



Human Services
Research Institute

Moving Forward

Hawaii Developmental Disabilities Division

June 2023

Prepared by: Yoshiko
Kardell, Colleen Kidney,
Jasmine Hepburn, and
John Agosta

Interim Evaluation Report Prepared for the
Hawaii Developmental Disabilities Division.

Contents

- Overview of the Evaluation 1
 - Introduction 1
 - Overview of the Evaluation Approach 2
- Initial Reflections.....5
 - Understanding DDD’s History..... 5
 - DDD Strategic Vision and Policy Intentions 8
 - Community Engagement..... 10
- DDD Initiatives..... 12
 - Engaging with Communities 13
 - Complying with the HCBS Final Settings Rule 14
 - Developing HCBS Waiver Infrastructure..... 17
 - Promoting Modernization 29
 - ARPA Spending Plan 33
- Next Steps for the Evaluation 35
 - Outcome Evaluation Plan 35
 - Data Sources 37
 - Concluding Thoughts..... 42



Overview of the Evaluation

Introduction

The Hawaii Department of Health, Developmental Disabilities Division (DDD), implemented a series of initiatives starting in 2016 to modernize delivery of services to people with intellectual and developmental disabilities (IDD) and improve the experience of those who rely on these services. The Human Services Research Institute (HSRI), in collaboration with Health Management Associates/Burns & Associates and the Hawaii Center on Disability Studies, were retained to evaluate the effectiveness of these reforms and to provide recommendations for DDD to consider.

The evaluation takes three years to complete (2022 – 2024) and is informed by extensive literature on evaluation best practices. We will use a data-driven mixed-methods approach that combines quantitative and qualitative methods to produce actionable analyses of the system’s strengths, assets, limitations, and challenges.

This evaluation documents several initiatives undertaken by DDD and gauges the impacts of these initiatives and related system changes, including activities in the 1915 (c) portion of Hawaii’s Spending Plan to implement Section 9817 of the American Rescue Plan Act.

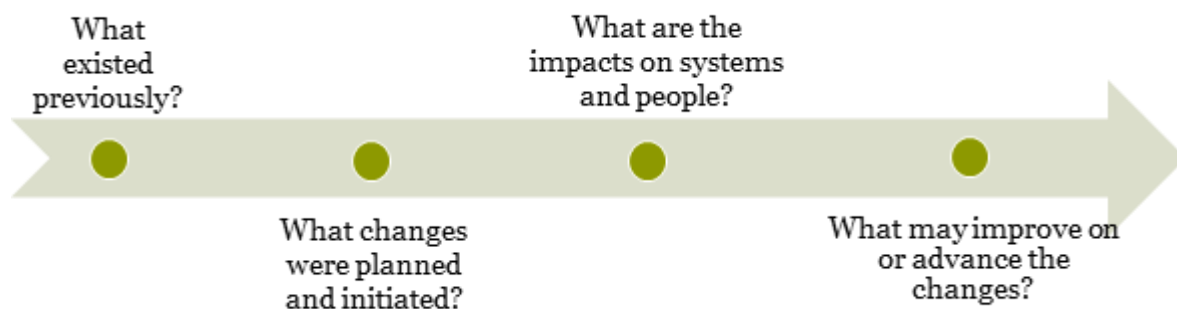
The primary vehicle by which DDD offers services is through the 1915 (c) Medicaid Home and Community Based Services (HCBS) waiver. This waiver is operated by DDD on behalf of the Hawaii State Department of Human Services, Med-QUEST Division (MQD), the Hawaii State Medicaid agency, through a memorandum of agreement. The study of services offered through the waiver and other complementing activities are central to this evaluation.

This report represents the midway point in the evaluation and presents: (a) an overview of the evaluation approach, (b) initial reflections on findings to date, (c) a description of DDD’s recent initiatives, and (d) next steps planned for the evaluation.

Overview of the Evaluation Approach

Our approach to this evaluation, including data collection, analysis, and interpretation, is to work collaboratively with DDD and an advisory group that was formed to provide feedback on the evaluation activities. Members of the advisory group represent key stakeholders with an understanding of the local context and initiatives being evaluated including self-advocates, family advocates, and service providers. The advisory group meets regularly to provide feedback at critical intervals over the course of the evaluation. Advisory group members offer guidance on how to make data collection, interpretation of data, and/or communications more accessible, respectful, and accurate. It is important that their input contributes to the evaluation. This way, state leadership and the IDD community can share a sense of ownership over the findings, increasing the likelihood of building consensus for what DDD may do to further improve services and supports for participants with IDD and their families.

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



The first phase of the evaluation was an assessment of “what existed previously” to the changes that began around 2016. This is broadly defined to include a range of factors such as organizational structures, policies, services and programs, number served, service utilization, service quality, and accessibility. The second phase included a review of “what changes were planned and initiated.” We worked with DDD to identify and document the changes that were sought at the outset of the initiatives. In this phase we examined these initiatives, including the intent behind them, and the extent to which the initiative was implemented. As this report represents the midpoint in the evaluation, phases one and two are complete.

The third—and upcoming—phase is to assess the impacts of changes on systems and people. Here, we will quantitatively assess these impacts on the system overall regarding service allocations, utilization, and spending. We may also measure impacts on the provider network overall. We are also interested in the impacts on people regarding their experiences, which we will explore qualitatively through focus groups and key informant interviews.

The fourth phase provides opportunity to consider what was learned through the first three phases of the evaluation and to arrive at a series of actionable recommendations for improving the system. These recommendations will be embedded in a detailed implementation plan developed in collaboration with DDD.

Throughout, our approach utilizes mixed methods 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.

During the first two phases of this evaluation, the two primary methods of data collection utilized were review of relevant documents and interviews with key informants. Further detail regarding these methods is provided below.

Document Review

To begin, we obtained pertinent historical documents that provided important information about the service system, DDD’s strategic goals, as well as the specific initiatives that were 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
- Stakeholder 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 to identify appropriate points of contact to gather perspectives from a range of key informants. Subsequently, we prepared an interview protocol and scheduled interviews with representatives from groups including:

- DDD Leadership
- DDD Branch Staff (Outcomes and Compliance, Community Resources, Case Management)
- DOH Leadership
- Service Providers
- Protection and Advocacy
- Self-Advocates
- Family Advocates

Thus far, we conducted a total of 42 interviews since October 2022. As part of phase one, we conducted 26 hour-long interviews with key informants. Of these 26 interviews, 11 interviews were with DDD staff, and 15 were with parent advocates, provider agencies, and others. Following interviews on the IDD service system, we turned our attention to phase two, documenting DDD's initiatives. During this phase we conducted 16 interviews—nine with DOH and DDD staff, and seven with outside partners—honing in on the implementation of specific DDD initiatives.

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. Many of the key informants we spoke to had been connected with DDD for many years—some, even decades. It was primarily through these key informant interviews that we understood what existed previously and the circumstances contributing to the direction that DDD was pursuing. They witnessed the system transform over time. Through these interviews, it became apparent that capturing information through a narrative storytelling approach was an important component to this evaluation.



Initial Reflections

Based on the activities completed to date, in this section we offer our initial reflections on what we have learned about the service system and the baseline we established. This will shape how we approach the subsequent evaluation phases related to assessing the impacts of DDD’s actions on systems and people and forming recommendations for going forward. The following presents a description of the circumstances in Hawaii around 2016, DDD’s strategic vision and policy intentions, and how DDD worked with staff, partner organizations, participants, and families to undertake a series of changes that aligned with its vision and intentions.

Understanding DDD’s History

Many of the interviewees we spoke with mentioned the closing of the Waimano Training School and Hospital (WTSH) in 1999. Hawaii was one of the first 10 states in the nation to close its large state-operated institution for people with IDD. This was often mentioned with a sense of pride. While the closure of WTSH predates the period under review in this evaluation, it is a significant reference point as it impacted the home and community-based system that was established thereafter,

including the development of dispersed residential options such as Adult Foster Homes.¹ During our interviews, we learned that many of these community-based residential homes were, and continue to be, operated by staff who formerly worked at WTSH. The reliance on this type of model was the primary way that the state shifted away from a large, segregated institutional setting to community residences.

Following the closure of WTSH and the focus on fielding a community-based system, several interviewees shared that the service system remained relatively static for many years after. Small incremental changes were introduced through the HCBS waiver renewal processes, but major system reforms were uncommon.

It is also important to set the stage in terms of how Hawaii compared with the rest of the nation in 2016. Consider that:

- While nationally the percent of people with IDD receiving services while residing in the home of a family member has steadily increased, Hawaii proportionally serves more people with IDD in the family home than the U.S. overall. For example, of the 2,735 people served by DDD in 2016, approximately 66% lived in the home of a family member compared to 58% nationally.²
- The national annual average Medicaid expenditures in 2016 across children and adults with IDD was \$43,928. Hawaii's average was slightly higher at \$48,552.³
- Service use patterns can also be viewed in terms of how many individuals receive services per 100,000 in population. In 2016, in Hawaii the total number of people with IDD receiving long-term services and supports was significantly lower than the national average; 191 served per 100,000 compared with 380 served per 100,000, respectively.⁴
- Another notable system indicator is the number of people with IDD receiving supports to get a job in the community. The percent of waiver participants with IDD receiving integrated employment supports in Hawaii in 2016 was 1% compared with 18.8% nationally.⁵ This low percentage is partially reflective of the integrated employment service array available

¹ Agosta, J., Melda, K., & Ashbaugh, J. (1994). *Hawaii at the crossroads: Opportunities to improve developmental disability services final report*. Cambridge, MA: Human Services Research Institute.

² Larson, S.A., Eschenbacher, H.J., Anderson, L.L., Taylor, B., Pettingell, S., Hewitt, A., Sowers, M., & Bourne, M.L. (2018). *In-home and residential long-term supports and services for persons with intellectual or developmental disabilities: Status and trends through 2016*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

³ Ibid.

⁴ Ibid.

⁵ Statedata.info. (2023). State IDD Agencies. Hawaii, U.S. Total: Integrated employment percentage. Retrieved 03/12/2023 from <http://www.statedata.info/data/showchart/320246>

through the waiver at that time and the fact that some participants may have received supports while at work through Personal Assistance/Habilitation (PAB). The number of people using PAB for this type of support would not be discernible in the data available from that time.

Additional Factors

To capture the most significant initiatives in recent years, we included those dating from approximately 2016 to the present. From 2020 forward, it is notable that 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 of Hawaii enacted strict policies to help protect its citizens. The circumstances surrounding the state's COVID-19 response will likely influence our evaluation findings. For example, qualitative approaches such as focus groups may be shaped by respondents' capacity to recall experiences from those years. Even so, it will be valuable to have a view of the ways system changes played out inside this challenging circumstance.

- | Four Additional Factors | |
|--------------------------------|---|
| • | The COVID-19 pandemic |
| • | Changing expectations for what constitutes best practice |
| • | Concern over the direct support professional (DSP) workforce shortage |
| • | Changes in leadership and DDD organizational structure |

Changing expectations for 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 the Centers for Medicare and Medicaid Services (CMS) regarding home and community-based settings through the CMS Final 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. In particular, teens and young adults with IDD, whose early life experiences differ from those of previous generations, may have expectations for a community life and for goal achievement that are similar to other people their age. Service systems necessarily must adapt to this reality.

Further, across the nation, there is concern over the direct support professional (DSP) workforce shortage. This is especially concerning in Hawaii, due to the population of aging caregivers and reliance on a network of community residences largely sustained by family homelike settings—including foster and domiciliary arrangements. Several people we interviewed described challenges locating staff, particularly on the outer islands. One interviewee noted that her family member has been authorized to receive services but has been without support for several months due to inability to find staff to provide the service. This challenge requires DDD to take steps to address the impacts of the workforce crisis by developing the necessary infrastructure and investing in service models and residential options that will meet future demand.

The pressure of these additional factors influenced why DDD needed to make changes to its programs and service delivery infrastructure to respond with urgency, while remaining thoughtful and planful to ensure that the system is efficient, sustainable, and person and family-centered now and in the future.

A few years before, in late 2014, a new administrator, Mary Brogan, was hired to lead DDD. In addition, around this time a new organizational structure was established within DDD with the creation of distinct branches—the DDD Administration, Case Management Branch, Community Resources Branch, Outcomes and Compliance Branch, and Dental Branch. Many of the initiatives that were developed within this timeframe were spearheaded by the new administrator and the DDD leadership team, which included branch chiefs and other key staff members. Over the past few years, DDD experienced some amount of turnover in staffing and reduction in staff positions among this leadership team. 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 as well other complementing initiatives. These initiatives were guided by a strategic vision and plan.

DDD Strategic Vision and Policy Intentions

Based on what we learned in the first two phases of the evaluation effort, we identified a range of actions—some concretely defined with others more loosely recalled—that define a package of actions that sought to push the system in a direction to:

1. Improve opportunities for people with IDD to have increased control over their own lives and belonging to community through improved quality of the services (enhanced service array, person-centered approaches, improved rate schedule and better quality monitoring);
2. Improve system operations through a focus on modernization, equitable distribution of resources, and efficiency (supports budgets based on assessment, updated information technology system).

To achieve these aims, the following objectives are reflected more concretely in DDD’s Strategic Plan as⁶:

- Building partnerships with individuals and families
- Promoting community integration for people with IDD

⁶ 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>

- Promoting employment opportunity for people with IDD through greater emphasis on Employment First initiatives
- 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

The initiatives under review in this evaluation are aligned with the strategic goals and objectives of the DDD.



As noted above, since 2016, DDD has been making adjustments to the system in furtherance of these goals. These adjustments are a prerequisite to create lasting change. Given 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 time-worn legacy practices, sometimes spanning back generations, and emerging practices that intend to push the system along a progressive trajectory. Together, these factors contribute to the complexity of fielding effective systems change. Effective 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 such as through person-centered approaches.

Based on our preliminary observations, we gather that the type of actions DDD undertook fall into two general categories including: 1) actions that resulted in concrete changes that are easily observed, and 2) actions aimed at shifting the culture and expectations. The series of actions included in the first category led to an infusion of resources into the system by starting with administering an objective assessment tool (the Supports Intensity Scale (SIS)), establishing an individual supports budget model, and implementing a rate study. These intentional actions allowed DDD to better understand the support needs of the service population and the resources necessary to support the DDD program. This contributed to successfully defending DDD's budget request presented to the legislature. The latter category included actions such as introducing the philosophy and tools of Charting the LifeCourse and person-centered thinking. The results of these actions are more difficult to define and measure as they relate to changing to people's perspectives and expectations for how people with IDD can be supported to live full lives. However, we surmise that taken together these changes have likely created an "action bias" to push the system forward whereby, more often than not, policy and practice decisions support desired change rather than subtract from it.

The next phase of this evaluation will focus on measuring the results of these changes to the system; however, it is worth noting that changes to infrastructure can take several years to manifest in ways that are evident in the data. The outputs we observe to evaluate systems may include: (a) aggregate system performance metrics, and (b) how people access, utilize, and experience services. These findings may be contrasted with the stated vision, mission, and principles meant to guide the service response. It will be essential going forward to monitor the same metrics over time to view trends and notice how the changes to system infrastructure are ultimately improving system operations and the lives of people with IDD and their families.

Community Engagement

Throughout the change process, DDD made an effort to engage with groups that have a vested interest in the services and supports available to people with IDD. Those groups often included internal DDD staff, including case management units, as well as external groups such as self-advocates, families, advocacy organizations, and service providers.

Members of these groups that we spoke with generally held positive regard for the DDD administrative team. Many noted that they are on a first name basis with members of the DDD

leadership. 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.

“I like that the Administration of DDD is reachable.”
– Interview participant, parent/advocate

While an overall positive regard for DDD was emphasized, a few concerns were identified:

- Several interviewees commented on the need for consistent messaging and training regarding service changes and related initiatives. At times, stakeholders felt that they did not have enough or the right kind of information to fully grasp what changes were occurring and how they would be affected. Some internal staff felt that the way that information was distributed to the field was inefficient and often resulted in feeling as though they received mixed messages. It was also mentioned that the order in which certain stakeholder groups received information was important. For example, by prioritizing case managers to receive selected information, these staff would have the information needed to implement any new policies and procedures as it related to service planning and delivery.
- Some stakeholders experienced challenges navigating the number, pace, and timing of initiatives that occurred simultaneously. They felt overwhelmed with all the changes, and it seemed difficult to keep track of how certain changes were related to what initiatives. There was some difficulty engaging with hard-to-reach stakeholders and setting up avenues for meaningful participation. Some interviewees we spoke with said they felt left out and did not receive timely information. At least one interviewee expressed a desire to build the type of partnership with DDD where they would be able to vet policy before the decisions are made, or to be a part of the development of policy and procedures from the start. One informant recommended that DDD would benefit from employing someone to be specifically in charge of communicating DDD initiatives.

While the pace and timing of initiatives felt swift, stakeholders acknowledged that a sustained effort was needed to continue to align with DDD’s strategic vision. Many key informants agree with the values that DDD has set forth to guide the direction of the system. While the COVID-19 pandemic did necessarily pull focus from some of the initiatives underway, DDD has been successful in continuing to prioritize actions that will push the system forward and prepare to meet future demands.



DDD Initiatives

In this section we describe in more detail the initiatives that DDD undertook starting in 2016. While an initial list of major initiatives was previously identified in the scope of work for this evaluation, we worked with DDD staff and leadership to expand and more clearly define the initiatives to be included in this review. We then grouped similar initiatives together into the following categories:

- Engaging with communities
- Complying with the HCBS Final Settings Rule
- Developing HCBS waiver infrastructure
- Promoting modernization

The descriptions of each initiative that follow include a high-level overview of the intent of the initiative, associated major activities, and additional commentary, if any, offered through key informant interviews.

Engaging with Communities

As previously mentioned, DDD made a concerted effort to develop and implement a variety of initiatives specifically aimed at engaging with communities that had an interest in shaping the IDD service system including self-advocates, families, providers, advocacy organizations, legislators, and other policy makers. The overall intent behind these engagement initiatives was to make sure that people were informed about changes happening at DDD, understood how the changes would impact them, and had opportunities to provide feedback to DDD along the way. Below are examples of the types of communication and engagement strategies, including advisory groups, that DDD has convened over the past several years.

Communication	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
Frequently Asked Questions 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 & 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 final 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

These mechanisms were intended to both share information broadly related to initiatives underway at DDD, provide operational detail geared toward different audiences, and get feedback from the IDD community. One interviewee we spoke with mentioned it was important for those operating in an advisory capacity to have 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.

Complying with the HCBS Final Settings Rule

In 2014, CMS issued new regulations to enhance the quality of services and provide additional protections for individuals receiving home and community-based services. The purpose of the final rule was to maximize opportunities for people receiving services to access the benefits of community living, including receiving services in the most integrated settings.⁷ The rule defines the qualities of, and sets expectations for, what is and is not considered a community-based setting, as well as specific requirements for provider-owned or operated residential settings. The rule also includes provisions for person-centered planning such as 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.

⁷ 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>

- Have opportunity to discuss friendships and relationships, accessing community, and employment.

States were originally given five years to comply with the HCBS settings requirements and while the initial timeline for compliance shifted due in part to the COVID-19 pandemic all states were required to comply with the rule as of March 2023. To satisfy this requirement, DDD along with the Department of Health, Med-QUEST Division (DHS/MQD) devised the statewide transition plan, *My Choice My Way*.⁸ This transition plan details the activities undertaken to launch a coordinated effort between the Divisions and the provider community to come into compliance by the due date.

Because of the substantial nature of the final rule, many of the subsequent initiatives were inextricably connected with the requirement to comply. The following describes those initiatives that most closely relate to the HCBS final rule including person-centered training, methods for provider monitoring, and data-informed decision making.

Person-Centered Training

The impetus of the HCBS final rule bolstered DDD's intentions to build a culture of person-centeredness in the planning and delivery of services and supports. The final rule describes requirements for person-centered planning for HCBS 1915 (c) waivers including that the plan is directed by the person along with others whom they freely choose. The rule also specifies that the plan must include the individual's goals, preferences, and choices.

"The continued use of language of person-centeredness in meetings, etc. is really important to maintain that culture and remind us who we're serving and how we should be serving them." - Interview participant, DDD staff

In response to the drive toward fielding a more person-centered system, initiatives such as trainings and other learning opportunities were offered. The types and content of trainings that were offered for different audiences varied. Examples included:

- LifeCourse planning tools workshops
- Framework Fridays drop-in series for DDD case managers
- Person-Centered Organizations, a joint effort with Med-QUEST Division and provided by Support Development Associates (SDA)
- DDD First Tuesday Training Series

⁸ https://medquest.hawaii.gov/content/dam/formsanddocuments/my-choice-my-way/1HI%20STP%20HCBS%20Transition%20Plan_Accessible%20Version%204-8-20.pdf

- Case Management Trainings
- Service Provider Trainings

These initiatives intended to shift expectations to focusing on the person with a disability 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.”⁹ One informant said, “Adopting the LifeCourse was really important and changed the conversation.” Key informants noted that the LifeCourse tools offer a way to be more consistent with support planning if used routinely.

Training initiatives such as this require ongoing effort to maintain expectations regarding the planning process. It begins with helping people involved in the planning process including the participant, members of their circle of support, and providers to understand the “why” behind the person-centered planning requirements as well as how to operationalize them in the context of developing an individual service plan. Based on our interviews, we inferred that there were varying levels of consistency as it relates to training, which may have been due in part to staff turnover in the training unit. One interviewee reported that the training unit required staff who could understand what information each target audience needed to effectively perform their role as it relates to person-centered planning and who could develop and deliver training with measurable training objectives.

Methods for Provider Monitoring

DDD oversees certification for adult foster homes that serve IDD waiver participants. In response to the HCBS settings rule, DDD had to modify the certification process and tools that were used to monitor these settings to look at each home for compliance. The monitoring tool included all the requirements that adult foster home providers had to meet. This tool was incorporated into the annual inspection. 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, through corrective action plans (CAP), to help them come into compliance. This new process also required a change to Hawaii Administrative Rules that pertain to the certification of adult foster homes.¹⁰

⁹ [LifeCourse Framework – LifeCourse Nexus \(lifecoursetools.com\)](https://lifecoursetools.com)

¹⁰ Department of Health. Repeal of Chapter 11-148 and Adoption of Chapter 11-148.1 Hawaii Administrative Rules. [ADMINISTRATIVE RULES FOR ADULT FOSTER HOMES \(hawaii.gov\)](https://hawaii.gov/doh/ADMINISTRATIVE_RULES_FOR_ADULT_FOSTER_HOMES)

The Community Resources Branch (CRB) also developed tools and processes for measuring compliance with the final 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 to demonstrate compliance. These tools were instrumental to operationalizing the intent of the settings rule and create mechanisms for ongoing monitoring. One interviewee explained that at times providers required technical assistance to understand how they could adhere to the settings rule and also meet the unique support needs of the participants they served.

Data-informed Decision Making

DDD leadership was interested in using data-informed practices to respond to the requirements of the HCBS final rule as well as shape the system going forward. Because of the focus on community integration inherent in the final rule, staff at DDD understood that this would likely require the ability to know how participants were using services to access the community. According to one key informant, prior to 2016, the three most widely used services were Personal Assistance/Habilitation (PAB), Residential Habilitation (ResHab), and Adult Day Service (ADH). The PAB service was used to support participants both at home and in the community; therefore, service utilization data, commonly used to discern service use patterns, would not reveal what percent of the time, if any, participants were receiving services in the community. Due to this circumstance, there was an interest in determining a way to show whether a participant was receiving services in the home or in the community and additionally whether they were being provided opportunities to access the community in ways that aligned with their personal goals and preferences. The solution was to add a waiver service called Community Learning Service (CLS). Introducing this new service represented a big shift in service delivery and required the addition of the service to the waiver, as well as the development of service definitions, provider qualifications, and training on the intent of the service.

DDD also enhanced its ability to better track data and information about service utilization and costs to make overall budget projections required to operate the IDD program. The advent of INSPIRE, and information technology solution, also supported DDD in tracking data and information to monitor quality through a provider portal and growing library of Power BI reports. This equipped DDD to enter into 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. Utilizing data to describe how investments in the program were being applied helped DDD to craft a compelling narrative and in some cases secure needed funding to build the infrastructure to support the goals and strategic objectives that DDD aspired to accomplish.

Developing HCBS Waiver Infrastructure

Over the past several years, DDD has made strides to fundamentally alter the waiver infrastructure that underpins the system. This is one of the areas of change that can be concretely described. These changes to the waiver infrastructure were necessary to provide pathways for people to experience services that support them to have full lives as members of their community. For

example, adding services such as Community Learning Services (CLS) provided additional options for people with IDD to explore and connect with others in their communities. However, adding a new waiver service is just one dimension of reaching the ultimate objective. Equally important are all the complementing activities such as developing an adequate reimbursement rate, preparing the provider network to offer the new service, establishing expectations for the service through clearly defined standards, building demand for the service by sharing information and training with case managers and people with IDD and their families, and monitoring for quality. The initiatives described in this section illustrate how DDD’s approach to changing the infrastructure set the stage to achieve the preferred outcomes that DDD sought by addressing these necessary components. The initiatives included in this section are often collectively referred to as *Possibilities Now!* DDD selected this overarching title and theme to represent DDD’s aim to “help participants live the life they want.”¹¹

“The intent of the waiver is to help people get a life that they’re choosing for themselves.” - Interview participant, DDD staff

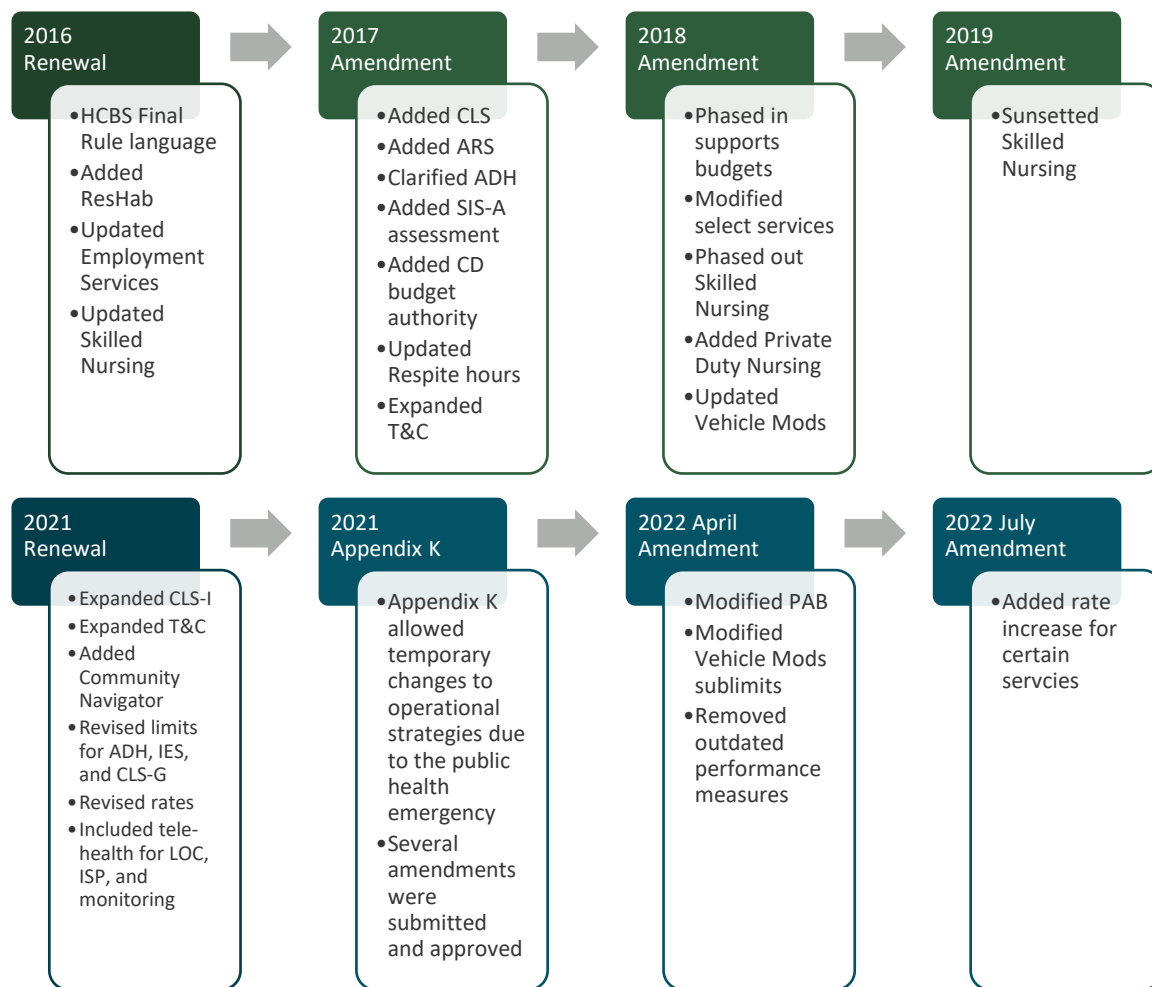
Below, we describe key changes to the infrastructure according to the following categories:

- HCBS waiver services
- HCBS waiver standards
- Rates and payment structures
- Individual supports budgets
- Assessment processes
- Exceptions and utilization review processes
- Quality assurance & improvement processes
- Access to waiver services

HCBS Waiver Services

DDD used a planned, iterative approach to design the services and supports available in the HCBS 1915 (c) waiver through the waiver application renewal and amendment processes. These processes necessarily include opportunity for public comment. The intent behind modifications to the waiver was to alter the service array to offer additional services aimed at supporting community integration, update rates and payment structures, introduce an assessment-informed individual supports budget framework, and come into compliance with the HCBS Final Settings Rule. The graphic below illustrates the evolution of changes that were made through the renewal and amendment cycles starting with the 2016 waiver renewal.

¹¹ <https://health.hawaii.gov/ddd/participants-families/possibilities-now/>



IDD 1915(c) HCBS Medicaid Waiver Renewal 2016

Approved on July 1, 2016, the 2016 IDD waiver renewal included multiple major changes from previous versions. The first significant change was the modification of language throughout the waiver to reflect the expectations of full community integration and person-centered planning in line with the CMS final rule.

Changes to waiver services included the addition of Residential Habilitation (ResHab) back from the previous waiver renewal in 2011. ResHab was added back into the waiver to better support shared living arrangements in licensed adult foster homes and to provide daily payment, rather than hourly Personal Assistance/Habilitation (PAB) services. Employment services (previously called prevocational services in this waiver amendment) were also revised in two primary ways. First, language stating that this service is not provided to people expected to join the general workforce in one year, was removed. Additionally, it was revised to enable participants to use this service 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. Finally, the Skilled Nursing service was revised to clarify terms.

Under Appendix G, Policies and Procedures (P&P) were developed by DDD and integrated into the 2016 waiver.

IDD 1915(c) HCBS Medicaid Waiver Amendment 2017

The 2017 technical waiver amendment went into effect on June 1, 2017. A major contribution 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).

Language changes in this waiver amendment included clarifying waiver emergency services and renaming Crisis Shelter to Out-of-Home Stabilization to better align with the services offered. Modifications to waiver services included the introduction of two new waiver services, Community Learning Services (CLS) and Additional Residential Supports; the addition of a 15-minute code to Adult Day Health (ADH) to provide participants the choice to attend ADH on an individualized schedule instead of half- or full-days to increase community- rather than center-based activities; Budget Authority was added to Consumer-Direction to support individuals and their families to control their resources and choices; finally, limits to daily respite provided in licensed or certified residential homes were put in place to change how Respite services were reported and billed. The amount of Respite hours was also capped at 760 hours annually and an exception process was put in place.

Other changes included expanding provider qualifications for Training and Consultation to include clinicians that specialize in working with families and licensed registered nurses for nurse delegation, revision of eligibility criteria to include children zero to nine (per Act 32 of 2016 that amended the Hawaii Revised Statutes 333F) and increasing the limits for Environmental Accessibility Adaptations and Vehicular Modification to take into account market costs.

IDD 1915(c) HCBS Medicaid Waiver Amendment 2018

This amendment added a methodology to the waiver 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. Services tied to the phase-in of supports budgets included Adult Day Health, Group and Individual CLS, PAB, Chore, and Respite, with the relevance of these services depending on the residential setting of individuals.

Language throughout the waiver was revised to reflect the phase-in of this methodology and specifications for services were modified for Adult Day Health, Assistive Technology, Community Learning Services (CLS), and Environmental Accessibility Adaptations (EAA).

Changes to services included phasing out Skilled Nursing as individuals transitioned to other services, for example the newly added Private Duty Nursing (PDN) service, which included a case-by-case analysis of individuals with complex medical needs who had previously received Skilled

Nursing. Vehicular Modifications also added coverage for repairs to adaptive equipment to ensure safe, operational lift systems for vehicles.

IDD 1915(c) HCBS Medicaid Waiver Amendment 2019

In 2019, there was a technical amendment to the IDD waiver to address the Skilled Nursing service that sunset on June 30, 2019. Considering this change to the Skilled Nursing service, participants were informed of their rights to be notified in advance of change in services, their rights to request an informal review by DOH, and their rights to request an administrative hearing before a DOH/DDD Hearing Officer and a DHS/MQD Hearing Officer. The amendment also estimated the number of participants that would continue to receive Skilled Nursing services while in the review and appeals processes in Waiver Year 4 of Appendix J.

IDD 1915(c) HCBS Medicaid Waiver Renewal 2021

DDD submitted a renewal for the IDD waiver on July 1, 2021, which included several major changes to waiver services. Two service descriptions were expanded in this waiver renewal. The service definitions for Community Living Service-Individual (CLS-I) were broadened to expand the ways the service can be used to reflect a variety of supports, reinforce CLS-I in work settings, and provide flexibility to support ongoing community engagement without the expectation of fading. Training and Consultation (T&C) was also expanded to include telehealth as a service delivery method and to allow for concurrent billing for professionals and paraprofessionals.

Service limits for three services were also revised. The limitations on Adult Day Health (ADH) and Community Learning Services-Group (CLS-G) related to Individual Supports Budgets were removed, and the service limits related to Individual Employment Services (IES) was increased to 80 hours per plan, per year, and the limit of three months was removed.

A new service, Community Navigator, was also added to the waiver. The Community Navigator service was meant to support participants in navigating their community by connecting them with natural supports and building relationships in the community through avenues such as volunteer opportunities, sports teams, and clubs, among others. In line with this change, payment rates were revised to establish a rate methodology for the new Community Navigator service. A similar change was also made to establish rates for CLS-I and CLS-G at 1:2 and 1:3 ratios.

Another important change to the IDD waiver was the inclusion of telehealth to conduct the annual re-evaluation of level of care (LOC), individual service plan (ISP), and monitoring by the case manager in line with participants' individual preferences and circumstances.

Finally, a host of general updates were made throughout the waiver. Changes were made to clarify language; provide information on the *My Choice My Way* transition plan towards compliance with the Final Settings Rule; enhance performance measures around the Quality Improvement Strategy; add staff qualifications to applicable service definitions in line with CMS requirements; expand provider qualifications for Environmental Accessibility Adaptations to include Licensed General Contractors and Licensed Specialty Contractors; change the service title from Vehicular Modifications to Vehicle Modifications; include statutory language to the criminal background check requirements to specify

the types of 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

DDD submitted an Appendix K to enact emergency measures to address circumstances caused by the COVID-19 pandemic and was approved on March 27, 2020. The option to apply for an Appendix K is given to all states that operate 1915(c) waivers for the duration of a declared national emergency, allowing states to operate aspects of their waivers with temporary flexibility as necessitated by the national emergency. Changes allowed under the Appendix K amendment can remain in effect six months following the end of the Public Health Emergency unless otherwise specified in the Appendix K application.

The COVID-19 pandemic presented multiple challenges around the delivery of waiver services. DDD utilized Appendix K in multiple ways and completed several amendments to adjust to arising circumstances. Below is a summary of the major provisions included in the series of Appendix K amendments.

- Initial Appendix K: Allowed for modifications to prior authorization and/or exceptions review, suspension of certain service limits, expansion of allowable purchases to include PPE when not otherwise covered in the state plan, exceptions as needed to individual budget limits, suspending of certain staff qualification requirements and minimum staff ratios, and some allowances for telehealth, and provisions for retainer payments.
- Second Amendment: Added new service – Medical Respite Modifications to existing services– Private Duty Nursing, 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.
- Third Amendment: Extended timeframes for federal reporting and data collection.
- Fourth Amendment: Further defined retainer payments.
- Fifth Amendment: Increased rates for selected services for the period from to help cover fixed costs as well as increased costs due to the pandemic.
- Sixth Amendment: Adjusted the anticipated end date to six months after the end of the public health emergency.
- Seventh Amendment: Temporarily increased payment rates for select services.

IDD 1915(c) HCBS Medicaid Waiver Amendment April, 2022

The amendment to the 2021 IDD waiver was approved on April 2, 2022. This amendment modified the service definition for PAB to include supports provided participants in acute-care hospital

settings. These changes to PAB were intended to support participants while they receive acute hospital care, to foster communication, provide intensive personal care, to maintain participants' functional abilities, and to support participants as they transition back to the community.

Changes were made to the previous waiver definition for Vehicle Modifications to add an exception review, enabling the State 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. Appendix J cost estimates for the Vehicle Modifications service were also modified to account for an anticipated increase in the projected number of users from these changes.

Finally, an outdated performance measure was removed from Appendix I Financial Accountability sub-assurance (a) as it was replaced by a new performance measure in the approved waiver.

IDD 1915(c) HCBS Medicaid Waiver Amendment July, 2022

A second amendment was made in July, 2022 to implement rate increases for waiver services in line with the recommendations from the rate study conducted in 2020. The following services received rate increases equal to one-half the difference between current rates and the rates recommended by the rates study which led to increases between approximately 1 – 40%:

- Personal Assistance/Habilitation
- Residential Habilitation
- Additional Residential Supports
- Adult Day Health
- Community Learning Service
- Discovery and Career Planning
- Individual Employment Supports
- Respite
- Chore
- Non-Medical Transportation
- Private Duty Nursing
- Training and Consultation
- Waiver Emergency Services

Rate increases were included in the State's spending plan to use funds made available through section 9817 of ARPA.

HCBS Service Standards

DDD has been working to develop progressively more detailed and robust service standards with each renewal and amendment of the IDD waiver.¹² 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 expectations related to quality measures. The redesign process of service standards included engaging with a range of partners within the IDD system including case managers, service providers, and DDD staff. The

¹² <https://health.hawaii.gov/ddd/files/2021/06/Waiver-Standards-Manual-July2021.pdf>

redesign process was collaborative and included discussions pertaining to what was working well and identifying pain points. Those in charge of redesigning service standards also reported that they intentionally designed the structure of the waiver standards so that they could continue to evolve with future iterations of the waiver.

Changes to waiver service standards were also accompanied by provider trainings on changes to waiver standards (November 2017, October 2018, June 2021, July 2021, February 2022) which DDD continues to house on its website as a public resource. In interviews with DDD staff, it was also noted that this development of waiver service standards was an effort to bring services closer in line with the overall DDD strategic vision for waiver services.

Rates and Payment Structures

One key component to supporting an agile provider network available to meet the needs of people with IDD is to devise a sound methodology for the rates of reimbursement paid to service providers for delivering services. Prior to the initiation of a rate study in 2016, rates of reimbursement had not been substantially altered for 12 years. DDD contracted with Burns & Associates, Inc. (B&A; now subsumed under Health Management Associates) to conduct the rate study and develop rate models that met the requirements of Medicaid waivers.

The rate models that B&A developed were designed to reflect the reasonable costs that providers incur to deliver services consistent with state requirements and individuals' service plans.

Information was collected from multiple sources such as:

- DDD policies and decisions
- Stakeholder input, including a provider survey
- Published sources (e.g., Bureau of Labor statistics, Internal revenue Service))
- Special studies¹³

The rate methodology sought to accommodate the changes in the costs associated with operations and service delivery. The results of the rate study generally indicated increased rates for many services. The rate methodology also included an adjustment for increased expenses in neighbor islands to accommodate the rural context.

New rates were strategically phased-in by services across three different cohorts of the service population:¹⁴

- Cohort 1: Participants residing in certified or licensed settings

¹³ DDD Waiver Rate Study Overview of Proposed Rate Model. October 9, 2020. Burns & Associates, Inc. <https://health.hawaii.gov/ddd/files/2020/10/Proposed-Rate-Models-Oct2020.pdf>

¹⁴ 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>

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

In October 2020, the rate study was updated as part of the 2021 waiver renewal package.

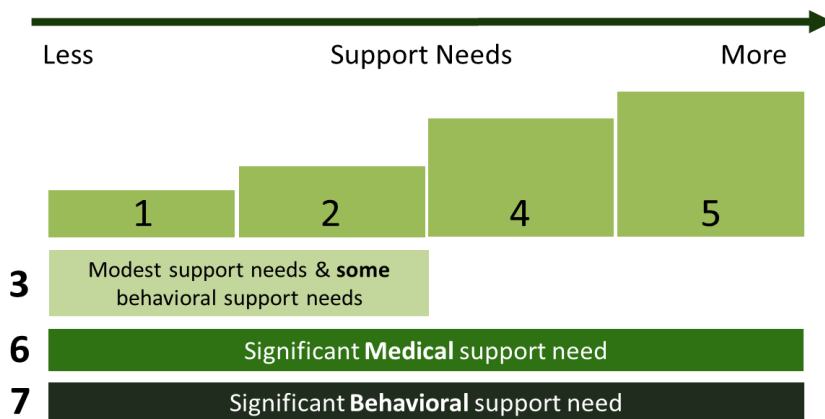
The providers we spoke with as part of the key informant interviews generally expressed appreciation for DDD's efforts to update service reimbursement rates. One interviewee expressed that size may have been a factor that influenced a provider's ability to easily adapt to a new payment structure, particularly with the switch to a per diem ResHab rate. For example, a larger provider that operates several residential homes may have an easier time implementing a new rate model than a smaller provider with less administrative infrastructure and capabilities.

Individual Supports Budgets

The implementation of a supports budget framework was intended to create a system of allocating resources in a way that is fair, efficient, person-centered, and flexible. It provides service recipients increased personal control over resources and encourages demand-driven service delivery, with the opportunity to alter service array and rates to match demands. The framework also offers increased predictability of overall system allocations and spending, as well as greater understanding of the service population. 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. Participants are made aware of the amount of their supports budget before planning for supports for the upcoming year. This makes the process of planning for and delivering services more predictable on the individual and systems level.

DDD embarked on a substantial effort to design and implement a support level framework determined by the extent of a participant's support needs, as measured by the Supports Intensity Scale (SIS), their type of residence (e.g., adult foster home, with family), and age (e.g., over 18 years old). While the framework provided an outline for determining support budgets, DDD undertook a number of activities to customize the process for its specific use. This includes the amount and variations of services included in the supports budget for participants according to available living arrangements.

Assessment results were used to assign individuals to one of seven levels, related to their support needs. The graphic below illustrates these levels. Levels 1, 2, 4 and 5 include individuals from less to more need, but Levels 3, 6 and 7 include individuals with modest behavioral challenges (3), complex medical needs (6) and extraordinary behavioral challenges (7).



The supports budget framework was phased-in over three years according to the three cohorts of the population through the waiver amendment process. 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. A complementing set of policies and procedures had to be developed to support the operations of the supports budget framework.

While the implementation of a supports budget framework was a substantial effort, it fundamentally altered the dynamics within a planning meeting to make service choices within a known amount of resources. The intent was to shift decision-making power in favor of the participant and their circle of support. Some of the interviewees we spoke with expressed that while the move to individual supports budgets was a significant lift, it did provide a guideline for case managers and planning teams to work within. Over time, case managers have adapted to the new model and increased their ability to create individual support plans that fall within a participant’s budget amount. This is evidenced by a reduction in the number of cases that are brought to the Exceptions Review Committee. One interviewee noted that there continues to be a need to educate case managers on how to have productive conversations about the supports budget in the service planning meeting and arrive at the best mix of services to help the participant be supported to live the life they choose, rather than conveying the budget as a barrier.

Assessment Processes

The seven-level assessment framework is informed by individual support needs as measured by the Supports Intensity Scale for Adults (SIS-A). The SIS had been introduced several years prior through pilot initiatives, which resulted in inconsistent use of this assessment tool. DDD did not commit to implementing the SIS as an official assessment tool until its planned use as the instrument aligned with the supports budget framework. The move to administer SIS 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 who were trained and endorsed by AAIDD, assessment interview protocols, scheduling procedures, and supporting assessment policies and procedures.

The SIS-A was created by researchers working with the American Association on Intellectual and Developmental Disabilities (AAIDD). It has been in use since 2004 and is a reliable and accurate tool for measuring the supports needs of individuals with IDD. There are three sections.

Section 1 Exceptional Medical and Behavioral Needs: This section documents extra support needed to deal with particular medical and behavioral conditions, above and beyond the regular daily supports covered in Section 1. Two sub-sections address these domains:

Part A: Medical Supports Needed

Part B: Behavioral Supports Needed

Section 2 Support Needs for Life Activities: This section documents the general support needs of individuals, in terms of how often the support is needed, how long it takes to provide the support each time, and what type of assistance is needed. Seven sub-sections address the major areas in which support is typically needed:

Part A: Home Living Activities

Part B: Community Living Activities

Part C: Health and Safety Activities

Part D: Lifelong Learning Activities

Part E: Work Activities

Part F: Social Activities

Part G: Advocacy Activities

Section 3 Supplemental Protection and Advocacy Scale: This section examines the types of activities the individual performs to protect and advocate for him or herself. Each activity is rated in terms of frequency, time, and type of support.

An important distinction with the SIS assessment is that it seeks to capture the amount of support a person with IDD needs to be successful, rather than the person's deficits or diagnoses. In this way, it is more closely aligned with person-centered approaches to assessment.

In addition to the SIS-A, DDD has been working on a few other areas related to assessment particularly for informing approaches for behavioral support needs. The intent is to change mindset

within DDD towards people with IDD who exhibit challenging behavior and start asking different 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?

There is interest in developing mechanisms to assess for root cause analysis for individuals with challenging behaviors. For example, ruling out physiological reasons that may be contributing to behavior by first conducting medical tests such as an MRI of the brain, a CT of the abdomen, or blood tests.

Exceptions and Utilization Review

As part of 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 additional supports above and beyond what was available with their individual support budget. Over time, this process was established and supported with policies and procedures. When a participant requests additional supports, the Exceptions Review Committee has 30 days to review and provide a response. The team sought to streamline operations for those cases that came to exceptions review that also had to be reviewed by the Clinical Interdisciplinary Team (CIT) to approve enhanced staffing ratios.

A by-product of implementing this process is that it helped to clarify the range of decisions that could be made at the case management level and those that required a review by DDD. This increased DDD's involvement and ability to determine the types 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 – approved/denied. These trends can be viewed over time and provide information about how well the supports budget framework is working. For example, if the exceptions review committee frequently receives similar requests for specific services tied to a certain support level, it may indicate that the service mix for that support level may need to be revisited.

Quality Assurance and Improvement Program

New quality assurance processes were initiated prior to the 2016 timeframe. There was an emphasis within the state as well as from the Centers for Medicare and Medicaid Services (CMS) on developing quality assurance structures and performance improvement. The Quality Assurance and Improvement Program (QAIP) was established in 2012 and utilizes a Steering Committee and subcommittee structure to review data and reports related to incident reporting, mortality reviews, and provider monitoring tools. 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 in ways that set expectations up front. This promotes a shift from merely compliance focus to methods that will encourage agencies to track performance data and make improvements based on a Continuous Quality Improvement (CQI) approach.

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, an annual report has not been released in recent years.

Access to Services

We heard from some interviewees that the current eligibility process to access waiver services is complex. An applicant must be determined eligible for DDD and also be approved for the waiver through Med-QUEST. Each step in this process has its own timeline requirements. DDD contracts with psychologists who do the required psychological assessments, or the applicant may choose to obtain a psychological evaluation by a psychologist independently, and then the Clinical Interdisciplinary Team (CIT) ultimately reviews all the documentation and determines eligibility. The applicant must also be approved through Med-QUEST before they are ready to receive waiver services. During our interviews, an issue was raised regarding the wait times for eligibility determination assessments. The availability of professionals to conduct the necessary psychological assessments is limited resulting in delayed eligibility for the waiver. Part of the current initiative is aimed at expanding the number of providers qualified to render this assessment.

One interviewee noted that when seeking support, many individuals with disabilities and families might not know what specific services they are seeking because they haven't had these services before and do not understand how they would use the services. Intake workers need to be skilled in helping applicants express what their support needs are and explaining what services and supports are available to meet those needs.

DDD is exploring options to streamline eligibility and has an initiative to study and improve the front-end process. Areas of process improvement include updated policies and procedures that implement interval communication with applicants, quality of information sharing, enhanced specificity that aligns additional documentation requests to both DDD and waiver eligibility criteria, INSPIRE for communication and document organization, and integration of data reporting into intake team meetings to drive productivity.

Promoting Modernization

Several interviewees noted the prevailing attitudes toward people with IDD as requiring care and protection, limited access to community integrated employment options, and limited independent housing options. In response to this, initiatives that developed around 2016 were also 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. The following initiatives in this group include Employment First, INSPIRE IT system for case management, expansion of dentistry services for people with IDD, and innovation in the Neurotrauma program.

Employment First

Like many other states around the nation, DDD adopted an Employment First approach to promote access to gainful employment options for people with IDD. 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 learned from employment providers about those aspects that were working and not working, and then took this information to DDD leadership to make necessary adjustments. This staff was also responsible for offering 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.

“Employment is in part an area that as a state and as providers we can improve on” – Interview participant, provider organization staff

INSPIRE Information Technology System for Case Management

The legacy information technology (IT) case management system that was used by DDD for many years was slow, did not support many of the functions that case managers needed to perform, and was not centrally organized across case management units. 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 is a comprehensive, multi-agency Intellectual

and Developmental Disabilities/Behavioral Health Case Management System that interfaces with other Medicaid assets to promote the goals of DDD. 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.

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 new 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.

The project is currently in Phase 3, which is comprised of 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.

Dental Services for People with IDD

The Hospital and 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 legislature, starting this year, Medicaid will cover comprehensive benefits for adults.

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.

ARPA Spending Plan

DDD in collaboration with the Med-QUEST Division, developed a spending plan totaling over \$30 million through the American Rescue Plan Act (ARPA), which was enacted by the Biden Administration to support economic recovery. Under ARPA, the increased federal match could be used to enhance, expand, or strengthen Medicaid HCBS. DDD's plan was developed through a collaborative process involving the IDD community and outlines the following five priority areas and 14 associated initiatives.

Priority 1: Supports for Participants and Families

1. Option for Individuals with Behavioral Challenges – a highly individualized residential option for people with complex behavioral support needs.
2. Family-to-family Peer Mentoring Service – a service where families help other family members navigate services, engage in person-centered planning processes, access community resources, and make community connections.
3. Host Participant and Family Forums – a mechanism to support regular engagement with the IDD community.

Priority 2: Strengthen Provider Capacities and System Infrastructure

4. Increase Provider Payment Rates – represents the largest spending plan investment and increases the rates by 50 percent of the difference between the current rates and the recommended rate in the 2020 rate study. The majority of these funds must be used to increase Direct Support Professional compensation.
5. Invest in Quality Management – provides technical assistance and training to build cultures of quality within provider agencies.
6. Support Community Integration – provides technical assistance and training to providers to deliver quality services that are focused on helping participants access and develop a sense of belonging in their communities.
7. Advance Competitive Integrated Employment (CIE) – technical assistance and training with the University of Massachusetts, Institute for Community Inclusion (ICI) to advance competitive integrated employment. This effort supports six organizations to engage in transformative activities to support the development of local champions focused on employment.
8. Support Community Navigator Practice Development – builds curricula to further develop this newly added waiver service.

Priority 3: Workforce Development

9. Develop the DSP Workforce – includes a focus on creating a credentialing framework to provide higher rates for DSPs.

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

10. Positive Approaches for Challenging Behaviors – provides training on best practices for person-centered and positive approaches for addressing the support needs of those with challenging behavior.
11. Improve Critical Incident Response through Analytics – builds an interface with Medicaid claims data to detect unreported events and identify opportunities for quality improvement.

Priority 5: Strengthen System Infrastructure & Accountability

12. Conduct System Evaluation - measures the extent to which the intended goals of these system changes are being achieved.
13. Strengthen Provider Monitoring – focuses on improving methods and tools for provider monitoring.
14. Implement the Spending Plan – focuses on managing the initiatives included in this spending plan to ensure efficiency and effectiveness.

The ARPA initiatives offer a unique opportunity for DDD to build on the work already underway to make further improvements to the system on a hastened timeline. DDD was well-positioned to act quickly to take advantage of this historic investment in HCBS. The developments related to the ARPA initiatives are included as part of this evaluation.



Next Steps for the Evaluation

Outcome Evaluation Plan

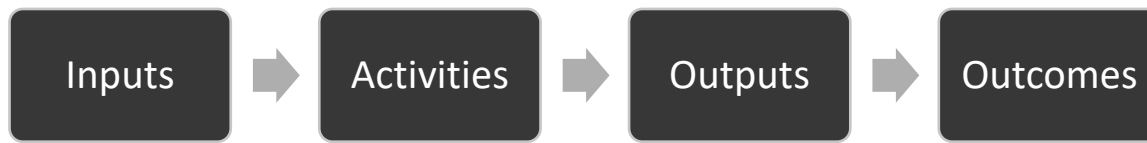
The upcoming phase includes the development of an outcome evaluation plan, which is aimed at understanding how successful the initiatives have been in achieving their goals and understanding any intended or unintended outcomes. The outcome evaluation will seek information in response to the following two questions:

- What are the impacts on systems and people?
- What may improve on or advance the changes?

To develop the outcome evaluation plan, we will formulate specific evaluation questions that seek to understand the impact of initiatives and what may improve on or advances the changes. For each evaluation question, the plan will include a data collection methodology that describes the approach to we will use to acquire data, the data source(s) and/or participants, and how data may be analyzed to respond to the evaluation question. By preparing the outcome evaluation plan, we will be able to incorporate information about what we now know about each initiative's implementation and tailor

the outcome evaluation plan accordingly. Some of DDD's evaluation needs may be best addressed via different approaches to data collection (e.g., quantitative versus qualitative) and may differ based on policy intentions (e.g., interest in a very specific outcome to inform a future initiative). We are interested in conducting an evaluation that is not only valid and reliable but has practical use for DDD. The outcome evaluation plan will describe our mixed method approach to the remaining tasks. Part of the plan will rely on a logic model to illustrate the system, initiatives, and desired outcomes. The logic model will include the inputs, activities, outputs, and outcomes associated with the initiatives under review.

Logic Model Components



Research Questions

Included in the scope of work were a series of questions that DDD would like to focus on as part of this evaluation. Evaluation activities will center around answering these questions in ways that reveal the extent to which DDD has achieved desired outcomes.

1. How well is DDD meeting the requirements of the federal CMS mandate for increased community integration?
2. What has the impact of changes been on service utilization and utilization patterns?
3. How has service quality changed?
4. How has quality of service plans and the service planning process changed?
5. What impact have new payment rate and rate structures had?
6. How well and what impacts have there been in relation to implementation of SIS assessments and Individual Supports Budgets?
7. What are the outcomes for DDD participants?
8. How well have intended goals of initiatives been achieved?

Table 1 shows these research questions in relation to the data sources that can be used to show process and outcomes.

Data Sources

As a part of our mixed methods approach, we will identify various sources of data. The following describes potential quantitative data sources such as data collected by DDD, and qualitative data such as National Core Indicators (NCI) and focus groups.

Quantitative Data sources

Service Utilization Data

We will look at trends in service utilization over time. We will want to pay particular attention to the uptake of new services that were added to the waiver in relation to other services. We might also view service utilization along with other variables such as living setting or age. This will give us an understanding of service patterns and gauge that against expected use.

Exceptions Data

The exceptions review committee routinely collects data related to the exceptions process. We can view trends over time and seek answers to questions such as:

- Are the number of exceptions requests increasing, decreasing, or staying the same?
- Are exceptions requests more frequent for certain support levels?
- What are the most common requests for exceptions?
- On average, how much additional service is granted when requests are approved?

Answers to these questions will help to understand how well the supports budget framework is working.

Supports Level Data

There are several metrics we can study that relate to the support levels such as the pace of SIS-A assessments by CMU, the distribution of the service population across support levels by other variable such as living setting and age, the number of participants that go through verification – and of those what is their resulting support level, etc. This type of information will illustrate the results of the support level framework. Supports level information can also be integrated with service utilization data to understand service use patterns by support level.

Cost Data

There are several ways that we may elect to look at cost data to aid in our understanding of the service system. For example, we may look at cost of the program overall, average costs per person, costs by support level and living setting, and average spend in relation to supports budget authorizations.

Qualitative Data Sources

National Core Indicators

DDD participated in the National Core Indicators® - Intellectual and Developmental Disabilities (NCI®-IDD) survey in 2016, 2018, and 2020. NCI is a national effort to measure and improve the performance of public developmental disabilities agencies.¹⁵ These indicators can be viewed to illustrate trends over time as well as compared to other states that participate in the NCI. The team will evaluate what items in the NCI survey that might be most tied to key elements that would likely be impacted by the initiatives included in this review. For example, this may include calculating multi-item scales on items such as:

- Community Inclusion
- Satisfaction with Community Inclusion (2018 and 2020 only)
- Life Decisions
- Everyday Choices
- Percent of people who want community employment who have this as a goal in their service plan

DDD also participated in the NCI staff stability survey, aimed at gathering data about the workforce of direct support workers and service supervisors. These data are particularly helpful in viewing trends in the DSP workforce and generating solutions to the complex issues related to hiring and retention of the workers available to support people with IDD.

Focus Groups

The next significant focus of the evaluation will be conducting a series of focus groups across the state with participants, families, and others. Here we will partner with the Center on Disability Studies at the University of Hawai'i at Mānoa. As appropriate for the subject matter, each focus group may center on particular groups (e.g., service recipients, families, case managers, providers) or other subgroups of interest to DDD (e.g., to probe at differences in experience across culture or ethnicity). The activities involved with completing focus groups include:

- Develop focus group protocols. Like the interview protocols, the focus group protocols will be guided by the evaluation plan and findings from the quantitative analysis. Focus group protocols will use accessible language and techniques to increase interaction among participants and in-depth conversation about focus group topics. The protocols will be

¹⁵ <https://idd.nationalcoreindicators.org/>

respectful of asking questions that may elicit the sharing of private or personal information in a group setting.

- Recruit focus group participants. Like recruitment for interviews, focus group recruitment will be based on individual role/experience in relation to the focus group topic, availability, and interest. We will work with DDD to create recruitment materials and work closely with participants to establish supports for accessibility and privacy.
- Conduct focus groups. We, in collaboration with our partners at CDS, will conduct a series of focus groups with various groups across the state in the latter part of 2023. There may be a mix of in person as well as virtual opportunities to participate in focus groups. The information collected will likely include perceptions of DDD initiatives and the impact initiatives have had on their lives.

Members of the Advisory Group assembled for this evaluation provided input on things to consider when engaging with members of the IDD community during the planned focus groups. They suggested clearly describing the services in ways that people would understand and avoid using jargon such as “waiver” and other acronyms such as “LTSS.” They also mentioned that the term “local culture” is more relevant and inclusive than saying “Hawaii.” It would also be helpful to clearly describe the intent, activities, target audience, and expected outcomes for each initiative. For example, participants might not be familiar with the INSPIRE IT case management system because they have not interacted with it, but case managers would be very familiar with this initiative as it likely impacted their day-to-day work.

“(There is) a role for everyone to play. Get people at the table and emphasize the importance of their contributions.” – Interview participant, parent/advocate

Advisory Group members will continue to be involved in shaping the evaluation plan as the project moves forward and their input will be incorporated.

Table 1: Evaluation Questions

EVALUATION QUESTION	PROCESS EVALUATION	OUTCOME EVALUATION
	METHOD: DATA SOURCE	METHOD: DATA SOURCE
How well is DDD meeting the requirements of the federal CMS mandate for increased community integration?	Document review: statewide transition plan, policies, monitoring tools, communications Interviews: DDD staff	Quantitative analysis: Provider assessments, claims data on community-based services Interviews/focus groups: providers, case managers, participants/families
What has the impact of changes been on service utilization and utilization patterns?	Document review: policies	Quantitative analysis: authorizations, claims
How has service quality changed?	Document review: published findings on quality	Qualitative analysis: survey data, NCI, AER, provider audits Interviews/focus groups: DDD staff, participants/families, advocacy orgs
How has quality of service plans and the service planning process changed?	Document review: policies, communications Interviews/focus groups: DDD staff, case managers, CMU staff	Document review: individual service plans Qualitative analysis: NCI data Interviews/focus groups: participants/families, case managers
What impact have new payment rate and rate structures had?	Document review: policies, communications Interviews/focus groups: DDD staff	Quantitative analysis: claims (number of providers, shifts to community-based services), exceptions, Staff stability survey Interviews/focus groups: participants/families, providers, advocacy orgs

<p>How well and what impacts have there been in relation to implementation of SIS assessments and Individual Supports Budgets?</p>	<p>Document review: policies, communications</p> <p>Interviews/focus groups: DDD staff, CMU staff, case managers</p>	<p>Quantitative analysis: SIS, authorizations/claims, exceptions</p> <p>Qualitative analysis: NCI</p> <p>Interviews/focus groups: DDD staff, participants/families, case managers, advocacy orgs</p>
<p>What are the outcomes for DDD participants?</p>		<p>Quantitative analysis: SIS, authorizations/claims, exceptions</p> <p>Qualitative analysis: NCI</p> <p>Interviews/focus groups: DDD staff, participants/families, case managers, advocacy orgs</p>
<p>How well have intended goals of initiatives been achieved?</p>		<p>Quantitative analysis: SIS, authorizations/claims, exceptions</p> <p>Qualitative analysis: NCI</p> <p>Interviews/focus groups: DDD staff, participants/families, case managers, advocacy orgs</p>

Concluding Thoughts

As we embark on the next phase of this evaluation, we reflect on the breadth of initiatives that DDD has undertaken over the past several years as cataloged in this interim report. It is evident that much has transpired through the efforts of DDD staff as well as other key parties who have contributed their time and expertise, and endeavor to make the system better for people with IDD and their families. Through this study, we will learn along the way what is working well and should be sustained or scaled up as well as what may require adjustment to achieve the strategic goals and objectives that DDD set forth. As outlined, many of the evaluation activities we have planned include hearing directly from people with disabilities and their families. It will be those who have the most at stake – people with IDD who rely on services and supports to achieve their vision of a good life – that will inform the best way forward.