## Office of Aging & Disability Services

2025-2026 BIENNIAL PLAN

# For Adults with Intellectual Disabilities or Autism

Pursuant to Title 34-B MRS Section 5003-A(3)

April 2025



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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**

**APS** Adult Protective Services

**ARP** American Rescue Plan

**ASD** Autism Spectrum Disorder

**BRS** Bureau of Rehabilitation Services

**CMS** Centers for Medicare & Medicaid Services

**DHHS** Maine Department of Health and Human Services

**DOE** Maine Department of Education

**DOL** Maine Department of Labor

**DRM** Disability Rights Maine

**DSP** Direct Support Professional

**HCBS** Home and Community-Based Services

**ICF-IID** Intermediate Care Facility – Individuals with Intellectual Disabilities

**IDD** Intellectual or Developmental Disability

Maine CDC Maine Center for Disease Control & Prevention

**OADS** Office of Aging and Disability Services

**OCFS** Office of Child and Family Services

**PNMI** Private Non-Medicaid Institutional Services

**TCM** Targeted Case Management

## **Executive Summary**

This plan describes the current initiatives and priorities of the Department of Health and Human Services (the Department) in the upcoming biennium (July 2025 through June 2026) for the system of services and supports offered to adults with intellectual or developmental disabilities or autism.

#### 2025-2026 Plans for Service Improvement

The Department continues to engage in reforms of Maine's Medicaid home and community-based services (HCBS) waiver programs, recognizing that these programs have not sufficiently kept up with changes in the way people with disabilities live their lives. Maine's first HCBS waiver, Section 21, was designed in 1983 to serve people transitioning out of Pineland, primarily by providing services in group homes and relying on workers to serve in roles that family or friends might have otherwise filled. Today, in the wake of the Americans with Disabilities Act (ADA) and the U.S. Supreme Court's 1999 *Olmstead* decision, people with disabilities have very different expectations for their lives. Many younger people with an intellectual disability or autism have attended integrated public schools, participated in community activities, and developed important relationships and roles in the community. This plan lays out a vision in which the Department supports people with disabilities to make their own choices about their lives, where they live and work, and how they engage with their communities.

Over the past two years, consistent with the 2023-2024 Biennial Plan, the Department continued developing a new comprehensive Lifespan HCBS waiver for individuals with IDD or autism ages 14 and older. The 2021 American Rescue Plan Act Section 9817 funded much of the work. 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.

To ensure that services meet the needs of those served, the Department is committed to ongoing engagement with individuals with intellectual disabilities or autism, their families, advocates, providers, and other community partners in developing program and system improvements.

## Introduction

The Office of Aging and Disability Services (OADS), within the Department of Health and Human Services (the Department), 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's 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.

#### Office of Aging and Disability Services

#### Mission

To promote the highest level of independence, health, and safety of older citizens, vulnerable adults, and adults with disabilities.

#### **Vision**

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

OADS's mission is aligned with the requirements of the Americans with Disabilities Act (ADA), the U.S. Supreme Court's 1999 *Olmstead* decision, and federal regulations promulgated by the Centers for Medicare & Medicaid Services (CMS) in 2014, which govern Medicaid-funded home and community-based services (HCBS). The ADA was enacted to eliminate the barriers that have kept many people with disabilities from equal access to the rights and privileges that those without disabilities have. The *Olmstead* decision interprets a state's responsibilities under the ADA to provide services to

<sup>&</sup>lt;sup>1</sup> Maine's Medicaid program is known as MaineCare. In this document, "Medicaid" is used when speaking generally about federal Medicaid policy or funding, and "MaineCare" is used when speaking specifically about policy and funding specific to the MaineCare program.

individuals with disabilities in the most integrated settings appropriate to a person's needs and preferences. 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>2</sup>

OADS is also responsible for stewarding public resources to ensure effective and efficient services and programs. Title 34-B MRS Section 5003-A(3) requires the Department to prepare a plan every two years that addresses the most effective and efficient way to implement services and programs for individuals with intellectual disabilities or autism while safeguarding and respecting their rights. This plan is submitted in fulfillment of those requirements.

<sup>&</sup>lt;sup>2</sup> More information about Maine's Transition Plan can be found on the OADS website.

## Services and Programs

OADS is committed to ensuring that people have the planning, services, and supports they need to live in places they call home, work for good pay and benefits, build relationships, and have opportunities to give back, grow, and learn. OADS supports adults of all ages who may need anything from intermittent support to 24-hour care and whose life goals and preferences vary widely. To address different preferences, needs, and circumstances and accommodate the individuality and choices of each adult that OADS serves, OADS continues to work toward providing services and programs that are:

#### ▶ Person driven

Services optimize individual choice and control and the pursuit of life goals and preferences identified by the individual served.

#### ▶ Flexible

Services can be tailored to an individual's strengths, needs, and preferences and can change over time, as an individual's needs, preferences, and circumstances change.

#### Complementary

Services are sufficiently comprehensive to help people live and work, pursue their own interests and relationships, and play the role they want to play in their community, without displacing the natural supports provided by friends and family.

Consistent with federal standards, OADS ensures that these person-centered characteristics are incorporated into the design, delivery, and quality of services and programs. These efforts are informed by the Charting the LifeCourse Framework, which

states that service planning is proactive to help individuals achieve their desired life outcomes, rather than reactive, in response to a crisis.<sup>3</sup>

Charting the LifeCourse is a framework developed to help individuals and families of all abilities, at any age or stage of life, create a vision for a good life, think about what they need to know and do, identify how to find or develop supports, and discover what it takes to live the lives they want to live. This framework emphasizes that services must be provided within the context of a person's relationship with family and friends and the larger community rather than something separate and apart that creates a barrier to relationships and community membership.

OADS based the Person-Centered Planning process on the Charting the LifeCourse Framework to promote personal choice and to reinforce the requirements of the Global HCBS Rule through focusing on the individual in the context of their family and friends. The planning process reinforces the idea that public services are only part of a larger set of resources that support an individual's life and pursuit of life goals. The Person-Centered Planning process includes eight life domains: Employment, Community Engagement, Communication & Advocacy, Home & Housing, Lifelong Learning, Social Relationship, Health &Wellness, and Safety & Security. The process acknowledges that the individual is the expert in their own life and what their good life looks like. The process listens and learns about what is most important to the individual:

- ▶ What to do and how to spend their time—working, learning something new, volunteering, pursuing hobbies and interests, or a mix of choices
- ▶ Who to have relationships with and how to be involved in chosen communities
- ▶ Where to live and with whom
- ▶ **How** to balance health, safety, and risks

Individuals work with their Case Manager/Care Coordinator, guardian (if applicable) and any other people that the person wants to help in the process. This group is the Planning Team, and together, members can use online tools to help develop the Person-Centered Plan that meets the individual's needs and preferences for their life.

<sup>&</sup>lt;sup>3</sup> More information about Charting the LifeCourse can be found at Charting the LifeCourse Nexus.

#### Covered Services, Programs, and System Supports

OADS offers a wide range of services and system supports designed to support key priorities in the lives of an adult with an intellectual disability or autism, including a place to live and be healthy, relationships and community membership, employment, and safety. These services are described more fully below.

#### TARGETED CASE MANAGEMENT AND PERSON-CENTERED PLANNING

Case management and Person-Centered Planning play central roles in ensuring that services are tailored to the personal goals, individual needs, and preferences of the person served. All people with an intellectual disability or autism eligible for OADS services have access to case management and planning services. Case managers are responsible for comprehensively assessing an individual's needs, coordinating the Person-Centered Planning process, linking the individual with services, and ensuring the services are provided. For the majority of those eligible, these services are funded by MaineCare Section 13 Targeted Case Management (TCM).

Case management services are provided primarily through fifty certified community-based targeted case management agencies. To ensure compliance with federal regulations that require case managers to be "conflict-free" – meaning they cannot have an incentive to steer their clients to make particular choices about services or service providers, the State does not serve as both case manager and guardian. Community-based case management agencies serve nearly all people receiving MaineCare-funded targeted case management. For people ineligible for MaineCare or those residing in settings where services are not reimbursable by MaineCare (e.g., people who are incarcerated), OADS staff provides case management services.

#### **EMPLOYMENT SERVICES**

Individuals who receive waiver services are supported to learn about and access the supports they require to explore careers and become employed. Individuals may need assistance with learning about different employers, preparing for an interview, or reporting their wages. As an Employment First state,<sup>4</sup> providers must offer employment services before offering other services, such as Community Supports. OADS coordinates

<sup>&</sup>lt;sup>4</sup> 26 MRS Section 3401-3403.

with the Office of Behavioral Health and the Bureau of Rehabilitation Services within the Department of Labor to help individuals with disabilities obtain and maintain employment. The Bureau of Rehabilitation Services and the Office of Behavioral Health partnered with OADS to form a Workforce Development System that provides basic staff certification, advanced training, and resources for professionals who provide employment services to people with disabilities. OADS provides support to over 800 waiver members per year who are on a path to employment or currently employed.

Providers assist with Career Planning, Employment Specialist services, and Work Support which can assist individuals with the support they need to prepare and then maintain employment. Accurate information and assistance with dispelling myths about work is provided through the MaineHealth Benefit Counseling Program. Individualized Benefit Counseling services are provided free of charge to assist the person with understanding and accessing work-related disability benefits.

#### **HCBS WAIVER SERVICES**

Maine's two HCBS waivers serving adults with an intellectual disability or autism are the primary pathway for accessing services supporting the pursuit of one's goals, employment, and engagement in the community. HCBS waivers are Medicaid-funded service packages designed specifically to help individuals who would otherwise require institutional services to live as independently as possible in the community.

Maine's HCBS waivers are often referred to by their section numbers in the MaineCare Benefits Manual,<sup>5</sup> Section 21, sometimes called the "Comprehensive Waiver," provides a broader array of services than available under Section 29, sometimes referred to as the "Support Waiver." Both Section 21 and Section 29 offer Home Supports,<sup>6</sup> Work Supports, and Community Supports, which are direct support services,<sup>7</sup> and assistive technology to support people in their homes, at work, and in the broader community.

<sup>&</sup>lt;sup>5</sup> The MaineCare Benefits Manual is found at 10-144 CMR Ch.1.

<sup>&</sup>lt;sup>6</sup> Home Support includes several categories of services, including Home Support – Agency (group home services), Home Support – Quarter Hour, Home Support – Remote, and Home Support – Family Centered Support

<sup>&</sup>lt;sup>7</sup> Direct support includes assistance with personal care and other tasks, exercising safe and responsible judgment, and promoting personal development and health and well-being.

Both waivers provide services and supports in a privately owned or rented home, apartment, or shared living arrangement. A side-by-side comparison of services covered under each waiver is provided in Appendix B: Detail on Covered Services, Programs, and Systems Support.

Enrollees under Section 21 have access to services in a provider-owned or controlled group home. In addition, under Section 21, enrollees also have access to therapies (e.g., physical, occupational, and speech therapy), as well as communication aids and other devices and services designed to overcome physical, sensory, or other barriers to mobility, communication, participation in the community, and other activities.

In 2021, based on partner input and support, the ability to self-direct services was added under Section 29 through Maine's Appendix K, a Medicaid policy utilized by states during the COVID-19 Public Health Emergency. Self-direction is now permanently included as a Section 29 service as of January 24, 2024. Self-directed services are home and community-based services that help individuals across all types of disabilities maintain their independence and determine what mix of supports and services work best for them. Self-direction provides participants with a flexible budget that enables them to hire their own workers and make decisions about when they will work, how much they get paid, and manage 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.

#### SECTION 29 SELF-DIRECTED OPTION FOR RECEIVING SERVICES

The self-directed option for receiving services allows an individual to self-direct a budget to hire staff, train, supervise, and discharge their own workers, set qualifications of staff, and direct how staff will provide support to meet the participant's goals. It also:

- Allows the member to delegate responsibilities to an authorized representative to act as the employer on behalf of the member.
- Creates Support Brokerage as an operational service to support the person using HCBS self-directing in hiring staff, setting expectations, leveraging community resources to meet needs, and maximizing the budget.
- Provides Financial Management Services to help with payroll and other related tasks.

#### **Waiting Lists**

Access to Section 21 and Section 29 waiver services is limited. States cap enrollment on a waiver and maintain a waitlist when the number of people wanting waiver services exceeds the available funding.

When a person is found eligible for waiver services, but funding is not immediately available, Section 13 TCM services are provided while the person waits for funding to become available. In addition, someone waiting for services under Section 21 might be accessing services under Section 29 or receiving other types of MaineCare-funded services. As of June 30, 2024, 73 percent of the people on the waitlist for Section 21 had other coverage (1,644 out of 2,254), and 40 percent of the people on the waitlist for Section 29 had other coverage (21 out of 52).

#### **OTHER RESIDENTIAL AND INTERMEDIATE CARE FACILITY SERVICES**

Individuals not accessing HCBS waiver services may be receiving residential services financed under MaineCare Section 97 Private Non-Medical Institution (PNMI) services or services provided in an intermediate care facility for individuals with intellectual disability (MaineCare Section 50 ICF-IID). PNMIs are funded to provide clinical and

personal care services<sup>8</sup> and vary in size. Intermediate care facilities are designed to meet the intensive, active treatment needs of persons with intellectual disabilities.

#### SYSTEM SUPPORTS AND PROTECTIONS

Numerous systems are in place to protect the rights and safety of people with an intellectual disability or autism in Maine, including:

- ► Adult Protective Services
- ► Maine's public guardianship and conservatorship program
- Statewide behavioral health and supports system for crisis prevention and intervention
- ▶ Advocacy services provided by Disability Rights Maine.

#### **Adult Protective Services**

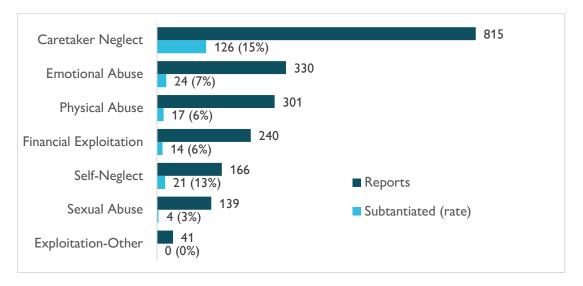
Through the Adult Protective Services (APS) program, OADS is responsible for protecting incapacitated and dependent adults from abuse, neglect, and exploitation, enhancing their welfare, and promoting self-care where possible. APS receives reports, investigates, and determines the validity of reports alleging abuse, neglect, or exploitation.

APS investigates allegations that are reported through a statewide APS Central 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.

In FY2024, APS Central Intake received 2,157 reports for clients receiving Section 21 and/or Section 29 services at the time of intake. Allegations of caretaker neglect were the most common type (815), followed by emotional abuse (330) and physical abuse (301). A total of 206 allegations involving individuals receiving services under Section 21 or Section 29 were substantiated. One hundred twenty-six allegations of caretaker neglect were substantiated, a substantiation rate of 15 percent. Self-neglect had the second-highest substantiation rate of 13 percent (Figure 1).

<sup>&</sup>lt;sup>8</sup> "Personal care services" are a subset of "direct support services," typically focusing on helping a person with activities of daily living (ADLs) such as mobility, bathing, toileting, etc.

Figure 1. **Caretaker neglect** was the most common allegation reported to and substantiated by APS for people receiving HCBS waiver services under Section 21 or Section 29, FY24.



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 Severity. 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 and Conservatorship

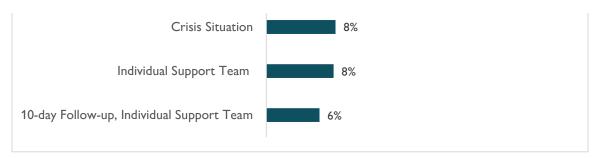
During an investigation, APS may determine that an incapacitated adult needs a guardian or that a private guardian is subjecting an individual under guardianship to abuse, neglect, or exploitation. In these cases, APS will search for a suitable private guardian. Under Maine's Uniform Probate Code, the 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 August 2024, 511 individuals receiving Section 21 or Section 29 HCBS waiver services were subject to public guardianship or conservatorship.

#### 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, these services aim to avoid removing people from their homes or communities whenever possible or when a different placement 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.

Crisis Prevention and Intervention Services (CPIS) had over 14,200 contacts statewide during FY2024. Sixty-four percent (9,066) of contacts were made by telephone (



).

Distribution of contact communication method, SFY2024
total contacts,14,299

24%

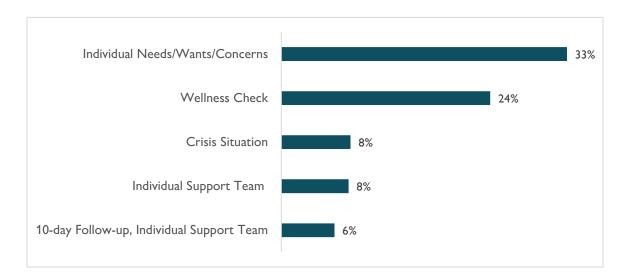
8%
3%
1%
0.4%

Phone In-Person Remote Email Records Review Unknown
(Zoom/Teams)

Figure 2. 64% of contacts with CPIS were over the phone

Source: Maine Office of Aging and Disability Services

Figure 3 Individual needs/wants/concerns were the top reason for calling CPIS in FY2024



Source: Maine Office of Aging and Disability Services

#### **Advocacy**

The Department contracts with Disability Rights Maine to provide statewide individuallevel advocacy for people with intellectual disabilities or autism. Disability Rights Maine provides direct representation, responds to reported rights violations, attends meetings to review behavior and safety plans, attends person-centered planning meetings, and conducts regular outreach and training statewide.

The Department also contracts with several other organizations to help identify opportunities for system improvements, including the Maine Developmental Services Oversight & Advisory Board, which provides system-level advice on system-level improvements, and Speaking Up for Us (SUFU), which facilitates direct input from self-advocates on policy and program improvements. The Department partners with the Maine Developmental Disabilities Council (MDDC), a federally funded partnership of people with disabilities, their families, and agencies that identify barriers to community inclusion, self-determination, and independence.

#### Quality Assurance and Compliance Structures

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 (CAHPS) satisfaction surveys, and Reportable Event<sup>9</sup> and APS reporting data to assure minimum compliance with program standards and to identify problems that require investigation and opportunities for improvement. OADS's Quality Assurance Unit reviews and triages all reportable events based on the severity of the event. Those that are most concerning will result in further investigation by the Quality Assurance staff to determine if there should be a Corrective Action Plan submitted by the agency to address possible deficiencies.

The Evergreen Data System is a single database system 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 the 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 make sure services are provided in accordance with 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.

<sup>&</sup>lt;sup>9</sup> A "reportable event" is defined to include these events when involving a person receiving services: death, a suicide attempt or threat, an emergency department visit, a hospital admission, a medication error, any emergency medical treatment, a serious injury, a physical plant disaster, a law enforcement intervention, a transportation accident, a physical assault or altercation, the use of an emergency restraint, a rights violation, or an imminent risk of harm to self or others.

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 are required to 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's 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.

## Plans for 2025-2026

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 2023-2024 was supported through federal funding available through the 2021 American Rescue Plan 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 (ARP) 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 (Figure 4). Additional information and details are available on the HCBS Lifespan Project website.

Figure 4 Proposed new Lifespan waiver services by domain

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

Domain to improve	Proposed Lifespan waiver services
Competitive integrated employment	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
Control over personal resources	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.
Prioritizing PCP/PCSP	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. In support of 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, running into 2025 until those funds expire.

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: 10

- ▶ 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

<sup>&</sup>lt;sup>10</sup> The federal HCBS quality measure set and CAHPS survey will be implemented for all HCBS waivers OADS administers.

- waiver participant, e.g., the successful completion of an employment plan or 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.
- Building prioritization for 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 (ASD) to create a training curriculum and comprehensive materials, including budgeting, recruiting/hiring, and supporting participants with managing staff. ASD 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, ASD has been guided by partner organizations through the Maine Developmental Disabilities Council to ensure member and family needs and preferences are reflected in the self-direction program design and operations.

In 2025, ASD 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 members self-directing 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 it needs 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. A beta version of the core competencies is scheduled to be released in late 2024.

#### **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 that are 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, OMS, and DLC, as well as partners, an overall systemic oversight framework that includes licensing, program standards, onsite reviews, and a process to provide ongoing technical support.
- ► Coordinate the implementation of the Non-Residential Standards and Framework Plan in winter 2025.

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.

## Conclusion

OADS will continue working to provide high-quality care, services, and programs to people with intellectual disabilities and autism that reflect individual needs and preferences, maximize community inclusion, and promote safety while respecting dignity and autonomy. With the implementation of the Lifespan waiver and other ongoing initiatives, OADS will continue engaging with individuals, families, providers, advocates, and other community partners to ensure the services are provided efficiently and with the best effect for the people who use them.

# Appendix A: Home and Community-Based Services for Adults with Intellectual Disabilities or Autism, At-a-glance

# Maine's Home & Community-Based Service (HCBS) Waivers

SECTION 21 Comprehensive Waiver & SECTION 29 Support Waiver

	Section 21	Section 29
Number of people served	3,240	2,640
Average age	45	34
Percent under 55 years old	70%	89%
Total expenditures	\$527,566,580	\$100,010,249

FY2023 expenditure data.

#### Section 21 Waiver

**COMPREHENSIVE WAIVER** 

## Living arrangements

Most people using Section 21 services live in group homes.



## Section 29 Waiver

SUPPORT WAIVER

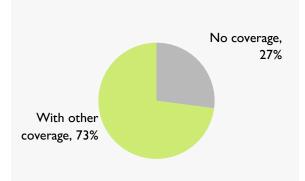
## Living arrangements

Most people using Section 29 services live in shared living settings.



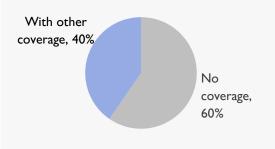
## 2,254 on waitlist

Most people on the Section 21 waitlist have other coverage through Section 29, the Support Waiver.



## 52 ON WAITLIST

Over half of the people on the Section 29 waitlist have no other coverage.



**Note:** Service data are from SFY2023; waitlist data are from 6/30/2024

# Appendix B: Detail on Covered Services, Programs, and Systems Support

This appendix provides additional detail on the HCBS waiver programs, Section 21 and Section 29, and targeted case management services for individuals with an intellectual disability or autism living in Maine.

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

Table 1. Covered services under Section 21 and Section 29

COVERED SERVICES	Section 21	Section 29
Home Support Agency – Per Diem	x	
Home Support – Family-Centered	X	
Home Support-Quarter Hour	x	x
Home Support-Remote Support	x	x
Shared Living (Foster Care, Adult)	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	Section 21	Section 29
Physical therapy (maintenance)	x	
Speech therapy (maintenance)	X	
Career Planning	x	×
Employment Specialist Services	x	×
Work Support-Group	x	×
Work Support-Individual	x	×
Community Support	x	×
Assistive Technology	x	×
Communication Aids	x	
Non-traditional communication	x	
Non-traditional communication	x	
Specialized Medical Equipment and Supplies	x	
Transportation Service	x	x

The most current and complete MaineCare expenditure data are from FY2022 and FY2023 due to delays in claims processing.

Table 2. Expenditures By Type of Service, Section 21 And Section 29, FY2022 And FY2023

SERVICES	Section 21	Section 21	Section 29	Section 29
	FY 2022	FY 2023	FY 2022	FY 2023

SERVICES	Section 21	Section 21	Section 29	Section 29
Assistive Technology Assessment	\$30,333	\$29,395	\$14,996	\$20,055
Assistive Technology Devices	\$100,449	\$141,274	\$68,837	\$134,531
Assistive Technology Transmission	\$34,372	\$31,933	\$21,141	\$28,411
Career Planning	\$46,364	\$55,184	\$90,847	\$130,658
Communication Aids	\$9,880	\$10,131	-	-
Community Support	\$28,739,295	\$31,370,786	\$23,530,720	\$27,516,061
Consultative Services	\$49,619	\$35,723	-	-
Counseling	\$821,522	\$334,370	-	-
Crisis Intervention	\$111,327	\$101,843	-	-
Employment Specialist Services	\$40,149	\$37,747	\$33,888	\$37,057
Home Accessibility Adaptations	-	-	\$9,920	-
Home Support - Agency	\$370,802,014	\$426,754,742	-	-
Home Support 1/4 Hour	\$15,056,031	\$16,068,277	\$6,558,077	\$7,544,399
Non-traditional Communication Consultation	\$80,881	\$73,083	-	-

SERVICES	Section 21	Section 21	Section 29	Section 29
OT/PT/Speech Therapy	\$65,145	\$66,612	-	-
Respite Services - Per Diem	-	-	\$331	-
Shared Living	\$46,931,632	\$50,002,072	\$47,731,013	\$62,185,743
Specialized Medical Equipment	\$16,575	\$23,518	-	-
Waiver Services not otherwise specified	\$1,115,892	-	-	-
Work Support	\$2,351,734	\$2,429,892	\$2,226,765	\$2,413,333
TOTAL	\$464,051,482	\$525,136,688	\$78,059,770	\$97,596,916

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

All people eligible for developmental services have access to case management services. The majority receives targeted case management services financed through MaineCare.

Table 3. Number Served and Expenditures for Targeted Case Management, FY2023

Number Served	Expenditures
6,778	\$24,052,368

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

Most calls to CPIS in FY2024 were for Individual Needs/Wants/Concerns, Wellness Checks, Crisis Situations, or Individual Support Team.

Table 4. Reason for Contacting Crisis Prevention and Intervention Services Contact, FY2024

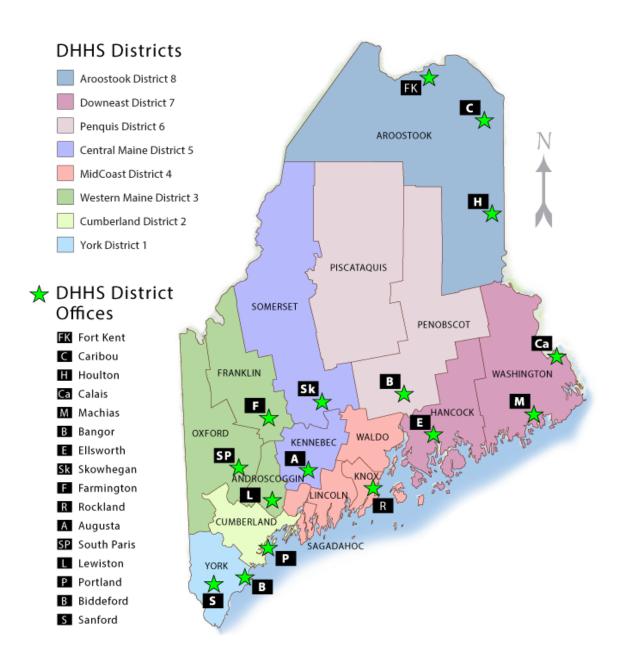
Contact Reasons	Number of Contacts, FY2024
Individual Needs/Wants/Concerns	4,634
Wellness Check	3,388
Crisis Situation	1,123
Individual Support Team	1,091
10-day Follow-up, Individual Support Team	862
Unknown	325
90-day Follow-up, Individual Support Team	303
ER Visit	299
Crisis Meet and Greet	247
24-hour 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

Contact Reasons	Number of Contacts, FY2024
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

# Appendix C: Department of Health and Human Services Districts and Offices

Figure 5. Map of DHHS Districts and Offices



To see this information in tabular form, please refer to Table 5 on the following page.

Table 5. DHHS 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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