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Office of Aging & Disability Services

2021–2022 Biennial Plan for :

Adults with Intellectual Disabilities or Autism

Pursuant to MRS Title 34-B §5003-A(3)

2021



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Executive Summary

This plan describes the priorities of the Department of Health and Human Services in the upcoming biennium (July 2021 through June 2023) for the system of services and supports offered to adults with intellectual disabilities or autism.

Priorities for Service Improvement

2021-2022

The design of Maine’s home and community-based services (HCBS) waiver programs has not 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 group homes 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 their communities. New federal regulations governing HCBS waiver services established new standards for how services are provided. Under these rules, HCBS services may not be provided in a segregated setting and they must be provided in a way that protects individual rights and choice and promotes independence and community integration.

As described in this plan, in the next two years, the Office of Aging and Disability Services (OADS) will work with stakeholders to identify strategies for updating the HCBS waivers serving adults with an intellectual disability or autism, so services are shaped by the life and life goals of the person receiving services and are delivered in a manner that complies with federal rules governing home and community-based settings. Stakeholders will also advise OADS on improving quality assurance and quality improvement capacity, an effort essential to assuring the health and safety of the people OADS serves, as well as their quality of life.

In addition, OADS will continue to address longstanding capacity issues and the structural challenges to ensuring effective transitions from children’s to adult’s services.

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

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 disabilities or autism. OADS' mission is to promote the highest level of independence, health and safety for older adults and adults with disabilities throughout Maine, while safeguarding and protecting the rights of those served. OADS' 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). 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. The HCBS regulations incorporate ADA and other protections into the definition of home and community- based services and condition the federal government's share of Medicaid² costs on compliance with that definition.

Maine Statute Title 34-B § 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 programs for individuals with intellectual disabilities or autism while safeguarding and respecting their rights. This plan is submitted in fulfillment of those requirements.

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.

Compliance with the Home and Community-based Services (HCBS) Settings Rule

The Department is in the process of ensuring that all HCBS services comply with the federal HCBS regulations enacted in 2014. In this plan, these HCBS regulations will be referred to by their common name, the “HCBS settings rule.” However, the HCBS settings rule reaches beyond the settings in which services are provided to address the way services are delivered. 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.

Ensuring compliance with the HCBS settings rule is a significant undertaking. The first phase, in which providers conducted a preliminary assessment of their own compliance with federal HCBS settings criteria, is now completed. OADS has now begun the process of validating these self-assessments. Onsite validations are conducted by Disability Rights Maine, Maine’s protection and advocacy agency. Residential settings not selected for onsite validation are validated by completing Individual Experience Assessments (IEAs) with individuals receiving waiver services in that setting. These IEAs are completed by case managers and care coordinators. In addition, these settings undergo a mini desk level review by OADS staff. As of November 2020, 1,654 IEAs have been completed, representing 1,207 residential settings; 685 mini desk level reviews have been completed with 642 remaining. OADS plans to complete all IEAs and mini desk level reviews by the end of February 2021 and the validation process for residential settings by the end of 2021.

OADS has also begun providing technical assistance to help providers make the changes needed to bring their services and settings into compliance. After all needed changes have been made, providers will attest that the required remediation is complete and they are in compliance. When this process is complete for all providers, OADS will be responsible for ongoing monitoring and quality assurance.

As of November 17, 2020, 316 residential settings and 27 non-residential settings have been validated by Disability Rights Maine. OADS had sent approximately 300 findings reports to providers and received 206 remediation responses in return. Findings to date indicate that coming into compliance will require a substantial transformation for some providers. To help with this process, OADS has hired a subject matter expert to provide training and technical assistance.

This plan also describes further efforts to develop new systems, training, and other resources to help providers comply on an ongoing basis.

Maine has until March 17, 2023, to demonstrate compliance with these rules for settings serving waiver participants prior to March 17, 2014. In addition, all providers coming into service after that date must also be in compliance. Noncompliant services will lose federal funding, which pays almost two-thirds of the cost for Medicaid-funded services.

Implementation of Maine's transition plan is guided by the HCBS Stakeholder Advisory Committee.

Communication and Stakeholder Engagement

This plan describes a series of initiatives OADS is undertaking to improve services and supports. OADS recognizes that ambitious 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.

In the past two years, OADS has worked hard to increase transparency and access to information and engage stakeholders directly in systemic reform. In the summer of 2019, the Director of OADS, in partnership with the Maine Developmental Services Oversight and Advisory Board, engaged in a series of listening sessions in Portland, Bangor, and Lewiston, to hear from people receiving services, their families, guardians, providers, and other interested community members. These sessions provided vital feedback regarding systemic issues, concerns, and successes, which in turn, have shaped OADS reform initiatives described in this plan.

To move forward with these reform initiatives, OADS is taking on an ambitious stakeholder process involving 10 stakeholder groups to guide changes in policy and practice, as well as important structural reforms. Some of these efforts were suspended in the wake of the COVID-19 public health emergency, while others have continued virtually (See the following section on The Impact of COVID-19 for more information). However, OADS has restarted some of these efforts and anticipates that all stakeholder activities will be underway again in 2021. Additionally, OADS has contracted with the Developmental Disabilities Council to conduct focus groups and surveys to gather input from families, guardians, and individuals with autism.

OADS has also focused on improving communication and transparency. OADS has improved access to information about OADS' services on the Department's website. In addition, OADS publishes information on a quarterly 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 also holds quarterly provider meetings to address opportunities for improving service quality.

Of necessity, OADS has increased this communication effort in response to the COVID-19 public health emergency. Since the start of the pandemic, the Department has hosted a wide array of regularly scheduled stakeholder calls with different groups. These virtual stakeholder meetings provide an opportunity to share COVID-19 related information and resources and provide a forum for responding to questions, hearing concerns, and sharing best practices among those

participating in the call. These calls have also included multiple state agencies and offices, including the Maine Center for Disease Control (CDC), the Division of Licensing and Certification (DLC), and others to help providers understand CDC guidance and access needed resources. In addition, these stakeholder calls have been used to provide updated information on flexibilities allowed under public health emergency waivers issued by CMS.

OADS meets monthly with the Maine Developmental Services Oversight and Advisory Board, a statutorily formed board responsible for providing independent oversight over services and programs for adults with an intellectual disability or autism. Through monthly meetings, the Board provides OADS with oversight and advice on systems issues, with a focus on rights, needs, quality of life issues, the use of physical restraints, and abuse, neglect, and exploitation. Additionally, the Board monitors data, including data related to waitlists and persons served out of state as well as provides representation for the review of severely intrusive behavior plans and safety plans. In 2019, the Board partnered with OADS to conduct the series of stakeholder listening sessions described above.

The Impact of COVID-19

The COVID-19 pandemic has impacted every Mainer, with distinct impacts for people with intellectual disabilities or autism, particularly those residing in congregate settings. Some people receiving in-home services also experienced hardship, choosing to forgo in-home services to reduce exposure or 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.

The Department has worked closely with residential and in-home providers and community-based organizations to help them respond to the pandemic. To lower the risk to those receiving and providing services, the Department requested emergency authority from the Centers for Medicare & Medicaid (CMS) to make temporary changes to home and community-based waiver programs and other services. These changes were approved by CMS in May 2020 and include:

- Transitioning to telehealth services and permitting virtual person-centered planning and community and work supports.
- Increasing flexibility for authorizing services and updating plans.
- Modifying administrative requirements to enhance provider flexibility, especially in regard to the workforce shortage.
- Adding new services, such as Emergency Quarantine Service for individuals who have tested positive for COVID-19.
- Increasing limits on some services (e.g., the number of people that may live in a shared living arrangement, the number of hours for direct support factored into the rates for group homes).
- Increasing rates for some services (e.g., residential, respite and in-home services).

OADS has also developed and distributed resources and tools to support the safe delivery of services. Maine also leveraged available state and federal funding to address immediate needs arising from the pandemic.

While distribution of COVID-19 vaccines is underway, the danger of COVID-19 remains high. Staff at the Department continue to focus many of its available resources on addressing the needs of the public, providers, and other community partners impacted by COVID-19. Staff participate in national, regional, and statewide calls and meetings; lead and facilitate regularly scheduled outreach to a wide array of providers and stakeholders; issue guidance and policy modifications; and conduct web-based training on policy changes and practice recommendations. The Department also actively works with providers experiencing outbreaks.

Although OADS' focus remains on the short-term priorities created by the public health emergency, the pandemic has highlighted opportunities for improving services and systems. OADS has begun collecting data and information that will inform future changes brought on by what has been learned through these unprecedented times.

Services and Programs

The services and programs for adults with an intellectual disability or autism are different from many other programs administered by the Department. Services offered through OADS serve people age 18 to late adulthood, who may need anything from intermittent support to 24- hour care, and whose life goals and preferences are as varied as those of their non-disabled counterparts. To address this wide variation in need 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:

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.

- ▶ **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.

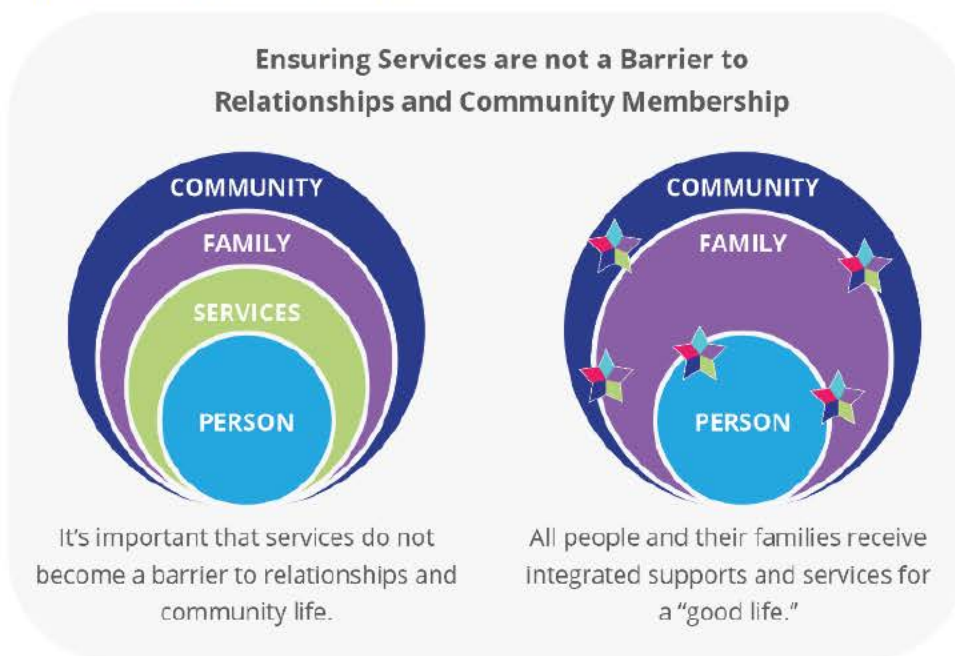
- ▶ **Complementary**

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 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.

This Framework also recognizes the limitations of services. 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. For example, a service provider might take a group of people to a public swimming pool. This service is "in the community" but if it is provided more for the convenience and preferences of the provider than the people served, it is unlikely to be furthering the personal goals of those served or affirming their membership in the community. Alternatively, that provider might provide support to a group of friends who want to go swimming together. In that case, the service becomes a way of deepening the friends' relationships to each other and going swimming becomes more of a typical, self-directed activity that others in the community enjoy on a regular basis.

As discussed below, OADS is using the Charting the LifeCourse Framework to redesign services to better help people with an intellectual disability or autism exercise the rights and freedoms promised them under the ADA.



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

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 Home and Community-Based Services (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 older adults and people with disabilities who would otherwise require institutional services to live as independently as possible in the community.

§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."

Maine's HCBS waivers are often referred to by their section numbers in the MaineCare Benefits Manual,³ §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,⁴ Work Supports, and Community Supports, which are direct support services,⁵ 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. 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

³ The MaineCare Benefits Manual is found at 10-144 C.M.R. ch.1: <https://www.maine.gov/sos/cec/rules/10/ch101.html>

⁴ 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

⁵ "Direct support" includes assistance with personal care and other tasks, exercising safe and responsible judgment, and promoting personal development and health and well-being.

other barriers to mobility, communication, participation in the community, and other activities. A side-by-side comparison of services covered under each waiver is provided in the Appendix B: Detail on Covered Services, Programs and Systems Support.

Findings from the early phases of implementing the HCBS settings rule indicate that some people receiving HCBS waiver services experience a loss of privacy or autonomy when it comes to phone and computer use; may not have control over their own money or electronic devices; may not have access to integrated employment options and may not have adequate access to community activities because of transportation barriers.

Employment Services

Over 1,200 individuals received employment-related supports and services in the past year. Maine continues to expand access to good jobs for individuals with a disability. Maine is an Employment First state. Under the Employment First Maine Act⁶ 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 is conducting several training events aimed at increasing the knowledge and skills of case managers and direct support professionals to successfully support individuals in obtaining and maintaining employment. Additionally, 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.

During the pandemic, OADS implemented a number of changes that have allowed people with intellectual disabilities or autism to continue to access employment-related services and advance or continue their employment. Providers have continued to provide Career Planning, Employment Specialist services, and Work Support remotely, 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 have been able to access accurate information about wages, benefits and unemployment services through Maine Medical Center's statewide Benefits Counseling Services.

⁶ 26 M.R.S.A. §§ 3401-3403.

Waiting Lists

Access to §21 and §29 waiver services is limited. States are allowed by the Federal government to cap enrollment on a waiver and keep 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 available, interim services are provided while the person waits. All eligible persons on the waiting list receive case management services under §13 of the MaineCare Benefits Manual. 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, 2020, 83 percent of the people on the waitlist for §21 with other services were receiving services under §29 (1,057 out of 1,281). Detail on the services 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. PNMI's are funded to provide clinical and personal care services⁷ and vary in size; they may serve up to 16 people.

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 Maine's public guardianship and conservatorship program, a statewide crisis prevention and intervention system, Adult Protective Services, and advocacy services provided by Disability Rights Maine.

Public Guardianship and Conservatorship

OADS acts on behalf of the Commissioner as the Public Guardian or Public Conservator representative for adults with an intellectual disability or autism. OADS assumes this role when an individual is found to be incapacitated by the Probate Court and no private party is willing or suitable. As a court-appointed guardian, OADS is responsible for making decisions on behalf of

⁷ "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.

the individual. OADS also helps those under public guardianship to make decisions about their life and how to safely live.

As of December 2020, 516 individuals receiving HCBS waiver services were under public guardianship or conservatorship.

Statewide Crisis Prevention and Intervention Services

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

OADS leadership has made significant improvements to the Crisis Services system. Notably, eight staff have been added 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. OADS has also procured a new phone system, which has been tailored to Maine's needs. The new system will allow OADS to respond to crisis calls effectively at all times and on a regional basis.

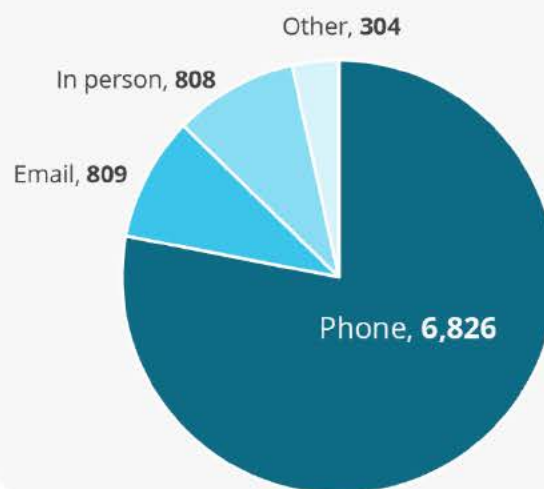
The most common method for contacting Crisis Services is over the phone, making up 78 percent of all contacts. Refer to Figure 1.

There were 31 different reasons for contact that ranged from individual concern (e.g., the person experiencing the issue made contact with the service) to coming from others who interact closely with the person (e.g., guardian concern) to medical settings (e.g., ER visit) to community-based interactions (e.g., wellness check or consultation). The most frequent reasons for contact were for

FIGURE 1

78% of contacts with Crisis Intervention and Prevention were over the **phone**

Number of contacts by communication method, FY2020



a general conversation (when an individual who may not be in crisis at that moment calls the Crisis Line to speak to a Disability Services Crisis Worker to discuss 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). For more detail, see Appendix B: Detail on Covered Services, Programs and Systems Support.

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. Protective services include social, medical, and psychiatric services necessary to preserve the adult's rights and resources and to maintain the adult's well-being.

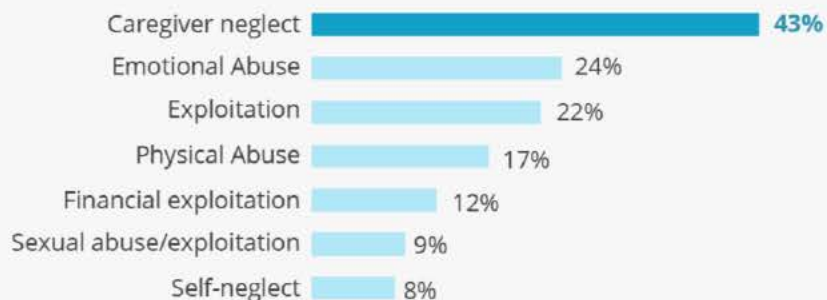
In July 2020, the APS program started using structured decision-making tools for conducting intake assessments and safety assessments. These tools enhance APS's ability to ensure consistent practice and documentation and enhance APS' capacity for collecting data and identifying trends. Also in July 2020, APS transitioned into the newly built data system,

Evergreen, to document all APS investigation activities and most public guardianship and conservatorship activities. (Financial account management remains in the legacy system and will transition in a future development cycle.) Evergreen offers many features not previously available in the legacy system, including assessment tools, enhanced search features, and updated data field options to support more accurate reporting and data analysis.

FIGURE 2

Caregiver neglect was the most reported reason for reports to APS for people receiving HCBS waiver services under §21 or §29.

Percent of Reports Involving Allegations of Abuse, Neglect, and Exploitation by Type, FY2019



In FY2019, APS Intake screened 10,504 reports (across all population groups, including individuals with an intellectual disability or autism). Of those, 1,680 (16 percent) involved clients receiving HCBS waiver services under §21 or §29. Forty- three percent of reports involved allegations of caregiver neglect, with emotional abuse following at 24 percent and exploitation at 22 percent. Refer to Figure 2. A total of 250 allegations involving individuals receiving services under §21 were substantiated; a total of 49 allegations were substantiated for those receiving services under §29.

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. In 2020, the Department contracted with MDDC and Autism Society of Maine to conduct surveys and focus groups of individuals with Autism Spectrum Disorder (ASD) and their families to gather their perspectives on the service system.

Targeted Case Management and Person-Centered Planning

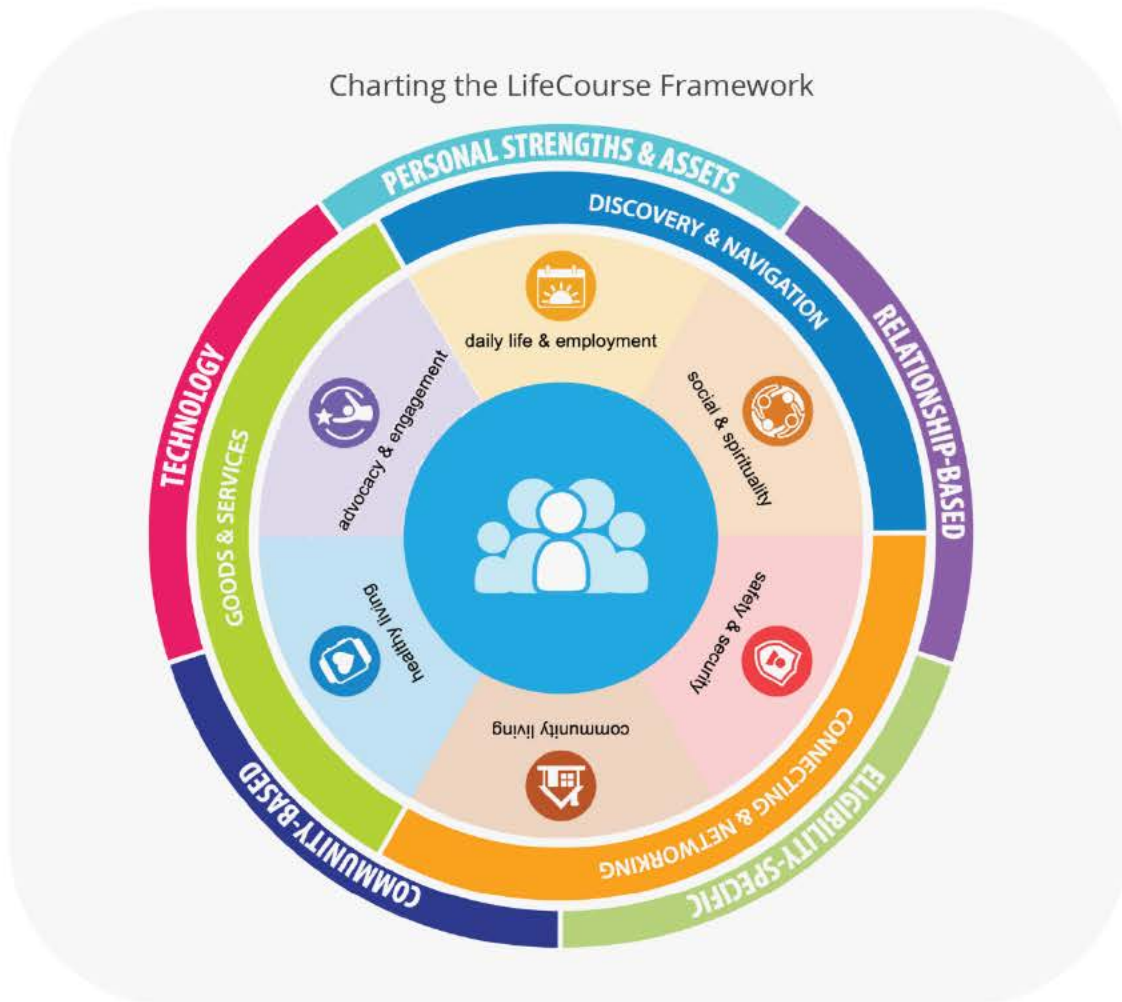
Case management and person-centered planning play central roles in ensuring that services are tailored to the personal goals and individual needs and preferences of the person served. All people with an intellectual disability or autism eligible for OADS services have access to case management and planning 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.

Today, case management services are provided primarily through 43 certified community-based targeted case management agencies. Previously, it was common for OADS staff to serve as both public guardian and as a case manager for the same individual. However, the HCBS settings rule requires that case managers be “conflict-free” – meaning they cannot have an incentive to steer their clients to make particular choices about services or service providers. Serving as both case manager and guardian created the potential that the case manager's responsibilities as guardian would unduly influence the types of choices an individual might be offered or allowed to make. Starting in 2017, OADS began transitioning case management services away from OADS staff. Today all people receiving MaineCare-funded targeted case management (99 percent of those served by OADS) are served by community-based case management agencies. The remaining one percent are people not eligible for MaineCare or people in settings where services are not reimbursable by MaineCare (e.g., they are incarcerated); this group receives case management services from OADS staff.

OADS designed the person-centered planning process to promote personal choice. However, as the Department moves forward with ensuring that the person-centered planning process is consistent with and reinforces the requirements of the HCBS settings rule, Maine has contracted with EconSys to provide subject matter expertise in updating the instruction manual that case managers use for conducting the person-centered planning process. The instruction manual will incorporate 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 is also premised on the idea

that service plans should be designed around an individual's vision for a "good life," with the services supporting the individual's efforts to achieve that vision. Charting the LifeCourse focuses on six life domains: Daily Life & Employment, Community Living, Healthy Living, Safety & Security, Social & Spirituality, and Advocacy & Engagement.⁸



Charting the LifeCourse Nexus, LifeCourseTools.com. Used with permission.

⁸ More information about Charting the LifeCourse can be found at Charting the LifeCourse Nexus, www.lifecoursetools.com

Quality Assurance and Compliance

While the design of services and programs and the person-centered plan might all align on paper, OADS' work is not complete unless OADS can assure that services are provided in a way to support health and safety and the personal preferences and aspirations of the person receiving services.

Responsibility for assuring quality is embedded throughout OADS, the Office of MaineCare Services, and other units within the Department, as well as throughout the delivery system, including providers and case managers. From the start, OADS intake and eligibility specialists provide information about rights and protections. OADS is responsible for reviewing and addressing all allegations of abuse, neglect, and exploitation, as well as all Reportable Events.⁹ OADS also monitors trends and identifies systemic issues. Significant findings are addressed at the executive level within OADS and the Office of MaineCare Services.

Case managers have a critical role to play in ensuring and monitoring quality. Case managers provide information about rights and protections annually. Case managers 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.

As discussed in Plans for 2021-2022, OADS is working to improve the design of programs as well as quality assurance and improvement capacity in order to strengthen OADS' ability to assure that individual goals and preferences are met.

⁹ 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 2021-2022

In addition to OADS' continued work on HCBS settings rule compliance, in the next two years OADS will focus on several other priorities, continuing to address long standing challenges and taking on new goals for improving systems and services. Plans for addressing these priorities are discussed below.

Priorities for Improving Services 2021-2022

As described above, OADS is committed to improving the lines of communication with stakeholders, and stakeholders will be guiding much of the work described in this section. Although not discussed in detail in this plan, a separate reform work group will be formed to develop recommendations for improving the accessibility of information (e.g., by using plain language); developing an ongoing stakeholder feedback loop, and other efforts aimed at improving transparency and communication. OADS' other priorities for 2021-2022 include:

Community Membership

OADS has convened a Community Membership Reform Work Group to identify strategies to promote full inclusion of people with disabilities into communities. The work group will address enhanced person-centered planning, self-advocacy, family support, community support, and implementation of Maine's Employment First statute. In addition, this group will identify 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 will explore 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.

Quality Assurance

In partnership with the Quality Work Group and informed by a consultant's recommendations, OADS will continue to strengthen quality assurance and quality improvement capacity.

System Capacity and Access to Services

OADS will continue to address longstanding challenges in the service delivery system, including waitlists, workforce shortages, limited access to transportation, and limited access to dental services.

Interagency Coordination to Improve Outcomes

OADS will continue ongoing efforts to improve coordination of services for individuals served by multiple agencies, or people transitioning from one service system to another.

Community Membership

In the previous year, OADS heard from stakeholders who asked for more choices that can change and adapt to people's needs as they progress through the natural stages of life, and a better planning process that starts with a conversation about life goals rather than service needs. Some people expressed their desire to be able to work and socialize with friends and choose to live with friends. In response to these voices, and as part of the work to ensure that the delivery of HCBS waiver services is consistent with the HCBS settings rule, OADS leadership launched the Community Membership Reform Work Group to advise OADS on how services need to be changed in order to promote greater inclusion in the community, through employment, access to community resources and places, self-advocacy, person-centered thinking, supported decision-making, and implementation of the HCBS settings rule.

The Community Membership Reform Work Group includes self-advocates, family members, guardians, providers, advocates and OADS staff members. Their work began in 2020 and will continue into 2021. OADS believes these efforts will help Maine prepare for significant systems transformation focused on improving outcomes related to person-centeredness, self-direction, individualization, inclusion, and quality in the future.

This work group will develop recommendations on how to expand choices for individuals and their families and move toward a system designed around individual needs. Their work has four areas of focus, listed below.

► **Community Support**

OADS has asked the Community Membership Reform Work Group to develop recommendations for education and training and technical assistance to ensure that community membership is a central tenet of all services. These resources will be targeted toward multiple audiences, including individuals receiving services, families, providers, communities, case managers, and others.

► **Employment First**

Shortly after the Employment First Maine statute was enacted, stakeholders identified a number of needed reforms for full implementation to occur. The Community Membership Reform Work Group has been asked to recommend tools and strategies for expanding access to employment and self-employment and ensuring that the Employment First Maine statute is effectively implemented for individuals with an intellectual disability or autism.

► **Person-Centered Planning, Self-Advocacy, Family Support, and Engagement**

The Community Membership Reform Work Group will develop recommendations for education and training to ensure that individuals and family members are driving the person-centered planning process, that the planning process is focused on the individual's life goals, community membership and building relationships.

► **Ongoing Compliance with HCBS Settings Rule**

The work group will develop recommendations for how OADS can monitor compliance with the HCBS settings rule on an ongoing basis and sustain implementation of the reforms. These recommendations will focus on the need for education, training, and mentorship for providers, as well as educational strategies for individuals and family members.

Innovation

With the guidance of the Innovations Work Group, OADS is exploring strategies for redesigning the two HCBS waivers serving adults with intellectual disabilities or autism. This initiative will use the Charting a LifeCourse Framework to inform efforts to ensure that services better conform to the lives of the people served rather than requiring people to sacrifice personal choice and self-determination in order to get the services they need.

The design of Maine's HCBS waiver programs have not 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 who were transitioning out of Pineland, which at the time was a state-operated institutional setting for people with an intellectual disability. The people living in Pineland were largely segregated from the community and many did not have the skills and experience to live successfully in the community, or family and friends ready and able to provide the type of supports they needed to do so. As a result, §21 was designed to fill many of these gaps by providing services in a group home and relying on workers to serve in roles that might otherwise have been served by family or friends.

Today, many younger people with an intellectual disability or autism have had very different life experiences, having attended public schools, participated in community activities, and developed important relationships and roles in the community. As a result, many people transitioning to adult services have very different expectations for how they want to live their lives. Many younger adults may wish to continue to live with their family, or they may want to live on their own or with a friend in their own home or apartment and with supports of their choosing.

In 2007, OADS created §29 to increase access to waiver services for people who did not need group home services. However, the two waivers have created artificial limitations on access to certain types of services, creating an incentive for people to apply for §21 waiver services instead of §29. As a result, §29 has become a temporary strategy for meeting the needs of people on the waitlist for §21. As of September 30, 2020 of the 2,276 people served under §29, 46 percent (1,057) were on the waitlist for §21. To ensure that access to §21 goes to those with the greatest needs, OADS manages the waitlist by prioritizing first those in need of Adult Protective Services, or those at risk for abuse, neglect or exploitation.

A lifespan waiver is designed to make sure people have the services they need, as their needs and circumstances change. For example, a younger adult might choose to remain at home with family or move into their own apartment, if the right level of in-home supports is available. Over time, plans can be put in place in anticipation of a change in needed supports as an individual ages. Currently, Maine's waivers do not provide this type of flexibility.

When available in-home supports are not sufficient to allow family members to work or attend to other responsibilities, many families have no option but to apply for group home services under §21.

In order to address these challenges, OADS would like to expand the range of housing options available to people receiving services under the waiver, so that people may choose their own living situation and who they want to live with; and explore innovative ideas for helping people to finance private housing. For example, one option might be to have a revolving loan account for down payments for people buying their own home or providing rental subsidies for people renting their own apartment. In addition, OADS would like to explore options for redesigning shared living arrangements. For example, currently people needing services might look for a placement in a shared living provider's home. This model could be reversed so that a shared living provider might find a placement supporting friends or a couple who want to live in their own place. OADS is tapping the expertise of the Maine Coalition for Housing and Quality Services and the Community Housing of Maine to inform this work. The Coalition has been an instrumental partner providing ongoing feedback in OADS' reform efforts.

Successfully redesigning the HCBS waivers will require other important innovations that will allow for greater individualization and flexibility. OADS will build off work led by Maine's Developmental Disabilities Council, to explore new ways of incorporating self-direction into HCBS waivers so that people will have greater control over how, where, when and what types of services are provided and by whom.

Self-direction provides greater control over how, where, when and what types of services are provided by whom.

In order to successfully implement a lifespan waiver, OADS needs to implement a standardized assessment tool. 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. OADS plans to review existing assessment tools used in other states to identify the best fit for Maine.

OADS would also like to explore 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 may provide people receiving services more privacy and autonomy while still providing important supports including behavioral supports to help avoid crises. With the guidance of stakeholders, OADS will also continue to focus on improving Crisis Services, with the goal of identifying additional strategies for enhancing the effectiveness of Crisis Services.

Moving forward with reforms this ambitious requires substantial stakeholder involvement, including people who use services, family members of people who use services, service providers, other provider agencies, and OADS staff members. OADS has convened the Innovations Work Group to guide this work. The Innovations Work Group is an umbrella for several other subgroups that will focus on specific reforms (e.g., self-direction or housing). OADS is committed to working with these stakeholders to make sure that any redesign of Maine's waivers merits the trust and confidence of those who need services and their families and guardians.

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, 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.

In 2017, the Office of the Inspector General (OIG) within the U.S. Department of Health and Human Services issued a report finding that Maine had not fulfilled its obligations for handling critical incidents involving individuals served under §21 residing in group homes. One source of concern were flaws in Maine's Reportable Event system. OADS has implemented a new Reportable Events system which addresses OIG's concerns. Currently OADS is in the process of transitioning to the new Evergreen Data System (Evergreen). OADS anticipates the transition to Evergreen will be complete by the end of 2021. When fully implemented, OADS anticipates that Evergreen will also strengthen quality assurance and improvement capacity for capturing timely, accurate and critical individual, provider and systemic information that will help OADS identify problems as they occur as well as trends over time.

OIG was also concerned about the absence of a mortality review committee for reviewing deaths occurring among people served under the waivers. The mortality review committee would conduct comprehensive multidisciplinary reviews on preventable deaths, suspicious deaths, and serious injuries. OADS is continuing to work on forming a mortality review committee that could include public health officials, health care and human service providers, Disability Rights Maine, and others if funds are available for a nurse to coordinate the reviews. As of this writing, a Maine Center for Disease Control Public Health Nurse position, which would be responsible for forming and overseeing this committee, is in the Governor's biennial budget.

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

OADS is in the process of restructuring and strengthening quality assurance and improvement capacity. In the past year, OADS has designated quality specialists and quality management supervisors to take the lead for quality management at the district level. OADS has also created a full-time management position to oversee quality and training. While OADS will have to manage these resources carefully given the many competing demands for their time, this team has already played several important roles. For example, this team has supported the assessment process for ensuring compliance with the HCBS settings rule.

District staff have also used the OADS reportable events system to monitor COVID-19 testing, exposure and outbreaks, as well as service interruptions and rights violations for individuals served under the HCBS waivers. Staff have identified training needs for internal staff and providers, including training related to oversight and monitoring, HCBS compliance, reportable events, and infection prevention control.

To help guide their work, OADS retained a consultant to review capacity for assuring and improving quality. The consultant has recommended improvements at three levels:

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.

Starting in 2021, OADS will convene a Quality Work Group to advise on plans to reform the quality assurance and quality improvement system, including the recommendations made by the consultant. The Quality Work Group will include self-advocates, family members, guardians, providers, representatives of Disability Rights Maine, Maine's protection and advocacy agency, and staff members.

OADS is reforming its quality management and improvement system at the individual level, the provider level and at a system level.

In moving forward with these reforms, OADS plans to take a proactive, positive approach to service quality, working constructively and supportively with providers. In addition to health and safety, OADS must also address quality of life issues of people served, including inclusion in the community and access to employment.

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. A lack of dental care can contribute to poor oral health as well as overall health.

OADS continues to address longstanding system capacity issues.

► Waitlist for HCBS Waiver Services.

One of the most significant challenges Maine faces is the waitlists for both HCBS waivers. The Governor took steps with the prior Legislature to address this by including funding in her budget for additional openings in §21 and §29. The Governor has also included in her budget for the upcoming biennium sufficient funding to add 30 additional people to §29 each month. The Department also reserves space in §21 for high priority individuals who are at risk of abuse or neglect. 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 would like to explore the continued use of telehealth to ensure access, when appropriate. Similarly, OADS has also increased the use of remote supports as a way 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.

► Direct Support Professional Workforce.

Maine also continues to experience a shortage of direct support professionals (DSPs) who provide Home Supports, which includes daily assistance with dressing and hygiene, addressing

challenging behaviors; 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. However, COVID-19 has exacerbated these challenges. Some DSPs have left their jobs to protect their own health, while others have been diverted to taking care of their children when schools have relied on remote learning, childcare capacity has been reduced, and summer camps have been closed.

OADS has recently sharpened the focus on the challenges facing this workforce and will partner with other departments and agencies to develop strategies for enhancing and streamlining training and pathways for career advancement to encourage workers to stay in the field. In 2021, OADS will explore cross-training for DSPs as well as specialized training in order to promote retention. Expanding professional development offerings will allow staff to learn new skills and information and enhance their competence to provide high quality services and supports.

In addition, the Governor has proposed a significant rate increase in her biennial budget for Section 21 and 29 services, to ensure adequate pay for front line workers. This comes following temporary rate increases provided during the pandemic.

► **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 an intellectual disability or autism, 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 2019, the Department

conducted a review of transportation services funded through the Department and identified opportunities for better quality and safety standards in provider contracts. In addition, the Department has engaged an evaluator to gather information about the quality of transportation services from those using them and the reasons why some eligible people do not use them. The evaluator will assess the Department's options for better aligning and managing the delivery of transportation services across programs and review the way financing from Maine's Department of Transportation impacts access to transportation for those served by the Department.

► **Dental and Dental Sedation**

The general population in Maine has limited access to dental services. However, for people with an intellectual disability or autism, the challenges are even greater and not unique to Maine. In general, there is a shortage of dental providers willing to use sedation or work with patients who might present behavioral challenges. Access to specialized providers is also limited. OADS maintains multiple contracts with dental providers around the state including small practice providers in rural areas and larger clinics in Portland and Bangor. OADS also monitors annual physicals and dental exams, documenting unmet needs.

Improving Service Coordination Across State Agencies

Multiple state agencies play a role in the lives of people with an intellectual disability or autism. Within the Department, the Office of Child and Family Services provides services to children with developmental disabilities; the Office of Behavioral Health provides services, including employment services, to people with mental health or substance use disorders; the Office of Family Independence determines eligibility; and the Office of MaineCare 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.

In some cases, coordination across state agencies can be challenging. Sometimes different constraints and priorities make aligning policy too challenging. However, even if policy can be aligned, the staff

OADS will continue to work with the Office of Child and Family Services to help children transition from children's developmental services to adult services provided through OADS.

resources needed for overseeing implementation or funding for needed services might not be available.

In spite of these challenges, many efforts at coordination are successful. For example, OADS works with the Department of Corrections when people with an intellectual disability or autism become involved in the criminal justice system. For a variety of reasons, people with developmental disabilities are at greater risk of arrest than people without disabilities although they are not more likely to commit a crime. Once in jail or prison they are at greater risk of being victimized. Without appropriate supports and protections, time spent in jail or prison can also prompt negative behaviors that further worsen their situation. On a case-by-case basis, OADS works closely 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.

OADS also continues to work with the Office of Child and Family Services (OCFS) to help children with developmental disabilities transition from school to adulthood, and from developmental services provided through OCFS to adult services provided through OADS.

Parents and children transitioning from children's to adult services confront several structural barriers.

There are 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. Children benefit from

Maine's Early and Periodic Screening, Diagnosis and Treatment (EPSDT) program (§94 of the MaineCare Benefits Manual), which requires MaineCare to cover medically necessary services identified through Maine's Bright Futures program, including rehabilitative services, which could be paid for by MaineCare but are not currently covered under the Medicaid state plan. Access to EPSDT services ends after age 21. As families look to the future, they are now 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.

As discussed earlier, for those who are eligible for adult developmental services, the waitlist for HCBS services is another structural challenge.¹⁰ 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. While alternative

¹⁰ 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.

services may be provided in the interim, some needed services may be unavailable, potentially resulting in negative consequences and setbacks. For example, for parents who work or are otherwise unable to provide the level of support during this interim period, a gap in needed services and supports may lead to a health and safety risk. In addition, starting no later than ninth grade, schools begin preparing children for the transition to adulthood, helping them set goals for what comes after school. For those with educational, employment and other community-based goals, a gap in access to needed supports may stall or even reverse progress.

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. Individuals transitioning from children's services to adult services may be eligible for up to 30 days of overlapping case management services from both the child and adult systems. While 30 days of overlapping services may be sufficient to effectuate transition once plans are in place, planning for the transition itself takes much longer than 30 days. 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 all of the other details that must be addressed to ensure a successful transition.

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

OADS is committed to working with OCFS to improve transitions on a case-by-case basis. In addition, OADS would welcome the opportunity to participate in system-level conversations about how to address the structural challenges that make transition so difficult for so many.

Conclusion

People with intellectual or developmental disabilities are served by multiple agencies with different funding, goals, and policies. The landscape in which OADS and its partners, clients, and advocates, are doing this work is continuously changing. Funding through the American Rescue Plan Act of 2021 to support HCBS services will expand and augment much of the work outlined in this plan. All of these efforts will help Maine continue to improve the services and quality of life for individuals with intellectual disabilities or autism.

Appendices

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

Maine's Home and Community-Based Service (HCBS) waivers:
§21 ("Comprehensive Waiver") and **§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](#).

	§21	§29
Number of people served	3,252	2,276
Average age	45	35
% under 55	69%	87%
Total expenditures	\$418,624,801	\$56,362,072

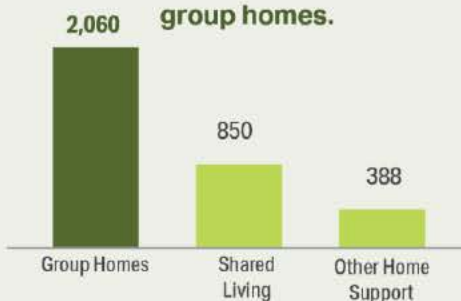
FY2020 expenditure data; number served as of September 30, 2020

§21 Waiver

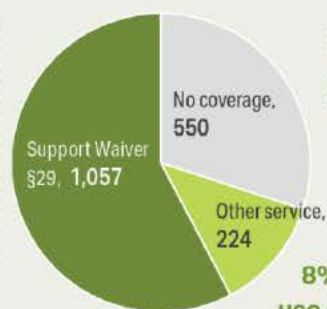
COMPREHENSIVE WAIVER

3,252 §21 Waiver PARTICIPANTS

Most people using §21 services live in **group homes**.



1,831 People on the §21 Waiver WAITLIST



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

8% of people on the waitlist use **Children's Services** (§28)

§29 Waiver

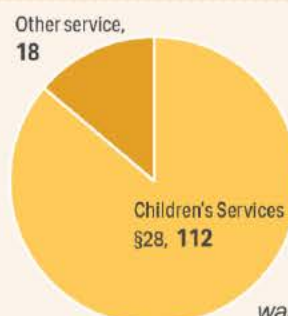
SUPPORT WAIVER

2,276 §29 Waiver PARTICIPANTS

Of people using §29 services, most received **other home supports**.



303 People on the §29 Waiver WAITLIST



The majority of people on the waitlist with **other coverage** receive **Children's Services** (§28)

173 people are on the §29 waitlist without other coverage

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.

Covered Services under §21 and §29

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

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

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

Expenditures by Type of Service, §21 and §29, FY2019 and FY 2020

SERVICES	§ 21		§ 29	
	FY19	FY20	FY19	FY20
Assistive Technology	\$12,253	\$15,451	\$6,498	\$9,906
Assistive Technology - Transmission	\$6,472	\$10,988	\$7,041	\$8,312
Assistive Technology Devices	\$23,239	\$47,181	\$20,121	\$34,810
Behavioral Health Counseling	\$336,404	\$393,135	-	-
Career Planning	\$8,718	\$18,770	\$15,113	\$24,642
Communication Aids	\$33,284	\$17,888	-	-
Community Support	\$44,962,667	\$35,205,943	\$31,757,596	\$24,364,652
Consultative Services	\$86,425	\$96,397	-	-
Crisis Intervention	\$250,425	\$46,820	-	-
Employment Specialist Services	\$28,640	\$21,224	\$25,644	\$18,906
Home Accessibility Adaptations	\$7,618	\$4,218	\$5,199	\$21,173
Home Support Agency	\$294,407,208	\$323,445,520	-	-

SERVICES	§ 21		§ 29	
Home Support 1/4 Hour	\$12,960,401	\$13,697,905	\$6,103,158	\$6,020,391
Mental Health Assessment	\$53,539	\$58,153	-	-
OT Maintenance	\$97,985	\$73,329	-	-
Respite Services Per Diem	-	-	\$3,536	\$4,519
Respite Services 1/4 hour	-	-	-	-
Shared Living	\$39,527,149	\$43,654,636	\$16,231,858	\$24,469,767
Specialized Medical Equipment	\$9,552	\$45,705	-	-
Work Support	\$2,213,667	\$1,757,561	\$1,509,810	\$1,384,995
Waiver Services not otherwise specified	-	\$13,971	-	-
TOTAL	\$395,025,648	\$418,624,801	\$55,685,574	\$56,362,072

Expenditures and Utilization for §21 and §29 HCBS Waivers, FY2020

EXPENDITURES AND UTILIZATION		
For §21 and §29 HCBS Waivers, 2020		
	§ 21	§ 29
Number of People Served	3,252	2,276
Total Expenditures	\$418,624,801	\$56,362,072

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

Waitlist Status, September 30, 2020

WAITLIST STATUS		
September 30, 2020		
	§ 21	§ 29
Waiver Participants	3,252	2,276
Waitlist	1,831	303
With Other Coverage	1,281	130
Without Other Coverage	550	173

Alternative Coverage While on Waitlist, September 30, 2020

Most people on the waitlist with alternative sources of coverage are receiving services under another HCBS waiver, or are receiving services in an ICF-IID, a nursing facility, or a PNMI.

ALTERNATIVE COVERAGE WHILE ON WAITLIST		
September 30, 2020		
Type of Alternative Coverage	Waitlist	
MaineCare Benefits Manual Section Number	§ 21	§ 29
Support Services for IDD/ASD HCBS Waiver (§29)	1,057	-
Children's Services (§28)	101	112
Private Non-Medical Institution (§97)	59	2
Family Provider Service Option (§96)	22	7
Elderly and Adults with Disabilities HCBS Waiver	17	5
Nursing Facility (§67)	10	1
Intermediate Care Facility for IDD (§50)	7	-
Adult Day Health (§26)	5	1
Other Related Conditions HCBS Waiver (§20)	2	-
Comprehensive Services for IDD/ASD HCBS	-	2
Brain Injury Services (§102)	1	-
TOTAL	1,281	130

Number Served and Expenditures for Targeted Case Management, FY2020

All people eligible for developmental services have access to case management services. The majority (99 percent) receives targeted case management services financed through MaineCare.

Number Served and Expenditures for TARGETED CASE MANAGEMENT, FY2020	
Number Served	Expenditures
13,025	\$15,133,799

Number Served and Expenditures by Type of Setting and Waiver Program, FY2020

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.

Number Served and Expenditures by TYPE OF SETTING AND WAIVER PROGRAM, FY2020				
Type of Setting	§ 21		§ 29	
	# Served	Expenditures	# Served	Expenditures
Group Homes	2,060	\$323,445,520	-	-
Other Home Support	388	\$13,697,905	702	\$6,020,390
Shared Living	850	\$43,654,636	574	\$24,469,767

Communication Method for Contacting Crisis Intervention and Prevention, FY 2020

COMMUNICATION METHOD for Contacting Crisis Intervention and Prevention	
Type of Contacts	Number
Phone	6,826
Email	809
In Person	808
Other	304
TOTAL CONTACTS	8,747

Reason for Contacting Crisis Intervention and Prevention, FY 2020

REASON for Contacting Crisis Intervention and Prevention	
Reason for contact	Number
General conversation	2,161
Wellness check	1,240
Community outreach	935
Phone outreach	699
Individual Support Team	663
Crisis situation	492
Other	408
Consultation	293
Individual concerns	238

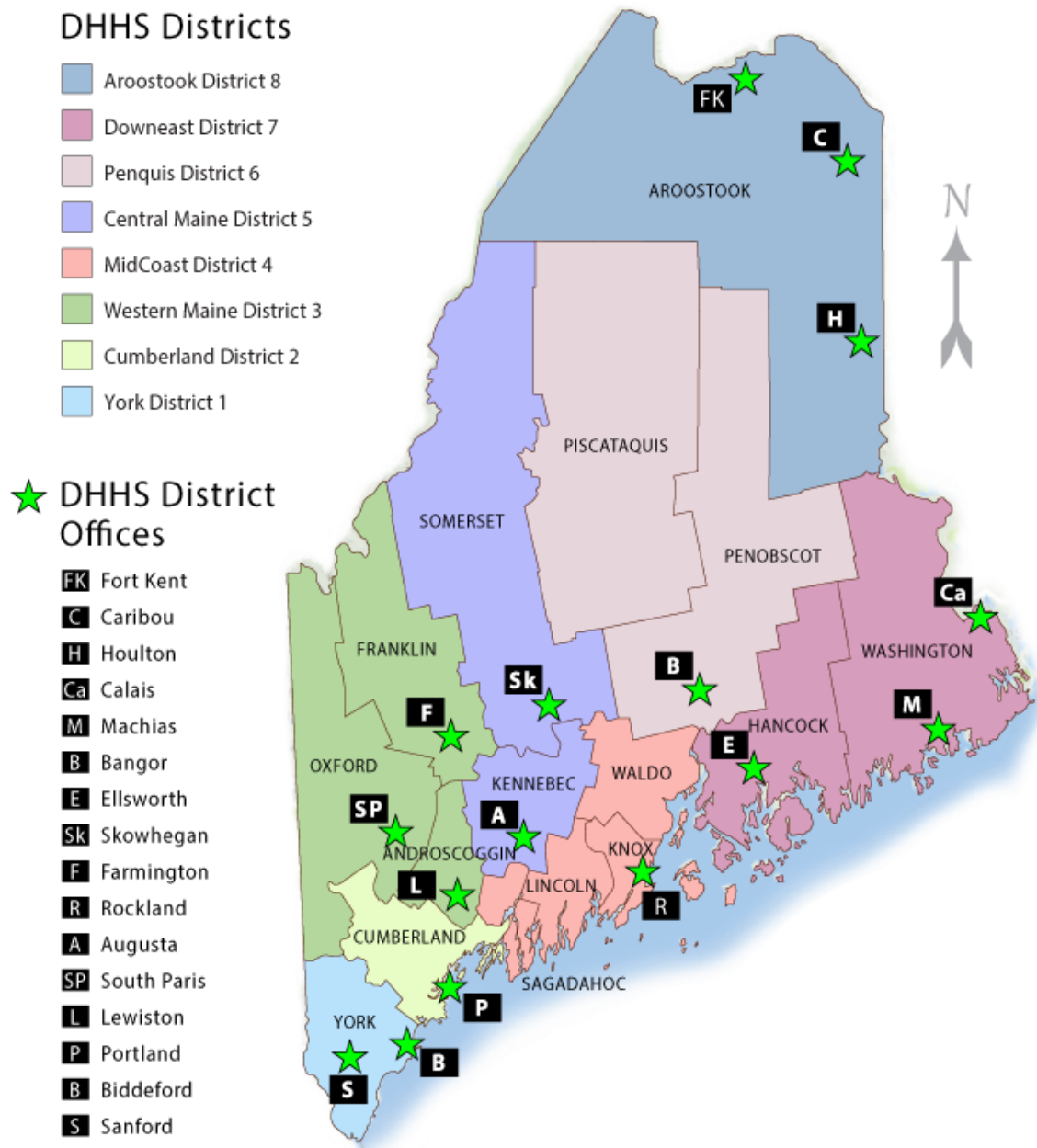
REASON for Contacting Crisis Intervention and Prevention	
10-day follow up, Individual Support Team	217
ER visit	215
24-hour follow up, Individual Support Team	199
90-day follow up, Individual Support Team	137
24-hour ER follow up	125
Client elopement	110
Individual needs	101
Agency concerns	91
Recurring pattern	76
Emergency situation	75
10-day ER follow up	72
Individual wants	64
Individual stuck in hospital ER	50
Police involvement	45
Scheduled Individual Support Team	38
Guardian concerns	33
Medical needs	32
Hospital visit	14
Behavior management plan	12
Home visit	5
Program visit	5
Community visit	3

Note: Total contacts and Total Reason for Contacting may not be the same as one contact may have more than one "reason for contact" associated with it.

Percent of Reports Involving Allegations of Abuse, Neglect, and Exploitation by Type, FY2019

Percent of Reports Involving ALLEGATIONS OF ABUSE, NEGLECT, AND EXPLOITATION BY TYPE	
Type of Allegation	Percent of Reports
Caregiver neglect	43%
Emotional abuse	24%
Exploitation	22%
Physical abuse	17%
Financial exploitation	12%
Sexual abuse/sexual exploitation	9%
Self-neglect	8%

Appendix C: DHHS Districts and Offices



Appendix D: Abbreviations

APS	Adult Protective Services
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
EPSDT	Early and Periodic Screening, Diagnostic, and Treatment
HCBS	Home and Community-Based Services
ICF-IID	Intermediate Care Facility – Individuals with Intellectual Disabilities
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
OIG	Office of the Inspector General
PNMI	Private Non-Medicaid Institutional Services
TCM	Targeted Case Management

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