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Office of Aging & Disability Services

2023-2024 BIENNIAL PLAN

For Adults with Intellectual Disabilities or Autism

Pursuant to Title 34-B M.R.S. §5003-A(3)

2023



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Executive Summary

This plan describes the priorities of the Department of Health and Human Services (the Department or DHHS) in the upcoming biennium (July 2022 through June 2024) for the system of services and supports offered to adults with intellectual or developmental disabilities (IDD) or autism spectrum disorder (ADS).

2023-2024 Priorities for Service Improvement

The Department continues to engage in reforms of Maine’s home and community-based services (HCBS) waiver programs, recognizing these programs have not sufficiently kept up with changes in the way people with disabilities live their lives. Maine’s first HCBS waiver, §21, was designed in 1983 to serve people transitioning out of Pineland,¹ primarily by providing services in a group home and relying on workers to serve in roles that might otherwise have been filled by family or friends. 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 people with disabilities make their own choices and are afforded opportunities about where they live and work.

Over the last two years, consistent with the 2021-2022 Biennial Plan, OADS convened several stakeholder workgroups to address opportunities for strengthening community inclusion, service innovation, and quality assurance and improvement activities. Stakeholders have advised OADS on how services can better promote greater inclusion in the community through employment, access to community resources and places, self-advocacy, person-centered thinking, and supported decision-making. These stakeholder recommendations serve as the basis for many of the initiatives set forth in this biennial plan. OADS has integrated stakeholder input on its quality improvement initiatives,

¹ Pineland was Maine’s state-operated institution where people with intellectual disabilities lived, segregated from their families and the larger community.

including strategies for meaningful data collection for monitoring system quality. The Department also continues to strengthen efforts to increase system capacity and access to services.

Notably, the passage of the American Rescue Plan Act (ARPA) of 2021, Section 9817, has provided unprecedented federal support to Maine to help stabilize and enhance the home and community-based (HCBS) service system. This funding will expand and augment many of the reform initiatives already underway to improve access, services, and quality of life for adults with IDD or ASD in Maine. This plan describes how those funds will be used to address longstanding system and capacity issues, made more critical with the current workforce shortages.

OADS, in partnership with the Office of Child and Family Services (OCFS), also plans to implement reforms to address structural challenges faced by youth with development disabilities transitioning to adulthood. This includes exploration of a new set of services that could offer different levels of support within a single program, as part of a transition process and providing greater support for individuals and their families during this period. While this would represent a multi-year initiative, OADS anticipates intensive stakeholder engagement and implementation planning during this plan period.

Introduction

The Office of Aging and Disability Services (OADS), within the Department of Health and Human Services (the Department or DHHS), 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 spectrum disorder (ASD). 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' vision is to promote individual dignity through respect, choice, and support for all adults. OADS is also responsible for stewarding public resources to ensure that services and programs are effective and efficient.

OADS' 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).² 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 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.³ States have until March 2023 to become fully compliant with all requirements.

Title 34-B M.R.S. § 5003-A(3) requires the Department to prepare a plan every two years that addresses the most effective and efficient manner in which to implement services and

² 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.

³ These regulations are commonly referred to as the "HCBS settings rule". More information can be found on the [OADS' website](#).

programs for individuals with intellectual disabilities or autism while safeguarding and respecting their rights. This plan is submitted in fulfillment of those requirements.

The American Rescue Plan Act of 2021, Section 9817

The American Rescue Plan Act (ARPA) of 2021, Section 9817, was signed into law in March 2021, providing unprecedented federal support for Mainers living with disabilities, and for their families, caregivers, and providers. This funding is intended to stabilize and improve the home and community-based (HCBS) system that was strained and harmed by the COVID-19 pandemic. Based on federal guidance to date, this law will provide over \$200 million in federal Medicaid matching funds to invest in MaineCare's HCBS workforce and system improvements. This includes an estimated \$75 million in one-time Federal Medical Assistance Percentage (FMAP) funds, which are expected to leverage \$131 million of additional federal match.

When the passage of the ARPA was announced, the Department hosted virtual listening sessions with stakeholders, welcoming the HCBS community of individuals, families, providers, and advocates to offer comments and recommendations as to how these resources should be allocated. Following this feedback from stakeholders, Maine's initial HCBS FMAP plan was submitted to the Centers for Medicare & Medicaid Services (CMS) in June 2021 and received conditional approval from CMS in November 2021. CMS approved amendments to the plan in July 2022.

Maine's plan invests the FMAP funds in three areas: timely access to services, innovating service delivery, and improving quality and accountability. To address the immediate and critical HCBS workforce challenges, approximately 60% of these funds will directly increase wages for the HCBS workforce through special recruitment and retention bonus payments. This funding will expand and augment many of the reform initiatives already underway to improve access, services, and quality of life for adults with IDD or ASD in Maine.

A summary of the preliminary HCBS FMAP plan is available on the OADS website here [Maine DHHS Preliminary HCBS FMAP Plan](https://www.maine.gov/dhhs/oads/about-us/initiatives/home-community-fmap-plan).⁴

⁴ <https://www.maine.gov/dhhs/oads/about-us/initiatives/home-community-fmap-plan>

Communication and Stakeholder Engagement

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.

Over the past four years, OADS has invested significant time and resources to increase transparency and access to information and engage stakeholders directly in systemic reform. To help design reform initiatives, OADS established an ambitious stakeholder process involving multiple stakeholder groups to guide changes in policy and practice, as well as important structural reforms. While the COVID-19 public health emergency paused some of these stakeholder activities, all activities fully resumed in 2021 and the work of key committees was completed in 2022. Stakeholder committee recommendations serve as the basis for many of the initiatives set forth in this biennial plan.

OADS has also improved access to information about OADS' services on the Department's website and is continuing efforts to ensure resources and information is shared using varying methods, styles, and types of approach. In addition to information for members and providers, OADS publishes information on an on-going basis about the number of people on the waitlists for waiver services and the extent to which they have been able to access other services while waiting. OADS continues to communicate regularly with members, family members, providers, and advocates to address opportunities for improving service quality.

OADS meets monthly with the Maine Developmental Services Oversight and Advisory Board, a statutorily formed board responsible for providing independent oversight over services and programs for adults with an intellectual disability or autism. Through monthly meetings, the Board provides OADS with oversight and advice on systems issues, with a focus on rights, needs, and quality of life issues.

The Continuing Impact of COVID-19

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

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

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

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 and grow and learn. Services offered through OADS serve 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

Consistent with federal standards, OADS continues to work to ensure that these person-centered characteristics are incorporated into the design of services and programs, the process for delivering services, and the system for assuring the quality of services and systems. These efforts are informed by the Charting the LifeCourse Framework where service planning is proactive, with the goal of helping an individual achieve their desired life outcomes, rather than reactive, in response to a crisis.

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



From Charting the LifeCourse Framework: Infographic (2020), University of Missouri. Accessed at LifeCourseTools.com

Services must also comply with transformational changes enacted by CMS in 2014 governing the delivery of HCBS. These HCBS regulations are commonly referred to as 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 overall goal is to ensure that HCBS programs provide an experience distinctively different from institutional care. Maine has until March 17, 2023, to demonstrate compliance with these rules for settings serving waiver participants prior to March 17, 2014.

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

Maine is on schedule to meet federal timelines for full implementation and has adopted final MaineCare rules on accordance with these standards.⁵ The Department submitted a Final Transition Plan to CMS dated September 16, 2022. These reform activities have been a priority as noncompliant services will lose federal funding, which pays almost two-thirds of the cost for Medicaid-funded services.

⁵ See Chapter 1, Section 6 of the MaineCare Benefits Manual (Global HCBS Waiver Person-Centered Planning and Settings Rule).

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.

HCBS WAIVER SERVICES

Maine’s two HCBS waivers serving adults with an intellectual disability or autism are the primary pathway for accessing services that support the pursuit of one’s own goals, employment, and engagement in the community. HCBS waivers are Medicaid-funded service packages designed specifically for helping 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,⁶ §21, sometimes referred to as the “Comprehensive Waiver,” provides a broader array of services than available under §29, sometimes referred to as the “Support Waiver.” Both §21 and §29 offer Home Supports,⁷ Work Supports, and Community Supports, which are direct support services,⁸ and assistive technology designed to support people in their homes, at work, and in the broader community. Both waivers provide services and supports in a privately-owned or rented home or apartment, or in a shared living arrangement.

⁶ The MaineCare Benefits Manual is found at [10-144 C.M.R. ch.1](#).

⁷ 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

⁸ “Direct support” includes assistance with personal care and other tasks, exercising safe and responsible judgment, and promoting personal development and health and well-being.

§21 AND §29 WAIVERS

§21, sometimes referred to as the “Comprehensive Waiver” provides a broader array of services than available under §29, sometimes referred to as the “Support Waiver.”

Enrollees under §21 have access to services in a provider-owned or controlled group home. In addition, under §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, the ability to self-direct services was added as an option under §29. Self-directed services are home and community-based services that help individuals across all types of disabilities maintain their independence and determine for themselves what mix of supports and services work best for them. Self-direction 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. This new option was added to the waiver based on stakeholder input and support.⁹

⁹ These rules are included in [Maine's Appendix K](#), a Medicaid appendix utilized by states during emergency situations to request changes to approved 1915(c) waivers.

A side-by-side comparison of services covered under each waiver is provided in [Appendix B: Detail on Covered Services, Programs and Systems Support](#).

§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.

Employment Services

Over 748 individuals received employment-related supports and services in FY21. Maine continues to expand access to good jobs for individuals with a disability. Maine is an Employment First state. Under the Employment First Maine Act¹⁰ providers are required to offer employment services before offering other services, such as Community Supports. In June 2020, Maine repealed the subminimum wage provision, making Maine one of only three states that ensure that all employees are paid at least minimum wage, regardless of disability.

OADS coordinates 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.

Providers assist with Career Planning, Employment Specialist services, and Work Support, meet with employers, and help with applications for unemployment and other work-related needs. Individuals experiencing job loss or who have been unable to work are able to access accurate information about wages, benefits, and unemployment services through Maine Medical Center's statewide Benefits Counseling Services.

Waiting Lists

Access to §21 and §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, case management services under §13 of the MaineCare Benefits Manual are provided while the person waits for funding to become available. In addition, someone waiting for services under §21 might be accessing services under §29 or they may be receiving other types of MaineCare-funded services. As of September 30, 2022, 67 percent of the people on the waitlist for §21 were receiving services under §29 (1,359 out

¹⁰ 26 M.R.S. §§ 3401-3403.

of 2,028). Detail on the services that people are accessing while on the waiting list may be found in Appendix B: Detail on Covered Services, Programs and Systems Support.

OTHER RESIDENTIAL AND INTERMEDIATE CARE FACILITY SERVICES

Individuals who are not accessing HCBS waiver services may be receiving residential services financed under MaineCare as Private Non-Medical Institution (PNMI) services (§97 in the MaineCare Benefits Manual), or services provided in an intermediate care facility for individuals with intellectual disability (ICF-IID) (§50 in the MaineCare Benefits Manual). Intermediate care facilities are designed to meet the intensive, active treatment needs of persons with intellectual disabilities. PNMIIs are funded to provide clinical and personal care services¹¹ and vary in size.

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, a statewide behavioral health and supports system for crisis prevention and intervention, and 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.

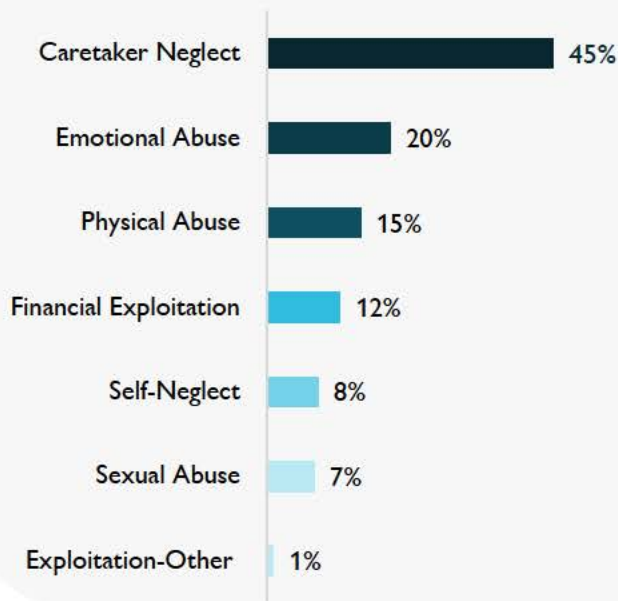
APS investigates allegations that are reported through a statewide APS Intake phone line (1-800-624-8404) and reported through a web referral form. Certain professionals are mandated by statute to make reports to APS. During an investigation, APS may determine that an incapacitated adult needs a guardian or that a private guardian is

¹¹ “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.

subjecting an individual under guardianship to abuse, neglect, or exploitation. In these cases, APS will conduct a search for a suitable private guardian or, if there are no capable family or friends to take on the role, APS will petition for public guardianship. Public guardianship or conservatorship is only considered as a last resort when all less restrictive options are available to ensure an individual's health and safety.

In FY2022, APS Central Intake received 14,567 reports (across all population groups, including individuals with an intellectual disability or autism). Of those, 1,977 (14 percent) involved clients receiving HCBS waiver services under §21 or §29. Forty-five percent of reports involved allegations of caregiver neglect, with emotional abuse following at 20 percent and physical abuse at 15 percent. Refer to [Figure 1](#). A total of 196 allegations involving individuals receiving services under §21 or under §29 were substantiated.

Figure 1. Caregiver neglect was the most common allegation in reports to APS for people receiving HCBS waiver services under §21 or §29, FY22.



Note: Totals do not add to 100% as reports may contain multiple allegation types.

Source: Office of Aging and Disability Services, Adult Protective Services, Evergreen

Public Guardianship and Conservatorship

Under Maine’s Uniform Probate Code, the Department of Health and Human Services may be appointed as an adult’s public guardian or conservator when the adult is deemed to lack decision-making capacity and no private party is able and willing to serve as a guardian or conservator. Adult Protective Services is the program within the Department of Health and Human Services designated to carry out the responsibilities of public guardianship and conservatorship. Adult Protective Services only pursues public guardianship after a comprehensive “guardianship study” that includes diligent attempts to identify all alternatives to public guardianship. APS pursues the level of guardianship authority required to meet the adult’s needs, which may involve petitioning for limited authority. When circumstances change, the APS Public Guardianship Program facilitates the transition of public guardianship to a suitable and willing private individual; or, when the existing level of guardianship authority is no longer necessary or valuable, petitions to limit or terminate guardianship authority. Consistent with the requirements of Maine’s Uniform Probate Code, the Public Guardianship Program endeavors to promote clients’ self-determination to the greatest extent possible, prioritizing clients’ preferences, values, opinions, beliefs, and directions in all decision-making. As of December 2022, 515 individuals receiving HCBS waiver services were subject to public guardianship or conservatorship.

Statewide Behavioral Health and Support Services

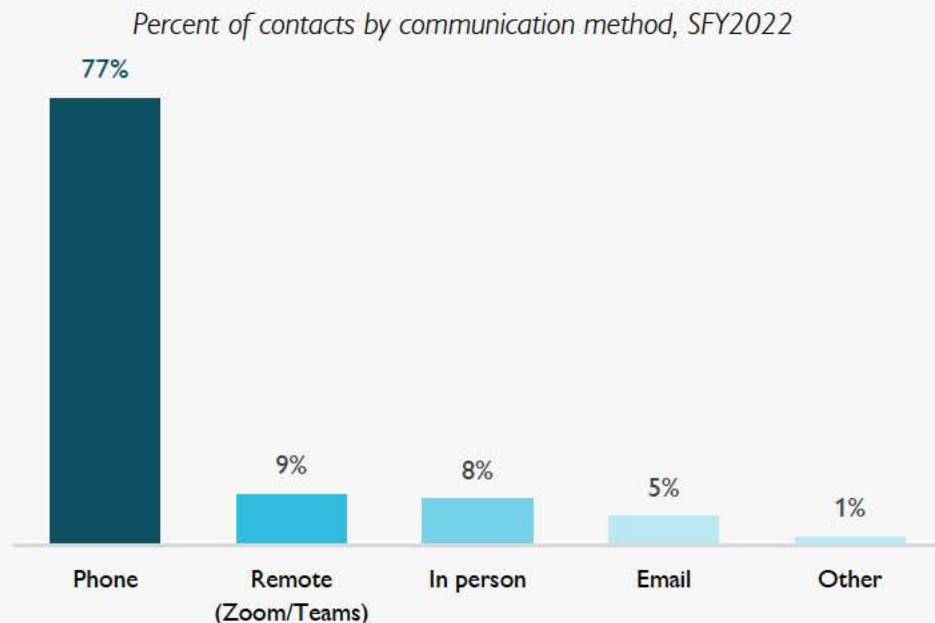
OADS provides statewide behavioral health and support services for adults with developmental disabilities and brain injury 24 hours per day, seven days a week. These services include assistance to individuals, families, guardians, and providers before, during, and after crisis incidents. When necessary,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

OADS leadership has made significant improvements to this system over the last several years. This includes adding eight staff to the regional offices to provide crisis response services, as well as outreach and prevention services. All crisis staff are being 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.

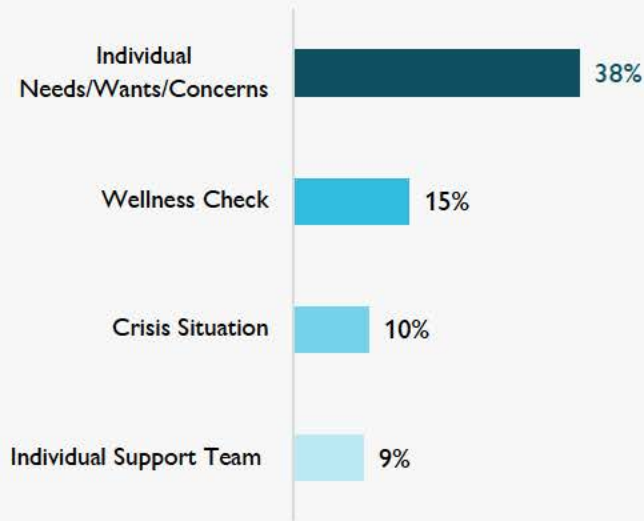
Phone contacts to Crisis Services made up 77 percent of all contacts in FY2022 (refer to [Figure 2](#)). There were 11,073 calls to Crisis Services with the most frequent reason being general conversation (when an individual who may not be in crisis at that moment calls the Crisis Line to speak to a Disability Services Crisis Worker to discuss general events in their life, or other issues or concerns); wellness checks; and community outreach (another category of service delivered by crisis workers to individuals, families, providers or other stakeholders regarding an individual served) (refer to [Figure 3](#)). For more detail, see [Appendix B: Detail on Covered Services, Programs and Systems Support](#).

Figure 2. 77% of contacts with Crisis Intervention and Prevention were over the phone



Source: Office of Aging and Disability Services

Figure 3. Individual needs/wants/concerns was the top reason for calling Crisis Services in SFY2022



Source: Office of Aging and Disability Services

Advocacy

The Department contracts with Disability Rights Maine to provide statewide individual-level advocacy for people with intellectual disabilities or autism. Disability Rights Maine provides direct representation, responds to reported rights violations, attends meetings for the review of 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 that provides system-level advice on system-level improvements and Speaking Up for Us (SUFU) that 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 which identifies barriers to community inclusion, self-determination, and independence.

Targeted Case Management and Person-Centered Planning

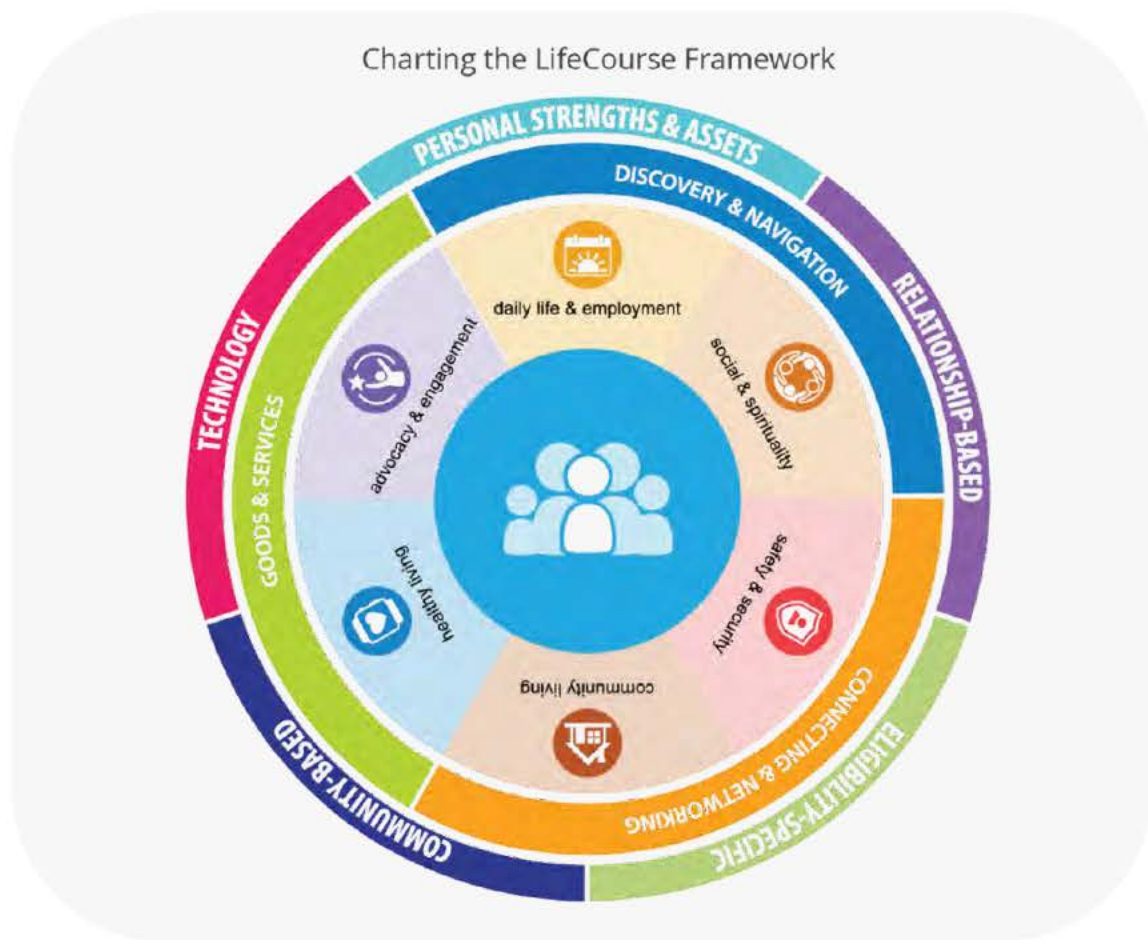
Case management and person-centered planning play central roles in ensuring that services are tailored to the personal goals and individual needs and preferences of the person served. All people with an intellectual disability or autism eligible for OADS services have access to case management and planning services. For the majority of those eligible, these services are funded by MaineCare as Targeted Case Management (TCM) (§13 in the MaineCare Benefits Manual).

Case managers are responsible for comprehensively assessing an individual's needs, coordinating the person-centered planning process, linking the individual with services, and making sure that the services are provided. Person-centered planning involves identifying and describing the person's goals and needs, as well as the support services the person requires to live a meaningful and self-directed life.

Case management services are provided primarily through 43 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. Nearly all people receiving MaineCare-funded targeted case management are served by community-based case management agencies. 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.

OADS designed the person-centered planning process to promote personal choice and to reinforce the requirements of the HCBS settings rule. Over the last reporting period (2021-2022), Maine updated the instruction manual that case managers use for conducting the person-centered planning process and incorporating the Charting the LifeCourse Framework to shape the curriculum. Using this framework provides a focus on the individual in the context of their family and friends and 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. Charting the LifeCourse focuses on six life domains: Daily Life

& Employment, Community Living, Healthy Living, Safety & Security, Social & Spirituality, and Advocacy & Engagement.¹²



Used with permission from Charting the LifeCourse Nexus.

Quality Assurance and Compliance

OADS is responsible for assuring that services meet personal preferences and aspirations and are provided in a way that supports the health and safety of the person receiving services. This includes on-going monitoring to ensure that federal and state requirements for quality assurances are met.

¹² More information about Charting the LifeCourse can be found at [Charting the LifeCourse Nexus](#).

Responsibility for assuring quality is embedded throughout OADS, the Office of MaineCare Services (OMS), and other units within the Department, as well as throughout the delivery system, including providers and case managers. OADS is responsible for reviewing and addressing all allegations of abuse, neglect, and exploitation, as well as all Reportable Events.¹³ OADS also monitors trends and identifies 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 make sure an individual's issue has been addressed.

When delivering the services described in the person-centered plan, providers are responsible for complying with licensing and other regulatory and contractual requirements. 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 OADS' ability to assure that individual goals and preferences are met.

¹³ 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.

Plans for 2023-2024

In addition to its work to ensure full implementation of the HCBS settings rule, OADS will focus on several other priorities over the next two years, continuing to address long standing challenges and taking on new goals for improving systems and services. As described above, OADS is committed to improving the lines of communication with a broad set of stakeholders, and having stakeholders help guide planning for the work described in this section. Beginning in 2019, OADS established three primary Work Groups: Community Membership, Innovation, and Quality Assurance and Quality Improvement. In addition to these work groups, OADS participated in other stakeholder work groups focused on transportation services, housing, and other aspects of the service delivery system.

These work groups were made up of a cross representation of individuals who were invested in improving developmental disability services in Maine including individuals receiving services, agency providers, family members, advocates, and state agency staff at OADS. Many of the priorities for 2023-2024 outlined below were developed as part of stakeholder work groups, and their input serves as the cornerstone of the Department's reforms.

The availability of ARPA funding will allow the Department to make significant progress over the next two years to address longstanding challenges in the service delivery system, including workforce shortages. This section outlines actions and strategies for 2023-2024 in several key areas, including: 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. This section describes plans for addressing these priority areas.

This section outlines actions and strategies for 2023-2024 in several key areas, including:

Person-Centered Planning and
Community Inclusion

Quality Improvement

System Capacity and Access to
Services

Statewide Behavioral Health
and Support Services

Transitions Across the Lifespan

KEY OADS STAKEHOLDER GROUPS CONVENED IN 2019-2022

Community Membership

OADS convened a Community Membership Reform Work Group in 2019 to identify strategies to promote full inclusion of people with disabilities into communities. The work group issued a report in January 2022 addressing enhanced person-centered planning, self-advocacy, family support, community support, and implementation of Maine's Employment First statute. In addition, this group identified strategies for ensuring compliance with the HCBS settings rule following complete implementation of the HCBS transition plan.

Innovation

In partnership with the Innovation Work Group, OADS developed new strategies for enhancing self-direction, developing innovative housing options, redesigning the delivery and operation of Maine's HCBS waivers to better ensure that people have the services they need when they need them, explore new options for expanding access through technology, and improving crisis services. The work group issued its report in January 2022.

Quality Assurance

In partnership with the Quality Work Group and informed by a consultant's recommendations, OADS has developed recommendations to strengthen quality assurance and quality improvement capacity at the individual, provider, and systemic level. These recommendations were finalized in July 2022.

Community Membership

Strategies and planned activities for 2023-2024 to strengthen engagement and inclusion build on past work and address several key areas consistent with the Department's commitment 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 and grow and learn. Initiatives for 2023-2024 in this priority areas fall into four categories:

- ▶ Person-Centered Planning, Self-Determination, and Self-Advocacy
- ▶ Community Integration and Compliance with the HCBS Settings Rule
- ▶ Increased Supportive Housing Options
- ▶ Implementation of Employment First Statute and Practices

Person-Centered Planning, Self-Determination, and Self-Advocacy

Person Centered Planning is an ongoing process that helps people plan for the life they want and is a central tenet of service delivery. The process includes supporting informed choice, exploring communities and options for support, and listening to people. Over 2023-2024, OADS will focus on implementing stakeholder recommendations designed to improve understanding of self-determination and self-advocacy and to ensure these principles are embedded into every aspect of the system. Additional detail is provided below.

- ▶ Working in partnership with self-advocates, OADS will develop and share resources and information on self-advocacy, self-determination, and informed choice, including training for individuals, families, providers, case managers, and the public. This includes providing practical, educational, and direct technical assistance opportunities for people-centric engagement through multiple training mediums and direct interfaces around the areas of self-determination, building interconnected inclusive communities, and supporting a pathway to employment for everyone with a disability in all services
- ▶ OADS will continue to improve communication strategies to ensure families have information that they need through multiple methods (e.g., subscribed emails,

website, and plain language information) and provide consistent messaging to members and families.

- ▶ OADS will continue to advance awareness of the self-directed service option as a means of promoting personal choice and control over the delivery of waiver services, including who provides the services and how services are provided.
- ▶ OADS will continue to develop and implement discovery tools that can be used to guide and inform the Person-Centered Plan with a focus on valued roles, places in communities, skills, and interests, including Charting the Life Course.
- ▶ OADS plans to enhance and maintain advisory committees that are inclusive of all persons of disabilities, self-advocates, advocates, providers, and community members to address elements of quality improvement within the HCBS waivers.

Community Integration and Compliance with the HCBS Settings Rule

People with disabilities have been historically excluded from certain social interactions, employment opportunities, and educational environments. Community integration is a way to ensure that all people have access to the full spectrum of social, educational, and professional opportunities embedded within the existing community. This not only promotes the well-being of individuals but also increases the overall health of the entire community.

Planning for 2023-2024 includes recommendations from stakeholders for enhancing community involvement and membership. This includes planning for on-going adherence to the principles of the HCBS Settings rule intended to ensure that individuals receiving HCBS have full access to the greater community and can enjoy the benefits of community living. Additional detail is provided below.

- ▶ To help create opportunities for individuals, families, providers, and case managers to understand how individuals can be successfully engaged in non-disability specific community places in valued roles, OADS will add Social Role Valorization (SRV) resources and training information to the OADS website. OADS will also determine interest in a Maine SRV group, in conjunction with people who have an SRV background.

SOCIAL ROLE VALORIZATION

Social Role Valorization (SRV) is a set of ideas useful in addressing the marginalization of people in society by supporting them to have access to the same good things in life enjoyed by all people. SRV can be easily understood and implemented by individuals, family members and human service staff on all levels. In human services broadly, it taps into existing practices deeply rooted in social science research.

- ▶ OADS is continuing work to expand its webpage on Community Involvement by adding more resources, links, and tools useful for providers, members, and family members.
- ▶ OADS will offer training and individualized technical assistance to providers of Community Support, focused on how to help individuals better access their communities and begin a pathway to employment. This includes development of a virtual guide with options for curriculum, resources, tools and shared success stories and best practices that can be used by providers.
- ▶ To ensure continuing compliance with HCBS regulations, OADS will provide resources for providers on its webpage on Rights and Standards of the HCBS regulations in plain language, with useable examples such as fact sheets by services, templates for self-assessment, easy to use remediation activities, and ability to provide feedback. OADS will also provide avenues for providers and others to share best practices and lessons learned.

Increase Supportive Housing Options

People with disabilities have a right to live in their own homes in their communities but exercising that choice can be difficult. People with developmental disabilities need and want more options to live independently in their communities and for some, equal access to affordable and accessible public housing can help fill that need. A key strategy is to improve coordination between the housing and service systems, including MaineCare-funded HCBS that often fund the residential supports needed for successful independent living. OADS has been partnering with stakeholders to provide people using HCBS in Maine to enable more housing opportunities and expand staffing choices and

possibilities. To assist in these efforts, OADS recognizes the need to dedicate resources and expertise. Additional detail is provided below.

- ▶ OADS plans to establish a permanent HCBS Housing Specialist position in its office, tasked with developing a collaborative partnership between OADS and the Maine State Housing Authority to work toward systemic housing innovations statewide for people who use HCBS. It is anticipated that this position will initially be funded using ARPA funds. The individual in this position will also provide information and develop, update, and maintain a resources for people who use HCBS, family members, interested community members, service providers, and housing developers. These resources will be housed on OADS's website and would provide information regarding essential elements of housing and community life for people who use HCBS.

Implementation of Employment First Statute and Practice

People with disabilities should have the supports necessary from individuals and systems to enable them to find and keep community jobs based on their preferences, interests, and strengths, work alongside people without disabilities, receive comparable wages, and be free from workplace discrimination. OADS will work to implement the following stakeholder recommendations to achieve these goals.

- ▶ OADS will work with stakeholders to capture and highlight stories of individuals in waiver programs who are successfully employed in various types of employment in Maine. These stories will be widely shared with individuals, families, case managers/care coordinators and others.
- ▶ OADS will work with others including state agencies, individuals and families, agencies, advocates, and system groups to develop and share a consistent vision and awareness of employment possibilities.
- ▶ Ensure access to employment services for individuals in waiver programs that includes tracking of individuals on a path to work, employment outcomes, joint training and technical support to providers, and access to statewide services both through the state Vocational Rehabilitation programs and through the waiver employment services.

Strengthening Quality Assurance and Improvement Capacity

OADS has responsibility for protecting 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:** Peoples' needs are met
- ▶ **Inclusion:** People are included
- ▶ **Management:** Systems are effective and efficient

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

After several years, a mortality review committee has been established. The mortality review committee conducts comprehensive multidisciplinary reviews on preventable deaths, suspicious deaths, and serious injuries.

This committee includes public health officials, health care and human service providers, Disability Rights Maine, and others. A nurse, who is housed in the Center for Disease Control coordinates the committee and the reviews.

OADS efforts to assure compliance with the HCBS settings rule has also highlighted opportunities to address other gaps in quality assurance systems and capacity. OADS management is working on multiple aspects of provider approval and training. OADS and OMS have been working collaboratively to improve and streamline the MaineCare

provider enrollment process to ensure new providers and settings are fully aware of the HCBS Settings rule requirements and their service provision obligations for compliance from the start of services. OADS has also working to ensure that complete and up-to-date information on all providers is collected and maintained.

Over the last reporting period, OADS restructured and strengthened quality assurance and improvement capacity, building on previous years' efforts designating quality specialists and quality management supervisors to take the lead for quality management at the district level. OADS has created a full-time management position to oversee quality and training. To help guide continued work, OADS retained a consultant to review capacity for assuring and improving quality. OADS also convened a Quality Work Group in May 2021 to advise on plans to reform the quality assurance and quality improvement system, including the recommendations made by the consultant. The Quality Work Group included self-advocates, family members, guardians, providers, representatives of Disability Rights Maine, Maine's protection and advocacy agency, and staff members.

2021-22 FOCUS AREAS

As recommended by the consultant's report, work in 2021-2022 focused in two areas:

1. Public-facing quality information
2. Meaningful data the Department should be monitoring to address system quality

Activities for 2023-2024 focus on three levels of quality improvement:

The Individual Level

These recommendations focus on creating tools and systems for improving case management services, reporting, and other activities related to individual health and safety and quality of life.

The Provider Level

These recommendations focus on provider licensing and certification, provider enrollment into MaineCare, provider communities of practice, onsite provider visits, and publishing provider reports to inform consumer choice.

The System Level

These recommendations focus on clarifying quality assurance and quality improvement roles and responsibilities for staff; information sharing; strengthening IT systems; forming a mortality review committee; and forming an incident review for reviewing data to identify patterns and trends.

In moving forward with reforms, OADS makes efforts to take a proactive, positive approach to service quality, working constructively and supportively with providers. In addition to health and safety, improvement initiatives must also address quality of life issues of people served, including inclusion in the community and access to employment. Initiatives for 2023-2024 focus on data and data collection; oversight; workforce training; and creation of quality measurement for use by program participants, families, and other members of the public. Additional detail is provided below.

- ▶ OADS will continue to collect and evaluate comprehensive data on key components of service delivery at the individual, provider, and system level. This includes data on unmet needs for both waiver members and those on a waitlist.
- ▶ OADS will ensure quality measures include assessment for the extent to which effective training and other processes are in place to prevent sexual assault and to respond appropriately to sexual assault when it occurs.

- ▶ With continued stakeholder involvement, OADS will review program rules and regulations to ensure the efficacy of accountability structures and adjust rules or regulations to assure effective progress in quality.
- ▶ OADS will explore strategies for how to incentivize providers to deliver quality services, such as a ‘provider of excellence’ designation or program for public recognition of providers that demonstrate commitment to quality services.
- ▶ In addition to other initiatives to improve training and certification for Direct Support Professionals (DSPs) (see below, *Improving System Capacity and Access to Services*), OADS will work to ensure that data on quality measures is analyzed and addressed in core and continuing education curricula for direct care staff. Stakeholder recommendations include incorporating an emphasis on behavioral health and trauma informed care and training on preventative physical and mental health, that includes promotion of healthy eating, physical activity, and other health promoting activities.

Improving System Capacity and Access to Services

Maine continues to experience several ongoing system capacity issues that result in unmet need. A gap in needed services can have a negative impact on the quality of life for the people OADS serves. A shortage of direct support professionals can limit a person’s ability to work, maintain relationships, and participate in community activities. In a rural state like Maine, inadequate access to transportation can contribute to social isolation, with negative consequences for physical and emotional health.

OADS continues to address longstanding system capacity issues.

Maine does not currently use a nationally validated tool to ensure that the needs of individuals receiving services are identified fairly and accurately. Without such a tool, Maine lacks a reliable picture of the range and types of supports required by individuals served. This constrains system planning efforts, both regarding expanding existing service models and developing innovations. Using a standard measure of need would establish a rational process for tailoring services to complement and support each person’s abilities and goals for having a good life. Over the last reporting period, OADS worked with stakeholders to review existing assessment tools used in other states to identify the best fit for Maine. This initiative is on-going, and the Department anticipates

procuring an independent assessment vendor to help with analysis and data collection, with a goal of a new assessment implemented over the next several years.

Addressing the Waitlist for HCBS Waiver Services

One of the most significant challenges Maine faces is the waitlists for both HCBS waivers for individuals with IDD or ASD. Governor Mills took steps with the prior Legislature to address this by including funding in the Governor's budget for additional openings in §21 and §29. The fiscal years 2020 budget provided funding for an additional 362 people to be served under §29 and the 2020-2021 biennial budget provided funding for 167 previously unfunded spaces for §21. Additional funding to address the waitlists are also part of the 2022-2023 budget, providing 720 spaces on §29 and reserving 50 spaces on §21 to ensure that urgent needs can continue to be met. In addition, as discussed in Services and Programs, OADS ensures that a community case manager is offered to individuals on a waitlist. The community case manager then actively works to coordinate other available services while people are on the waitlist.

Under waivers granted in response to the COVID-19 public health emergency, OADS has had an opportunity to use telehealth services for services that would otherwise be provided in person. Based on this experience, OADS is exploring the continued use of telehealth to ensure access, when appropriate. Similarly, OADS has also increased the use of remote supports to minimize infection and to compensate for workforce shortages. OADS has found that some people prefer remote supports because they have more control over when to access them.

Strengthening the Direct Support Professional Workforce

Maine continues to experience a severe shortage of Direct Support Professionals (DSPs) who provide Home Supports, which includes daily assistance needs such as dressing and hygiene; Community Supports, including access to community activities and places; and Work Supports, including job coaching. Difficulties in recruiting and retaining workers can be at least partially attributed to competition from other industries, where the work is less stressful, or the pay is higher. COVID-19 exacerbated these challenges, and workforce shortages are currently wide-spread across service sectors.

Increasing reimbursement rates is one of the necessary strategies for addressing these challenges. Effective January 2021, Governor Mills raised MaineCare rates for many types of HCBS, accelerating higher rates initially planned for July 1, 2022,

and supporting providers in increasing pay for direct care workers to at least 125 percent of the state's minimum wage. In February 2022, the Department distributed \$116 million to home and community-based providers, bringing the total number of workers receiving bonuses to 20,925. An additional \$4 million was distributed in March 2022, bringing the total number of providers receiving funding to 354. Of the \$120 million, \$57 million is supporting providers of services for people with intellectual and developmental disabilities. Providers may use the funding to retain current workers or for recruitment bonuses to fill vacancies with new workers. The bonuses aim to address short-term health care worker shortages. The approximately \$120 million in bonus payments were available as part of ARPA funding and represent a major component of the Department's plan to improve access to high-quality services that help ensure Maine people can remain in their communities.

Additionally, the biennial budget for fiscal years 2022 and 2023 plans to invest \$90.6 million to increase MaineCare rates for HCBS waiver services for older adults and people with disabilities and brain injury. The supplemental budget would add another \$68.5 million, for a combined total of \$159.1 million. Should the supplemental budget proposal be enacted, spending on §21 would increase by an estimated 18.4 percent between fiscal years 2020 and 2023, which does not include the HCBS bonus payments.

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

OADS, working with DLC and the Office of Behavioral Health (OBH), launched the Direct Care and Support Worker Portability and Training Initiative during the last report period (2021-2022) to develop a streamlined training and certification system to support career progression, specialization, and cross-training. Key aspects of this project include the design of a competency-based training that reduces redundancy, facilitates access to

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

Transportation

For most parts of Maine, transportation is critical for getting to work, participating in community activities, and getting to medical appointments, the grocery store, and any number of other tasks. Unfortunately, public transportation options are often very limited and may not be the right choice for some people with IDD or ASD, if the right supports are unavailable.

When people accessing HCBS waiver services cannot access public transportation, it may be provided as part of a waiver service such as Home Support, Community Support, and Work Support. Or an individual might rely on a family member, neighbor, or friend for transportation. In addition, OADS is working with the Office of MaineCare Services to determine options available to cover non-emergency transportation services necessary to gain access to services covered under the waiver.

The federal government funds transportation through multiple programs, each with different limitations and priorities. As a result, many state agencies may have a role in shaping transportation resources, but limited ability to coordinate policies and resources to make meaningful change. In addition to MaineCare-funded transportation, the Department has several other contracts for transportation services funded through other programs. The Department wants to better align both the delivery and management of these programs.

In June 2021, the Department issued a report evaluating the quality of transportation services from those using them and the reasons why some eligible people do not use them. The report includes recommendations for better aligning and managing the delivery of transportation services across programs and review the way financing from the Maine Department of Transportation (DOT) impacts access to transportation for those served by the Department.

OADS, along with OMS and other DHHS agencies, will continue to explore alternatives for establishing more effective delivery of transportation services in Maine, addressing member and provider concerns to improve reliability of the service, improved service efficiency, and improved communication and information sharing. These

recommendations involve the need for consideration of structural changes that reflect short and long-term goals for administering the Department's transportation services, including MaineCare's Non-Emergency Transportation (NET) program providing services under the waiver programs administered by OADS.

Assistive Technology

With input from stakeholders, OADS has also explored options for using technology to help people remain independent, as well as options for advancing digital equity to support greater access to community life. Technology solutions can provide some people receiving services more privacy and autonomy while still providing important supports. Today, there are many innovations in technology that can help people receive care, work, communicate, enjoy everyday activities, and participate in community life. A key goal is to increase the system's capacity for providing people using HCBS timely assistive technology assessments and follow-up support. OADS plans to implement the following stakeholder recommendations and strategies in 2023-24.

- ▶ OADS plans to develop a website accessible to providers, family members and people using HCBS with resources and links to resources and webinars related to the use of assistive technology and remote support to create more opportunities for people using HCBS to live independently.
- ▶ OADS will develop trainings and ongoing technical assistance to providers, direct support professionals, and people using HCBS on safely using the Internet and social media to increase community connections. Training will also be developed on the rights of people using HCBS to technology and information access.
- ▶ OADS will coordinate with other existing resources within the state, as feasible, to develop and test innovative technologies that can be used to promote both a higher quality of life and greater independence for people using HCBS.

Statewide Behavioral Health and Support Services

Recent Improvements

OADS has made several improvements in recent years to services for adults with IDD who are in crisis or have other mental health needs. In 2019, Governor Mills proposed and the Legislature approved eight new community response worker positions for the OADS crisis team, bringing the total team size to sixty. The team operates statewide. It provides both telephonic and in-person support to individuals in crisis and operates four crisis houses.

In 2020, OADS began a partnership with the [National Center for START Services](#) at the University of New Hampshire (UNH) to provide ongoing clinical consultation and training to the crisis team. Consultation has included:

- ▶ Training for all crisis team staff
- ▶ Assessment and treatment of mental health symptoms amongst individuals with IDD
- ▶ Strengths-based, biopsychosocial case conceptualization
- ▶ Systemic consultation/systems linkage approaches
- ▶ Crisis prevention and intervention strategies
- ▶ Effective outreach strategies and active, positive engagement
- ▶ Developing a clinical educational team
- ▶ Formulating appropriate disposition recommendations
- ▶ Specific case consultation as needed
- ▶ Office hours availability

In 2021, the crisis services offered by OADS were made more transparent through adoption of [rules](#). Prior to 2021, crisis services were delivered under broader statutory authority alone. The process of rulemaking provided a direct opportunity for stakeholders to weigh in on those services. Also in 2021, community support workers on the crisis team were reclassified to recognize the increasing complexity and expectations of their roles.

These recent developments were necessary to improve longstanding challenges in the system, but the pandemic made clear that they are not sufficient. In order to obtain more input from stakeholders and prioritize the next phase of improvements, OADS contracted with the START program to engage with a range of stakeholders to get their perspective on system needs. The START program used a number of methods to obtain input in the summer of 2022, including an on-line survey, focus groups, and telephone interviews with families. Although the results of the START assessment represent the views of a relatively small sample of stakeholders and cannot be generalized, they do validate many of OADS' perceptions regarding system needs.

In Progress

In response to the START assessment, OADS is taking the following actions to address continuing needs of individuals with IDD who have mental health needs.

- ▶ OADS will extend its partnership with UNH to implement a pilot of the START model that includes IDD provider agencies so their staff can access training on mental health and IDD practices. To date, the START program's involvement in Maine has been limited to the state-operated crisis team, but going forward, training will be made available to provider agencies so they can also build their expertise and capacity.
- ▶ OADS is developing a Complex Behavioral Care Team (CBCT) pilot with Maine Behavioral Healthcare's Glickman Lauder Center of Excellence in Autism and Developmental Disorders. The goal of this pilot is to keep individuals with significant behavioral needs in their homes by providing them and their provider agencies with wrap-around clinical support.
- ▶ With the goal of decreasing inpatient hospital admissions, OADS will increase access to the Becket multimodal team. Becket offers a comprehensive, multi-disciplinary team that consists of a psychologist, psychiatrist, physician, occupational therapist, and others who specialize in working with individuals with complex needs. Upon completing an assessment, the team presents findings and recommendations to enhance support.
- ▶ OADS is working closely with the Department's Office of Behavioral Health and Office of MaineCare Services to ensure that individuals who have both IDD and behavioral health diagnoses will have access to outpatient services through

Certified Community Behavioral Health Clinics (CCBHCs), which are under development in Maine. CCBHCs are expected to be offered in all parts of the state and will help improve access to outpatient behavioral health services for everyone, including those with disabilities.

- ▶ OADS is working with the Office of MaineCare Services to implement a new Intensive Outpatient Program (IOP) service under Section 65 that is targeted to individuals with IDD and behavioral health needs. The new service was [adopted](#) by MaineCare in November 2022.
- ▶ OADS is implementing the Supports Intensity Scale (Sis-A ®), which we refer to as “A Path for ME,” based on a nationally validated individual needs assessment tool used in multiple states. The tool includes a behavioral health module, and OADS will test the efficacy of the tool as a potential trigger for enhanced behavioral health supports. An independent third-party vendor has been selected to administer the tool, and individuals will be invited to have voluntary assessments beginning early in 2023.
- ▶ OADS will lead a year-long stakeholder engagement to update the [process for development, implementation and monitoring of behavior plans](#). The process, outlined in OADS’ Chapter 5 rule (Regulations Governing Behavioral Support, Modification and Management for People with Intellectual Disabilities or Autism in Maine), was originally adopted in 1987. While many stakeholders are critical of the process and its outcomes for individuals, little consensus exists currently as to how it should be amended or replaced.
- ▶ OADS will undertake an analysis of the use among individuals with IDD of psychotropic medication, emergency departments, and hospitalizations for psychiatric reasons.
- ▶ In late 2022, OADS issued a competitive Request for Applications seeking proposals for innovative services to promote independence among persons with disabilities, including innovative approaches to supporting individuals with IDD who have mental health needs. Awards will be made in early 2023.
- ▶ OADS will continue to engage stakeholders in a continued analysis of the crisis services and supports programs. In 2023-2024, OADS plans to implement the following strategies.

Improving Transitions across the Lifespan

Multiple state agencies play a role in the lives of people with an intellectual disability or autism. Within the Department, OCFS provides services to children with developmental disabilities; OBH provides services, including employment services, to people with mental health or substance use disorders; the Office of Family Independence determines eligibility; and OMS sets policy and finances MaineCare-funded services. Outside of the Department, the Department of Education sets policy for the transition services provided by schools to children with disabilities. The Department of Labor provides vocational services to people with disabilities.

The Department of Corrections has a role when individuals served by the Department become involved in the criminal justice system and OADS works closely on a case-by-case level with the Department of Corrections to optimize outcomes for each person with an intellectual disability or autism who becomes involved in the criminal justice system.

Different constraints in policies, funding, and priorities can make aligning systems and programs across state agencies challenging at times, particularly when children with developmental disabilities transition from school to adulthood, and from developmental services provided through OCFS to adult services provided through OADS.

There are several long-standing structural challenges for parents and their children navigating this transition. First, there is mismatch between the services available to children and those available to adults. Access to adult services is limited to those with an intellectual disability or autism, while eligibility criteria for children's developmental services is more broadly defined. As individuals and families look to the future, they are faced with the challenge of learning about the different service options, finding out which they might be eligible for, and learning about how the level and type of support might be different in adult programs.

Although Medicaid allows a 30-day overlap in children's and adult case management services, planning for the transition takes much longer.

For those who are eligible for adult developmental services, the waitlist for HCBS services is another structural challenge.¹⁴ Although some people may continue to receive children's services while on the waitlist for one of the adult waiver programs, not all are able to transition directly from children's services to the adult HCBS waiver services. Alternative services may be provided in the interim, but some needed services may be unavailable. Another challenge is the limited access to case management services from the adult services system while still receiving case management services in the children's services. Without the help of a case manager in the adult system, it is difficult to learn about what adult services options are available, what services an individual is eligible for, what alternative services might be available while on a waitlist for services, and other details that must be addressed to ensure a successful transition.

During this past reporting period, several efforts have been underway to address these barriers and improve the transition process. LD 924¹⁵ directed DOE to establish a task force focused on reducing the barriers that inhibit young adults with developmental disabilities from accessing higher education and vocational opportunities. OADS has participated in this work. Building on past efforts, a group of staff from OCFS and OADS have also been meeting weekly since July 2021 to assess the current state of transition planning and recommend improvements moving forward. This group has also engaged experts from OMS, DOE, and DOL to inform planning.

Along with continued collaboration with DOE, the Department plans to use ARPA funding to implement a pilot program designed to provide regional supports focusing on transition issues and consistent engagement of key stakeholders (e.g., schools, families, and others) to improve communication and collaboration. A lack of training, time, and resources contributes to inconsistent approaches to transition. This pilot will address the lack of specialized case management services available to assist people during transitions and reduce the risk of disruptions and poor outcomes that can occur with a change or loss of services and supports. Plans for 2023-2024 include the following strategies.

¹⁴ OADS reserves up to four openings on §21 for individuals aged 18 to 21 transitioning to adult services who are receiving out-of-home services out of state.

¹⁵ See [PL 2021, Chapter 116](#), Resolve, To Establish a Task Force To Study the Coordination of Services and Expansion of Educational Programs and Vocational Opportunities for Young Adults with Intellectual or Developmental Disabilities or Acquired Brain Injury

- ▶ As a pilot, creating four transition liaison positions withing OCFS and OADS that have specific and exclusive focus on transitions. Plans for the Transition Services Pilot Program include establishing a full-time project manager to oversee transition staff and continue to facilitate and coordinate efforts to improve the transition process. These positions will assist in identifying cohorts of transition-age youth, provide transition case management support and implementation, triage cases for family-members/caregivers involving individuals without case managers, help facilitate access to state systems to ease application processes, provide training and education, and assist with systems-level reporting and monitoring.
- ▶ The Department has also initiated work on its Lifespan Project, which is exploring stakeholder interest and the feasibility of developing a service program designed to make sure people have the services they need as their needs and circumstances change, particularly as youth age into adults. The Lifespan Project could potentially eliminate the need to changing program based on age and provide more robust supports for youth focused on in-home supports, life skills, and employment services to better prepare people for adulthood.

TRANSITION SERVICES PILOT PROGRAM KEY GOALS

1. Streamlined eligibility process for MaineCare services
2. Reduced wait-times for services/case management during transition period
3. Improved youth and family/caregiver satisfaction
4. Connecting youth to employment and housing to maximize independence
5. Ensuring access to supports in the least restrictive and costly setting
6. Reducing poor outcomes that may result from gaps in care
7. Increased public information and awareness
8. Supporting implementation of a lifespan waiver

Innovation

Successfully delivering services requires constant consideration of opportunities for innovations that allow for greater individualization and flexibility. Funding under the ARPA has provided an unprecedented opportunity to explore innovative approaches to service delivery.

In August 2022, the Department issued a Request for Application (RFA) open to all providers of CMS-services in good standing. Through the RFA, the Department intends to provide one-time grant funding to approved applicants for the implementation of projects which are currently outside the scope of MaineCare services, that upon successful completion, comply with the HCBS waiver rules and related state and federal rules and regulations. Projects will be able to expand an existing service with new features or services to address a specific problem or provide services for a new population. Pilot projects are encouraged that address gaps in service to address transitions across the lifespan, peer support models, and independence-enhancing living options. Consistent with federal requirements, these approved funds may be used to supplement but not supplant existing services.

Applications were due by November 2022, and the Department plans to make multiple awards as a result of this RFA process, including partial awards, with a maximum award amount of \$500,000. The Department has applied priority scoring for projects which provide services in under-served geographic areas, specifically Aroostook, Franklin, Hancock, Penobscot, Piscataquis, and Washington counties. The Department anticipates issuing awards for a contract period beginning early 2023 and ending March 2025.

Appendices

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

§21 Comprehensive Waiver & §29 Support Waiver

Waivers §21 and §29 both offer a core set of services including home supports, work supports and community supports, in addition, §21 offers a more extensive array of services. For more information on this data, please see [Appendix B: Detail on Covered Services, Programs and Systems Support](#).

	§21	§29
Number of people served	3,276	2,339
Average age	45	34
Percent under 55 years old	69%	88%
Total expenditures	\$423,577,805	\$60,142,531

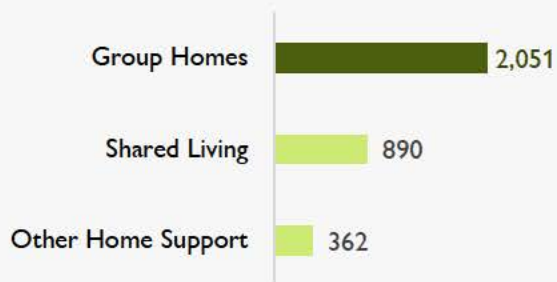
FY2021 expenditure data; number served as of September 30, 2021

§21 Waiver

COMPREHENSIVE WAIVER

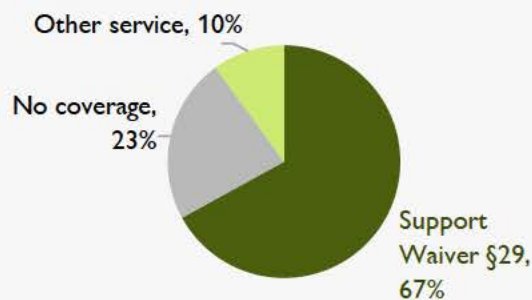
3,276 PARTICIPANTS

Most people using §21 services live in group homes.



2,028 ON WAITLIST

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



§29 Waiver

SUPPORT WAIVER

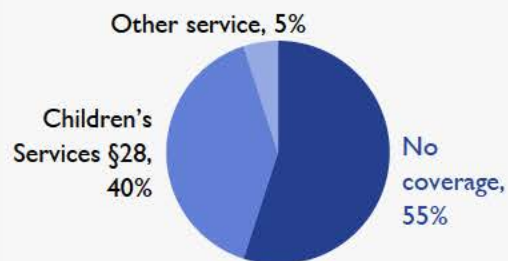
2,339 PARTICIPANTS

802 people on §29, approximately one-in-three, use shared living services.



218 ON WAITLIST

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



Note: Participant data from 9/30/2021; waitlist data from 9/30/2022

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

This appendix provides additional detail on the HCBS waiver programs, §21 and §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, §21 covers other services, including communication services, therapies, and crisis.

Table 1. Covered services under §21 and §29

COVERED SERVICES	§21	§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	x
Home Accessibility	x	x
Respite Services		x
Consultation Services	x	
Counseling	x	
Crisis Assessment	x	
Crisis Intervention Services	x	
Occupational therapy (maintenance)	x	

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

The most current and complete MaineCare expenditure data are from FY2020 and FY2021 due to delays in claims processing. Expenditure data from FY2022 will be included in future reports.

Table 2. Expenditures By Type Of Service, §21 And §29, FY2020 And FY2021

SERVICES	§21		§29	
	2020	2021	2020	2021
Assistive Technology Assessment	\$17,805	\$33,790	\$9,906	\$15,826
Assistive Technology Devices	\$48,312	\$98,480	\$34,810	\$56,670
Assistive Technology Transmission	\$10,988	\$22,508	\$8,362	\$16,562
Career Planning	\$18,770	\$78,981	\$24,642	\$80,577
Communication Aids	\$17,888	\$8,210	-	-
Community Support	\$35,259,061	\$23,534,033	\$24,388,449	\$17,444,911
Consultative Services	\$59,697	\$56,252	-	-
Counseling	\$396,204	\$891,933	-	-
Crisis Intervention	\$46,820	\$140,857	-	-
Employment Specialist Services	\$21,224	\$32,916	\$18,906	\$22,375
Home Accessibility Adaptations	\$4,218	\$30,082	\$21,173	\$15,477

SERVICES	§21		§29	
Home Support - Agency	\$323,953,324	\$336,881,541	-	-
Home Support 1/4 Hour	\$13,731,244	\$13,813,597	\$6,024,267	\$6,195,453
Non-traditional Communication Consultation	\$96,586	\$83,074	-	-
OT/PT/Speech Therapy	\$73,329	\$28,567	-	-
Respite Services - Per Diem	-	-	\$4,519	\$7,053
Shared Living	\$43,692,560	\$45,845,456	\$24,583,288	\$34,693,634
Specialized Medical Equipment	\$45,705	\$16,005	-	-
Waiver Services not otherwise specified	\$13,971	\$424,421	-	\$11,975
Work Support	\$1,758,797	\$1,557,103	\$1,378,807	\$1,582,017
TOTAL	\$419,266,502	\$423,577,805	\$56,497,128	\$60,142,531

Source: Maine Office of Aging and Disability Services

Table 3. Expenditures and Utilization for §21 and §29 HCBS Waivers, FY2020 and FY2021

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

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

Source: Maine Office of Aging and Disability Services

Table 4. Waitlist Status, September 30, 2022

	§21	§29
Waiver Participants	3,337	2,674
Waitlist	2,028	218
With Other Coverage	1,554	98
Without Other Coverage	474	120

Source: Maine Office of Aging and Disability Services

Most people on the waitlist with alternative sources of coverage are receiving services under another HCBS waiver, a PNMI, or through a Family Provider Service Option.

Table 5. Alternative Coverage While on Waitlist, September 30, 2022

Type of Alternative Coverage <i>MaineCare Benefits Manual Section Number</i>	§21	§29
Support Services for IDD/ASD HCBS Waiver (§29)	1,359	-
Children's Services (§28)	80	87
Private Non-Medical Institution (§97)	56	2
Family Provider Service Option (§96)	18	2
Elderly and Adults with Disabilities HCBS Waiver (§19)	18	2
Nursing Facility (§67)	4	-
Intermediate Care Facility for IDD (§50)	8	-
Adult Day Health (§26)	5	-
Other Related Conditions HCBS Waiver (§20)	3	-
Comprehensive Services for IDD/ASD HCBS Waiver (§21)	-	5
Brain Injury Services (§102)	2	-
Attendant Services (§12)	1	-
TOTAL	1,554	98

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 6. Number Served and Expenditures for Targeted Case Management, FY2021

Number Served	Expenditures
6,627	\$21,446,827

Source: Maine Office of Aging and Disability Services

The majority of people served under §21 receive services in a group home. The majority of those served under §29 receive other types of home support.

Table 7. Number Served and Expenditures by Type Of Setting and Waiver Program, FY2021

Type of Setting	§21		§29	
	# Served	Expenditures	# Served	Expenditures
Group Homes	2,051	\$337,130,086	-	-
Other Home Support	362	\$13,809,285	634	\$6,196,336
Shared Living	890	\$45,838,145	802	\$34,691,840

Source: Maine Office of Aging and Disability Services

Table 8. Communication Method for Contacting Crisis Intervention and Prevention, FY2022

Type of Contacts	Number
Phone	8,494
Remote (Zoom/Teams)	970
In Person	887
Email	556
Other	166
TOTAL CONTACTS	11,073

Source: Maine Office of Aging and Disability Services

Table 9. Reason for Contacting Crisis Intervention and Prevention, FY2022

Contact Reason	Number of Contacts
Individual Needs/Wants/Concerns	4,205
Wellness Check	1,696
Crisis Situation	1,105
Individual Support Team	1,023
Consultation: Provider unable to support individual needs	371
ER Visit	307
10-day Follow-up, Individual Support Team	275
24-hour ER Follow-up	264
24-hour Follow-up, Individual Support Team	232
90-day Follow-up, Individual Support Team	201

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

Source: Maine Office of Aging and Disability Services

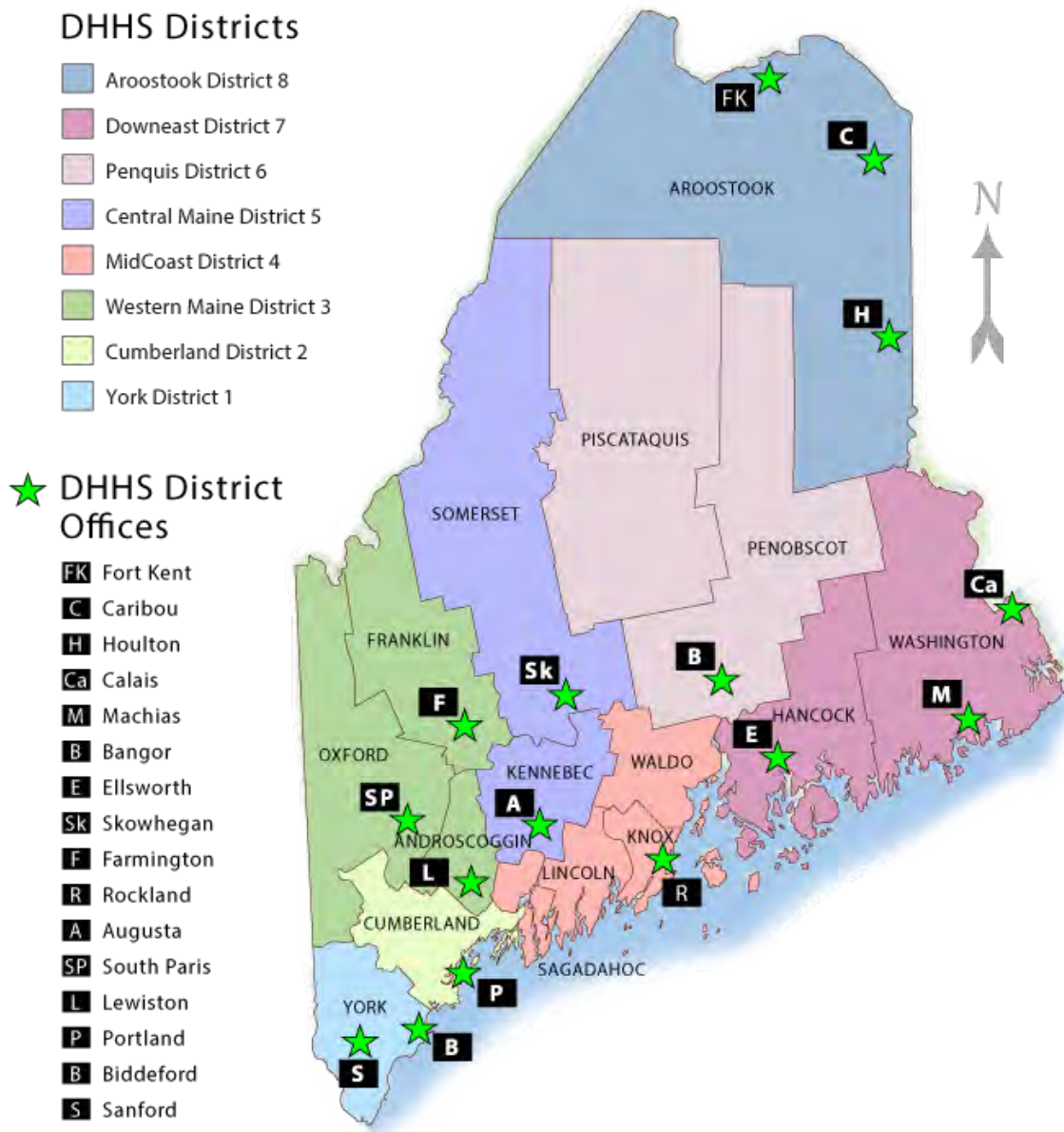
Table 10. Percent of Reports Involving Allegations of Abuse, Neglect, and Exploitation by Type, FY2022

Type of Allegation	Percent of Reports
Caregiver neglect	45%
Emotional abuse	20%
Physical abuse	15%
Financial exploitation	12%
Self-neglect	8%
Sexual abuse/sexual exploitation	7%
Exploitation-Other	1%

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

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

Figure 4. Map of DHHS Districts and Offices



To see this information in tabular form, please refer to [Table 11](#) on the following page.

Table 11. 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

Appendix D: Abbreviations

APS	Adult Protective Services
ARPA	American Rescue Plan Act
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
OBH	Office of Behavioral Health
OCFS	Office of Child and Family Services
PNMI	Private Non-Medicaid Institutional Services
TCM	Targeted Case Management

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