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Office of Aging & Disability Services

2022 ANNUAL REPORT

Maine's System of Care for Adults with Intellectual Disabilities or Autism

*Pursuant to 34-B MRS §5003-A(6) and
§5201(8)(B)*



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Executive Summary

The Department of Health and Human Services (DHHS, the Department), through the Office of Aging and Disability Services (OADS), supports adults with intellectual and developmental disabilities (IDD) or autism spectrum disorder (ASD) to achieve, through self-determination, a quality of life consistent with the community in which they live. OADS oversees a range of long-term services and supports, including home and community-based services that enable people to live as independently as possible in the community. This report provides annual information related to Maine's system of care for adults with IDD or ASD, fulfilling reporting requirements under 34-B MRS Sections 5003-A and 5201(8)(A-B).

The COVID-19 Public Health Emergency (PHE) continued to impact adults with IDD or ASD and how the Department supports them. In response to the PHE, DHHS was able to add flexibility to its home and community-based services (HCBS) waivers including allowing for telehealth services, permitting virtual person-centered planning and community and work supports, enhancing provider flexibility, especially regarding the workforce shortage, and increasing the rates for some services. While the intensity of this response has lessened since the start of the PHE, the Department continues to work with residential and in-home providers and community-based organizations to monitor and provide information and assistance to help address COVID-19 and its impacts.

Highlights of 2021-2022

SERVICE SYSTEM REFORM ACTIVITIES

Informed by the *2021-2022 Biennial Plan for Adults with Intellectual Disabilities or Autism* and guided by on-going stakeholder engagement with families, guardians, providers, and others, OADS has undertaken several reform initiatives to improve the system of service and supports for adults with IDD or ASD. In 2021-2022, OADS continued to make progress in addressing long-standing challenges in the service delivery system, including waitlists, workforce shortages, limited access to transportation and other access issues.

The passage of the American Rescue Plan Act of 2021, Section 9817, provided unprecedented federal support to Maine to help stabilize and enhance the home and community-based service system. This funding has expanded and augmented many of the reform initiatives already underway to improve access, services, and quality of life for adults with IDD or ASD in Maine.

Reform activities during 2021-2022 focused on several key areas:

Table 1. Key Areas for 2021-2022 Reform Activities

Focus Area	Activities
Improving Services and Supports	<ul style="list-style-type: none"> ▶ Person-centered planning, self-determination, and self-advocacy ▶ Charting the LifeCourse Framework ▶ Employment First and minimum wage ▶ Home and Community-Based Services Settings Rule compliance
Strengthening Quality	<ul style="list-style-type: none"> ▶ Public-facing quality information ▶ Monitoring meaningful data
Improving Coordination across Agencies	<ul style="list-style-type: none"> ▶ Transition process reform collaboration with Office of Child and Family Services, Department of Education, Department of Labor ▶ Lifespan Project to investigate the feasibility of a single service program from childhood through adulthood
Improving System Capacity and Access	<ul style="list-style-type: none"> ▶ Workforce training ▶ Self-direction as a mechanism to access alternative providers

SERVICE SYSTEM OPERATIONS

OADS has continued to provide public information on waitlists for MaineCare HCBS waiver services and access to other coverage. The majority (77%) of people on the waitlist for MaineCare Section 21 waiver had other coverage while on the waitlist compared to less than half (45%) of people on the waitlist for Section 29 waiver services.

OADS implemented a new Reportable Events system, the Evergreen Data System

(Evergreen), to strengthen quality assurance and improvement capacity by capturing timely, accurate and critical individual, provider and systemic information that helps OADS identify problems as they occur as well as trends over time. In FY2022, there were over 24,000 Reportable Events reported in Evergreen. “Dangerous situations” was the largest category of events for both Section 21 and Section 29 services. Other top categories included emergency department, emergency restraints, medication errors, physical assaults, and rights violations.

Statewide Behavioral Health and Support Services responded to over 11,000 contacts to the Crisis Prevention and Intervention System (CPIS) during FY2022, the majority of which were over the phone. A new phone system, when fully implemented, will allow OADS to respond to crisis calls effectively, at all times, and on a regional basis.

Maine Adult Protective Services (APS) investigated over 1,100 cases of alleged abuse, neglect, or exploitation of adults receiving Section 21 or Section 29 waiver services in FY2022. Nearly 180 of these cases were substantiated, and caretaker neglect was the most common form of abuse.

Utilization and expenditures for MaineCare Home and Community-Based services increased in FY2019-FY2022, with Home Support and Shared Living services accounting for the highest costs.

OADS continues to engage with members, families, providers, advocates, and other stakeholders in its commitment to promoting the highest level of independence, health, and safety of all adults with disabilities including IDD and ASD, while safeguarding and protecting the rights of those served.

Introduction

The Department of Health and Human Services (DHHS, the Department), through the Office of Aging and Disability Services (OADS), supports older adults and adults with disabilities throughout Maine. OADS oversees a range of long-term services and supports, including home and community-based services for older adults and adults with brain injuries, other related conditions, physical disabilities, and intellectual and developmental disabilities (IDD) or autism spectrum disorder (ASD). In addition, OADS administers Maine’s Adult Protective Services (APS) program which investigates allegations of abuse, neglect, or exploitation of incapacitated and dependent adults and operates the Department’s public guardianship and conservatorship program.

OADS VISION

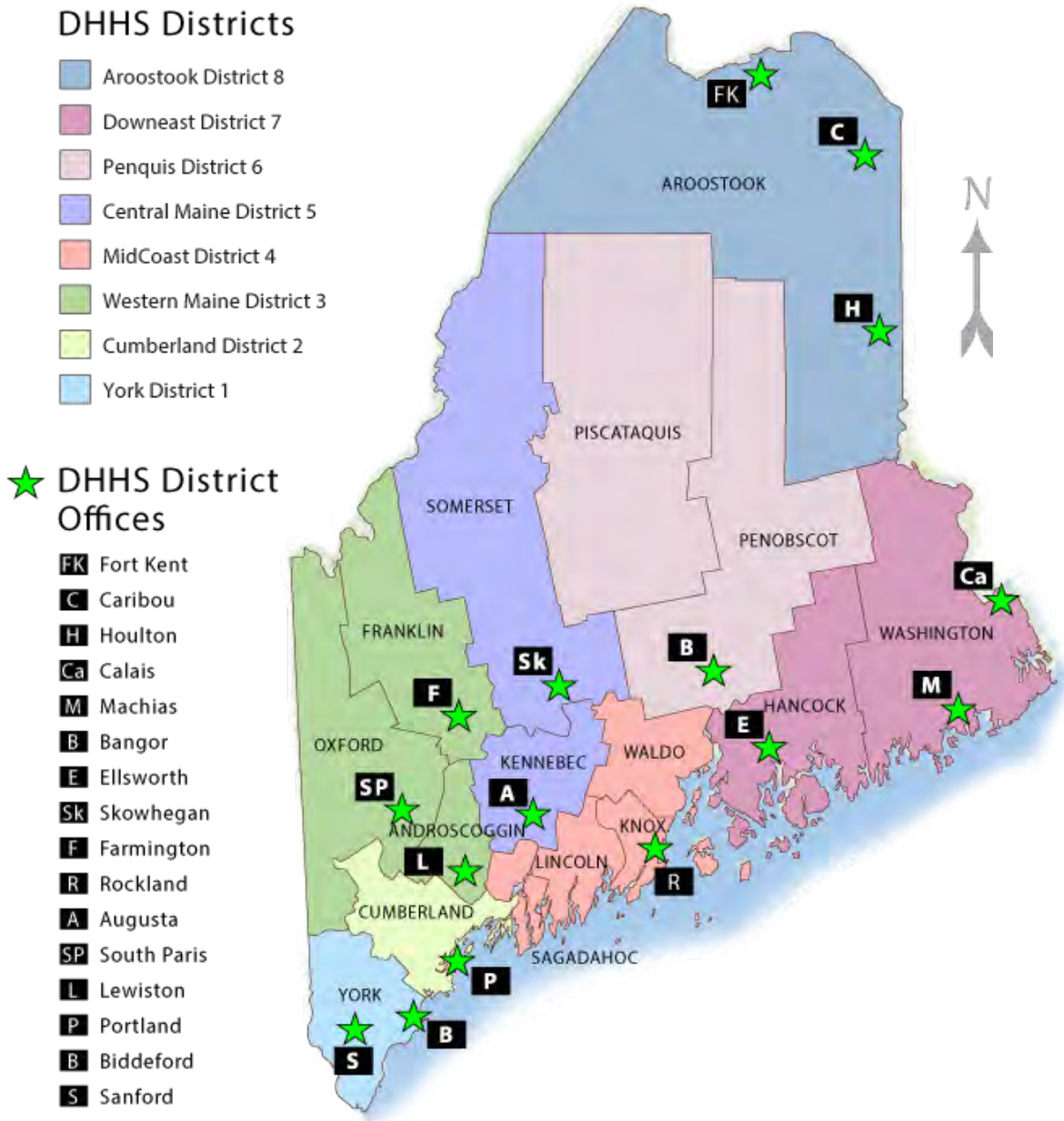
We promote individual dignity through respect, choice, and support for all adults

OADS MISSION

To promote the highest level of independence, health, and safety of older adults and adults with disabilities throughout Maine

Staff in sixteen district offices (Figure 1) oversee services provided by a network of organizations serving adults with IDD or ASD. These organizations provide case management, community support, and residential services statewide. Crisis services for adults with IDD or ASD are provided directly by the State. OADS oversees its programs and benefits to assure they operate consistently with state and federal policies and Department goals.

Figure 1. DHHS Districts and Offices



To see this information in tabular form, please refer to Appendix C.

A core tenant of OADS’ mission is that all individuals, through self-determination, can achieve a quality of life consistent with the community in which they live. The key services provided by MaineCare to meet this mission for adults with IDD and ASD are Targeted Case Management Services and Home and Community-Based Services provided through waiver programs.¹

Targeted Case Management Services

The MaineCare Benefits Manual² defines *Targeted Case Management Services* as “services provided by a social services or health professional, or other qualified staff, to identify the medical, social, educational, and other needs (including housing and transportation) of eligible members, identify the services necessary to meet those needs, and facilitate access to those services. Case management consists of intake/assessment, plan of care development, coordination/advocacy, monitoring, and evaluation.”

Home and Community-Based Services (HCBS) Waivers

Home and Community-Based Services (HCBS) waivers are Medicaid-funded service packages designed specifically to help older adults and people with disabilities, who would otherwise require institutional services, to live as independently as possible in the community. Maine’s two HCBS waivers serving adults with IDD or ASD are the primary pathway for accessing services that support the pursuit of one’s own goals, employment, and engagement in the community.

Maine’s HCBS waivers are often referred to by their section numbers in the MaineCare Benefits Manual. Section 21 Home and Community Benefits for Members with Intellectual Disabilities or Autism Spectrum Disorder (sometimes referred to as the “Comprehensive Waiver”) provides a broader array of services than available under §29 Support Services for Adults with Intellectual Disabilities or Autism Spectrum Disorder

¹ A Medicaid waiver is a provision in Medicaid law which allows the federal government to waive rules that usually apply to the Medicaid program. Waivers are state-specific Medicaid programs that often allow for services to be provided outside of an institutional setting.

² See [MaineCare Benefits Manual](#) for more information on covered services.

(sometimes referred to as the “Support Waiver”). See Table 2 for a description of the types of services available through the §21 and §29 waivers and Appendix A for a comparison of services available under both waivers.

Table 2. Home and Community-Based Waiver Service Definitions

Service	Definition
Home Support: Agency or Family-Centered; Shared Living	Home Support is direct support to a member and includes primarily habilitative training and/or personal assistance with Activities of Daily Living (ADL) and/or Instrumental Activities of Daily Living (IADL), self-care, self-management, development, and personal well-being. Shared Living is direct support to a member and includes personal care, protective oversight and supervision and supportive services provided in a private home by a principal care provider who lives in the home and is a Direct Support Professional.
Work Support	Direct Support provided to improve a member’s ability to independently maintain employment
Community Supports; Community Membership	Community Supports and Community Membership are services provided to increase or maintain a member’s ability to successfully engage in inclusive social and community relationships and to maintain and develop skills that support health and well-being. These are habilitative services with a focus on community inclusion, personal development, and support in areas of daily living skills if necessary. Community Supports can be provided in centers and in the community, and Community Membership services can only be provided in the community.
Ancillary Services	Goods and services related to a member’s home accessibility, assistive equipment, communication equipment, specialized medical equipment and supplies, occupational, physical, and speech therapies, and other services.

Notes: No additional Family-Centered Support providers have been approved since December 30, 2007. See Sections 21 and 29 of the MaineCare Benefits Manual for detailed service definitions.

The Department is committed to meeting the needs and expectations of individuals with disabilities and complying with the requirements for providing home and community-based services consistent with the U.S. Supreme Court's 1999 *Olmstead* decision. For adults with IDD or ASD, pursuant to 34-B MRS §5003-A and within existing resources, the Department ensures the system of care is efficient and meets their needs.

This report fulfills the annual reporting requirements under 34-B MRS §5003-A and §5201(8)(A-B) and, unless otherwise noted, focuses on the following services provided by the Department to adults with IDD or ASD:

- MaineCare Benefits Manual, §13 - Targeted Case Management
- MaineCare Benefits Manual, §21 - Home and Community Benefits for Members with Intellectual Disabilities or Autism Spectrum Disorder
- MaineCare Benefits Manual §29 - Support Services for Adults with Intellectual Disabilities or Autism Spectrum Disorder

The report presents updates and available data on:

- Key reform initiatives in 2021-22
- Current quality assurance and improvement structures and activities, case management capacity, and unmet need measured by waitlists for services
- Data on FY2022 Reportable Events, Behavioral Health and Support Services activities, FY2021-22 Adult Protective Services activities, and FY2019-21 MaineCare costs trends for §21 and §29 services

The Continuing Impact of COVID-19

The COVID-19 pandemic impacted every Mainer, with distinct impacts for people with intellectual disabilities or autism, particularly those residing in congregate settings. People receiving in-home services also experienced hardship, with some choosing to forgo in-home services to reduce exposure or having interruptions in services because of provider shortages exacerbated by the pandemic. Family caregivers assumed additional responsibilities when day and employment programs experienced intermittent closures.

The public health emergency spurred the immediate need for an unprecedented level of partnership among state agencies and offices. Within the Department of Health and Human Services, a number of agencies have been closely coordinating and collaborating with the Office of Aging and Disability Services, including the Office of MaineCare Services, the Division of Licensing and Certification, the Maine Centers for Disease Control and other agencies outside of the Department, including the Emergency Management Agency.

While the intensity of this response has lessened since the start of the public health emergency, the Department continues to work with residential and in-home providers and community-based organizations to monitor and provide information and assistance to help address COVID-19 and its impacts.

Updates on Key Reform Initiative Activities

This report summarizes and provides updates on the initiatives undertaken by the Department to improve the system of services and supports for adults with IDD or ASD over the last year. These activities were consistent with initiatives and activities set forth in the *2021-2022 Biennial Plan for Adults with Intellectual Disabilities or Autism (2021-2022 Biennial Plan)*.³

Reforms and activities focused on several key areas including:

- Improving services and supports
- Strengthening quality assurance and improvement
- Improving service coordination across state agencies
- Improving system capacity and access to services

During 2021-2022, OADS continued convening and participating in numerous stakeholder group meetings. The *2021-2022 Biennial Plan* set forth the full array of stakeholder committee and activities. While OADS continues to embed stakeholder voices throughout its work, several of the established work groups finalized recommendations in key areas including community inclusion, innovation, and quality reform. In 2021-2022, OADS also continued to make progress in addressing long-standing challenges in the service delivery system, including waitlists, workforce shortages, limited access to transportation, and other access issues.

Importantly, the passage of the American Rescue Plan Act (ARPA) of 2021, §9817, provided unprecedented federal support to Maine to help stabilize and enhance the home and community based (HCBS) service system. This funding has expanded and augmented many of the reform initiatives already underway to improve access, services, and quality of life for adults with IDD or ASD in Maine.

³ See *2021-2022 Biennial Plan*.

Improving Services through Community Inclusion

With input from the Community Membership Reform Work Group and the Innovation Work Group,⁴ OADS has continued efforts to promote greater inclusion in the community to ensure that people have the services and supports they need to live in a choice of community setting, build relationships, and work alongside people without disabilities for comparable pay. Activity highlights from 2021-2022 include efforts in person-centered planning, community inclusion, and compliance activities with the federal HCBS setting rule.

PERSON-CENTERED PLANNING, SELF-DETERMINATION, AND SELF-ADVOCACY

OADS continues to work to ensure that person-centered characteristics are incorporated into the design of services and programs, the process for delivering services, and the system for assuring the quality of services and systems. In 2021-2022, a key focus was to ensure that these efforts are informed by the Charting the LifeCourse Framework where service planning is proactive, with the goal of helping an individual achieve their desired life outcomes. This framework emphasizes that services must be provided within the context of a person's relationship to family and friends and the larger community.

EMPLOYMENT SERVICES

OADS supports people to be full members of their communities through opportunities to volunteer, join groups, and be employed. Assisting people to connect to communities is a primary focus of employment and community services accessed through the §21 and §29 waivers. Services support people to build and strengthen relationships and assist them to find community connections based on their interests, skills, and needs.

Maine has implemented several reforms to reduce barriers and improve employment outcomes by providing effective, seamless support for individuals with disabilities to obtain and maintain employment. These initiatives are coordinated across several DHHS

⁴ The Community Membership Reform Work Group and the Innovation Work group were made up of a cross representation of individuals who are invested in improving developmental disability services in Maine including representatives from agency providers, family members, advocates, and state agency staff from the Developmental Disability Services unit at OADS.

offices and the Maine Department of Labor’s Bureau of Rehabilitation. This coordination effort is essential to providing effective employment services to individuals during assessment, evaluation, career development, and on-going support to maintain and advance in employment. OADS continues to align its practices, procedures, and funding to support employment across all waivers.

In June 2020, Maine repealed the subminimum wage provision, making Maine one of only three states that ensure that all employees are paid at least minimum wage, regardless of disability. In 2022 OADS conducted several training events aimed at increasing the knowledge and skills of case managers and direct support professionals to successfully support individuals in obtaining and maintaining employment.

HCBS SETTINGS RULE COMPLIANCE INITIATIVE

Ensuring compliance with the federal Home and Community-Based Settings Rule (HCBS Settings Rule) is a significant undertaking and has been underway for several years. OADS continues to provide technical assistance to help providers make the changes needed to bring their services and settings into compliance. Coming into compliance has required substantial transformation for some providers. To help with this process, OADS hired a subject matter expert to provide training and technical assistance. After providers are brought into compliance with all requirements, OADS will be responsible for ongoing monitoring and quality assurance.

The Department submitted a Final Transition Plan to CMS dated September 16, 2022, and Maine is on schedule to meet federal timelines for full implementation by March 17, 2023. These reform activities have been a priority because services that are noncompliant after March 2023 will lose federal funding which pays almost two-thirds of the cost for Medicaid-funded services.⁵ The Department has finalized MaineCare rules to align with these new requirements, adding a new section (§6) to Chapter I of the MaineCare Benefits Manual.⁶ This new rule implements the federal HCBS Settings Rule requirements and includes standards for person-centered service planning.

⁵ More information on the [HCBS Settings Rule](#) can be found on the [OADS website](#).

⁶ See Chapter 1, Section 6 of the MaineCare Benefits Manual (Global HCBS Waiver Person-Centered Planning and Settings Rule).

Strengthening Quality Assurance and Improvement

To help guide continued work, OADS retained a consultant in 2020 to review capacity for assuring and improving quality. As recommended by the consultant's report, work in 2021-2022 focused in two areas: public-facing quality information and meaningful data the Department should be monitoring to address system quality. OADS also convened a Quality Work Group in May 2021 to advise on plans to reform the quality assurance and quality improvement system, including the recommendations made by the consultant. The Quality Work Group included self-advocates, family members, guardians, providers, representatives of Disability Rights Maine, Maine's protection and advocacy agency, and staff members.

Improving Coordination across State Agencies during Transition

TRANSITION PROCESS

During 2021-2022, several efforts have been underway to address barriers encountered by people with IDD or ASD as they age out of children's services and improve the transition process to the adult service system. LD 924⁷ directed the Department of Education (DOE) to establish a task force focused on reducing the barriers that inhibit young adults with developmental disabilities from accessing higher education and vocational opportunities. OADS has participated in this work. Building on past efforts, a group of staff from the Office of Child and Family Services and OADS have also been gathering weekly since July 2021 to assess the current state of transition planning and recommend improvements moving forward. This group has also engaged experts from DOE, the Office of MaineCare Services, and the Department of Labor (DOL) to inform planning.

Along with continued collaboration with DOE, the Department plans to use ARPA funding to implement a pilot program designed to provide regional supports focusing on transition issues and consistent engagement of key stakeholders (e.g., schools, families,

⁷ See PL 2021, Chapter 116, Resolve, To Establish a Task Force To Study the Coordination of Services and Expansion of Educational Programs and Vocational Opportunities for Young Adults with Intellectual or Developmental Disabilities or Acquired Brain Injury

and others) to improve communication and collaboration. A lack of training, time, and resources contributes to inconsistent approaches to transition. This pilot will address the lack of specialized case management services available to assist people during transitions and reduce the risk of disruptions and poor outcomes that can occur with a change or loss of services and supports.

LIFESPAN PROJECT

The Department has also initiated work on a Lifespan Project which is exploring stakeholder interest and the feasibility of developing a service program designed to ensure people have the services they need as their needs and circumstances change, particularly as youth age into adults. The Lifespan Project could potentially eliminate the need to change programs based on age and provide more robust supports for youth focused on in-home supports, life skills, and employment services to better prepare them for adulthood.

Improving System Capacity

WORKFORCE TRAINING

In April 2022, Governor Mills launched the Healthcare Training for ME, an initiative that is part of the Maine Jobs & Recovery Plan to strengthen Maine’s healthcare workforce by expanding availability of free and low-cost career training to help healthcare workers, including direct care workers such as Direct Support Professionals (DSPs), advance their careers, support workforce training needs of healthcare employers, and attract new workers to fast-growing fields. The initiative is a partnership of DHHS, DOL, DOE, the Maine Community College System, and the University of Maine System. It is supported by \$21 million from the Maine Jobs & Recovery Plan, which includes \$8.5 million allocated to DOL and \$12.5 million allocated to the Maine Community College System for workforce training.

OADS, working with the Division of Licensure and Certification and the Office of Behavioral Health, launched the Direct Care and Support Worker Portability and Training Initiative to develop a streamlined training and certification system to support career progression, specialization, and cross-training. Key aspects of this project include the design of a competency-based training that reduces redundancy, facilitates access to

entry-level training, improves opportunities for career advancement, and better meets the needs of people who rely on these critical services. OADS continues to work towards implementation of this streamlined training, which would include certification for DSPs.

SELF-DIRECTION

Effective 2021, enrollees under §29 can choose to self-direct some of their services. Self-directed services are home and community-based services that help individuals across all types of disabilities maintain their independence and determine for themselves what mix of supports and services work best for them. Self-direction is consistent with person-centered planning and self-determination and provides a mechanism for hiring alternative providers outside of traditional service agencies which have experienced severe workforce shortages. Self-direction provides participants with a flexible budget that enables them to hire their own workers. This allows decisions about who is hired, when they will work, how much they get paid, and managing the worker. If an individual wishes to use this option but prefers to have another person manage these responsibilities, they can appoint a representative to act on their behalf. Based on stakeholder input and support, this service option has been made available to people receiving services under the §29 waiver.⁸

⁸ These rules are included in [Maine's Appendix K](#), a Medicaid appendix utilized by states during emergency situations to request changes to approved 1915(c) waivers.

The Impact of the American Rescue Plan Act of 2021

The American Rescue Plan Act (ARPA), signed into law on March 11, 2021, allows for states to receive increased funding for their Medicaid HCBS programs to support Mainers living with disabilities, and for their families, caregivers, and providers. Maine will receive over \$200 million in Federal Medicaid matching funds to invest in Maine's HCBS workforce and system improvements. This includes an estimated \$75 million in one-time Federal Medical Assistance Percentage (FMAP) funds, which are expected to leverage \$131 million of additional federal match. These dollars must be spent by March 31, 2024.

When the passage of the ARPA was announced, the Department hosted virtual listening sessions with stakeholders, inviting service recipients, providers, family members, and advocates to offer comments and recommendations as to how the resources from this unprecedented opportunity should be allocated.

To address stakeholder recommendations and further improve the HCBS system, the Department developed a preliminary plan, subject to approval by the federal Centers for Medicare & Medicaid, to invest the FMAP funds in three areas: timely access to services, innovating service delivery, and improving quality and accountability. To address the immediate and critical HCBS workforce challenges, approximately 60% of these funds will directly increase wages for the HCBS workforce through special recruitment and retention bonus payments. This funding will expand and augment many of the reform initiatives already underway to improve access, services, and quality of life for adults with IDD or ASD in Maine.

A summary of the preliminary HCBS FMAP plan is available on the OADS website here [Maine DHHS Preliminary HCBS FMAP Plan](#).⁹

⁹ <https://www.maine.gov/dhhs/oads/about-us/initiatives/home-community-fmap-plan>

Quality Assurance and Quality Improvement Structure

OADS reviews and monitors specific system outcomes to support quality service delivery to individuals with IDD or ASD. OADS provides oversight through data collection, monitoring, critical incident review, follow-up, and investigation and has established program specific indicators to measure broad-based, policy-oriented program outcomes:

- **Health:** People are healthy
- **Safety:** People are safe
- **Unmet Needs:** Peoples' needs are met
- **Inclusion:** People are included
- **Management:** Systems are effective and efficient

OADS meets monthly with the Maine Developmental Services Oversight and Advisory Board, a statutorily formed board responsible for providing independent oversight over services and programs for adults with an intellectual disability or autism. Through monthly meetings, the Board provides OADS with oversight and advice on systems issues, with a focus on rights, needs, quality of life issues, the use of physical restraints, and abuse, neglect, and exploitation. Additionally, the Board monitors data, including data related to waitlists and persons served out of state, and provides representation for the review of severely intrusive behavior plans and safety plans.

OADS management relies on multiple strategies for assuring the quality of service delivery, including routine system and program monitoring activities, monitoring and investigating critical incidents and other indications of a potential problem, and monitoring data to identify trends. In addition to licensing investigation reviews conducted by the Division of Licensing and Certification, OADS uses regular program site visits, measurement of consumer and family satisfaction, and critical incidents, APS, and grievance reporting, to assure minimum compliance with program standards and to identify problems that require investigation and opportunities for improvement.

QUALITY ASSURANCE/IMPROVEMENT MONITORING ACTIVITIES

In 2021-2022 OADS implemented a new Reportable Events system, which involved transitioning to a new data system known as the Evergreen Data System (Evergreen). Evergreen has strengthened quality assurance and improvement capacity by capturing timely, accurate and critical individual, provider and systemic information that helps OADS identify problems as they occur as well as trends over time.

In the fall of 2022, the Aging and Disability Mortality Review Panel was established to review deaths of and serious injuries to all adults receiving services. This panel meets quarterly and is coordinated by a staff member of the Maine Center for Disease Control and Prevention.

OADS' efforts to assure compliance with the HCBS settings rule has also highlighted opportunities to address other gaps in quality assurance systems and capacity. OADS management is working on multiple aspects of provider approval and training. OADS and the OMS are working collaboratively to improve and streamline the MaineCare provider enrollment process to ensure new providers and settings are fully aware of the HCBS Settings rule requirements and their service provision obligations for compliance from the start of services. OADS is also working to ensure that complete and up-to-date information on all providers is collected and maintained.

Measuring member satisfaction with services is another method of assessing quality of care. To assist with this activity, OADS is in the process of procuring an entity that will administer the Consumer Assessment of Healthcare Providers and Systems for Home and Community-Based Services (HCBS CAHPS). HCBS CAHPS, developed by CMS, is an in-person or telephonic survey that asks individuals about their experiences with:

- Getting needed services
- Communication with providers
- Case managers
- Choice of services
- Medical transportation

- Personal safety
- Community inclusion and empowerment
- Employment

Data collected from the HCBS CAHPS survey is included in CMS's quality measure set and may be used to evaluate quality assurances associated with all HCBS waiver programs OADS administers.

Case Management

Case management is a central part of supporting people with IDD or ASD to identify needs and facilitate access to services that meet them. People who are eligible for this service have a case manager responsible for coordinating the person's planning process and for ensuring that the services recommended in the person's plan are provided.

Case managers are trained in the person-centered planning process and the importance of identifying and documenting needs and developing action plans to meet those needs. Case managers are required to maintain at least monthly contact with each member to ensure that there have not been any changes that may affect the person's plan which would initiate a review of the plan and a possible revision, and to assess satisfaction with services. The case manager must visit the member's program site and home at least twice a year or more frequently, if necessary, to conduct monitoring of these services.

Case management services are provided primarily through certified community-based Targeted Case Management (TCM) agencies. As of September 2022, there were forty-three certified TCM agencies employing approximately 500 case managers and providing services to 6,914 adults with IDD or ASD statewide.¹⁰ Additionally, OADS provides management services to members who may have unique circumstances such as being Maine citizens but living out of state, not having MaineCare eligibility, or in settings where services are not MaineCare reimbursable (for example, during incarceration).

Case managers have a responsibility to identify and meet the service needs of the member and must have sufficient availability to conduct these critical functions. To ensure that case managers can fulfill their duties, 14-197 CMR Chapter 10 VI.D.1 specifies that each case manager's caseload ratio shall not exceed one case manager to every thirty-five members. Per 34B MRS §5201, the ratio must be calculated separately for staff employed by the Department and by TCM agencies, and this ratio must be maintained for each group. OADS promotes quality case management services by ensuring caseload ratios within certified TCM agencies do not exceed 1:35. OADS monitors this ratio as part of

¹⁰ See [Appendix A](#) for a listing of the forty-three agencies.

its quality monitoring. As of October 12, 2022, the statewide average caseload ratio for community case managers was 1:14. No agencies exceeded the required caseload ratio.

Measuring Unmet Need

To better understand the gaps in Maine’s system of care for people with IDD or ASD, OADS monitors the number of people who are eligible for waiver services but who are unable to access them. Maine’s HCBS waivers are limited in the number of people they can serve. Members who qualify for waiver services are placed on waitlists for services until a funded opening is available. OADS publishes information on a quarterly basis about the number of people on the waitlists and their ability to access other services while waiting. Collecting and publishing this data are part of OADS’ strategy to improve transparency in operations and inform stakeholders about the number of members on the waitlists and alternatives for services. Table 3 shows the number of people on waiver waitlists and the percentage with and without other coverage as of September 30, 2022. The majority (77%) of people on the waitlist for §21 waiver had other coverage while on the waitlist compared to less than half (45%) of people on the waitlist for §29 waiver services.

Table 3. Waiver Participants, Members on Waitlists, and Other Coverage Status, as of 9/30/2022

	§21	§29
Waiver Participants	3,337	2,674
Waitlist Total	2,028	218
Waitlist <i>With</i> Other Coverage	1,554 (77%)	98 (45%)
Waitlist <i>Without</i> Other Coverage	474 (23%)	120 (55%)

Notes: Members can be on multiple waitlists simultaneously.

Source: Maine Office of Aging and Disability Services

To help improve system capacity and access to services, Governor Mills included additional funding as part of prior State budgets to fund additional openings in §21 and §29. The Governor also included additional funding in this biennium budget sufficient to add 30 additional people to §29 each month.

All individuals on a waitlist are offered a community case manager to help connect them to other existing resources. Table 4 shows that many members on the waiver waitlists receive other MaineCare services, including other HCBS waiver services. The majority (1,359 or 67%) of people on the §21 waitlist already receive §29 services.

Table 4. Number of Members on HCBS Waiver Waitlists with other MaineCare Coverage, as of 9/30/2022

Type of Alternative Coverage	Waitlist for §21	Waitlist for §29
Support Services for IDD/ASD HCBS Waiver (§29)	1,359	-
Children’s Services (§28)	80	87
Private Non-Medical Institution (§97)	56	2
Family Provider Service Option (§96)	18	2
Elderly and Adults with Disabilities HCBS Waiver (§19)	18	2
Nursing Facility (§67)	4	-
Intermediate Care Facility for IDD (§50)	8	-
Adult Day Health (§26)	5	-
Other Related Conditions HCBS Waiver (§20)	3	-
Comprehensive Services for IDD/ASD HCBS Waiver (§21)	-	5
Brain Injury Services (§102)	2	-
Attendant Services (§12)	1	-

Type of Alternative Coverage	Waitlist for §21	Waitlist for §29
TOTAL	1,554	98

Source: Maine Office of Aging and Disability Services

Reportable Events/Critical Incidents

Data

Monitoring events that impact the health, safety, and human rights of adults with IDD or ASD enables the Department to:

- ▶ Identify events that warrant the attention of key people involved in the support of an individual receiving services;
- ▶ Ensure that key people involved in the support of an individual receiving services are made aware of such Reportable Events;
- ▶ Initiate a response to ensure the ongoing health and safety of an individual receiving services when a Reportable Event has occurred; and
- ▶ Ensure that the Department and provider agencies recognize and analyze patterns and trends to improve service delivery.

Reportable Events are the mechanism by which OADS collects information on critical incidents that occur in programs serving individuals with IDD or ASD. Examples of Reportable Events are “dangerous situations,” “physical assault/altercations,” or “medication errors.”¹¹ The Reportable Events System rule (CMR 14-197 Chapter 12) requires any provider of services who is licensed, funded, or regulated in whole or in part by DHHS to report certain events to the Department within one business day, and sets forth the steps involved to review Reportable Events and identify preventive and corrective action. Department staff meet regularly with provider agencies to review data on the timely entry, incident category, and follow up requirements related to reportable events.

In FY2022, there were a total of 24,489 unduplicated Reportable Events reported into

¹¹ The full listing of Reportable Event types is included in [Table 5](#).

Evergreen for adults receiving §21 or §29 waiver services. Individuals may have had multiple events during the year. Figure 2 shows the number of Reportable Events by waiver and the percentage of waiver participants with Reportable Events. Members served by §21 accounted for the majority of Reportable Events.

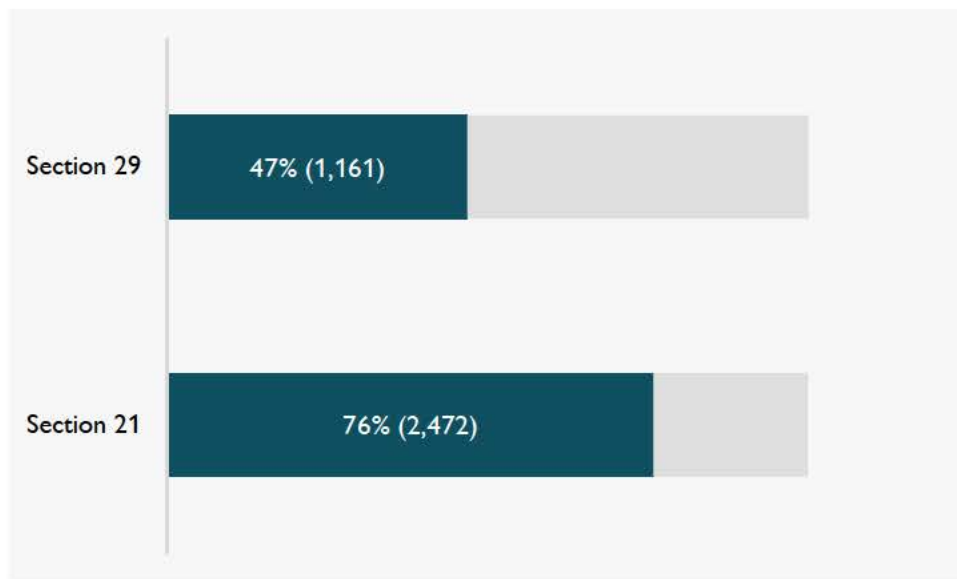
Figure 2. Members Served by both Section 21 and Section 29 tend to have more than one event



Source: Maine Office of Aging and Disability Services, Evergreen Data System

The proportion of members having Reportable Events varied by waiver with seventy-six percent of §21 participants having reportable events compared to forty-seven percent of §29 participants. This may be a factor of differences in type and duration of services, settings, group dynamics within settings, and provider types and under §21 and §29. Refer to Figure 3.

Figure 3. Percentage of Members with Reportable Events by Waiver, FY2022



Source: Maine Office of Aging and Disability Services, Evergreen Data System

Table 5 presents the number of Reportable Events by type. Dangerous Situations was the largest category of events for both waivers. Other top categories include Physical Assaults, Medication Errors, Emergency Department Visits, Emergency Restraints, and Rights Violations. As noted earlier, OADS staff screen each event to assure all appropriate reporting and follow-up has been conducted.

Table 5. Number of Reportable Events by Category for Members Receiving §21 and §29 Services, FY2022

Event Category	§21	§29
Dangerous Situation	8,059	1,248
Death	66	7
Emergency Department Visit	2,831	487
Emergency Restraint	2,189	112

Event Category	§21	§29
Hospital Admission Planned/Unplanned	458	125
Law Enforcement Intervention	1,502	163
Lost or Missing Person	182	7
Medical Treatment other than Hospital	1,539	373
Medication Error	2,079	100
Physical Assault/Altercation	2,525	217
Physical Plant Disaster	33	6
Rights Violation	4,797	431
Serious Injury	170	33
Suicide attempt	61	11
Suicide Threat	452	67
Transportation Accident	152	75
Total Events	21,522	2,967

Source: Maine Office of Aging and Disability Services, Evergreen Data System

Statewide Behavioral Health and Support Services

OADS provides statewide behavioral health and support services for adults with developmental disabilities and brain injury 24 hours per day, seven days a week. These services include assistance to individuals, families, guardians, and providers before, during, and after crisis incidents. When necessary, an individual in crisis may be supported in a state-operated crisis home or another contracted short-term residential service. However, the goal of crisis services is to avoid removing people from their home or community whenever possible, or when removal is necessary, to help them return home or identify a safe alternative, as quickly as possible.

OADS leadership made significant improvements to the Crisis Prevention and Intervention Services (CPIS) system over the last several years. Notably, eight staff were added to the regional offices to provide crisis response services, as well as outreach and prevention services. All crisis staff have been trained to adhere to an evidence-based approach to crisis management, and the Department contracted with the University of New Hampshire (UNH) Institute on Disability National Center for START (Systemic, Therapeutic, Assessment, Resources, and Treatment) Services to provide ongoing training, certification, and clinical resources to crisis staff. To date, all community response workers and crisis case managers have been certified as crisis mobile response workers, and any new hires are signed up for quarterly trainings to provide ongoing consultation and training.

In 2022, OADS requested the UNH National Center for START to conduct a statewide assessment of the mental health services and support experiences of people with IDD who have mental health needs. Approximately 400 people from across the state participated in the evaluation through an online survey of stakeholders, focus groups, and family caregiver structured interviews. Volunteer participants included individuals with IDD, families, mental health service providers, service funders, law enforcement, advocates, OADS staff, and IDD service providers. In addition, the evaluation included an analysis of MaineCare claims data from 2019-2021. Findings from the evaluation

indicate that behavioral health and support services may not reach all who need them, and that greater dissemination of information about available services and improved linkages across systems of care may be needed. For more information about the assessment and recommendations, see [OADS 2022 START Assessment](#). In response to the START assessment, OADS is taking several actions to address continuing needs of individuals with IDD who have mental health needs which can be found under “Resources” at [OADS Innovative Service Delivery](#).

Workforce shortages within the developmental services provider community continued to present challenges for CPIS. Due to staffing shortages, there were only 8 OADS crisis beds available statewide which served 28 individuals in FY2022. Fifteen individuals were served by Emergency and Transitional Housing, and [Table 6](#) shows their length of stay statistics.

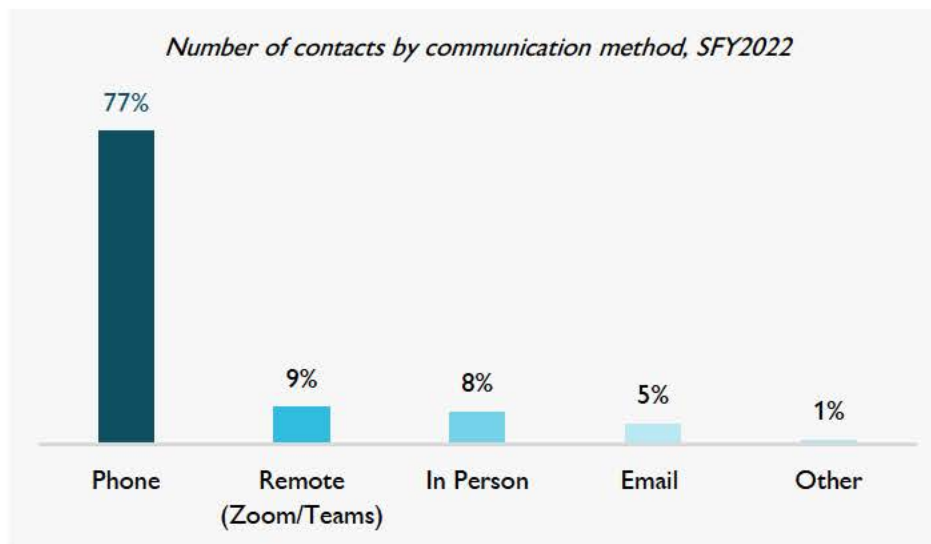
Table 6. Duration of Stay in Emergency Transitional Housing, FY2022

Duration of Stay	Days
Average length of Stay	44
Longest Stay	105
Shortest Stay	1

Source: Maine Office of Aging and Disability Services

CPIS had over 11,000 contacts involving 1,009 members statewide during FY2022. Seventy-seven percent (8,494) of contacts were made by telephone ([Figure 9](#)). Of the telephone contacts, 4,882 were directly with clients. The most frequent reasons for contact were for a general conversation (when an individual who may not be in crisis at that moment calls the Crisis Line to speak to a Disability Services Crisis Worker to discuss their needs, wants, or concerns); wellness checks; and community outreach (another category of service delivered by crisis workers to individuals, families, providers, or other stakeholders regarding an individual served). [Figure 4](#) shows the number of CPIS contacts by reason in FY2022.

Figure 4. 77% of contacts with Crisis Intervention and Prevention were over the phone



Source: Office of Aging and Disability Services

Table 7. Reasons for Crisis Prevention and Intervention Services Contact Between Members and Crisis Staff, FY2022

Contact Reason	Number of Contacts, FY2022
Individual Needs/Wants/Concerns	4,205
Wellness Check	1,696
Crisis Situation	1,105
Individual Support Team	1,023
Consultation: Provider unable to support individual needs	371
ER Visit	307
10-day Follow-up, Individual Support Team	275
24-hour ER Follow-up	264
24-hour Follow-up, Individual Support Team	232

Contact Reason	Number of Contacts, FY2022
90-day Follow-up, Individual Support Team	201
Client Elopement	191
Individual stuck in ER/Hospital	182
ER: Individual in Crisis	144
Scheduled Individual Support Team	126
10-day ER Follow-up	122
Consultation: Guardian/family unable to support individual needs	116
Police Involvement	110
Consultation: Behavior Management Plan, Crisis intervention Plan, Crisis Needs Assessment	89
Other	84
Crisis Meet and Greet	83
Individual Support Team Recommended	76
24-hours Follow-up: Crisis Contact	37
Recurring Pattern	25
10-day Follow-up: Crisis Contact	9

Source: Maine Office of Aging and Disability Services

Adult Protective Services for Members Receiving Section 21 or Section 29 Services

Through the Adult Protective Services (APS) program, OADS is responsible for protecting incapacitated and dependent adults from abuse, neglect, and exploitation; enhancing their welfare; and promoting self-care where possible.

This section presents information on FY2021 and FY2022 reports to Adult Protective Services and substantiated investigations, as well as information and data related to the Public Guardianship/Conservatorship program within APS, with a focus on those adults receiving §21 or §29 services. The data in this report was extracted from the Evergreen Data System.

ADULT PROTECTIVE SERVICES INVESTIGATIONS

Pursuant to the Adult Protective Services Act (22 M.R.S. ch. 958-A), Adult Protective Services is the program that receives reports, investigates, and determines the validity of reports alleging abuse, neglect (including self-neglect), or exploitation of incapacitated and dependent adults. APS investigates allegations that are reported through a statewide APS Intake phone line (1-800-624-8404) and reported through a web referral form.¹² Certain professionals are mandated by statute to make reports to APS.¹³ During an investigation, APS may determine that an incapacitated adult needs a guardian or that a private guardian is subjecting an individual under guardianship to abuse, neglect, or exploitation. In these cases, APS will conduct a search for a suitable private guardian or, if there are no capable family or friends to take on the role, APS will petition for public guardianship. Public guardianship or conservatorship is only considered as a last resort when all less restrictive options are available to ensure an individual's health and safety.

¹² The online referral form is available here [Adult Protective Services Online Referral Form](#).

¹³ 22 MRS §3477. Training for APS mandated reporters is currently not required by statute, though training is available at this link: [Mandated Reporter Training](#)

Across FY2021 and FY2022, APS Central Intake received over 28,000 reports resulting in over 23,000 cases (relating to all populations of incapacitated and dependent adults), which were sent to APS District Offices for review and investigation. Table 8 details the number of cases involving clients receiving §21 or §29 services by year.

Table 8. APS Cases Involving Clients Receiving §21 or §29 Services

APS Cases and Allegation Types	FY2021	FY2022
Total APS Cases with §21 or §29 Clients	1,650	1,977
Cases Assigned to Investigation	1,034	1,115
Cases Closed after Review	616	861
Allegations Reported to APS with §21 or §29 Clients		
Caretaker Neglect	654	916
Emotional Abuse	371	396
Financial Exploitation	267	235
Physical Abuse	257	301
Null	156	170
Self-Neglect	151	165
Sexual Abuse	130	152
Exploitation-Other	38	23

Notes: Reports to APS frequently involve multiple allegations; Null means a report was generated without allegations reported. Null may signal a report of a client death requiring APS review, a guardianship study request, or a discretionary override.

Source: Evergreen Data System, Maine Office of Aging and Disability Services

Table 9 shows the total number of substantiated cases involving clients who receive §21 or §29 services and the number of substantiated allegations by type.

Table 9. Substantiated APS Cases Involving Clients Receiving §21 or §29 Services

Substantiated APS Cases	FY2021	FY2022
Substantiated §21 or §29 Client Cases	173	179
Allegations Substantiated by APS		
Caretaker Neglect	99	126
Emotional Abuse	32	30
Financial Exploitation	27	9
Self-Neglect	17	11
Physical Abuse	14	9
Exploitation-Other	7	3
Sexual Abuse	4	8

Notes: Reports to APS frequently involve multiple allegations.

Source: Evergreen Data System, Maine Office of Aging and Disability Services

PUBLIC GUARDIANSHIP

Under Maine’s Uniform Probate Code, the Department of Health and Human Services may be appointed as an adult’s public guardian or conservator when the adult is deemed to lack decision-making capacity and no private party is able and willing to serve as a guardian or conservator. Adult Protective Services is the program within the Department of Health and Human Services designated to carry out the responsibilities of public guardianship and conservatorship. Adult Protective Services only pursues public guardianship after a comprehensive “guardianship study” that includes diligent attempts to identify all alternatives to public guardianship. APS pursues the level of guardianship authority required to meet the adult’s needs, which may involve petitioning for limited authority. When circumstances change, the APS Public Guardianship Program facilitates the transition of public guardianship to a suitable and willing private individual; or, when the existing level of guardianship authority is no longer necessary or valuable, petitions to

limit or terminate guardianship authority. Consistent with the requirements of Maine’s Uniform Probate Code, the Public Guardianship Program endeavors to promote clients’ self-determination to the greatest extent possible, prioritizing clients’ preferences, values, opinions, beliefs, and directions in all decision-making.

At the conclusion of FY2021, the Department had legal relationships (public guardianship/conservatorship) with 1,164 adults.¹⁴ A total of 492 of these clients were eligible for OADS Developmental Services. This may include adults with Brain Injury or Other Related Conditions. Individual staff, (i.e., licensed social workers) are assigned to maintain contact with each adult subject to guardianship (including regular face-to-face visits) and coordinate with service providers, medical professionals, and family and friends (if available) to ensure the health and safety of each adult subject to guardianship. Table 10 shows the number of clients receiving §21 or §29 services subject to public guardianship, by type of legal relationship.

Table 10. Number of Clients Receiving §21 or §29 Services under Public Guardianship by Type of Legal Relationship, FY2021 and FY2022

Legal Relationship Type – Clients Receiving DS (§21 and §29)	FY2021		FY 2022	
	N	%	N	%
Guardianship – Full	430	86%	449	85%
Guardianship – Limited	35	7%	39	7%
Guardianship and Conservatorship – Full	24	5%	24	5%
Guardianship and Conservatorship – Limited	0	0%	0	0%
Conservatorship – Full	4	1%	4	1%
Conservatorship – Limited	0	0%	0	0%
Emergency Guardianship – Full	6	1%	9	2%

¹⁴ Point in time data based on FY2021 Evergreen data extraction.

	FY2021		FY 2022	
Emergency Guardianship – Limited	1	0%	1	0%
Emergency Conservatorship – Full	0	0%	0	0%
Emergency Guardianship/Conservatorship – Full	0	0%	0	0%
Interim Order	2	0%	2	0%
Total	502	-	528	-

Notes: Point in time data extractions, FY2021 and FY2022, Evergreen Data System.

Source: Evergreen Data System, Maine Office of Aging and Disability Services

Trends in MaineCare Utilization and Costs for Section 21 and Section 29

Overall utilization of HCBS waiver services increased between FY2020 and FY2021. Point in time data, showed participation in §21 went down by 8 members while participation in §29 went up by 74 (Table 11).

Table 11. Expenditures and Utilization for §21 and §29 HCBS Waivers, FY2020 and FY2021

	§21		§29	
	2020	2021	2020	2021
Number of People Served	3,284	3,276	2,265	2,339
Total Expenditures	\$419m	\$424m	\$56m	\$60m

Notes: FY2020 expenditure data; number served as of September 30, 2020; FY2021 expenditure data; number served as of September 30, 2021.

Source: *Maine Office of Aging and Disability Services*

This report provides an aggregate analysis of spending on four groups of services common to both waivers:¹⁵

- Home Support: Agency or Family-Centered; Shared Living
- Work Support
- Community Supports
- Ancillary Services

¹⁵ See *MaineCare Benefits Manual* for detailed definitions.

Annual expenditure trends show Home Support accounts for the majority of §21 waiver spending. Spending for this service increased by nearly \$50 million from FY2019 through FY2021 (Table 12).

Table 12. §21 Annual Expenditures by Service Type over time, FY2019-2021¹⁶

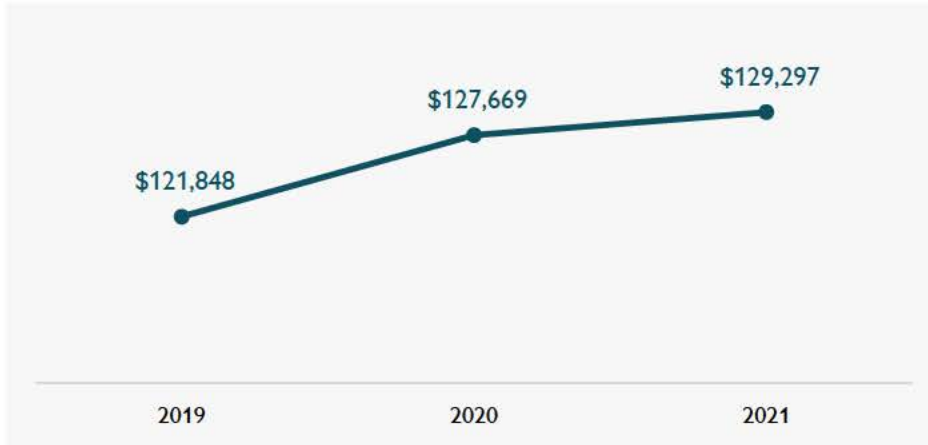
Service	FY2019	FY2020	FY2021
Shared living; Home support (agency, family-centered, and in-home not agency owned/operated)	\$347,144,160	\$381,423,949	\$396,681,451
Work support	\$2,251,025	\$1,798,791	\$1,669,000
Community supports	\$44,962,667	\$35,259,061	\$23,534,033
Ancillary services	\$672,652	\$784,701	\$1,693,320
Total	\$395,030,505	\$419,266,502	\$423,577,805

Source: Maine Office of Aging and Disability Services

¹⁶ Costs shown for FY2019 and FY2020 may differ slightly from previous reports due to claim reconciliation.

Average spending per member receiving §21 services increased by over \$7,400 between FY2019 and FY2021 (Figure 5).

Figure 5. §21 average per member cost increased between FY2019-2021



Source: Maine Office of Aging and Disability Services

Prior to FY2019, Community Supports accounted for the bulk of spending for the §29 waiver. In 2019, a rule change allowed Shared Living to be funded under §29, and since then, Home Support has become the largest component of §29 spending, increasing by over \$18 million during that time (Table 13).

Table 13. §29 Annual Expenditures by Service Type over time, FY2019-2021¹⁷

Service	FY2019	FY2020	FY2021
Home support (in-home not agency owned or operated); Shared living	\$22,334,553	\$30,607,555	\$40,889,088
Work support	\$1,540,051	\$1,422,354	\$1,684,969

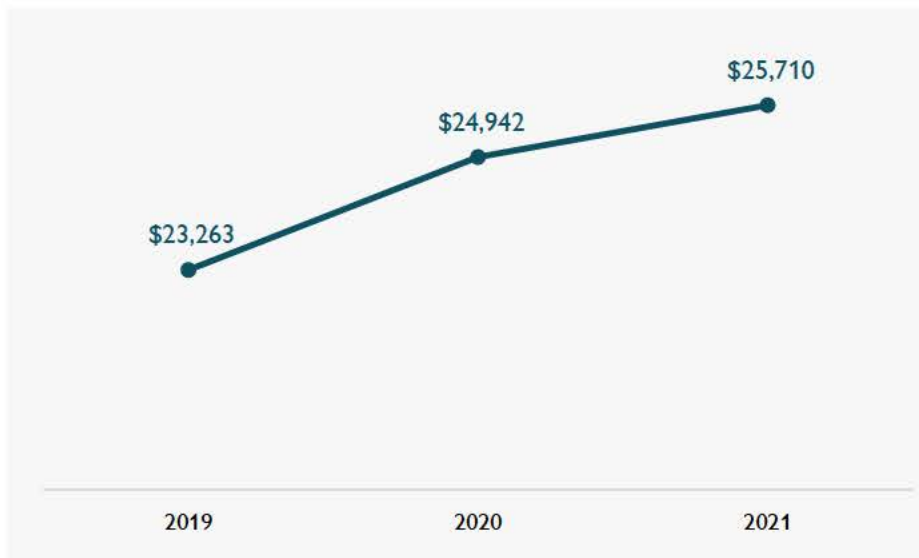
¹⁷ Costs shown for FY2019 and FY2020 may differ slightly from previous reports due to claim reconciliation.

Service	FY2019	FY2020	FY2021
Community supports	\$31,754,662	\$24,388,449	\$17,444,911
Ancillary services	\$38,859	\$74,251	\$116,510
Total	\$55,668,125	\$56,492,609	\$60,135,477

Source: Maine Office of Aging and Disability Services

Average costs for §29 increased in FY2019-2021 by close to \$2,500 (Figure 6).

Figure 6. §29 average per member cost increased between FY2019-2021



Source: Maine Office of Aging and Disability Services

Conclusion

OADS is committed to its mission of promoting the highest level of independence, health, and safety of adults with disabilities, while safeguarding and protecting the rights of those served. Importantly, OADS has worked over the last several years to increase transparency and access to information and engage stakeholders in systemic reform to improve services, quality, and system capacity. Plans for continuing this work and additional reforms are described in the *2023-2024 Biennial Plan for Adults with Intellectual Disabilities or Autism*.

Appendix

Appendix A: Section 21 and Section 29 Waiver Services

COVERED SERVICES UNDER §21 AND §29

Although both waivers cover a core set of services, §21 covers other services, including communication services, therapies, and crisis.

COVERED SERVICES	§21	§29
Home Support Agency – Per Diem	x	
Home Support – Family Centered Support	x	
Home Support-Quarter Hour	x	x
Home Support-Remote Support	x	x
Shared Living (Foster Care, Adult)	x	x
Home Accessibility	x	x
Respite Services		x
Consultation Services	x	
Counseling	x	
Crisis Assessment	x	
Crisis Intervention Services	x	
Occupational therapy (maintenance)	x	

COVERED SERVICES	§21	§29
Physical therapy (maintenance)	x	
Speech therapy (maintenance)	x	
Career Planning	x	x
Employment Specialist Services	x	x
Work Support-Group	x	x
Work Support-Individual	x	x
Community Support	x	x
Assistive Technology	x	x
Communication Aids	x	
Non-traditional communication assessments	x	
Non-traditional communication consultation	x	
Specialized Medical Equipment and Supplies	x	
Transportation Service	x	x

Appendix B: Community Case Management Agencies

The following is a list of Community Case Management Agencies in Maine.

Agency Name
Alliance Case Management
Amicus
Bridge To Success
Central Aroostook Association
Coastal Opportunities
Community Living Association
Creative Works
Elmhurst Inc
Employment Specialists of Maine
GMS
Graham Behavioral Services, Inc.
Granite Bay Care Inc
Great Bay Services
Hcli, Inc
Hope Association, Inc.
Independence Association Inc
Independent Service Coordination for Me, Llc
John F. Murphy Homes Inc.
Kendall Community Case Management Agency
Kennebec Behavioral Health

Agency Name
Kennebec Valley Case Management Services
Leap Inc
Lighthouse Community Care
Milestone Family Services, Llc
Mobius Inc
Morrison Center
New Tides Residential
Nfi North Inc
Northern Maine General
Ohi
Opportunity Enterprises, Inc.
Peregrine Corp
Pine Tree Society for Handicapped Children And Adults Inc
Sequelcare Of Maine, Llc
Spectrum Generations
Spurwink Corporation
Summit Support Services, Llc
The Progress Center Inc
United Cerebral Palsy of Northeastern Maine
Uplift Inc
Waban Projects Inc

Agency Name

Wings For Children and Families, Inc.

Woodfords Family Service

Source: Maine Office of Aging and Disability Services, Enterprise Information System, Community Case Manager Liaison Agency Assignment Report 10/12/2022.

Appendix C: Maine Department of Health and Human Services Districts and District Office Locations

District	Counties in District	District Offices
Aroostook District 8	Aroostook	Fort Kent, Caribou, Houlton
Downeast District 7	Washington, Hancock	Calais, Machias, Ellsworth
Penquis District 6	Piscataquis, Penobscot	Bangor
Central Maine District 5	Somerset, Kennebec	Skowhegan, Augusta
MidCoast Maine District 4	Waldo, Knox, Lincoln	Rockland
Western Maine District 3	Oxford, Franklin	Farmington, South Paris, Lewiston
Cumberland District 2	Cumberland	Portland
York District 1	York	Biddeford, Sanford

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