to take effect at the start of the next plan year. This will give the team advance notice to begin preparing for adjustments to services. The current practice is to administer the reduction at the time that a new SIS is administered, which could be several months prior to the expiration of the current ISP.

We suggest revisiting policies, procedures, and notifications related to the supports budget and when an exception process should be initiated. The calculator tool includes a notification when the plan exceeds the supports budget amount, and CMU supervisors are responsible for reviewing every instance where this occurs. From an aggregate data collection perspective, these will look like ISPs that are authorized over the budget. Perhaps there are additional mechanisms that can be included in the calculator tool, or elsewhere, that provide more detail about exceptions proceedings. It would also be helpful to establish other parameters in policy that dictate certain timeframes that a plan can be approved above the budget while awaiting exception review decisions to try and expedite the process. These policies would aim to avoid the situation where a person is authorized above the budget for several months into the plan year with no decision on whether the exception has been officially approved or denied.

Reset the Quality Assurance and Improvement Plan (QAIP) Process

DDD may assess what parts of the QAIP plan might be possible to reinstate. While the QAIP process has an established framework, it has not been fully operational due to staff shortages and other internal barriers. To reinvigorate this program, a first step might be to assess if there are smaller, more manageable parts of the process that might be feasible to reengage even if the entirety of the program cannot be fully implemented at this time. This assessment process might include first documenting what parts of the process are currently happening and by whom, detailing the ideal process, and then setting reasonable goals to achieve within a specific timeframe.

Modernization and Innovation

Some of the initiatives DDD starting in 2016 were aimed at modernization through the development of technology solutions, engagement with national consultants, and research into best practices employed by other states to shift expectations and increase choice and control for people with IDD. In this section, we describe the initiative to create the INSPIRE IT solution. We also describe initiatives related to Employment First, innovation in the Neurotrauma program, and the expansion of dentistry services for people with IDD.

INSPIRE Case Management System

In 2019, DDD went live with a new IT system, INSPIRE — a comprehensive, multiagency intellectual and developmental disabilities/behavioral health case management system that interfaces with other Medicaid assets to promote the goals of DDD. The intention was to offer a solution that enabled DDD to support efficient, timely, accountable person-centered service delivery for participants through an integrated case management system with secure data sharing — and to move away from paper-driven legacy systems.

INSPIRE also supported DDD in tracking data and information to monitor quality through a provider portal and growing library of *Power BI* reports.

Core areas of system functionality completed in Phase 1 of INSPIRE implementation included Intake, Assessments, Case Management, Service Planning, Billing, Provider Management, Service Management, Quality Management, Adverse Event Reporting, Appeals Management, and Reports. Phase 2 introduced new areas of functionality, including LifeCourse service planning tools, a budget and service authorization tool (Calculator 3.0) fully integrated with INSPIRE, and Targeted Case Management billing support.

Phase 3 included enhancements to Adverse Events as well as new functionality such as Referrals, Individual Support Budget Exception Reviews, Care Teams, Clinical Review Process, Critical Incident Analytics Reporting, Customer Portal, Mortality Reviews, Mid-Year Service Authorization Change Support, Service Plan Cloning, DDD Provider Portal, Help Desk Tool, Electronic Visit Verification Support, Interoperability Regulatory Compliance (FHIR), Interactive Training Modules, and Automated Regression Testing Tools. Phase 3 will evolve INSPIRE from a minimum viable product to a robust and interoperable case management system capable of informing decision-making at all levels of DDD.

Several interviewees mentioned the ability to track adverse event reporting (AER) in INSPIRE. This ability has made the process faster and reduced the risk of missing an AER. Prior to the ability to track AERs in the system, providers would call and report verbally and a written report would be delivered in different ways. The new process has helped with tracking and coordination as INSPIRE generates notifications for the person’s team (unit nurse, CM, supervisor, OCB, etc.)

INSPIRE has also helped to streamline the intake process. Prior to this the application process was largely managed through a paper process. Now, these documents are available within INSPIRE, and when the participant is assigned to a case management unit, the case manager can access the individual’s record. Information is also available to clinical team through INSPIRE. For example, if a participant is referred to CIT, members of that team can review contact notes, ISPs, and supporting documentation all together. Another notable improvement with INSPIRE is the ability to generate reports to assist DDD leadership in decision-making.

Future plans for INSPIRE include a provider portal that will support streamlining access to participant information.

Implementation

The legacy IT case management system that DDD used for many years was slow, did not support many of the functions that case managers needed to perform, and was not centrally organized across CMUs. In addition, there was a separate access database that managed authorizations that was not connected at all to the case management system. This resulted in the development of manual and rather inefficient processes that relied on the transfer of paper documents and/or faxes across disparate systems.

This led DDD to invest in a new case management system, INSPIRE, to address and resolve many of the issues that users experienced with legacy system – including the ability to link individual support plans with service authorizations. The INSPIRE solution went live with core functionality in February 2019. This solution enables DDD to support efficient, timely, accountable person-centered service delivery for its customers through an integrated case management system with secure data sharing. The INSPIRE solution transitioned the DDD from paper-driven and non-HIPAA compliant legacy systems to a modern solution that supports integrated service delivery, efficiency, and transparency.

DDD contracted with a vendor for the development of the INSPIRE system and used an iterative approach to build and enhance the system's functionality over time. A staff member at DDD was responsible for overseeing the development of INSPIRE and coordinating with end-users of the system to gather requirements to make sure the system could accommodate the necessary case management processes. During the development, DDD provided training and technical assistance to help CMUs get familiar with the system and understand transition timeframes.

American Rescue Plan Act (ARPA) Initiative

Improve Critical Incident Response through Analytics. DDD has executed a contract with a vendor to develop a platform that will enable DDD to use predictive analytics to detect unreported critical incidents in INSPIRE. This initiative is currently in process.

Employment First

This strategic goal is aimed at increasing opportunities for people with IDD to achieve community integrated employment. Like many other states around the nation, Hawaii adopted an Employment First approach to promote access to gainful employment options for people with IDD.

Implementation

To support this effort, around 2015, DDD applied for the Employment First Leadership mentoring program and received a grant for technical assistance. A collaboration was established between the Department of Education, Division of Vocational Rehabilitation, Hawaii Developmental Disabilities Council, and Department of Labor to discuss customized employment. Technical assistance was provided to help draft a memorandum of understanding (MOU) to establish a working partnership among these entities.

DDD also created a staff position to support the development of the enhanced suite of employment services. This staff member spoke with employment providers to learn what was working and not working and took this information to DDD leadership to make necessary adjustments. This staff member also offered training and customized support to employment providers to help them think creatively about how to best support people with IDD to reach their employment goals. This included monthly opportunities for providers to ask questions and get resources. It was through these relationships with employment providers that staff identified that benefits counseling was integral to helping people with IDD pursue employment opportunities without experiencing interruption in needed services and supports; and as a result, benefits counseling was added to the service array.

American Rescue Plan Act (ARPA) Initiative

Advance Competitive Integrated Employment (CIE). As part of this initiative, DDD hired a contractor to provide training and technical assistance to a cohort of seasoned employment providers as well as those who were interested in expanding into this area. Each provider crafted an action plan suited to their needs.

While not specifically part of the core waiver program that was the primary focus of this evaluation, two additional programs are included under DDD. Here we provide a high-level overview of Dental Services and the Neurotrauma Program, both of which engaged in innovative approaches to expand their reach.

Dental Services for People with IDD

The Hospital & Community Dental Services Branch is housed within DDD. The primary goal of the dental branch is to provide comprehensive direct dental services for specific populations including:

- Medicaid recipients aged 65 and older
- Blind, disabled or other special needs populations who do not have access to dental care
- Individuals with severe chronic mental illness, the frail elderly, the medically fragile, and persons with intellectual and developmental disabilities (IDD)
- Individuals who live in Hawaii State facilities, including the Hawaii State Hospital and Kalaupapa Settlement.

Of those served, approximately one-third are persons with IDD. Previously adult Medicaid recipients were only covered for emergency services such as extractions, etc., and this created a major issue around access to care. The dental branch has always sought to restore adult dental benefits. After consistently working with the legislature, starting in 2023, Medicaid will cover comprehensive benefits for

The dental branch has taken a two-pronged approach to increasing oral health for people with IDD through focusing on reaching individuals with IDD, families, and service providers as well as increasing knowledge and skills of other dentists to serve patients with IDD.

The branch has also used grant funding to expand access to routine dental care through the virtual dental home model. This is a delivery care model using telehealth and tele-dentistry to treat patients. It consists of two teams including a clinic with dentists in the office who can offer support to a dental hygiene team that goes out into the community. The dental hygienist brings equipment such as portable chairs and other devices to take x-rays and perform cleanings. This breaks down barriers around transportation and is more convenient for people with IDD. At this time, this is mostly provided through WIC programs and nursing homes, however there is an interest in expanding this option with DDD service providers.

Neurotrauma Program

The Neurotrauma Program is also housed under DDD for individuals with traumatic brain injuries, stroke, or spinal cord injuries. This program is currently supported through a Special Fund made up of partial payments from traffic citations. The program does not offer any case management or direct services but does operate a help line to connect people with resources in the community. The Neurotrauma program also conducts outreach activities to increase awareness about topics such as head injury prevention.

In addition, the Neurotrauma program can support innovation through issuing grant funding. For example, the program recently supported the development of a pilot program to equip rural hospitals with tele-stroke equipment. This program allowed for specialists to review information on urgent cases involving individuals experiencing stroke symptoms via tele-medicine equipment and make real time determinations regarding the best course for care. This was particularly impactful for neighbor islands and in some case, individuals could be treated remotely where they were and avoid having to be transported to Queen’s Hospital.

Findings

The following presents our high-level summary of our findings for this section.

Summary Findings:

- New IT solution (INSPIRE) created efficiencies in case management practices, and data collection and reporting.
- Efforts to promote employment have promise but have yet to show significant gains in people using employment services or having community jobs.

The following presents our detailed findings related to the initiatives included in this section. At the very end of this section, we present findings that connect to overall outcomes that represent a culmination across all the initiatives included in this study.

INSPIRE Case Management System

Most of what we learned about INSPIRE came from focus groups and interviews. There were differing opinions among case managers about the INSPIRE system. When INSPIRE first launched, some found it useful and workable once they got used to it; others expressed frustration over its poor design and the lack of training on INSPIRE's functions, stating that they relied on self-directed learning and peer assistance as they operated INSPIRE.

Despite the initial challenge, several case managers appreciated the ability to centralize documents and records, which made it easier for them to access and manage client information. There were comments about INSPIRE's user-friendly interface and its capacity to facilitate seamless transitions between case managers, ensuring that work progress is maintained and easily accessible to colleagues. Even though entering the data into the system took time at first, the users viewed it as a worthwhile investment, anticipating increased efficiency with ongoing use. Case managers emphasized the helpfulness and promptness of IT staff in resolving INSPIRE-related problems, highlighting the value of continuous support and cooperation in maximizing system efficacy and usability.

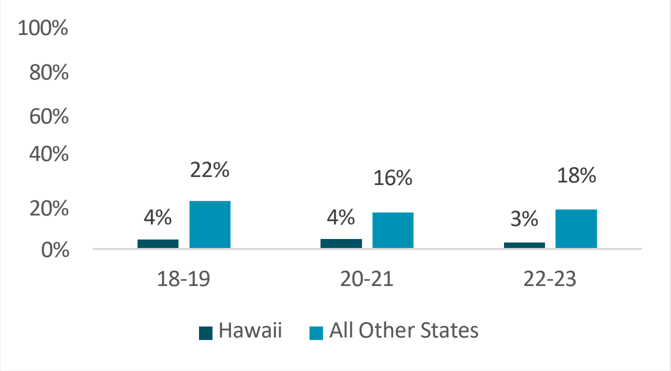
On the other hand, some case managers voiced frustration and dissatisfaction with INSPIRE. Quite a few case managers complained that the system was not user-friendly, inconsistent, and required extensive navigation through multiple screens and websites to input information. The disjointed nature of various online platforms and the frequent updates to the system contribute to the complexity and frustration experienced among case managers. They criticized the system for being cumbersome, time-consuming, and prone to errors, making their jobs more complicated and less efficient. Some users commented on specific issues such as limited space for inputting text, confusing user interfaces, and the need for more training to navigate the system effectively.

Employment

As previously mentioned, the use of employment supports is very low, accounting for only one percent of total spending. (However, as was also mentioned previously, some employment supports are delivered under other services such as CLS-I.)

The NCI survey contains several employment-related items, including whether people have community jobs, want a community job, or have employment as a goal in their ISP. Again, we looked at how Hawaii compares to the other participating NCI states for context.

Figure 17: Has Paid Community Job



Based on data provided by the State, the percentage of participants with a paid community job was significantly below other states in all survey years. In 2022-23, Hawaii's figure decreased to 3 percent, compared to 18 percent in other states.

Figure 18: Wants a Paid Job in the Community

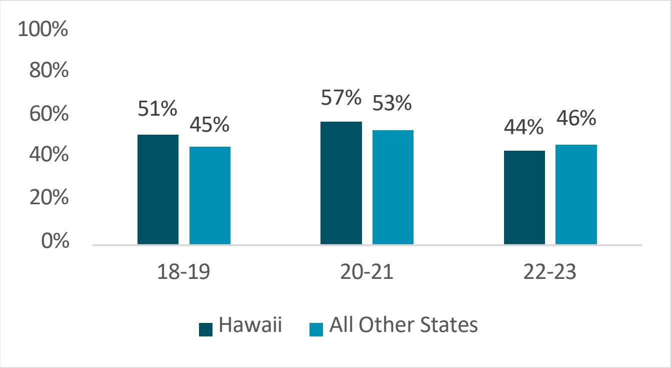


Figure 19: Employment as Goal in Service Plan

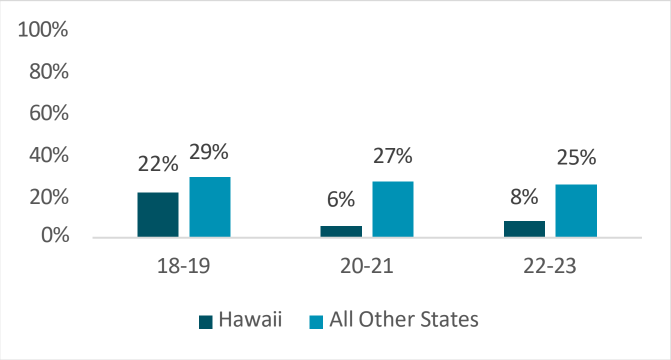


Figure 18 shows the number of Hawaii participants without a paid community job who expressed a desire for one peaked at 57 percent in 2020-21. In 2022-23, this percentage was 44 percent. There were no significant differences between Hawaii and other states during the three survey years.

Figure 19 shows that compared to other NCI states, a lower percentage of Hawaii participants have a paid community job included as a goal in their service plan. Hawaii had a significant drop in this measure between 2018 (22 percent) and 2020 (6 percent) and remained significantly lower than other states in 2022-23 (8 percent vs. 25 percent).

The reason we selected these NCI items is because we note that having a goal for employment in the ISP for those who want a job has been linked to greater likelihood of competitive integrated employment.[27]

We gathered a wealth of information during our focus groups and interviews on the topic of employment. Interview participants emphasized the importance of employment for individuals with disabilities. Comments included that work provided a sense of purpose and identity; getting paid reinforced their worth and sense of value, thus improving their overall well-being and confidence. Service providers also highlighted the opportunities for growth and learning that come with employment. Even in cases where a job did not work out, it was considered a worthwhile educational experience. In addition to helping the individuals themselves, this growth attitude broadened the perspectives of others who assisted them, including career coaches and program coordinators. Waiver participants expressed pride in the work they accomplish and the financial support they give their families, saying things such as, “I pay my rent and help my [family] with the phone bills and stuff like that. I personally pay my $95 monthly phone expenses” (Waiver Participant, 2024).

An advocate cautioned against imposing work on waiver participants who don't want to work, while one service provider criticized the complacency of providing people with IDD with volunteering activities. She cautioned, “There is this fundamental thing that happens when a person goes to work

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[27] DuBois LA, Bradley V, Isvan N. An observational investigation of unemployment, underemployment, and competitive integrated employment of people with intellectual and developmental disabilities in 2021-2022. Disabil Health J. 2024 Mar 29:101620. doi: 10.1016/j.dhjo.2024.101620. Epub ahead of print. PMID: 38584036.

and gets a paycheck and gets to make choices, even if it's a tiny amount of money. There's just a dignity piece that is so paramount that I feel like people don't realize" (Service Provider, 2023).

Employment-related conversations take place at the annual ISP meetings or during the intake process. Case managers work together with agencies and community members to inform participants and themselves about job opportunities: "We had a number of nonprofit organizations that focus on employment come and talk about what they do." One case manager was able to share the resources with family members but concluded that "In terms of job openings, there's hardly much here" (Case

The service providers underlined the need for early intervention and greater agency collaboration in order to provide effective employment services. Repeatedly, interview participants discussed the overlap and confusion between the roles of DDD and DVR. Service providers commented on the lost opportunities during high school for equipping young people with job skills like greeting customers and filling out applications. Families echoed the lack of adequate skill development and advocated for improved employment training and support services for individuals with disabilities. A few family members talked about the time and effort they invested to help their adult child secure job assistance or locate employment. For one family, it resulted in an employment situation after 2 years, while on-the-job support remained a continuous struggle. Another family stopped their efforts to secure employment.

Interviewees also shared success stories pertaining to employment. Waiver participants expressed their pride about the work they were doing, while direct support professionals and service providers spoke about successful one-on-one job support that focused on fostering long-term relationships with businesses and growing the independence and responsibilities of the waiver participant. A family member revealed how their path for employment started: "He went to an adult day service right after high school, so he was there for a year. Then he said he wants to work. So gradually we got DVR involved, and then he stopped going to adult day health program" (Family Member, 2023).

The interviewees revealed a multitude of challenges faced by individuals with IDD in securing meaningful employment. Since there is a shortage of personnel to offer job services, particularly in rural regions, case managers wanted to be realistic about expectations. Case managers and service providers criticized the lack of appropriate employment opportunities, which are frequently restricted to low-skilled jobs that raise doubt about job satisfaction or opportunities for personal development. Furthermore, a concentration on particular job categories, like big-box stores, disregarded the preferences and abilities of the individual. Another interviewee expressed concern about misperceptions that assumed people with disabilities can't make significant contributions to the workforce. "A lot of it does come down to finding employers who are able to work with the constraints and limitations of what's required for a direct support worker to be there with a participant while they are at work to make sure everything goes well" (Service Provider, 2023).

There was a prevailing worry among families and caregivers that "waiver participants' wages could potentially affect their Medicaid and Social Security, and the focus tends to be more on maintaining those services rather than the participant having as much independence as possible" (Case

Manager, 2023). Service providers also highlighted the difficulty of persuading family members to consider work for participants. One waiver participant explicitly stated that her parents were against her working. Interviewees often brought up the issue of case managers and families not being fully informed about Achieving a Better Life Experience (ABLE) savings accounts that help people with disabilities save money, and the possibility of earning income without losing Medicaid benefits.

> "It's been pretty consistent. Families are just too worried about them losing their benefits. And then employers are still afraid to hire participants with disabilities because of the liability."
>
> —Case manager, 2020

Interview participants appreciated legislation that enabled individuals with disabilities to explore employment options without affecting their benefits. They highlighted the importance of initiatives like ABLE accounts and suggested the need for ongoing parent support groups to address these concerns and promote independence for individuals with IDD. There's a desire for continued legislative support to ensure individuals can pursue meaningful work without financial repercussions.

The scarcity of employment opportunities demands more structural support in working with employers and building acceptance for the workforce. Regarding their experience working with a coordinator in their agency, a direct support worker stated, "For me, having a program coordinator who opens the doors, and then I get to be boots on the ground; having it be more of a team is much more successful" (Direct Support Professional, 2023). Other service providers and direct support professionals underlined the value of establishing relationships and understanding employer needs. One successful tactic shared was to ask the hiring person, "When do you most need an extra pair of hands?" Offering to hire someone for that particular hour with assistance frequently resulted in employment consideration. It often began with only a few hours per week but in more than one case, the hours increased.

We conclude this section with the results related to the remaining questions posed for this evaluation: **What are the outcomes for DDD participants?**

We chose to close this final section with data related to overall goals and outcomes because it represents the culmination of DDD's efforts across all the initiatives previously described. This last section aims to present information and reflect on indicators that illustrate, at the end of the day, how people with IDD are faring when it comes to connection and belonging — answering questions like: Do they do enjoyable things in their community? Do they have friends?

Most of the data to support this reflection comes from NCI and from information gathered during focus groups and interviews.

Figure 20: Able to Do Things They Like

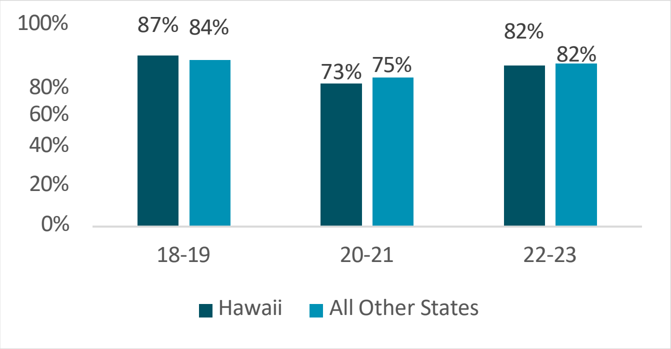


Figure 21: Wants Help to Make/Contact Friends

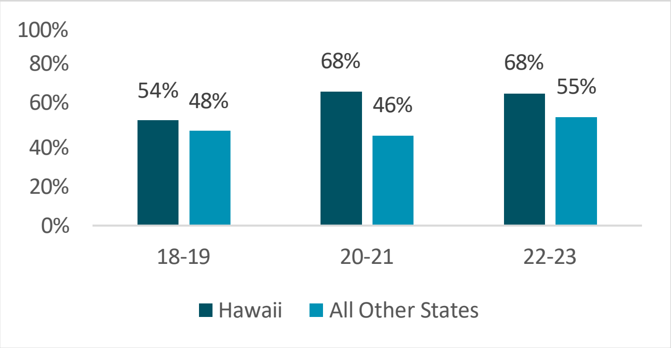


Figure 20 shows that the percentage of those who report they are able to do things they liked remained above 80 percent for all NCI states through 2022-23, with the exception of 2020-21 when it dipped (to 73 percent for Hawaii and 75 percent overall), possibly due to the pandemic. No significant differences were observed between Hawaii and other NCI states in this measure.

As shown in Figure 21, the percentage of Hawaii participants who indicated they needed more support with social relationships remained higher than other states throughout the four survey years. The difference became significant in the 2020-21 survey (68 percent vs. 46 percent). This indicator reads slightly different from the other NCI graphs in that it is asking about supports needed in this area.

Technology played a significant role in maintaining friendships, with participants using texting, social media, and video calls to stay in touch with friends. Family members, caregivers, and agency staff also played a crucial role in facilitating friendships by providing transportation, organizing outings, and supporting communication. Some family members advocated for social thinking skills training to enhance waiver participants' ability to initiate and maintain conversations and friendships. Additionally, group activities, social connection programs, and self-advocacy groups foster camaraderie and mutual support among individuals with IDD, providing platforms for social interaction and belonging.

> "I create opportunities for them to learn it more, really helping them learn how to make friends as much as creating the opportunity for them to be around people. I mean, that's how we all learn. And I feel like we all had to relearn a little bit after COVID."
>
> —Service Provider, 2023

Opportunities for Consideration

Data to Inform Action

It was clear from information gathered for this study that DDD had a particular focus on improving data capture, through INSPIRE, to guide decision-making about access to quality community services. There are new CMS requirements on the horizon that will likely mean new developments for the INSPIRE system.

Prepare for Access Rule requirements

In early 2024, CMS issued the Ensuring Access to Medicaid Services (Access Rule). The provisions of this rule will require states to increase their reporting capabilities, including as relates to wait-lists, quality measures, critical incidents, and annual assessments. DDD must assess current capabilities with existing tools such as INSPIRE to produce the necessary reporting features by the deadlines established by the Access Rule.

Recent Activity:

- ✓ **Data on Incident Reporting.** The INSPIRE system's capabilities have increased DDD's ability to track incident reporting. Routine reports are made available to DDD personnel who are responsible for monitoring the occurrence of reportable incidents and can view trends over time.
- ✓ **New Analytics Program.** The Med-QUEST Health Analytics Office and the Social Science Research Institute are partnering on a new endeavor to enhance data-driven decision making across healthcare programs in the state. DDD will be a key player in this work to include data and information about individuals served by the Division. The aim of the program is to collect and integrate data that can be used to create reports, analyses, and data visualizations that are most relevant to inform system needs.
- ✓ **ACCESS Rule Review.** DDD leadership has begun to assess what will be needed to comply with the upcoming Access Rule. As with other initiatives of this magnitude, DDD is preparing a focused planning effort to build the necessary capabilities within the

Support Employment Goals

Scale-up promising practices that emerged from the State's ARPA initiative focused on employment. There are promising practices resulting from the focused technical assistance and group learning offered through the ARPA-funded employment initiative to grow capacity to offer employment supports.

Expand access to benefits counseling. Many people we spoke with mentioned that access to benefits counseling would help participants and their families understand the ways that people can have a job and earn income without it interfering with their Medicaid benefits. Right now, the services included in the employment array do support access to benefits counseling; developing a pool of qualified providers to provide this service would also pose a challenge.

Build relationships with area businesses to make job connections. This area of employment development requires a unique skillset and the ability to discuss the benefits of having a workforce that includes people with disabilities and meeting businesses' needs.

Recent activity:

- ✓ **DDD staff position to focus on employment supports.** DDD recently hired for a position in the Community Resources Branch to be responsible for overseeing and supporting the development of employment services. Having a staff position with a dedicated focus on employment will be beneficial to support overall efforts in this area.

Research Methods

Limitations to this Study

As with any evaluation effort, it is important to discuss potential limitations. For example, in some cases we show data that compares Hawaii to other states using National Core Indicators® for Intellectual and Developmental Disabilities (NCI®-IDD) as a proxy for U.S. averages on certain indicators. It should be noted that not all NCI-IDD states conduct the survey every year. Therefore, the group of states being used as comparison varies from year to year. Another point to consider is that while a comparison can provide valuable information, factors unique to Hawaii may need to be taken into consideration to fully explain certain differences. Wherever possible, we include these considerations alongside the data.

The overall attendance at focus groups conducted as part of this evaluation was low. Therefore, what was learned during focus groups provides a valuable perspective, however, we must be careful to avoid making broad generalizations regarding any particular topic or community group.

From 2020 forward, the COVID-19 pandemic greatly impacted the DDD system. The circumstances surrounding the state's COVID-19 response influenced our evaluation findings. For example, we would expect to see a decrease in the utilization of group services due to isolation protocols, etc. Even so, it is valuable to have a view of the ways that system changes played out inside this challenging circumstance.

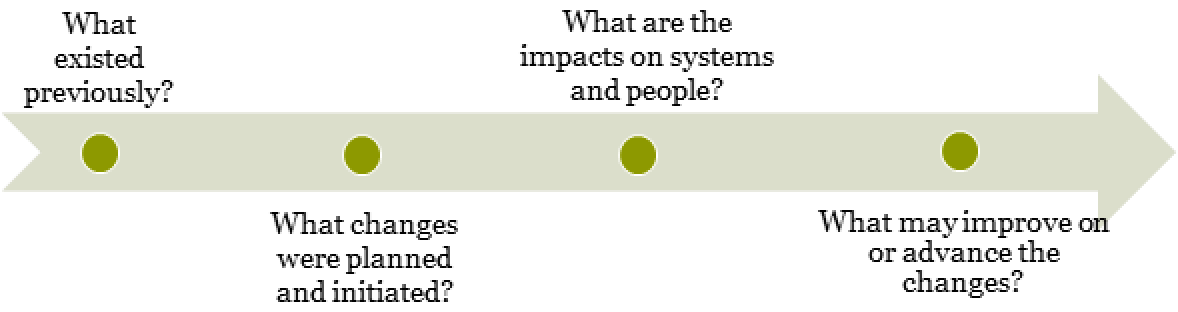
Positionality Statement

This statement is included to acknowledge the perspectives of the researchers involved in this study. Most of the staff involved in this evaluation project, except for researchers at the Center on Disability Studies at the University of Hawaiʻi Mānoa, are located on the U.S. mainland. We recognized that this may influence what we heard and the way we perceived information that was gathered throughout the course of this evaluation. To offset this limitation, we made an effort to vet our project activities by reflecting with our project team as well as HSRI’s Equity Review Board at intervals throughout the project to discuss our evaluation design and our observations and check for unintended cultural biases.

Evaluation Approach

Our approach to this evaluation — including data collection, analysis and interpretation — was to work collaboratively with DDD and an advisory group that was formed to provide feedback on the evaluation activities. Members of the advisory group represented key communities with an understanding of the local context and initiatives being evaluated; composition included self-advocates, family advocates and service providers. The advisory group met regularly to provide feedback at critical intervals over the course of the evaluation. Advisory group members offered guidance on how to make data collection, interpretation of data, and/or communications more accessible, respectful, and accurate.

To understand the impact of recent initiatives more holistically on individuals and families, the evaluation encompassed the following four phases.



The first phase of the evaluation was designed to assess what was in place prior to 2016. This is broadly defined to include a range of factors such as organizational structures, policies, services and programs, numbers served, service utilization, service quality, and accessibility.

The second phase included a review of the changes planned and initiated. We worked with DDD to identify and document the changes that were sought at the outset of the initiatives (beginning around 2016). In this phase we examined these initiatives, including the intent behind them, and the extent to which the initiative was implemented.

The third phase assessed the impacts of changes on systems and people. Here, we assessed these impacts on the system overall regarding service allocations, utilization, and spending. We also explored the impacts on people, listening to their experiences through focus groups and key informant interviews.

The fourth phase provided an opportunity to reflect on the first three phases of the evaluation and to arrive at a series of actionable recommendations for improving the system.

Throughout, we used a mixed-methods approach to document what was changed in relation to what existed previously, determine the impacts of changes on systems and people, and reach conclusions over how DDD may improve its service response — all while acknowledging a challenging and dynamic context.

Figure 22: DDD Evaluation Logic Model

Inputs

- 1915 (c) Waiver
- ARPA Funds
- State Funds
- CMS Final Settings Rule

Activites

- Community Engagement Activites
- CMS Final Rule Activities
- Employment First Initiative
- Person-Centered/LifeCourse Training
- HCBS Waiver Improvments
- ARPA Initiatives (14)
- Leadership Training
- Neurotrauma Initiatives
- INSPIRE IT System Operations and Analytics
- Dental Health Intitiatives

Outputs

- Transparent and understandable communications with participants and families
- Settings rule templates and processes to monitor and track compliance
- MOU between entities engaged in supporting employment outcomes
- TA provided to agencies offering employment supports
- Enhanced HCBS service array
- Adjusted rates/payment methods
- Enhanced waiver service standards
- QNQI processes
- Increased wages for DSPs
- IT system to support CM operations, link plans with authorizations and track adverse events
- Increased data analytics capabilities
- LifeCourse tools added to service planning

OUTCOMES

Short Term

- Clear agency policies and procedures
- Supportive agency leadership
- Adequate rate schedule to support service delivery
- Adequate overall DDD budget
- Sufficient staff capacity (e.g., number of open state staff positions)
- Adequate infrastructure to support initiatives (e.g., policies, trainings, etc.)

Mid Term

- Positive impact of changes on case management
- Positive impact of support budgets
- Improved access to services (e.g., reasonable promptness with waiver eligibility and access to services)
- Participants/families have access to information about services and supports
- Participants/families have access to leadership and providers

Long Term

- Participants have access to needed supports
- Participants express satisfaction with services & supports
- Participants have enhanced choice and control over life decisions
- Participants have enhanced choice and control over daily activities
- Participants have improved community integration
- Participants have needed employment support
- Participants have needed access to dental care
- Paricipants/families have a sense of influence over system-level decisions
- Outcomes associated with service planning rules compliance
- Participants/families are satisfied with supports budgets
- Equitable access to and satisfaction with services
- Participants live the life they want to live

Document Review

To begin, we obtained pertinent historical documents that provided important information about the service system, DDD's strategic goals, and the specific initiatives included in this evaluation. This documentation included items such as:

- DDD's strategic planning documents
- DDD's 1915(c) waiver renewals and amendments from 2016 to present
- Waiver service standards
- Exceptions review policies
- Annual adverse event reports
- Internal monitoring reports
- Administrative rules
- Communications and presentations
- Trainings offered to service providers and case managers

These documents were collected, reviewed, and summarized as part of the first two phases of this evaluation.

Key Informant Interviews

We consulted with DDD leadership to identify appropriate points of contact to gather perspectives from a range of key informants. Throughout this report we use the phrase "community" to include all those with a connection to DDD services including people with disabilities, their family members, service providers, advocates, and other interested community members. This represents an intentional move away from the term "stakeholder" because it is largely considered offensive to Indigenous Peoples due to its roots in colonialism. Following that, we prepared an interview protocol and scheduled interviews with:

- DDD leadership
- DDD branch staff (Outcomes and Compliance, Community Resources, Case Management)
- DOH leadership
- Service providers
- Protection and advocacy organization
- Self-advocates
- Family advocates

A total of 42 interviews took place during Phase 1. During our interviews, we wanted to understand the circumstances in Hawaii, how and when changes occurred, as well as the major drivers influencing the direction of policy and practice within the IDD system.

Quantitative Data

National Core Indicators

National Core Indicators® for Intellectual and Developmental Disabilities (NCI®-IDD) In-Person Survey (IPS) is conducted with adults receiving services funded through their state's DD system. NCI®-IDD is a collaboration between the National Association of State Directors of Developmental Disabilities Services (NASDDDS), the Human Services Research Institute (HSRI), and NASDDDS member agencies. The purpose of the program is to support state DD systems to track their performance and establish national quality benchmarks.

States draw probability samples from the population eligible for their services and their sample must meet the criteria of a maximum margin of error of 5 percent at 95 percent confidence level. Background information about survey participants — including demographics, personal characteristics, legal status, services received, and clinical diagnoses — is collected from administrative records prior to the interview and linked to survey responses, resulting in a single data record containing both administrative and survey data for each participant. Some questions require the participant's own answers, while others allow for proxy responses. After administering the first section which requires participants' own responses, the interviewer records whether the participant appeared to provide consistent and valid responses. Responses considered invalid by the interviewer are excluded from all analyses.

For this evaluation, we used data from three survey waves: 2018-19, 2020-21, and 2022-23. The four datasets were merged after harmonizing data fields corresponding to questions with minor changes from one year to the next. If a question wording was revised beyond minor changes, it was coded as a different measure and its responses were not merged with data from other years.

The merged multiyear data were used to make four types of comparisons for each of the measures included in the evaluation:

1. Hawaii was compared with the average of the other NCI states during each year for each measure.
2. Hawaii's value on each measure was compared across the four years to assess change. The same year-to-year comparisons were also conducted for the pooled average of the other NCI states.
3. Using Hawaii data pooled across the four years, each measure was stratified by race/ethnicity (White non-Hispanic vs. all other race ethnicity groups combined) and values of the two race/ethnicity categories were compared for each measure.
4. The comparisons described in Step 3 were repeated separately for each of the four years.

We assessed whether comparisons yielded statistically significant differences, we conducted two-sample z-tests for proportions. Statistical significance was defined as $p < .05$.

Claims Data

We analyzed reimbursement claims data from 2015 through 2023 to produce average costs per person, costs by support level and living setting, and average spend in relation to supports budget authorizations.

These claims data were also used to view service utilization over time. We paid particular attention to the uptake of new services that were added to the waiver in relation to other services.

Qualitative Data

Focus Groups and Interviews

To explore whether the DOH-DDD initiatives impacted the quality of services provided to people with intellectual or developmental disabilities, this part of the evaluation explored participants' experiences through focus groups and interviews.

Participant Groups

Table 9 shows the number of people we anticipated interviewing and the actual number of interview participants, reaching about 50% of the originally planned number of interviews. Table 10 outlines the distribution of focus groups and interviews among participant groups. The largest focus group included waiver participants and case managers (five individuals), while most focus groups had two or three participants.

Table 9: Planned and Actual Number of Participants

Original planning of focus group (FG) and 1-1 interviews	Planned # Participants	Actual # Participants
2 FG case managers	20	11
2 FG service providers and up to 15 interviews	35	18
7 FG waiver participants	35	10
Up to 15 interviews with waiver participants/family members/caregivers/advocates	10	13
Total:	**100**	**52**

Table 10: Interview and Focus Group Participants

Participants	Focus Groups	1-1 Interviews	Total Participants
Case managers	3	1	**11**
Service providers	4	9	**18**
Advocates	0	3	**3**
Waiver participants	2	3	**10**
Family members/caregivers	1	8	**10**
Total:	**10**	**24**	**52**

Participant Demographics

In collaboration with the evaluation's advisory group, we identified priority groups for outreach. Figure 23 breaks down the distribution among the participant groups for interview participants: case managers (11), individuals who receive services, referred to as waiver participants (10), family members (8), service supervisors (5), adult day health providers (4), direct support professionals (4), advocates (3), employment providers (3), caregivers (2), and other service providers (2).

Figure 23: Percent of Focus Group Participants by Category

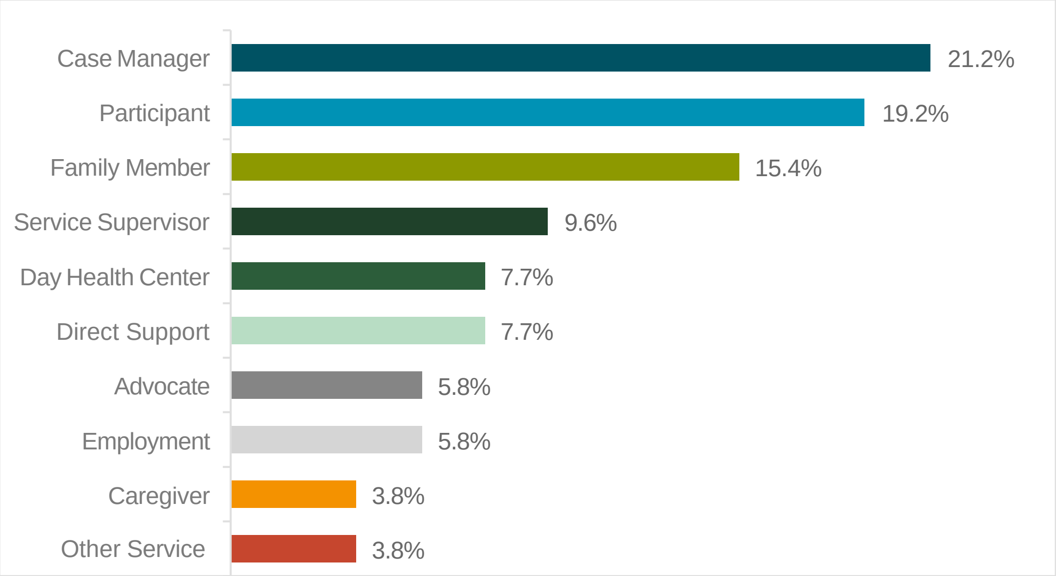
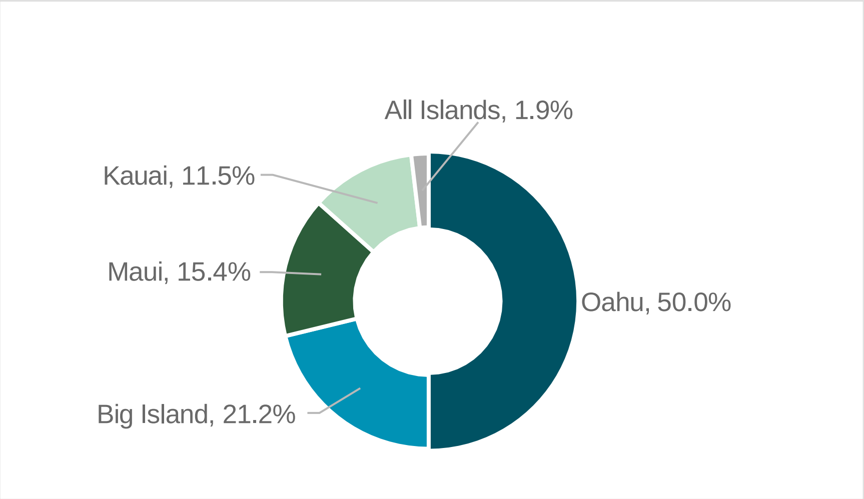


Figure 24: Focus Group Participants by Island

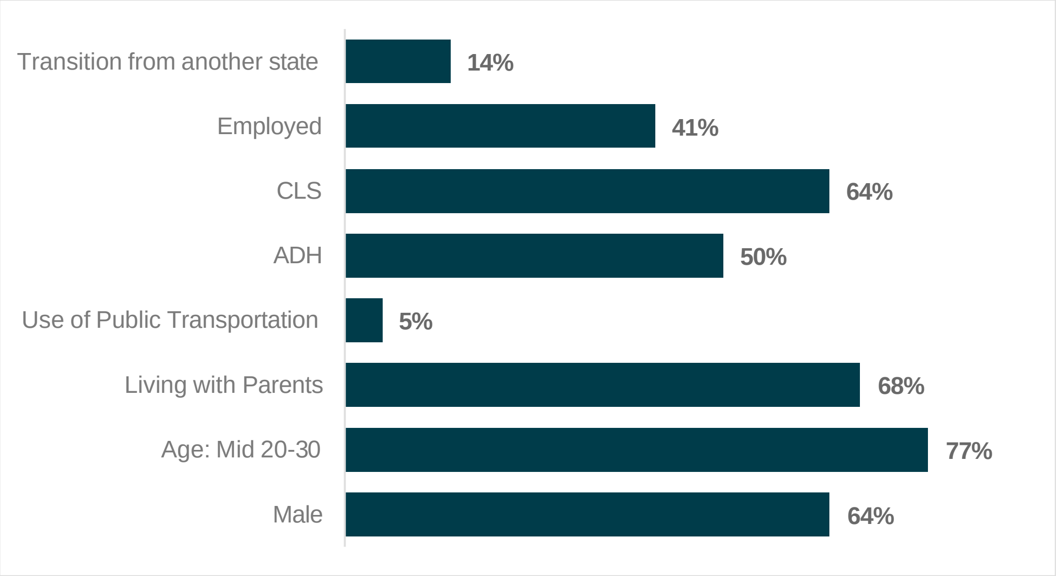


As demonstrated in Figure 24, interview participants lived and provided services across the islands of Oahu (26), Kauai (6), Maui (8), and the Island of Hawaii (11). We did not conduct interviews with individuals living or serving the islands of Molokai and Lanai.

None of the participants had a primary language other than English. Therefore, we did not meet our goal of having representation of diverse language and cultural groups. However, most of the people we talked to grew up in Hawai‘i, and/or had a multiethnic background, and some participants were bilingual (e.g., Japanese).

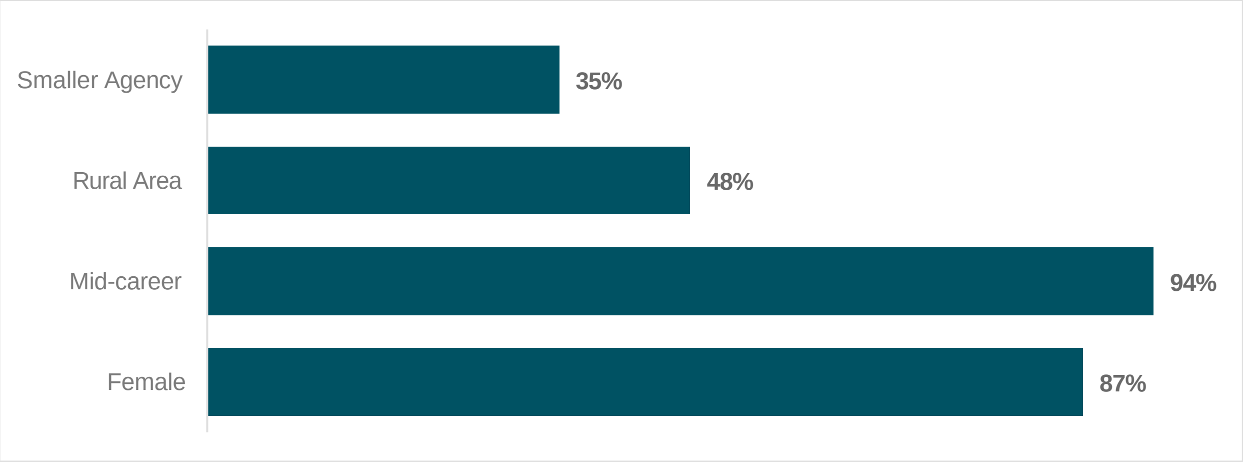
Interviews provided information for 22 individuals who received HCBS (Figure 25). The demographic background is an estimate because not all the information was collected for each participant. Additionally, Figure 26 summarizes the demographic background of 31 individuals in the group of service providers and case managers, excluding caregivers and advocates. Despite the gaps in this information, we believe they provide a picture of the people we interviewed.

Figure 25: Demographic Background of Participants



As seen in Figure 25, 14 (64 percent) of the 22 waiver recipients were male. In terms of age, most (77 percent) were in their early-20s to mid-30s; two waiver participants were minors; the oldest participant was 42; age information was unknown information for another two waiver participants. Fifteen lived with their parents (68 percent). Other types of living situations were foster homes, living with relatives, and independent living arrangements. Most participants relied on accessible transportation organized by their family or offered through their program. Half of the waiver participants (50 percent) attended ADH programs, and some had additional CLS services. Others (64 percent) only had CLS services. Nine waiver participants were in a regular employment setting. Three participants experienced the transition from another state into the Hawaii DDD system.

Figure 26: Demographic Background of Service Providers



As seen in Figure 26, 27 (87 percent) of the service providers and case managers were female and almost all were at a mid-career level; two individuals were approaching retirement. All case managers and service providers had extensive experience in their field of work. In terms of location, 15 (48 percent) served rural areas, including the neighbor islands. Of the 20 service providers who participated in the interviews, seven (35 percent) represented smaller agencies (fewer than 50 employees).

Procedures

Data collection through focus groups and interviews began in September 2023 and ended in March 2024 (Table 11). Interview participants registered through a Google Form, and we reached out to confirm the date and time, as well as the Zoom link, via email or phone call.

Table 11: Timeline of Interviews

	Months			
	September - October 2023, including Pilot	**November - December 2023**	**January - March 2024**	**Total**
Number of focus groups	4	6	0	**10**
Number of 1:1 interviews	8	9	7	**24**
Participant count	19	26	7	**52**

Selection of Participants for Focus Groups and Interviews

We applied purposeful sampling to the population of individuals with intellectual and developmental disabilities and their families.[28] DOH-DDD shared contact lists of case managers and service providers with HSRI. The Center on Disability Studies (CDS) reached out to case managers and service providers via email, phone, and selected site visits. Additionally, CDS reached out to collaborating partners with posts and fliers to recruit participants and connect with groups in the community — for example, the Special Parent Information Network, Hawaii State Council on Developmental Disabilities, and the Hawaii Disability Rights Center. The project was embedded on the CDS website and the link was referenced in any communication to provide additional information and contact information.

We applied snowball sampling to recruit additional participants for the study by reaching out to CDS faculty members and personal connections. In most interviews, we advocated for the interview participant to spread the word about the interviews. This was especially successful in recruiting additional waiver participants from January 2024 through March 2024.

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[28] Teddlie & Yu, 2007

We translated the invitation and Google Form into Tongan, Tagalog, Spanish, Marshallese, Ilokano, Chuukese, Chinese, and Korean and offered translation services.

Everyone who took part in the interview was given a $35 Amazon or Visa gift card.

Confidentiality

At the beginning of each interview and focus group, the facilitator informed participants about the purpose of the study as well as their option to withdraw from the study at any time.

To secure participants' confidentiality, we refer to them by their participant group: waiver participant, family member (including caregiver), service provider, direct support professional, and advocate.

Instrumentation

We piloted the interview questions with a trial run of an interview to test materials, procedures, and overall feasibility. Participants in this pilot interview were recruited through the Self-Advocacy Advisory Council meeting. We asked participants to provide input on how the interview went overall, how well they understood the questions, and their overall experience.

CDS staff facilitated the focus groups and 1-1 interviews. We tried to have a facilitator and a notetaker present during the interview whenever it was feasible. Every interview was conducted through Zoom.

Focus groups lasted about 60 to 90 minutes, with no more than five participants. We held ten focus groups in total. Approximately 12 participants were absent from a focus group. Additionally, we had to end two focus groups because the participants failed to clearly identify as either Hawaii residents or as connected to a person who received services in Hawaii. Key informant individual interviews lasted 30 to 90 minutes, and we interviewed 24 individuals.

Semi-Structured Interviews

CDS developed a semi-structured interview protocol that was in line with HSRI's evaluation logic model as well as the evaluation research questions. The interview protocol provided a script to ensure consistency across all focus groups and interviews. We used a standardized set of interview questions for each group.

Accommodation and Accessibility

The evaluation team applied universal design principles and provided accommodations, to achieve a barrier-free environment to promote full participation of all members.[29, 30] We used plain language in all recruitment fliers, at least 16-point sans serif font, high-contrast colors, and checked for screen reader accessibility. Recruitment and registration materials include a statement informing potential participants about the availability of language interpreters and disability accommodations.

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[29] ADA National Network, 2015

[30] NCHPAD, *n.d.*

Data Analysis

All interviews were audio recorded via Zoom, and transcripts were generated through Zoom and otter.ai (a transcribing software). We also took notes for every interview conducted.

In data analysis, we applied grounded theory as a mode of analysis in this single case study.[31] Employing an inductive method to compare and find meaning in participants' experiences is a process of taking apart the data, consolidating, reducing, and interpreting it, and putting it back together.[32, 33] Data analysis followed directly from data collection. We used Dedoose, a HIPAA-compliant qualitative data analysis software, to code and analyze qualitative data. As a team of researchers, we individually analyzed the first transcribed interview and focus group to compare and align our categories and to define subcategories for inter-rater reliability.[34, 35] The six primary categories — Building Partnerships, Community Inclusion, Employment Opportunities, Effective Services, Technology, and Dental Care — align with the subjects covered in the evaluation questions. Under each category, we summarized the findings according to the subcategories we defined.

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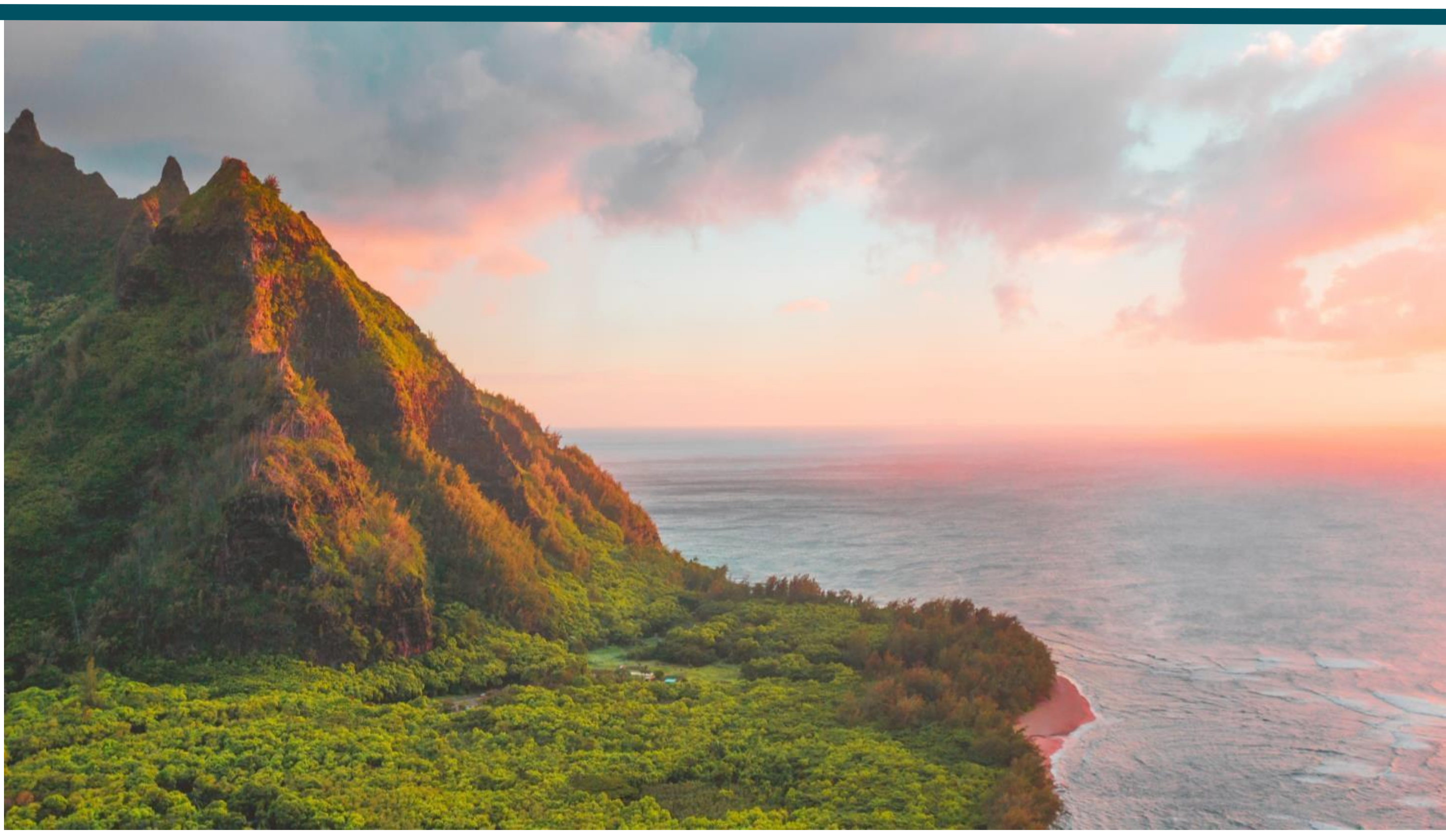
[31] Glaser & Strauss, 2017
[32] Merriam & Tisdell, 2015
[33] Stake, 2010
[34] Chamaz, 2006
[35] Merriam & Tisdell, 2015



Conclusion

Based on our experience working with state IDD HCBS systems, we note that systems evolve based on policy decisions over time. These decisions result in a mosaic of approaches that include both long-standing practices, and emerging practices that intend to push the system along. Together, these factors contribute to the complexity of fielding effective systems change. Approaches to systems change often consider three aspects: why the changes are needed based on guiding principles and policy intentions, what needs to be changed related to system infrastructure (i.e., service array, planning protocols, rate schedule, policy and procedure), and how changes will be implemented through person-centered approaches. Given the significant efforts to transform the DDD service system, this evaluation offered a moment of reflection to celebrate the wins and accomplishments, take in the lessons learned, and decide the best way to press on.

We learned through this evaluation that DDD took an ambitious approach to systems change and intended to implement improvements to infrastructure and operations in order to ultimately enhance services and supports for people with IDD and their families.

At the starting point, DDD was faced with numerous pressures as well as opportunities. Leadership sought to set a new direction for the Division and outlined several aspects of the system to target. These became the 16 initiatives that were part of this study.

The results of our research indicate that significant progress has been made; however, the complex nature of the work required to transform the service system felt challenging for some connected with the service system. Along the way, DDD had to achieve a balance between striving for system advancements and working alongside the community — including people with IDD, family members, service providers, and others — in ways that feel supportive and aligned with common goals.

For anyone who is connected with the goals and aspirations of the IDD community in Hawaii the question now becomes: How can you contribute to moving the system forward?

- Based on what was presented in this evaluation report, what is a priority for you?
- Where do you see yourself and/or your organization fitting into these priorities?
- What knowledge, skills and talents can you lend to making things better in the lives of people with IDD and their families?

Ultimately, it is through collective action that DDD will keep moving forward and supporting people with IDD to have the supports they need to live full lives as valued members of their community.

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Appendix A: Summary Table of DDD Evaluation Findings and Opportunities for Consideration

Community Engagement	**Initiatives**	**Summary Findings**	**Opportunities**
	Engagement initiatives to inform people about changes and how the changes would impact them, and provide opportunities to provide feedback	Successful engagement was noted around systems change activities among advisory groups and those with an established connected with DDD. Ongoing communications will require consistency in methods and messaging.	• Establishing consistent communication with case managers. • Working alongside the advocacy community. • Employing people with lived experience to design inclusive communications. • Building partnerships with agencies or communities that are not currently connected with DDD.

Community Access & Person-Centered Practices	**Initiatives**	**Summary Findings**	**Opportunities**
	DDD's activities around the HCBS Settings Rule, person-centered planning, and the addition of the Community Learning Service to support community access	Technical requirements of the HCBS Settings Rule were successfully met but work with the community is still needed to promote choice and control. Commitment to person-centered principles was evident but will require consistent effort.	• Enhance methods to support community access through strategies such as community asset-mapping. • Bolster person-centered practices through ongoing training on person-centered practices and Charting the LifeCourse principles for planning and problem-solving.

Services & Provider Network	**Initiatives**	**Summary Findings**	**Opportunities**
	Significant changes to the IDD waiver including service array to support community integration and payment structures to stabilize the service network to improve the quality and accessibility of IDD services	Changes to the service array have supported a significant level of access to the community. Updates to the rates were well received among the provider community. The provider network remained stable throughout the evaluation period, although there are a limited number of providers outside of Oahu. The wages of direct support professionals increased markedly in recent years, which contributed to reduced turnover rates.	• Reevaluate the intended purpose of Community Learning Services and provide training and education as needed. • Continue to ensure adequacy of provider payment rates. • Implement the DSP certification framework that is in development. • Consider additional services like shared living and family to family networking.

Appendix A: Summary Table of DDD Evaluation Findings and Opportunities for Consideration

System Operations & Oversight	Initiatives	Summary Findings	Opportunities
	Initiatives to enhance system operations such as assessment processes, managing distribution of resources through individual supports budgets, managing exceptions and utilization review processes, supporting quality assurance/quality improvement plans, and streamlining eligibility and enrollment processes	New methods for assessments, allocating resources, and managing exceptions were successfully implemented. Certain policies and practices need refinement and support with ongoing communication.	• Increase assessment capacity by identifying additional local SIS-A assessors, refreshing scheduling protocols, and continuing to monitor assessor quality. • Refine the individual supports budget process to include sharing information about the supports budget with participants and families, and clarifying policies and procedures around budget exceptions. • Reset the quality assurance and quality improvement plan to align with the initial strategy.

Modernization & Innovation	Initiatives	Summary Findings	Opportunities
	Development of the INSPIRE information technology solution, and employment first activities	New IT solution (INSPIRE) created efficiencies in case management practices, and data collection and reporting. Efforts to promote employment have promise but have yet to show significant gains in people using employment services or having community jobs.	• Continue data-informed practices including for the HCBS ACCESS rule requirements. • Scale up promising practices learned through the ARPA employment initiative to support employment goals.