

# MAINE STATE LEGISLATURE

The following document is provided by the  
**LAW AND LEGISLATIVE DIGITAL LIBRARY**  
at the Maine State Law and Legislative Reference Library  
<http://legislature.maine.gov/lawlib>



Reproduced from electronic originals  
(may include minor formatting differences from printed original)

Office of Aging & Disability Services

2024 ANNUAL REPORT

# Maine's System of Support for Adults with Intellectual and Developmental Disabilities or Autism

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

**April 2025**



# Contents

<b>ABBREVIATIONS</b>	<b>4</b>
<b>EXECUTIVE SUMMARY</b>	<b>5</b>
Highlights of 2023-2024	5
<b>INTRODUCTION</b>	<b>8</b>
<b>UPDATES ON KEY REFORM INITIATIVE ACTIVITIES</b>	<b>14</b>
The Lifespan Waiver	14
Additional HCBS Improvement Projects	20
<b>QUALITY ASSURANCE AND QUALITY IMPROVEMENT STRUCTURE</b>	<b>24</b>
Communication and Partner Engagement in Quality and Oversight	26
<b>CASE MANAGEMENT</b>	<b>29</b>
<b>MEASURING UNMET NEED</b>	<b>31</b>
<b>REPORTABLE EVENTS/CRITICAL INCIDENTS DATA</b>	<b>32</b>
<b>STATEWIDE BEHAVIORAL HEALTH AND SUPPORT SERVICES</b>	<b>36</b>
<b>ADULT PROTECTIVE SERVICES FOR MEMBERS RECEIVING SECTION 21 OR SECTION 29 SERVICES</b>	<b>40</b>
Adult Protective Services Investigations	40
Public Guardianship	43
<b>TRENDS IN MAINECARE UTILIZATION AND COSTS FOR SECTION 21 AND SECTION 29</b>	<b>45</b>

<b>CONCLUSION</b>	<b>50</b>
<b>APPENDICES</b>	<b>51</b>
Appendix A: Maine Department of Health and Human Services Districts and District Office Locations	52
Appendix B: Section 21 and Section 29 Waiver Services	53
Appendix C: Community Case Management Agencies	55
<b>NON-DISCRIMINATION NOTICE</b>	<b>59</b>

This report was prepared for the Maine Department of Health and Human Services by the Catherine Cutler Institute, Muskie School of Public Service, University of Southern Maine, under agreement #ADS-25-9813.

# Abbreviations

<b>CAHPS</b>	Consumer Assessment of Healthcare Providers and Systems
<b>CBHS</b>	Children's Behavioral Health Services
<b>CDC</b>	Centers for Disease Control
<b>CDS</b>	Child Development Services
<b>EPSDT</b>	Early and Periodic Screening, Diagnostic, and Treatment
<b>HCBS</b>	Home and Community-Based Services
<b>HCT</b>	Home and Community-Based Treatment
<b>IDD</b>	Intellectual or Developmental Disabilities
<b>ICF-IID</b>	Intermediate Care Facility for Individuals with Intellectual Disabilities
<b>IDEA</b>	Individuals with Disabilities Education Act
<b>IEP</b>	Individualized Education Plan
<b>OADS</b>	Office of Aging and Disability Services
<b>OCFS</b>	Office of Child and Family Services
<b>OMS</b>	Office of MaineCare Services
<b>PCP</b>	Person-Centered Plan
<b>PNMI</b>	Private Non-Medical Institution
<b>RCS</b>	Rehabilitative and Community Services
<b>TCM</b>	Targeted Case Management

# Executive Summary

The Department of Health and Human Services (the Department), through the Office of Aging and Disability Services (OADS), is responsible for implementing services and programs to support older adults and adults with disabilities, including adults with intellectual or developmental disabilities (IDD) or autism. OADS' mission is to promote the highest level of independence, health, and safety for older adults and adults with disabilities throughout Maine while safeguarding and protecting the rights of those served. 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 autism, fulfilling reporting requirements under 34-B MRS Sections 5003-A and 5201(8)(A-B).

## Highlights of 2023-2024

### **SERVICE SYSTEM REFORM ACTIVITIES**

Informed by the [2023-2024 Biennial Plan for Adults with Intellectual Disabilities or Autism](#) and guided by ongoing engagement with individuals receiving services, families, guardians, providers, and others, OADS has undertaken several reform initiatives to improve the system of service and supports for adults with IDD or autism. In FY23 and FY24, OADS continued progress in addressing long-standing challenges in the service delivery system, including waitlists, workforce shortages, limited access to transportation, and other access issues through developing a new comprehensive Lifespan Home and Community-Based Services (HCBS) MaineCare waiver.

The 2021 American Rescue Plan Act Section 9817 funded many of the activities supporting the development of the Lifespan waiver and improving the service system for adults with IDD or autism. This new waiver, anticipated to open for enrollment in 2025, will operationalize system reforms addressing:

- ▶ Person-Centered Planning and Community Inclusion

- ▶ Quality Improvement
- ▶ System Capacity and Access to Services
- ▶ Statewide Behavioral Health and Support Services
- ▶ Transitions across the Lifespan
- ▶ Innovation

Designed to respond to the needs of individuals as they transition from childhood to early adulthood and beyond into older age, the Lifespan waiver furthers the federal policy objectives for all HCBS programs to “provide opportunities for Medicaid beneficiaries to receive services in their own home or community rather than institutions or other isolated settings.” The Lifespan waiver also provides a framework for reducing or minimizing waitlists for services.

The Department has proposed new services in the Lifespan waiver to improve Community Inclusion, Competitive Integrated Employment, and member control over personal resources while prioritizing the Person-Centered Plan/Person-Centered Service Plan that reflects member needs, desires, and goals; preferences for living arrangements; what covered services they wish to receive; and who they want providing such services. In addition, a new case management role, the Community Resource Coordinator, has been designed to address all transitions throughout members’ lives.

In addition to developing the Lifespan waiver, OADS implemented several Section 9817 initiatives around workforce training and curriculum development, access to assistive technology for individuals with IDD or autism, and Community and Employment Support. OADS also implemented a two-year pilot of the Consumer Assessment of Healthcare Providers and Systems (CAHPS), which will become part of the quality assurance activities across all HCBS waiver programs.

## **SERVICE SYSTEM OPERATIONS**

OADS has continued to provide public information on waitlists for MaineCare HCBS waiver services and access to other coverage. As of June 30, 2024, the majority (73%) of people on the waitlist for MaineCare Section 21 waiver had other coverage while on the waitlist compared to less than half (40%) of people on the waitlist for Section 29 waiver services.

The transition to the Evergreen Data System was completed in January 2024. In FY2024, Evergreen captured timely, accurate, and critical individual, provider, and systemic information to help OADS identify problems as they occurred and trends over time. Over 30,000 Reportable Events were reported in Evergreen. “Dangerous situations” was the largest category of events for both Section 21 and Section 29 services. Other top categories included rights violations, emergency department visits, medical treatment other than hospital, medication errors, and hospital admissions.

Statewide OADS crisis teams had over 14,200 contacts with individuals with IDD and autism and their support teams during FY2024.

Maine Adult Protective Services investigated over 2,100 cases of alleged abuse, neglect, or exploitation of adults receiving Section 21 or Section 29 waiver services in FY2024. Over 200 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 FY2020-FY2023, with Home Support and Shared Living services accounting for the highest costs.

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

# Introduction

The Department of Health and Human Services (DHHS or 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. 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**

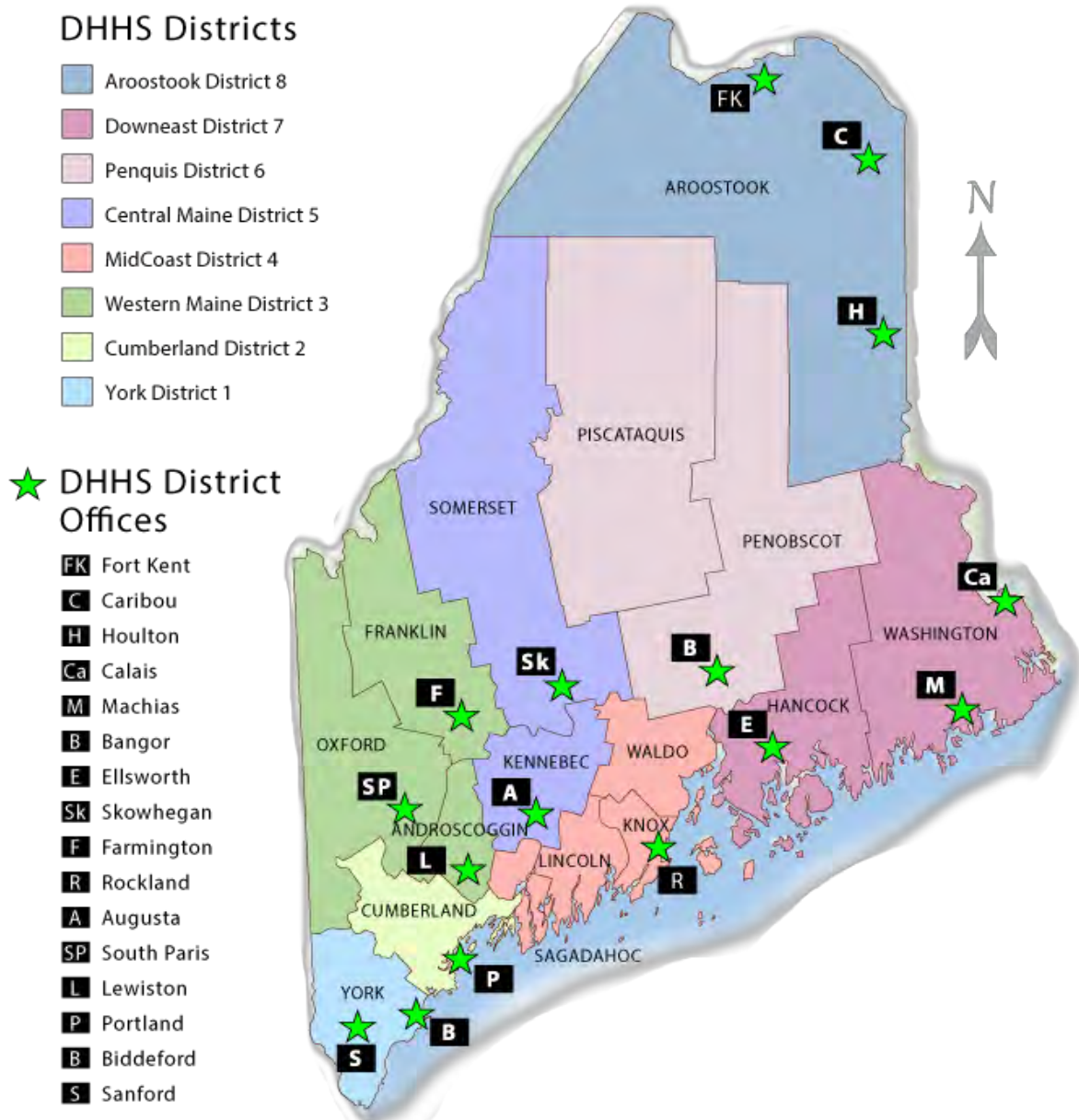
We promote individual dignity through respect, choice, and support for all adults

## **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 autism. These organizations provide case management, community support, and residential services statewide. Crisis services for adults with IDD or autism are provided directly by the State. OADS oversees its programs and benefits to ensure 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 A: Maine Department of Health and Human Services Districts and District Office Locations](#).

A core tenet 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 or autism are Targeted Case Management Services and Home and Community-Based Services provided through waiver programs.<sup>1</sup>

### **Targeted Case Management Services**

The MaineCare Benefits Manual<sup>2</sup> 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 autism are the primary pathway for accessing services supporting the pursuit of one’s 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 Section 29 Support Services for Adults with Intellectual Disabilities or Autism Spectrum

<sup>1</sup> 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.

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

Disorder (sometimes referred to as the “Support Waiver”). Table 1 provides an overview of the types of services available through the Section 21 and Section 29 waivers. See Appendix B: Section 21 and Section 29 Waiver Services for a comparison of services available under both waivers.

Table 1. Home and Community-Based Waiver Service Definitions

Service	Definition
<p><b>Home Support: Agency or Family-Centered; Shared Living</b></p>	<p>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.</p>
<p><b>Work Support</b></p>	<p>Direct Support is provided to improve a member’s ability to maintain employment independently</p>
<p><b>Community Supports; Community Membership</b></p>	<p>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 maintain and develop skills that support health and well-being. These are habilitative services focusing 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.</p>

Service	Definition
<b>Ancillary Services</b>	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. Under federal rules adopted in 2014, OADS must also ensure that HCBS services are provided in settings that do not segregate people and in a way that protects individual rights and choice and promotes independence and community integration. These HCBS regulations are commonly called the "HCBS settings rule."

Reflecting the evolution in society's recognition of the rights and personhood of individuals with a disability, the HCBS settings rule requires states to desegregate the physical settings in which people with a disability live and ensure that services are delivered in a way that protects individual rights and choice and promotes independence and community integration. This means that individuals receiving HCBS services have full access to the greater community and can enjoy the full range of benefits associated with community living. The goal is to ensure that HCBS programs provide an experience distinctively different from institutional care. The MaineCare Global HCBS Waiver Person-Centered Planning and Settings Rule (Global HCBS Rule) implements the federal requirements for HCBS waiver services. Maine received final approval of its Final Statewide Transition Plan for Implementing the Federal HCBS Settings Rule in 2022 and requested a corrective action plan extending the transition to compliance deadline from March 17, 2023, to March 17, 2024.<sup>3</sup>

<sup>3</sup> More information about Maine's Transition Plan can be found on the OADS website.

For adults with IDD or autism, pursuant to 34-B MRS Section 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 Section 5003-A and Section 5201(8)(A-B) and, unless otherwise noted, focuses on the following services provided by the Department to adults with IDD or autism:

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

The report presents updates and available data on:

- Key reform initiatives in FY24
- Current quality assurance and improvement structures and activities, case management capacity, and unmet need measured by waitlists for services
- Data on FY2024 Reportable Events, Behavioral Health and Support Services activities, FY2022-24 Adult Protective Services activities, and FY2020-23 MaineCare cost trends for Section 21 and Section 29 services.

# Updates on Key Reform Initiative Activities

The [2023-2024 Biennial Plan for Adults with Intellectual Disability or Autism](#) described several key areas of planned improvements: Person-Centered Planning and Community Inclusion, Quality Improvement, System Capacity and Access to Services, Statewide Behavioral Health and Support Services, Transitions across the Lifespan, and Innovation. Much of the Department’s work in these areas in 2023 and 2024 was supported through federal funding available through the 2021 American Rescue Plan (ARP) Act Section 9817. The results from these initiatives are impacting and informing ongoing work in 2025-2026.

## **The American Rescue Plan Act Section 9817 Projects to Improve Home and Community-Based Services**

The American Rescue Plan Act of 2021 was enacted in response to the COVID-19 pandemic. Section 9817 of the ARP provided a temporary 10 percentage point increase to the federal medical assistance percentage (FMAP) for certain Medicaid expenditures for HCBS. Originally scheduled to end on March 31, 2024, this funding was extended through March 31, 2025. States have been able to use Section 9817 funding to initiate improvement projects in HCBS services.

Maine has developed and administered many initiatives to improve the HCBS service system for all its waivers. More information on all Section 9817 projects can be found at [Home and Community-Based Services Improvement Plan](#).

## The Lifespan Waiver

With ongoing engagement with people with intellectual disabilities or autism, their families, providers, advocates, and other partners, OADS has developed a new

comprehensive Lifespan HCBS waiver. The planning activities for Lifespan encompassed many key areas of improvement outlined in the 2023-2024 Biennial Plan.

Designed to respond to the needs of individuals as they transition from childhood (age 14) to early adulthood and beyond into older age, the Lifespan waiver further operationalizes the federal policy objectives for all HCBS programs to “provide opportunities for Medicaid beneficiaries to receive services in their own home or community rather than institutions or other isolated settings.” The Lifespan waiver also provides a framework for reducing or minimizing waitlists for services.

In Maine’s [Final Statewide Transition Plan for Implementing the Federal HCBS Settings Rule](#), the Department identified several areas of improvement to align Maine’s policy with the federal HCBS rule that could be addressed through the Lifespan waiver:

- ▶ Community Inclusion
- ▶ Competitive Integrated Employment (CIE)
- ▶ Control over Personal Resources
- ▶ Prioritizing the Person-Centered Plan/Person-Centered Service Plan (PCP/PCSP) reflecting
  - member needs, desires, and goals
  - preferences for living arrangements
  - what covered services they wish to receive
  - who they want to provide such services.

The proposed Lifespan waiver includes new services designed to enhance these and other service priorities (Table 2). Additional information and details are available on the [HCBS Lifespan Project website](#).

Table 1. Proposed new Lifespan waiver services by domain

Domain to improve	Proposed Lifespan waiver services
<b>Community inclusion</b>	Community Connections Assistance Community and Relationship Connecting Community Transportation Services

Domain to improve	Proposed Lifespan waiver services
<b>Competitive integrated employment</b>	Career Planning Co-worker Supports Employment Exploration Job-career Development Plan and Outcome Integrated Employment Path Services Self-employment Start-up Plan and Outcome Individual Job Coaching
<b>Control over personal resources</b>	Expansion of Self-Direction, where many new services can be elected to be managed by the member Individual-Directed Goods and Services for members who self-direct Family Empowerment and Systems Navigator Home-Based Independent Living Skills Training Peer Support, provided by other waiver members who choose to participate and assist with skills and tasks, providing lived experience to other members. The service will also provide support for waiver members with PCP and for defining who they want to attend and support the PCP process.
<b>Prioritizing PCP/PCSP</b>	Housing Counseling to encourage more independent residential options, including housing rental or ownership by waiver participants Community Supported Living where participants can rent or own their own home and have services come to them as needed 24/7 Transition Case Management and Community Resource Coordinator

The proposed Transition Case Management service will be provided by a specialized case manager role called a Community Resource Coordinator. The Community Resource Coordinator (CRC) will address all forms of transition, including the transition of youth to adult services, but also any other life transition, including the transition to a less restrictive residential setting, discharge from a hospital, or other significant life change such as managing the end-of-life transition. To support Lifespan's new case management function, OADS has hired six Community Resource Coordinators and a supervisor in a pilot project using ARP Section 9817 funds.

OADS anticipates the Lifespan waiver will open by July 2026, contingent on federal waiver approval and major substantive rule development following the Maine Administrative Procedures Act process. Before Lifespan opens, OADS expects to have ended the waiting list for Section 29 services, and Sections 21 and 29 will be closed to new enrollment. When Lifespan opens, OADS proposes three priority groups for the first year:

- ▶ Youth in transition, ages 14-17
- ▶ Adults (18+) on the Section 21 waiting list receiving no other waiver services (i.e., they are not receiving Section 29 waiver services).
- ▶ Reserve slots for emergencies, similar to existing waivers' reserve slots.

After these priority groups are enrolled, OADS plans to open enrollment to individuals new to OADS services with other related conditions like cerebral palsy. There will be no required transition from other waiver programs to the Lifespan waiver. However, voluntary transitions will be possible from Sections 21 and 29 and from Section 20 HCBS for Adults with Other Related Conditions in subsequent years.

OADS anticipates that, through the enrollment framework of the Lifespan waiver, within five years, there will be no significant waitlists for the waivers supporting people with intellectual disabilities, autism, or other related conditions. OADS estimates that it will take five years to process those who want a comprehensive waiver but for whom Section 21 is closed to new participants.

In addition to improving person-centered planning and community inclusion, quality,

system capacity, and access through innovative service delivery for all people with intellectual disabilities and autism, OADS anticipates that the Lifespan waiver will lead to fewer people experiencing crises in the service system. Currently, priority for an available slot on the Section 21 waiver is reserved for those who are at imminent risk of abuse, neglect, or exploitation. This has resulted in members on Section 29 who want Section 21 services having to wait until they have an urgent need or crisis to access Section 21. With the anticipated reduction on the waitlist, members will be able to enroll as soon as they apply for services.

## **LIFESPAN QUALITY ASSURANCE, IMPROVEMENT, AND MONITORING STRUCTURES**

Across all HCBS programs, the Department has focused on improving Quality Assurance using federal funds available through the ARP Section 9817. The Department used this funding to add contracted positions to the district offices to increase efforts related to monitoring and technical assistance support to agencies regarding reportable events, develop plans of correction as needed, and develop and initiate Maine’s ongoing monitoring plan as outlined in the [Statewide Transition Plan](#). This funding has also allowed the Department to hire quality consultants who are helping to define an improved system and a new provider licensing rule. These efforts continue with work on building quality assurance and monitoring into the Lifespan waiver and rules, including:<sup>4</sup>

- ▶ Using the new [federal HCBS quality measures set](#) for federal reporting
- ▶ Implementing the Consumer Assessment of Healthcare Providers and Systems (CAHPS) survey to assess waiver participant experiences
- ▶ Basing provider certification on state standards, required training in the delivery of services, and defined expectations for delivery and outcomes
- ▶ Using outcomes-based services reimbursement. Payment for several services, notably in the employment domain, will be based on achieving outcomes for the waiver participant, e.g., the successful completion of an employment plan or

<sup>4</sup> The federal HCBS quality measure set and CAHPS survey will be implemented for all HCBS waivers OADS administers.

successful placement in a job.

- ▶ Enhancing behavioral and communication supports for individuals with exceptional needs
- ▶ Including waiver-funded case management, the CRC, so that greater oversight and control of the quality of case management can be sustained. In addition, there will be a formal training program for the CRC, and competency standards will be established focusing on the functions of the role as well as on the PCP and planning process expectations. Regular professional development will be required to remain current with the range of public services available and local community resources and services.
- ▶ Standardizing the assessment of service needs through the Supports Intensity Scale. By using a standard tool delivered by high-quality, conflict-free, certified assessors, with quality assurance processes built into the delivery of the assessment, the case managers will have better quality data to define support options and will provide a fair and level playing field so that all individuals get the supports they need.

## **WORKFORCE, STAFFING, AND ADMINISTRATIVE BURDEN IMPROVEMENT STRATEGIES UNDER LIFESPAN**

Recruiting and maintaining qualified staff across the human services and healthcare fields has been challenging for some time. Lifespan proposes several strategies to support the hiring and retention of direct care staff, easing administrative burden and increasing efficiency.

- ▶ Establishing Direct Support Professional (DSP) career lattices that enable them to obtain additional certifications for supporting individuals with exceptional behavioral or medical needs and establishing tiered DSP reimbursement rates that reflect these additional skill sets. Better-trained specialists can offer better quality and more effective services.
- ▶ Reducing caseload sizes for CRCs. Because the CRC will require additional time to fully address all the intersections of a person with their community,

employment options, other state and federal resources, and housing options, the Department proposes a lower caseload to improve quality and responsiveness in these complex cases and to improve the sustainability of the CRC role.

- ▶ Reducing paperwork by establishing rates of reimbursement for the CRC role in Lifespan that are by day or month instead of fifteen-minute intervals, for example. Increasing the billable unit size will reduce the documentation requirements.
- ▶ Prioritizing administrative efficiencies in database systems development,

### Additional HCBS Improvement Projects

When the Lifespan waiver begins enrollment, members currently on Section 21 and Section 29 will continue to use their waiver services. The HCBS improvement projects described in this section will continue to improve service delivery, quality, and workforce training for those waivers in addition to the Lifespan waiver. Details on the projects included in this report can be found at [HCBS Improvement Projects under Section 9817](#).

### **TRAINING AND DEVELOPMENT OF SERVICES/SUPPORTS TO ADD SELF-DIRECTION**

Self-direction is a service available under three HCBS waivers, Sections 18, 20, and 29. This project aims to ensure all individuals who self-direct have the option to choose among fully qualified independent support brokers. There are multiple components to implementing a successful self-direction program, including the need to provide training and technical assistance to waiver members and case managers, determine which goods and services should be included, and a process allowing full budget authority of the waiver member or guardian.

OADS collaborated with Applied Self-Direction to create a training curriculum and comprehensive materials, including budgeting, recruiting/hiring, and supporting participants with managing staff. Applied Self-Direction also developed and delivered training to case managers on introducing self-direction to members for the first time and how to support members and families who chose this service. Throughout the project, partner organizations have guided Applied Self-Direction through the Maine Developmental Disabilities Council to ensure member and family needs and preferences

are reflected in the self-direction program design and operations.

Before the implementation of the Lifespan waiver, Applied Self-Direction will create informational videos for members who self-direct and support the state through technical assistance with creating training and tools for reporting critical incidents for self-directing members to ensure an adequate system for monitoring health and safety.

## **SUPPORTING ACCESS TO TECHNOLOGY BY INDIVIDUALS WITH IDD**

Research has shown that adults with IDD often lack access to those technologies that most citizens use to connect with others, obtain and maintain employment, obtain products and services, engage in telehealth, and participate in their communities. A survey of providers of support to Maine adults with IDD revealed that most of the people they serve do not access the internet daily, and few have their own digital devices. Furthermore, DSPs often need more expertise to provide technological support to the people they serve.

This initiative aims to increase access to technology for individuals with IDD by providing stipends to support certification through the Rehabilitation Engineering and Assistive Technology Society of North America (RESNA) and increasing participation in the Maine CITE Consortium for continued collaboration with experts in smart home and Assistive Technology.

The three primary outcomes of the project are to:

- ▶ Increase the number of Assistive Technology Professionals certified assessors to provide Assistive Technology (AT) assessments to people diagnosed with IDD.
- ▶ Create an online technology resource site with Maine CITE for IDD service providers.
- ▶ Create a plan for the sustainability of an online website, recruitment and retention of trained AT assessors, and support to providers, case managers, and members/families.

Three rounds of stipends have been provided to applicants, and funding will be available until January 1, 2025. A final report will be prepared in 2025.

## **CURRICULA DEVELOPMENT**

The Department is establishing streamlined curricula and training requirements that ensure competency of the direct care workforce. The goal is to build a comprehensive and accessible training and certification system that would enable career progression, specialization, and portability. This will give Maine the tools and flexibility to reshape its workforce in response to an ever-increasing and increasingly complex population of eligible adults who need long-term services and support.

OADS has been working on a Direct Service Worker (DSW) course, which will serve as the base credential for HCBS. The course is estimated to be approximately 50-55 hours of online and in-person instruction, including six modules and roughly 30 lessons. The course is being created based on partner organization feedback collected at the start of the course and emerging national best practices.

## **COMMUNITY AND EMPLOYMENT SUPPORT REFORM**

This initiative aims to develop and implement a comprehensive oversight, quality, and monitoring of all Community Support and Employment Services throughout Maine funded under Sections 18, 20, 21, and 29 HCBS waivers. Because these services are provided in typical community settings that are not provider-owned or controlled, and the services are provided individually, these settings are assumed to be compliant with the Global HCBS Rule. While these settings are, therefore, not subject to assessment, validation, and remediation during the transition period, they must be included in ongoing monitoring activities to ensure that members have an ongoing experience consistent with the Global HCBS Rule.

The Community and Employment Support Initiative will build upon prior work that the Department completed when validating all the Non-Residential Settings as a requirement to show the state's compliance with the HCBS settings rule. This project will include the following:

- ▶ Complete a review of the findings from all Non-residential HCBS oversight agencies and determine what common areas of deficiency were identified. Research and suggest Program Standards for Non-residential Services that can be implemented through rulemaking.

- ▶ Develop, with input from OADS, the Office of MaineCare Services, and the Division of Licensure, as well as partners, an overall systemic oversight framework that includes licensing, program standards, onsite reviews, and a process to provide ongoing technical support.

The next steps for this project include implementing licensing of all Community Support and Employment Services providers (provider level) based on the new statute and continuing implementation and ongoing partner organization engagement in planning and developing tools for monitoring.

# Quality Assurance and Quality Improvement Structure

OADS has a responsibility to protect the health and safety of adults with an intellectual disability or autism. OADS is also responsible for using public dollars responsibly and cost-effectively and ensuring that the services meet the standards OADS has set for them. The quality assurance and quality improvement system is designed to ensure that OADS is fulfilling these responsibilities, with quality assurance activities aligned around a set of broad-based, policy-oriented program outcomes in five core areas:

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

Quality assurance structures are embedded throughout OADS, the Office of MaineCare Services (OMS), and other units within the Department and throughout the delivery system, including providers and case managers. OADS management relies on multiple strategies for ensuring service delivery quality, 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 license investigation reviews conducted by the Division of Licensing and Certification (DLC), OADS uses regular program site visits, Consumer Assessment of Healthcare Providers and Systems satisfaction surveys, and Reportable Event and APS reporting data to ensure minimum compliance with program standards and to identify problems that require investigation and opportunities for improvement.

The Evergreen Data System is a single database that replaces three different data systems used by the Department across Developmental Services, Adult Protective Services, and Long-Term Services and Supports. The system supports Department compliance with federal HCBS rules. OADS completed the transition to Evergreen for developmental services in January 2024. Evergreen captures timely, accurate, and critical individual, provider, and systemic information to help OADS identify problems as they occur. With Evergreen, OADS can monitor trends and identify systemic issues. Significant findings are addressed at the executive level within OADS and OMS.

Case managers have a critical role to play in ensuring and monitoring quality. Case managers provide information about rights and protections annually. They are responsible for monitoring the implementation of the service plan to ensure services are provided per the person-centered plan, that the services are adequate to meet the individual's needs, and that no changes to the service plan are required. The case manager can also be involved with Reportable Events to ensure an individual's issue has been addressed.

OADS takes a proactive, positive approach to service quality, working constructively and supportively with providers. In addition to health and safety, improvement initiatives must address quality of life issues of people served, including inclusion in the community and access to employment.

Providers are responsible for complying with licensing and other regulatory and contractual requirements when delivering the services described in the person-centered plan. To assure health and safety, providers must report all Reportable Events and all allegations of abuse, neglect, or exploitation. When a Reportable Event occurs, providers are responsible for identifying any root causes and any needed remediation. OADS uses quarterly provider meetings to address systemic concerns.

OADS continues to work to improve the design of programs, as well as quality assurance and improvement capacity, to strengthen its ability to ensure that individual goals and preferences are met. See Lifespan Quality Assurance, Improvement, and Monitoring Structures in this report for more information about current quality assurance initiatives.

## Communication and Partner Engagement in Quality and Oversight

OADS recognizes that change can only move forward with the trust of those receiving and delivering services and the confidence of the Legislature and public who provide the funding for services. To ensure that services meet the needs of those they serve, program and system improvements must include the input of people with firsthand experience receiving or delivering services.

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, focusing on rights, needs, and quality of life issues.

OADS has improved access to information about OADS' services on the Department's website and is continuing efforts to ensure resources and information are shared using varying methods, styles, and types of approaches. In addition to providing information for members and providers, OADS publishes information on an ongoing basis about HCBS Access Measures, including the number of people on the waitlists for waiver services and the extent to which they can access other services while waiting. OADS continues to communicate regularly with members, family members, providers, and advocates to address opportunities for improving service quality.

### **HCBS CAHPS SURVEY**

Measuring member satisfaction with services is a method of assessing the quality of care. To assist with this activity, OADS contracted with Knowledge Services, Inc. to 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 to gather feedback about waiver services and ask 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 from the HCBS CAHPS survey is collected anonymously and included in CMS's quality measure set and may be used to evaluate quality assurances associated with all HCBS waiver programs OADS administers. OADS conducted a two-year pilot to administer the survey for the first time in Maine in 2023-24. The results presented here are from the first year. Participants in waiver services were randomly selected to complete this survey from 10/16/2023-12/29/2023.

Out of 7,760 members sampled, 1,991 completed this survey, resulting in a response rate of 26%. Section 21 and Section 29 participants comprised many of those who responded to the study. Of the 1,991 respondents, 528 (27%) were receiving Section 21 services, and 578 (29%) were receiving Section 29 services. Section 29 members were further divided into those without self-direction and those with self-direction. Section 29 self-direction participants comprised less than 1% of the total survey respondents and were overall more satisfied than other participants. For this report, Section 29 survey results discussed below focus solely on those without self-direction.

Overall findings from year one indicated that people felt good about their safety and respect and that staff were reliable and helpful. Eighty-five percent of Section 21 and 93% of Section 29 survey respondents said that staff mostly or always treated them how they wanted to be treated, and 96% stated they could contact their case manager when needed (in Section 29 self-direction, this was 100%).

Challenges were related to transportation and accessing the community. Thirty-seven percent of Section 21 and 31% of Section 29 members reported they sometimes did not have a way to get places. For those who used transportation services, 29% from Section 21 and 47% from Section 29 said their ride sometimes did not arrive on time. Forty-four percent of Section 21 and 39% of Section 29 respondents also reported they could

sometimes not do things they liked within their community. Thirty percent of respondents for both Section 21 and 29 also stated their services did not include some of the things they thought were important.

Year two of the HCBS CAHPS survey began in June 2024. All surveys were completed by September 20, 2024, and survey findings were presented to OADS in November 2024. The HCBS CAHPS two-year pilot project survey results will help inform future HCBS-related quality improvement efforts in Maine and will be used as part of Maine's quality measurement system for all HCBS programs. All HCBS CAHPS survey results can be found [here](#).<sup>5</sup>

<sup>5</sup> HCBS CAHPS Initiative on OADS website.

# Case Management

Case management is a central part of supporting people with IDD or autism 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 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 monitor these services.

Case management services are provided primarily through certified community-based Targeted Case Management (TCM) agencies. As of June 2024, fifty certified TCM agencies were employing approximately 855 case managers and providing services to 7,067 adults with IDD or autism statewide.<sup>6</sup> Additionally, OADS provides State case 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). OADS serves less than 1% of individuals receiving case management services.

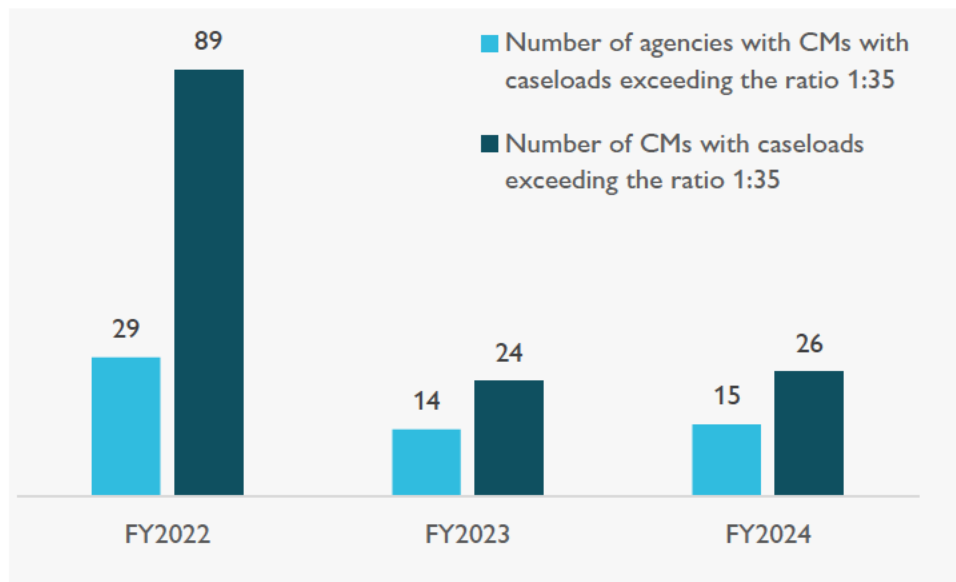
Case managers have a responsibility to identify and meet the member's service needs and must have sufficient availability to conduct these critical functions. To ensure that case managers can fulfill their duties, 14-197 CMR Chapter 10 VI.D.1 specifies that each case manager's caseload ratio shall not exceed one case manager to every thirty-five members. Per 34B MRS Section 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

---

<sup>6</sup> See Appendix B for a listing of the fifty agencies.

certified TCM agencies do not exceed 1:35. OADS monitors this ratio as part of its quality monitoring. As of June 30, 2024, the statewide average caseload ratio for community case managers was 1:23. At the individual level, 26 case managers from 15 agencies exceeded the required caseload. This is an improvement from FY2022 where 89 case managers from 29 agencies exceeded the caseload ratio (Figure 2).

Figure 2. Number of agencies and number of case managers (CMs) exceeding caseload ratio 1:35, FY2022-FY2024.



**Source:** Maine Office of Aging and Disability Services

# Measuring Unmet Need

To better understand the service gaps for people with IDD or autism, 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 every quarter 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 partners 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 June 2024. Seventy-three percent of people on the waitlist for Section 21 and 40% of people on the waitlist for Section 29 had other coverage.

Table 2. Waiver Participants Members on Waitlists and Other Coverage Status, as of June 2024.

	Section 21	Section 29
<b>Waiver Participants</b>	3,425	3,064
<b>Waitlist Total</b>	2,254	52
Waitlist <i>With</i> Other Coverage	1,644 (73%)	21 (40%)
Waitlist <i>Without</i> Other Coverage	610	31

**Notes:** Members can be on multiple waitlists simultaneously.

**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 autism 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
- ▶ Ensure that the Department and provider agencies recognize and analyze patterns and trends to improve service delivery

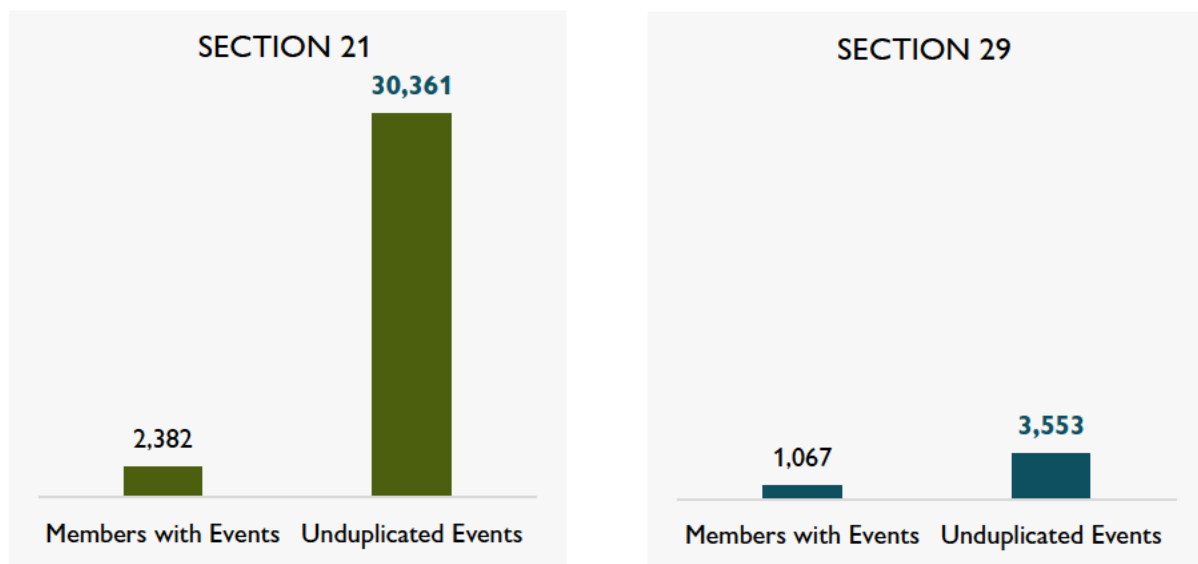
Reportable Events are the mechanism by which OADS collects information on critical incidents that occur in programs serving individuals with IDD or autism. Examples of Reportable Events are “dangerous situations,” “physical assault/altercations,” or “medication errors.”<sup>7</sup> The Reportable Events System rule (CMR 14-197 Chapter 12) requires any provider of services who is licensed, funded, or regulated in whole or in part by the Department 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.

<sup>7</sup> The full listing of Reportable Event types is included in [Office of Aging and Disability Rules](#).

In FY2024, 33,914 unduplicated Reportable Events were reported into Evergreen for adults receiving Section 21 or Section 29 waiver services. Individuals may have had multiple events during the year.

Figure 3 shows the number of Reportable Events by waiver. Members served by Section 21 accounted for the majority of Reportable Events.

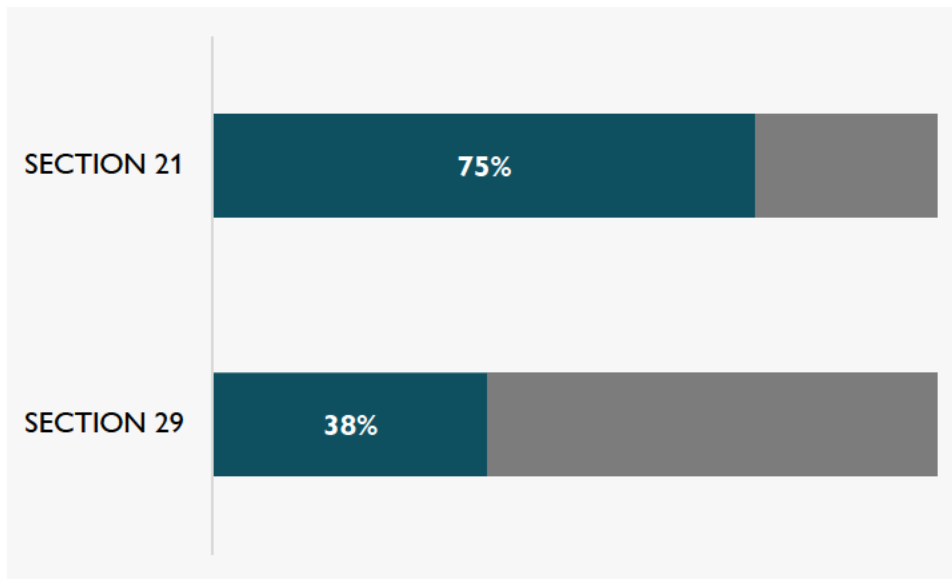
Figure 3. Members served by Section 21 and Section 29 tend to have more than one event.



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

The proportion of members having Reportable Events varied by waiver, with seventy-five percent of Section 21 participants having reportable events compared to thirty-eight percent of Section 29 participants. This may be a factor of differences in the type and duration of services, settings, group dynamics within settings, and provider types under Section 21 and Section 29 (Figure 4).

Figure 4. Percentage of members with Reportable Events by waiver, FY2024



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

Table 4 presents the number of Reportable Events by type. Dangerous Situations were the largest category of events for both waivers. Other top categories include Rights Violations, Emergency Department Visits, Medical Treatment other than Hospital, and Medical Error. As noted earlier, OADS staff screen each event to ensure that all appropriate reporting and follow-up have been conducted.

Table 3. Number of Reportable Events by category for members receiving Section 21 and Section 29 services, FY2024

Event Category	Section 21	Section 29
Dangerous Situation	8,810	939
Death	46	11
Emergency Department Visit	3,875	684

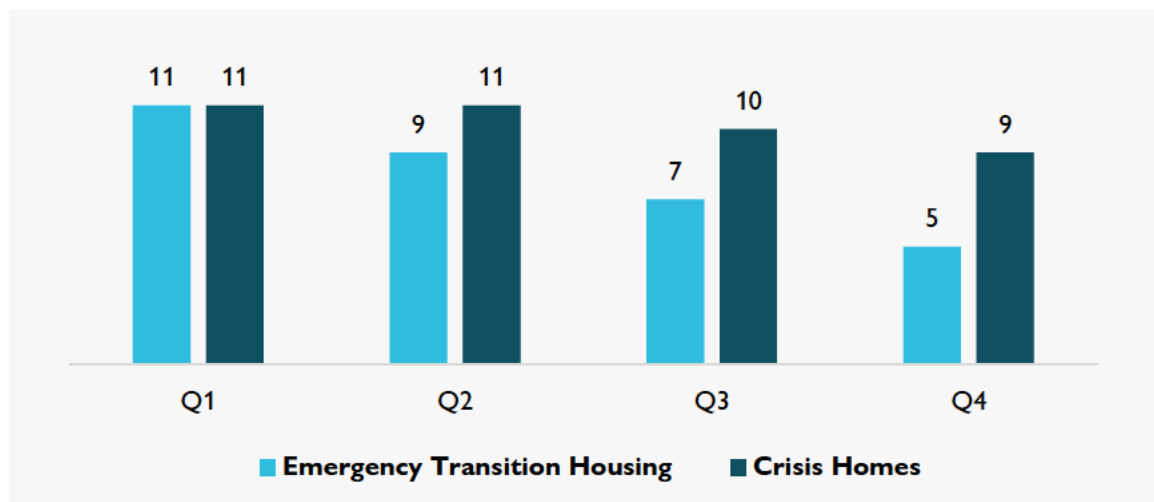
<b>Event Category</b>	<b>Section 21</b>	<b>Section 29</b>
Emergency Restraint	402	103
Hospital Admission Planned/Unplanned	1,387	157
Law Enforcement Intervention	161	9
Lost or Missing Person	1,255	268
Medical Treatment other than Hospital	3,130	185
Medication Error	2,374	299
Physical Assault/Altercation	787	12
Physical Plant Disaster	1,428	39
Rights Violation	5,784	633
Serious Injury	180	45
Suicide attempt	55	3
Suicide Threat	535	72
Transportation Accident	152	94
<b>Total Events</b>	<b>30,361</b>	<b>3,553</b>

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

# Statewide Behavioral Health and Support Services

OADS provides statewide behavioral health and support services for adults with developmental disabilities and brain injury 24 hours a 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, crisis services aim to avoid removing people from their homes or communities whenever possible, or when removal is necessary, to help them return home or identify a safe alternative as quickly as possible. All crisis staff are trained to adhere to an evidence-based approach to crisis management, and the Department has contracted with the University of New Hampshire to provide ongoing consultation and training. In FY2024, 32 individuals used Emergency Transitional Housing, and 41 were served in Crisis Homes (Figure 5).

Figure 5. Individuals residing in Emergency Transitional Housing and Crisis Homes in FY2024



Source: Maine Office of Aging and Disability Services

Forty-one individuals were served in Crisis Homes, and Table 5 shows the length of stay statistics by district.

Table 4. Duration of stay in Crisis Homes, FY2024

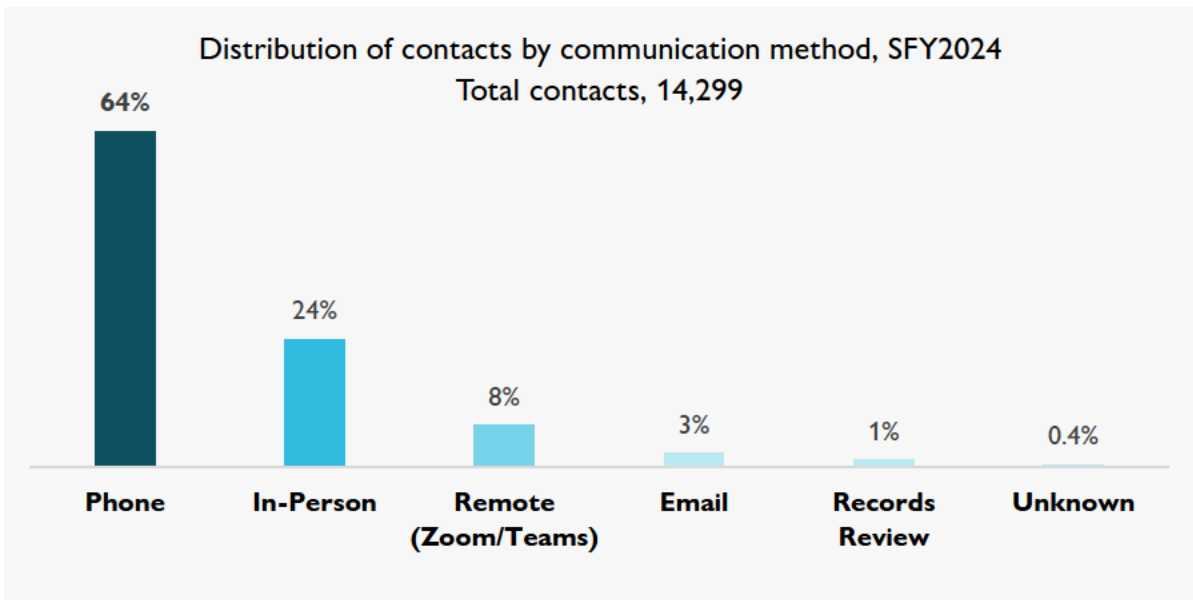
<b>Crisis Homes</b>	District 1&2	District 3, 4, &5	District 6&7	District 8
Individuals Served	11	9	11	10
Average length of stay	49 days	69 days	73 days	77 days
Shortest Stay	19 days	63 days	36 days	39 days
Longest Stay	72 days	82 days	108 days	122 days

**Note:** Length of stay is reported as an average by quarter.

**Source:** Maine Office of Aging and Disability Services

CPIS had over 14,200 contacts statewide during FY2024. Sixty-four percent (9,066) of contacts were made by telephone (Figure 6). Of the telephone contacts, 5,988 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 individuals currently in crisis. Table 6 shows the number of CPIS contacts by reason in FY2024.

Figure 6. 64% of contacts with Crisis Intervention and Prevention were over the phone.



Source: Maine Office of Aging and Disability Services

Table 5. Reasons for Crisis Prevention and Intervention Services contact between members and crisis staff, FY2024

Contact Reasons	Number of Contacts, FY2024
Individual Needs/Wants/Concerns	4,634
Wellness Check	3,388
Crisis Situation	1,123
Individual Support Team	1,091
10-day Follow-up, Individual Support Team	862
Unknown	325
90-day Follow-up, Individual Support Team	303
ER Visit	299

Contact Reasons	Number of Contacts, FY2024
Crisis Meet and Greet	247
24-hour ER Follow-up	225
24-hour Follow-up, Individual Support Team	221
10-day ER Follow-up	184
Police Involvement	176
ER: Individual in Crisis	164
Individual Support Team Recommended	153
Consultation: Provider unable to support individual needs	151
Individual stuck in ER/Hospital	136
Client Elopement	132
Scheduled Individual Support Team	130
Document Review	80
24-hours Follow-up: Crisis Contact	72
Consultation: Guardian/family unable to support individual needs	69
Goals: Reviewed with individual	35
Consultation: Behavior Management Plan, Crisis intervention Plan, Crisis Needs Assessment	29
Recurring Pattern	28
10-day Follow-up: Crisis Contact	6

**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. Pursuant to the Adult Protective Services Act (22 MRS ch. 958-A), APS 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.

This section presents information on FY2022 to FY2024 reports to APS, substantiated investigations, and information and data related to the Public Guardianship/Conservatorship program within APS, focusing on those adults receiving Section 21 or Section 29 services. The data in this report was extracted from the Evergreen Data System.

## Adult Protective Services Investigations

APS investigates allegations that are reported through a statewide APS Intake phone line (1-800-624-8404) and reported through an [online referral form](#). Certain professionals are mandated by statute to make reports to APS and, as of 2023, are also required to complete training every four years. For clients receiving Section 21 or Section 29 services, caretaker neglect is the most common allegation type. Table 7 details the number of cases involving clients receiving Section 21 or Section 29 services by year.

Table 6. APS cases involving clients receiving Section 21 or Section 29 services

APS Cases and Allegation Types	FY2022	FY2023	FY2024
<b>Total Cases with Section 21 or Section 29 Clients Assigned to Investigation</b>	1,034	1,556	2,157
<b>Allegations Reported to APS with Section 21 or Section 29 Clients</b>			
Caretaker Neglect	916	716	815
Emotional Abuse	396	306	330
Physical Abuse	301	263	301
Financial Exploitation	235	197	240
Self-Neglect	165	140	166
Null	170	146	125
Sexual Abuse	152	104	139
Exploitation-Other	23	9	41

**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 8 shows the total number of substantiated cases involving clients receiving Section 21 or Section 29 services and the number of substantiated allegations by type.

Table 7. Substantiated APS Cases Involving Clients Receiving Section 21 or Section 29 Services

Substantiated APS Cases	FY2022	FY2023	FY2024
<b>Substantiated Section 21 or Section 29 Client Cases</b>	179	193	206
<b>Allegations Substantiated by APS</b>			
Caretaker Neglect	126	126	126
Emotional Abuse	30	24	24
Self-Neglect	11	21	21
Physical Abuse	9	17	17
Financial Exploitation	9	14	14
Sexual Abuse	8	4	4
Exploitation-Other	3	0	0

**Notes:** Reports to APS frequently involve multiple allegations.

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

As of April 14, 2024, new APS rules went into effect that no longer allow for two levels of substantiation - Level I - High Severity and Level II low to moderate. Maine APS now only has the substantiation of High Severity. Because of this, it is predicted that the allegation investigations for 2024 and the years going forward will have a lower substantiation rate than prior years.

## Public Guardianship

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. Under Maine’s Uniform Probate Code, the Department 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. APS only pursues public guardianship after a comprehensive “guardianship study” that includes diligent attempts to identify all alternatives to public guardianship. Public guardianship or conservatorship is only considered a last resort when all less restrictive options are available to ensure an individual’s health and safety.

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 Maine’s Uniform Probate Code requirements, the Public Guardianship Program promotes clients’ self-determination to the greatest extent possible, prioritizing clients’ preferences, values, opinions, beliefs, and directions in all decision-making. As of

At the conclusion of FY2024, a total of 511 clients eligible for OADS Developmental Services had legal relationships (public guardianship/conservatorship) with the Department. 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 9 shows the number of clients receiving Developmental Services subject to public guardianship by type of legal relationship.

Table 8. Number of clients receiving Section 21 or Section 29 services under Public Guardianship by type of legal relationship, FY2022, FY2023, and FY2024.

Legal Relationship Type – Clients Receiving Developmental Services	FY2022		FY2023		FY2024	
	N	%	N	%	N	%
<b>Conservatorship – Full</b>	4	1%	1	0%	1	0%
<b>Conservatorship – Limited</b>	0	0%	0	0%	0	0%
<b>Emergency Conservatorship – Full</b>	0	0%	0	0%	0	0%
<b>Emergency Guardianship – Full</b>	9	2%	17	3%	16	3%
<b>Emergency Guardianship – Limited</b>	1	0%	3	1%	2	0%
<b>Emergency Guardianship/Conservatorship – Full</b>	0	0%	0	0%	0	0%
<b>Guardianship – Full</b>	449	85%	444	85%	437	86%
<b>Guardianship – Limited</b>	39	7%	46	9%	46	9%
<b>Guardianship and Conservatorship – Full</b>	24	5%	9	2%	8	2%
<b>Guardianship and Conservatorship – Limited</b>	0	0%	0	0%	0	0%
<b>Interim Order</b>	2	0%	1	0%	1	0%
<b>Total</b>	<b>528</b>	<b>-</b>	<b>521</b>	<b>-</b>	<b>511</b>	<b>-</b>

**Notes:** Point in time data extractions, FY2022, FY2023 and FY2024, 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 FY2021 and FY2023. Point-in-time data showed participation in Section 21 went down by 36 members, while participation in Section 29 went up by 301 members (Table 10).

Table 9. Expenditures and Utilization for Section 21 and Section 29 of unduplicated members, FY2021 through FY2023.

	Section 21			Section 29		
	2021	2022	2023	2021	2022	2023
<b>Number of People Served</b>	3,276	3,269	3,240	2,339	2,488	2,640
<b>Total Expenditures</b>	\$424m	\$466m	\$528m	\$60m	\$80m	\$100m

*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:<sup>8</sup>

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

Annual expenditure trends show that Home Support accounts for the majority of Section 21 waiver spending. Spending for this service increased by over \$96 million from FY2021 through FY2023 (Table 11).

<sup>8</sup> See [MaineCare Benefits Manual](#) for detailed definitions.

Table 10. Section 21 Annual Expenditures by Service Type over time, FY2021-2023<sup>9</sup>

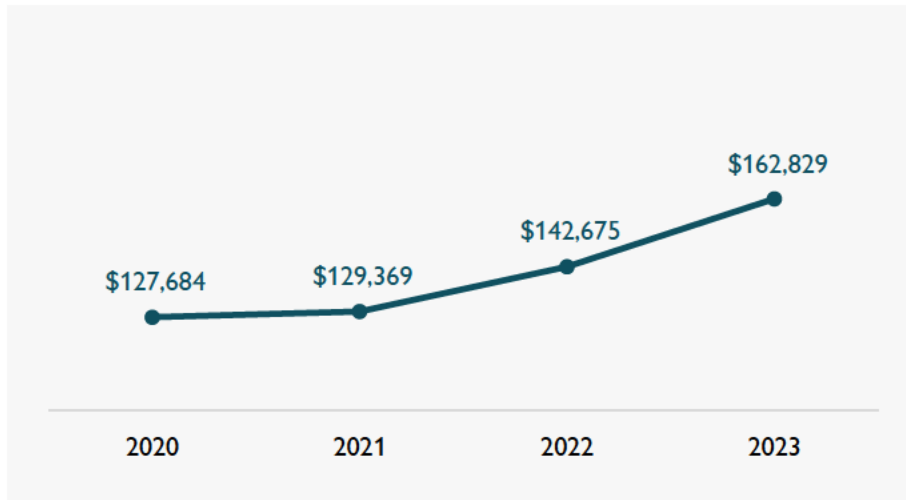
Service	FY2021	FY2022	FY2023
<b>Shared living; Home support</b> (agency, family-centered, and in-home, not agency owned/operated)	\$396,918,373	\$432,901,004	\$492,926,934
<b>Work support</b>	\$1,669,370	\$2,438,247	\$2,522,824
<b>Community supports</b>	\$23,544,827	\$28,739,295	\$31,370,786
<b>Ancillary services</b>	\$1,680,940	\$2,324,669	\$746,038
<b>Total</b>	<b>\$423,813,510</b>	<b>\$466,403,216</b>	<b>\$527,566,580</b>

*Source: Maine Office of Aging and Disability Services*

<sup>9</sup> Costs shown for FY2021 and FY2022 may differ slightly from previous reports due to claim reconciliation.

Average spending per member receiving Section 21 services increased by \$35,000 between FY2020 and FY2023 (Figure 7).

Figure 7. Section 21 average per member cost increased between FY2020-2023



**Source:** *Maine Office of Aging and Disability Services*

Prior to FY2019, Community Supports accounted for the bulk of spending for the Section 29 waiver. In 2019, a rule change allowed Shared Living to be funded under Section 29, and since then, Home Support has become the largest component of Section 29. Spending from this service has increased by nearly \$29 million from FY2021 to FY2023 (Table 12).

Table 11. Section 29 Annual Expenditures by Service Type over time, FY2021-2023<sup>10</sup>

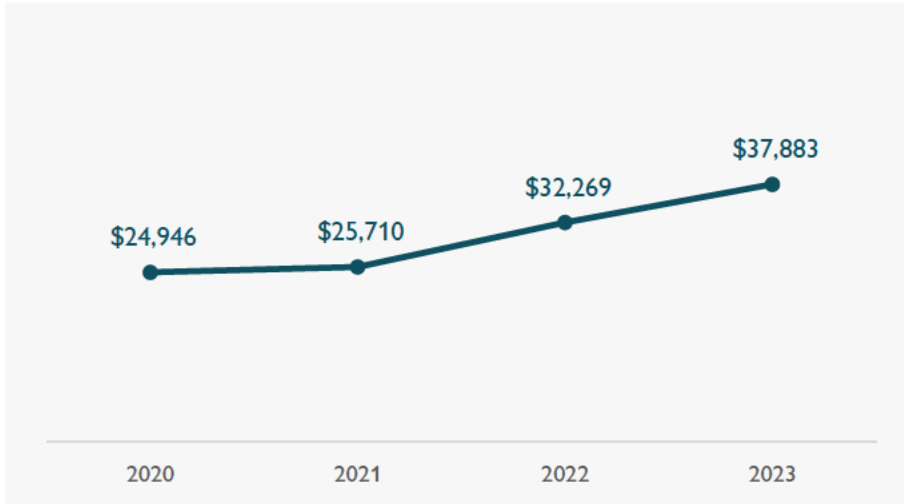
Service	FY2021	FY2022	FY2023
<b>Home support</b> (in-home, not agency owned or operated); <b>Shared living</b>	\$40,888,177	\$54,289,090	\$69,730,143
<b>Work support</b>	\$1,685,138	\$2,351,500	\$2,581,049
<b>Community supports</b>	\$17,456,632	\$23,530,720	\$27,516,061
<b>Ancillary services</b>	\$104,647	\$114,894	\$182,996
<b>Total</b>	\$60,134,594	\$80,286,204	\$100,010,249

Source: Maine Office of Aging and Disability Services

<sup>10</sup> Costs shown for FY2021 and FY2022 may differ slightly from previous reports due to claim reconciliation.

Average costs for Section 29 increased in FY2020-2023 by almost \$13,000 (Figure 8).

Figure 8. Section 29 average per member cost increased between FY2020-2023



**Source:** Maine Office of Aging and Disability Services

# Conclusion

OADS is committed to 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 partners in systemic reform to improve services, quality, and system capacity. Plans for continuing this work and additional reforms are described in the *2025-2026 Biennial Plan for Adults with Intellectual Disabilities or Autism*.

# Appendices

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

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

## Appendix B: Section 21 and Section 29 Waiver Services

### COVERED SERVICES UNDER SECTION 21 AND SECTION 29

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

COVERED SERVICES	Section 21	Section 29
<b>Assistive Technology</b>	x	x
<b>Career Planning</b>	x	x
<b>Communication Aids</b>	x	
<b>Community Support</b>	x	x
<b>Consultation Services</b>	x	
<b>Counseling</b>	x	
<b>Crisis Assessment</b>	x	
<b>Crisis Intervention Services</b>	x	
<b>Employment Specialist Services</b>	x	x
<b>Home Accessibility</b>	x	x
<b>Home Support – Family-Centered Support</b>	x	
<b>Home Support Agency – Per Diem</b>	x	
<b>Home Support-Quarter Hour</b>	x	x
<b>Home Support-Remote Support</b>	x	x

<b>COVERED SERVICES</b>	<b>Section 21</b>	<b>Section 29</b>
<b>Non-traditional communication</b>	x	
<b>Non-traditional communication consultation</b>	x	
<b>Occupational therapy (maintenance)</b>	x	
<b>Physical therapy (maintenance)</b>	x	
<b>Respite Services</b>		x
<b>Self-Direction</b>		x
<b>Shared Living (Foster Care, Adult)</b>	x	x
<b>Specialized Medical Equipment and Supplies</b>	x	
<b>Speech therapy (maintenance)</b>	x	
<b>Transportation Service</b>	x	x
<b>Work Support-Group</b>	x	x
<b>Work Support-Individual</b>	x	x

## Appendix C: Community Case Management Agencies

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

Agency Name
Alliance Case Management
Amicus
Apple Appliance
Bridge Support Services
Bridge To Success
Broad reach Family and Community Services
Care Lync Maine LLC
CCCM-4U, LLC
Central Aroostook Association
Coastal Opportunities
Community Health and Counseling Services
Community Living Association
Creative Works
Elmhurst Inc
Employment Specialists of Maine

## Agency Name

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.

Kennebec Behavioral Health

Kennebec Valley Case Management Services

Leap Inc

Lighthouse Community Care

Milestone Family Services, LLC

Mobius Inc

Morrison Center

New Tides Residential

## Agency Name

NFI North Inc

Northern Maine General

OHI

Opportunity Enterprises, Inc.

Peregrine Corp

Pine Tree Society Inc

SequelCare of Maine, LLC

Spectrum Generations

Spurwink Corporation

Summit Support Services, LLC

Test Inactive

The Progress Center Inc

Ubuntu Care LLC

United Cerebral Palsy of Northeastern Maine

Uplift Inc

Waban Projects Inc

Wings For Children and Families, Inc.

**Agency Name**

Woodfords Family Service

**Source:** *Maine Office of Aging and Disability Services, Enterprise Information System, Community Case Manager Liaison Agency Assignment Report 10/11/2024.*

# Non-Discrimination Notice

The Department of Health and Human Services (“DHHS”) does not discriminate on the basis of disability, race, color, sex, gender, sexual orientation, age, national origin, religious or political belief, ancestry, familial or marital status, genetic information, association, previous assertion of a claim or right, or whistleblower activity, in admission or access to, or the operation of its policies, programs, services, or activities, or in hiring or employment practices.

This notice is provided as required by and in accordance with Title II of the Americans with Disabilities Act of 1990 (“ADA”); Title VI of the Civil Rights Act of 1964, as amended; Section 504 of the Rehabilitation Act of 1973, as amended; Age Discrimination Act of 1975; Title IX of the Education Amendments of 1972; Section 1557 of the Affordable Care Act; the Maine Human Rights Act; Executive Order Regarding State of Maine Contracts for Services; and all other laws and regulations prohibiting such discrimination.

Questions, concerns, complaints or requests for additional information regarding the ADA and hiring or employment practices may be forwarded to the DHHS ADA/EEO Coordinators at 11 State House Station, Augusta, Maine 04333-0011; 207-287-1877 (V); 207-215-5980 (C); or Maine Relay 711 (TTY).

Questions, concerns, complaints or requests for additional information regarding the ADA and programs, services, or activities may be forwarded to the DHHS ADA/Civil Rights Coordinator, at 11 State House Station, Augusta, Maine 04333-0011; 207-287-3707 (V); Maine Relay 711 (TTY); or [ADA-CivilRights.DHHS@maine.gov](mailto:ADA-CivilRights.DHHS@maine.gov).

Civil rights complaints may also be filed with the U.S. Department of Health and Human Services, Office of Civil Rights, by phone at 800-368-1019 or 800-537-7697 (TDD); by mail to 200 Independence Avenue, SW, Room 509, HHS Building, Washington, D.C. 20201; or electronically at <https://ocrportal.hhs.gov/ocr/portal/lobby.jsf>. Individuals who need auxiliary aids for effective communication in program and services of DHHS are invited to make their needs and preferences known to the ADA/Civil Rights Coordinator. This notice is available in alternate formats, upon request.