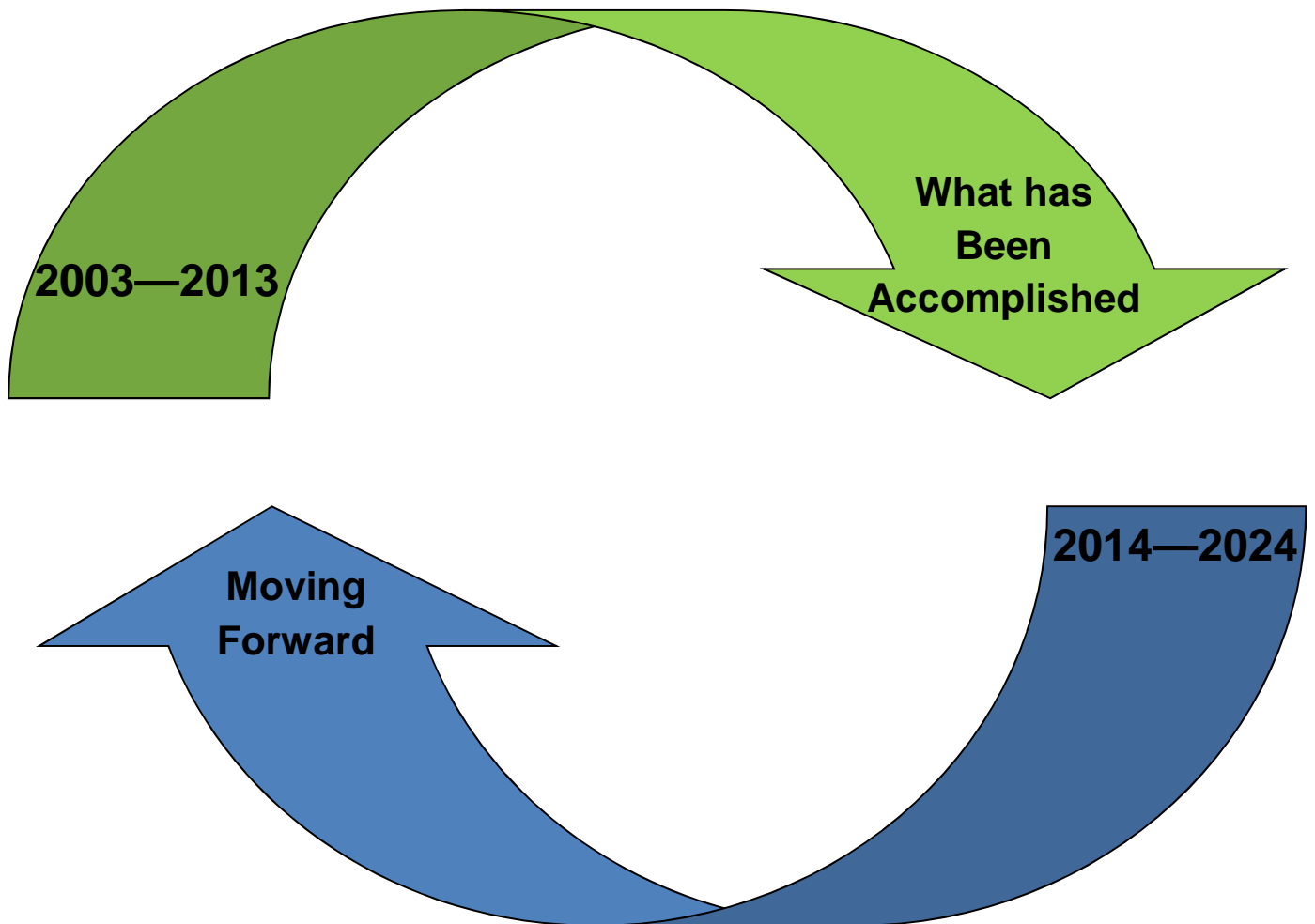


Maine Department of Health and Human Services
Office of Aging and Disability Services

Olmstead Roadmap for Change

Update for Developmental Services



Contents

Vision and Values	1
Introduction	2
 Part 1: What Has Been Accomplished, 2003-2013	 5
Consumer Voice and Organized Consumer Advocacy	5
Choice and Control.....	8
Person-Centered Services	11
No Wrong Door	13
Coherent System of Services.....	15
Responsive Service Coordination	16
Funding and Planning	18
Home- and Community-Based Service Waivers	20
Wait Lists.....	24
Availability of Direct Care Providers	26
Quality Services	30
Integrated, Accessible, Affordable Housing.....	31
Jobs.....	36
 Part 2: How We Move Forward, 2014 – 2024	 1
Introduction	1

Office of Aging and Disability Vision and Values

Mission:

We offer the highest level of independence, health and safety to older and vulnerable adults, and adults with disabilities.

Vision:

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

Values:

- Be centered on the person and focus on strengths and abilities
- Support each person to make their own informed choices
- Promote respect of adults and their valued roles within their communities
- Provide opportunities for quality employment that pays a fair wage and benefits
- Maximize opportunities for independence and self-sufficiency
- Provide quality case management services including conflict-free person centered planning
- Support and encourage family, friends and neighbors to help meet the individual's needs
- Ensure health and safety while promoting choices for new growth and development
- Build a coordinated, streamlined service and support system using resources wisely

Source: Maine DHHS, Aging and Disability Services. Service & Support Planning: Vision and Values. 2012. <http://www.maine.gov/dhhs/oads/disability/planning.shtml>¹

Introduction

In 1999, the United States Supreme Court issued its landmark decision in *Olmstead v. L.C. ex rel. Zimring*, requiring states to provide services to individuals with disabilities in the most integrated settings appropriate to their needs. In rendering its decision, the Supreme Court encouraged states to develop comprehensive plans for placing qualified disabled individuals in less restrictive settings. Maine undertook this work through a collaboration between State departments, consumers, family members and advocates. This broad array of stakeholders, known as the Workgroup for Community Living, was charged with *developing a coherent plan, across departments and programs, to make certain that the State is providing services to people with disabilities in the most integrated setting appropriate to the needs and preferences of the individual.*²

The Workgroup released its final plan, titled Roadmap for Change: Maine's Response to the *Olmstead* Decision, in 2003. The product of three years' collaboration by the Workgroup, the Roadmap delivered a broad, detailed set of recommendations aimed at building on Maine's strong foundation for community integration of people with disabilities. The vision of the Workgroup—*All of us together in community with equality in rights and dignity, in pursuit of happiness and fulfillment*³ guided the group's effort and shaped the recommendations. The Roadmap details some 100 specific recommendations in all the important domains of a person's life, with a particular focus on improving access to community services, housing, transportation, and employment, as well as improving inter-departmental coordination. As a whole, the Roadmap sets out a framework to guide the development of public systems to serve people with disabilities living in communities. It also reorients the emphasis for individuals to move from institutional care to home- and community-based services and supports.

Now a decade out from the publication of Maine's Roadmap, the Department of Health and Human Services is issuing this report as an update to the initial plan. This particular report focuses solely on the status of services for individuals with intellectual disabilities or autism served by the Office of Aging and Disability Services / Developmental Services (OADS/DS) within DHHS. It is not a comprehensive review of the progress made by the State, or even inter-departmental efforts. Rather, it is a more targeted look at what has been accomplished by OADS/DS over the past decade and the challenges that still lie ahead for increasing community integration for people with intellectual disabilities or autism.

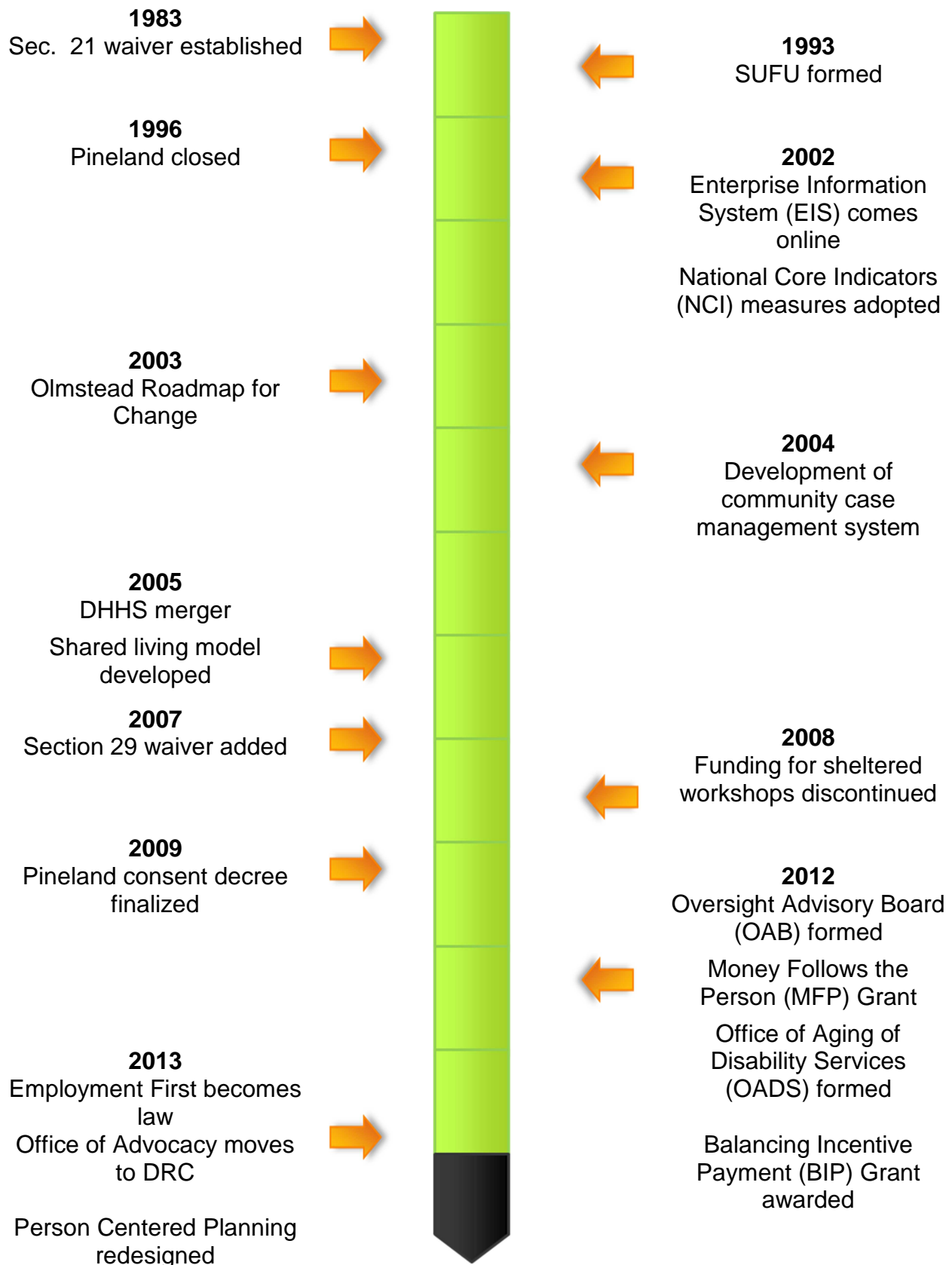
This report comes in two parts, the first of which is a comprehensive status update. The Department gathered information from a wide array of sources in order to track progress against the original recommendations outlined in the 2003 Roadmap for Change: Maine's Response to the *Olmstead* Decision.⁴ This portion of the report is organized around the fourteen categories of recommendations laid out in the original Roadmap.

OADS/DS has made a great deal of progress on many of the categories, and still has ways to go to improve the system of services to enhance community integration for people with intellectual disabilities or autism. As noted in the 2003 Roadmap, Maine has been moving in the direction of community integration for many years. The closure of Pineland was a significant impetus for the development of the community-based system. Maine was one of the early states across the nation to close its state institution for people with intellectual and developmental disabilities. Similarly, Maine's establishment of a comprehensive Home- and Community-Based Services waiver program for individuals with developmental disabilities in 1983 was another milestone in building a community-based system that doesn't rely on institutional placement and improves services for people with disabilities. Those two significant events predate the timeframe for this report, but are clearly markers which set the direction for increased community integration for people with intellectual and developmental disabilities.

OADS/DS has continued to make significant decisions which have enhanced the efforts for community inclusion. Closing the State-run sheltered workshop and making the policy decision not to fund sheltered work demonstrated the State's strong commitment to work for people with disabilities in the most integrated settings. OADS/DS has also diversified and expanded its service system, adding, among many other things, a Supports Waiver to allow individuals capable of more independent living to thrive in the community.

The second part of this report details the Department's plan for continuing to strengthen community integration efforts over the coming decade. The plan touches upon several key areas, among them improving employment outcomes, building a better transition process for eligible youth moving to the adult service system, reducing wait lists for services, and improving access to health and dental care.

While much has been accomplished there continue to be plenty of challenges. This review of progress has spurred new conversations and new thinking about the directions for future efforts. The Department invites comment from our stakeholders, which will play a critical part in shaping our future direction together.



Part 1: What Has Been Accomplished, 2003-2013

Consumer Voice and Organized Consumer Advocacy

At the very beginning of the 2003 Roadmap for Change; Maine's Response to the *Olmstead Decision*,⁴ the state is encouraged to seek out voices of people with disabilities and support consumer participation in policy-making and program development. Thirteen specific recommendations for improving consumer input and participation are offered, including recommendations for organizing consumer advocacy and increasing consumer leadership, advocacy supports and trainings. OADS/DS has made some progress on many of the recommendations and will continue to work on others.

Speaking Up for Us (SUFU)

Speaking Up for Us is Maine's self-advocacy network for people with intellectual disabilities and autism. First organized in 1993, SUFU trains and supports consumers to speak up for themselves in local, state, and federal policy arenas as well as in situations, such as Person-Centered Planning (PCP) meetings, where individual services and rights are at stake. SUFU provides a critical function by assuring that consumers have the skills, supports, and confidence to advocate for their interests at the individual and policy levels. SUFU is a member of Self Advocates Becoming Empowered (SABE), a national organization working for the full inclusion of people with developmental disabilities. OADS/DS supports SUFU through an annual contract. See SUFU website for more detailed information <http://sufumaine.org/>⁵

SUFU is a key resource for peer support and learning. The organization provides training and education aimed at enhancing individuals' abilities to advocate for themselves. Specific training programs range from Self-Advocacy and ADA Rights in the Community to skill-building programs on how to be an effective leader and/or a speaker. Developing leadership skills is a special priority area for SUFU, and the organization works with members to build leadership qualities through a variety of experiences. SUFU also holds regular conferences where members determine the topics and workshops based on the issues that are important to them. SUFU is a member of Self Advocates Becoming Empowered (SABE), a national organization working for the full inclusion of people with developmental disabilities. See <http://www.sabeusa.org/> for more information.⁶

OADS/DS senior staff are regularly present at SUFU workshops and attend SUFU meetings and conferences to hear directly from self-advocates about their concerns, suggestions and questions. SUFU representatives are consulted prior to major policy

and programmatic changes, with OADS/DS regularly seeking SUFU input and feedback on key issues. This two-way communication between OADS staff and SUFU is an important feedback loop to help assure that the services and supports offered meet the needs of the people served.

Consumer Participation

OADS/DS supports consumer participation in Departmental policy development using several strategies. In addition to contracting with SUFU, OADS/DS strives to ensure that written materials are available in plain language format and are accessible to a wide range of people-served. In partnership with MaineCare, all rules and communications are screened for readability. The Muskie School has also provided technical assistance in developing plain language materials. OADS/DS reimburses self-advocates for travel expenses related to participation in DHHS or OADS/DS approved meetings and/or events. These strategies help to reduce communication and financial barriers to participation.

Consumer Voice

Individuals are encouraged to register dissatisfaction with the Department's services, decisions, and/or providers using the OADS/DS's grievance process. OADS/DS regularly publicizes its grievance process to ensure that individuals are aware of their rights to file grievances. Every notice communicating an OADS/DS service decision contains information on the grievance process.⁷ Likewise, OADS/DS requires service providers to not only post notice of the Grievance Process in common areas but regularly remind individuals of their grievance rights and train all staff on the process. Additionally, OADS/DS offers a guide to the Grievance Process on its website, which outlines for consumers, family members and guardians how to proceed if they are unhappy with their services. Documents on the website include information about what a grievance is, who can help, the timeframe for solving problems, and levels of grievance up to the formal administrative hearing. Links to relevant statute and forms are included. The Grievance Process is an important mechanism for allowing consumers and their families to provide feedback on individual experiences. User-friendly forms and more information can be found at

<http://www.maine.gov/dhhs/oads/disability/ds/grievance/home.html>

Consumer Input

OADS/DS meets quarterly with the following advocacy groups:

- The Developmental Disabilities Council,
- The Developmental Services Oversight and Advisory Board,
- The Disability Rights Center,⁸ and
- SUFU.

These well-established linkages help ensure that consumers' voices are heard in the policy-making process and that problems with existing programs and policies are quickly brought to light.

The Maine Coalition for Housing and Quality Services (CHOM),⁹ a parent-led advocacy organization based in Portland, focuses on housing and quality services for people with intellectual and developmental disabilities. Comprised of self-advocates, family members, guardians and providers, this group meets regularly to advance important change initiatives. OADS/DS staff attend the meetings to provide information and solicit feedback on policy and program updates. In 2010, a subset of this group initiated ideas to redesign the service delivery system for people with intellectual disabilities and autism. Called the Continuum of Care model, this new service model puts the person at the center and examines the transition to adulthood with a goal of community inclusion maximizing natural supports within the community. The Continuum of Care Committee's work resulted in a whitepaper in 2011 and the development of legislation and action steps. OADS/DS is working collaboratively with CHOM as they redesign the service system to be more flexible and responsive to individual needs and preferences.

Change for Advocacy Office

Maine has long maintained a system of independent advocates to assist individuals with intellectual disabilities and autism in vindicating their rights. The Office of Advocacy, historically located within Maine DHHS (and the Department of Behavioral and Developmental Services prior to its merger with the Department of Human Services), was moved in 2013 to the Disability Rights Center, an independent non-profit organization that serves as Maine's protection and advocacy organization for people with disabilities. This move allows for a more independent relationship between the Office of Advocacy and OADS/DS and gives more autonomy to the consumer voice. As noted in the 2003 Work Group's recommendations, independent advocacy groups are necessary in order for consumers, family members, providers, and other stakeholders to challenge the State's positions without jeopardizing an organization's funding. The advocacy functions now conducted at the Disability Rights Center are partially funded through a contract with the State, but the Disability Rights Center is largely funded through federal grants and private donations. The Disability Rights Center's core mission is to protect individual rights and promote systems change.

Choice and Control

Self-determination was a dominant theme in the recommendations produced by the Work Group for Community Living and they identified policy and practice recommendations aimed at increasing consumers' control over their lives, and choices in services and supports. Specifically, the Work Group highlighted:

- Expansion of self-directed services
- Individual budgets for service purchases to meet their needs
- Independent employment management services
- Development of intermediate supports for people who don't want all the responsibility of self-direction.
- Development of standards for surrogate decision makers
- Strategies to reduce forced medications and involuntary hospitalization

OADS/DS has focused a great deal of attention in this area with significant policy changes that dovetail with many of the recommendations identified in 2003. Additional areas remain which continue to need attention.

Supporting Individual Success

Supporting Individual Success is currently a major initiative of OADS/DS. The aim of this initiative is to better match consumers' needs to resource allocation and continue to build a system that is person-centered and community oriented. Through these efforts individuals will get the services they require, no more and no less. And the system will be realigned to be more fair, efficient, sustainable and responsive to individual needs.

Individual standardized assessments are a central part of this effort. Trained interviewers use a standard assessment tool (the Supports Intensity Scale or "SIS,"¹⁰ which was developed by the American Association on Intellectual and Developmental Disabilities) to assess the support needs of individuals with intellectual and developmental disabilities served by the office. The results of those assessments are used to inform the Person-Centered Planning process and, in the near future, will be linked to resource levels. At the Person-Centered planning meeting individuals will have their assigned budget which they can use to purchase what they need from an array of services and providers.

The Human Services Research Institute (HSRI) has been a partner in this effort for the past four years. They analyzed expenditures and services for those individuals who received a SIS assessment prior to June 2013 in order to better understand how services, expenditures and assessed needs are currently aligned. In brief their study

found that the SIS could be used to develop a resource allocation model in Maine. In addition the study allowed Maine to be placed in a national context. When compared to other states, Maine's population has somewhat lower scores on key SIS indicators and uses more residential habilitation services than other states. Their findings, published in a report dated June 2013, can be found at

<http://www.maine.gov/dhhs/oads/disability/ds/sis/documents/Analysis-Expenditures-HSRI-Report.pdf>.¹¹

Using the findings, HSRI and OADS/DS have developed resource levels which take into account the individual's assessed needs, residential options and service packages that address those needs. In the future, individuals will be assigned to a level depending on the severity of their assessed need and living situation. At annual planning meetings individuals will know their funding level and will be able to choose services and supports to best meet their needs within their funding level and based on DHHS/OADS and CMS rules. Individuals will have much more control over the services they choose to meet their support needs as opposed to a one-size fits all approach of service delivery. This significant OADS/DS initiative holds a great deal of promise for transforming the current service system into one in which individual consumers have more control over their lives, and choices in their service packages.

See "Supporting Individual Success" section on the OADS website for further details on the initiative <http://www.maine.gov/dhhs/oads/disability/ds/sis/index.shtml>.

As part of this effort OADS/DS has undertaken a thorough analysis of the existing service system with an eye toward building a more flexible and responsive individualized system. This past summer through November 2013, OADS/DS staff led twelve separate discussions with a wide variety of stakeholders in order to elicit input regarding the Service Array. Participants were asked to comment on which services were working well and what services were either missing or inadequate. Data were collected and analyzed to inform future waiver amendments and other changes to help build a more flexible array of services to meet individual needs and preferences. As OADS/DS moves forward in re-designing the service system this information will continue to inform changes.¹²

Behavior regulations revised

In 2010, OADS/DS formed a Behavioral Regulations Committee¹³ in order to revise the regulation governing behavioral treatment for individuals with intellectual and developmental disabilities (Maine Regulation 14-197 C.M.R. Ch. 5). Among other things, this regulation outlines the process for approval of behavior management plans for individuals with intellectual and developmental disabilities, and implements Maine

Part 1: What Has Been Accomplished, 2003-2013

law regarding the Rights of Maine Citizens with Intellectual Disabilities or Autism at 34-B M.R.S.A. §§ 5601 *et seq.*

The Committee's overall goal was to improve Maine's system of monitoring and approval for behavioral treatment, behavioral management and safety plans in order to increase accountability and transparency. It focused on revising regulations so that they would reflect best practice by reducing the systemic use of restraint through increased use of positive behavioral supports, documented functional assessments, psychiatric medical support plans, and other clinical input. This has been a substantial effort and one that will result in significant revision to these regulations.

The membership of the Behavior Regulations Committee consisted of representatives from provider agencies, the Disability Rights Center, the Maine Psychological Association, the Consumer Advisory Board, and crisis workers, advocates, and other representatives from DHHS. Throughout the process the Committee also invited other stakeholders to participate and provide comment. The Committee met several times during this period and gathered extensive materials on best practices and policies from states, including New Mexico, Ohio, Vermont, and Washington.

Thirty-six attendees representing a broad array of stakeholders participated in this event including the Consumer Advisory Board, the Autism Society of Maine, the Maine Psychological Association, the Disability Rights Center, the Children's Center, the Center for Community Inclusion and Disability Studies, Speaking Up for Us in Maine, Maine's Developmental Disability Council, provider agencies, Maine's Office of Child and Family Services and OADS/DS met in June 2010 to provide input. Members facilitated a series of focus groups on five topic areas: *positive supports, environment and communication; medical treatment and medications; mental health and trauma; restrictions of rights (allowed/prohibited); and procedural requirements and review structure*. After a period of analysis and review the Committee used the information gathered to develop draft regulations.

The Behavioral Regulations Committee reconvened these stakeholders in a follow-up meeting in November 2010 to review the draft regulations and gather additional feedback. Their feedback was reviewed and analyzed and used to develop the latest version of *Draft Regulations Governing Behavioral Support, Modification and Management for People with Intellectual Disabilities or Autism in Maine*.

In 2011 the Behavioral Regulations Committee established a hierarchy of review for the use of safety devices for persons with developmental disabilities. Those devices are defined by 34-B M.R.S.A. §5605(14-C) and distinguished safety devices under that law from mechanical supports, as that term is used in 34-B M.R.S.A. §5605(14-B). The

regulation also prescribes the frequency of review of the use of safety devices and the procedure for requesting approval for the use of safety devices. The Committee incorporated these regulations into the *Draft Regulations Governing Behavioral Support, Modification and Management for People with Intellectual Disabilities or Autism in Maine* in 2013. These regulations, which represent significant revision and are reflective of best practice in the field, are expected to be approved and implemented in 2014.

Crisis Services

OADS/Developmental Services has developed a comprehensive crisis response system available to anyone with an intellectual disability or brain injury that allows them to remain in their homes and local communities during and after a crisis. The crisis system is comprised of five major components: Prevention Services, 24-hour Crisis Telephone Services, Mobile Crisis Outreach Services, In-home Crisis Services, and Crisis Residential Services Through this system, assistance is provided to individuals, families, guardians, and providers.¹⁴

Person-Centered Services

Individualized, person-centered services were identified as a central pillar in the Workgroup's recommendations. Instead of a one-size fits all approach to services, the Workgroup recommended that the State implement a variety of strategies to enhance the person-centeredness across the systems. In particular the Workgroup identified:

- Organize services around the person
- Provide the option for one comprehensive resource plan
- Have an independent person facilitate the plan development
- Create accountability mechanisms
- Adopt accountability standards that allow consumers to actively participate in planning, register complaints, make informed choice and document progress.

OADS/DS has had a highly developed person-center planning process for many years, recently there has been a significant effort to refine and enhance the model and process through creating new tools and enhanced training for staff.

Person-centered planning is an annual event for most consumers served through OADS/DS and is the foundation for individualized services (Those residing in Intermediate Care Facilities for Individuals with Intellectual Disabilities or ICF/IID, or nursing facilities participate in planning processes led by staff from the facility). In the late 2005 into 2006, OADS worked with international leader and consultant John O'Brien to raise profile of the Person-Centered Planning process and provide training

for staff leading the process. O'Brien has been a pioneer and leader in Person-Centered Planning and Community Inclusion. His approach involves learning with each person what direction their lives could take and setting goals to overcoming barriers.¹⁵

OADS/DS uses the "Five Essential Service Accomplishments" framework developed by O'Brien to drive the individual planning process.¹⁶ The aim of this framework is to ensure that programs promote community participation and staff assists people with severe disabilities to form and maintain a variety of community ties. Consumers determine their goals, which are not services but are instead individualized, personal goals that the consumer wants to achieve and that give meaning to their life. Planning is facilitated and coordinated by case managers, who are independent of agencies providing direct services in order to enhance choice and control by the person served. The consumer and his/her family drive the planning process and are assisted to identify goals. The case manager ensures that the person understands available services and how they can be used to help the person meet their goals.

Redesigned Person-Centered Planning process

Maine's Person-Centered Planning (PCP) process is defined to ensure personal choice, self-direction and opportunities. At the same time it meets regulatory requirements, addresses the resource allocation process, communicates changes and ensures consistency and accountability.¹⁷

OADS/DS most recently updated the PCP process with new guidelines going into effect in November 2013. Significant changes include the role of case managers in coordinating the PCP. Case managers, who are not employed by agencies providing other services for the consumer, facilitate and coordinate the planning process. In this manner the consumer's needs and choices remain the focus of the planning effort and the case manager provides neutral, conflict-free facilitation as required by CMS. It is a universal plan design facilitated by the Enterprise Information System (EIS), OADS/DS's management information system, which links all providers to the plan.

Each provider constructs their portion of the approved plan created by the team to meet the needs and desires of the individual. The online plan is then used to account for performance and efforts made to meet the individual's needs. More than 1000 case management and direct service staff were trained during the fall of 2013 in the use of the universal PCP plan. (Email from Lisa Sturtevant, Employment Services Specialist, OADS, January, 2014).

Consumer Driven

The newly revised process for Person-Centered Planning describes how service recipients and their families are involved in the planning process.¹⁷ Persons receiving services from OADS/DS are the drivers of the planning process. The individual (and family or guardian as appropriate) determines who will participate in the planning meeting, where the meeting will be held and when. He/she also decides who facilitates the meeting itself. These changes help to ensure that the consumer is an active, as opposed to, passive participant in the planning process and enhances the voice of the consumer.

OADS/DS has a standard practice of collecting feedback from consumers. As stated in the PCP Instruction Manual each plan must include a description of how the Planning Team will evaluate the person's ongoing satisfaction with:

- 1) The planning process
- 2) The plan that is developed, and
- 3) The progress being made in accomplishing the goals in the plan.

For additional information on the PCP see

<http://www.maine.gov/dhhs/oads/disability/ds/pcp-action-plan/index.html>

No Wrong Door

The 2003 Workgroup envisioned a system of long term services and supports that was easy to understand and navigate for people needing services. Instead of the existing patchwork of services, they aimed their recommendations at creating a coherent system of services. Critical to that system are multiple entry points that are integrated, provide necessary information to persons needing services, streamline eligibility and are easy to navigate.

OADS/DS has made some progress on those recommendations and has undertaken additional efforts to achieve these goals.

Organizational Realignment

In 2004, Maine's legislature approved the merger of the two legacy agencies, Department of Human Services and Department of Behavioral and Developmental Services, into the Department of Health and Human Services (DHHS), creating a foundation for a more integrated and efficient service delivery system. This organizational restructuring brought the various offices providing services across the

long term services and supports systems under one roof, along with the regulatory functions, to create more opportunity for coordination and streamlining.

More recently, in an effort to promote further consolidation, the Office of Elder Services and the Office of Adults with Cognitive and Physical Disabilities merged and integrated their operations, programs and services into the Office of Aging and Disability Services (OADS) in September 2012. This move realigns the Office and combines district operations under one organizational structure, creates clear lines of communication, coordinates central and regional office functions, and establishes a unified program and service model. The mission of OADS is to promote the highest level of independence for older citizens and for adults with disabilities. The safety and well-being of vulnerable adults is a priority. Both of these organizational realignments have built strong infrastructure for better coordinated and integrated systems for long term services and supports.

Increasing Access to Community-Based Services

The Balancing Incentive Program (BIP)¹⁸ is recently awarded federal grant that OADS will employ to continue to re-shape the long term services and supports (LTSS) system. BIP is a federal program that offers an increase in federal funding for non-institutional long term services and supports provided through state Medicaid programs. In return, states that are awarded BIP funding make a commitment to structural changes in the LTSS system aimed at rebalancing the programs toward community settings.

Specifically, DHHS agreed to make the following changes:

- 1) A No Wrong Door-Single Entry Point System
- 2) Conflict-free case management services; and
- 3) A core standardized assessment.

Access to community-based services was one of the key areas of focus for the Work Group for Community Living. These three elements identified in the BIP are the foundation of an accessible system of services for elders and people with disabilities. With the enhanced BIP funding, OADS has additional resources to continue expanding community options for people with significant disabilities and complex needs.

Getting the Word Out

OADS, leading the BIP effort for DHHS, is working to expand streamlined infrastructure to provide easy access to information about long term services and supports and eligibility. Maine 211, the toll-free statewide directory for health and human services, is a principal component of the resource infrastructure. As the guidance from Centers for

Medicare and Medicaid Services (CMS) sets out, states can develop their No Wrong Door –Single Entry Point using several mechanisms including coordinated networks of information and referral, an agency or organization or, portal. The goal is the same; to provide easily accessible information for persons in need of long term services and supports. Under the BIP program, DHHS will explore a partnership with Maine 211 to broaden the reach and make this vital service readily available to Mainers needing help to find resources and navigate the service system, 24 hours a day/ 7 days a week. The 211 system, staffed by trained call specialists and accessible either by phone or over the internet, provides access to a broad array of health and human services including those specific to people with intellectual and developmental services as well as many others.

As part of the BIP program, OADS is working with various partners—including, but not limited to, the Aging and Disability Resource Centers (ADRCs), Maine's Center for Independent Living (CIL), supported by Alpha One, Long Term Care Ombudsman (LTCOP), community providers and Maine 211—to enhance their capacity to provide comprehensive and accurate information about options for LTSS. These community based agencies already provide coverage statewide and, with enhanced efforts under the BIP program, there is an opportunity to expand their visibility and expand the information on available LTSS resources for Maine citizens. Under the BIP, the ADRCs will serve as a hub where individuals can inquire about community LTSS and receive comprehensive information, eligibility determinations, options counseling and enrollment assistance. The overall intent is to make it easier for Maine citizens looking for long term services and supports to find the information they need. With BIP resources, OADS and its partners will conduct a marketing campaign to increase the public visibility of long term services and supports in an effort to increase awareness of these valuable resources for Maine citizens needing services.¹⁹

Coherent System of Services

Since 2002, OADS/DS has used the Enterprise Information System (EIS) for its information management system. The EIS is the single information management tool for OADS/DS, providing fully integrated information from planning to service delivery for consumers of intellectual and developmental disability services. Emergency intervention and protective services can be activated and tracked through the EIS application. OADS/DS management can view the plan, case management documentation and other service delivery information through this one tool. Community-based case management providers also use this application in order to maintain a comprehensive system for all case management across the intellectual and

developmental disability system. (Email from Terry Sandusky, Information Services Manager, OADS, February 2, 2014).

Since 2002, DHHS has expanded use of EIS within OADS and in the Office of Substance Abuse and Mental Health Services (for adult mental health) and the Office of Child and Family Services (for children's behavioral health services). Within OADS, EIS is used to manage information on consumers with intellectual and developmental disabilities, brain injury, and other related conditions, as well as for aging services. The OADS EIS user base extends to over 2,000 state and community provider staff including case management services, provider work services, financial services and quality assurance and improvement services. Among the information managed through EIS is Reportable Event/Incident Information; Adult Protective Services Investigation information (for individuals with intellectual or developmental disabilities); prior authorization for Home- and Community-Based Services; eligibility determinations; youth transition documentation; crisis services documentation; and general case management information. CMS has given federal certification to the EIS because of its extensive management of MaineCare services. The application is built on an Oracle 11g database platform and meets today's general business standards for scalability and flexibility in large web-based applications. (Email from Terry Sandusky, Information Services Manager, February 2, 2014).

Responsive Service Coordination

Service coordination is a big topic and one that often generates a great deal of passionate conversation. Individuals served and their families want reliable, accurate, up-to-date information on services and supports. They count on case managers to help navigate a still confusing array of services. As the Workgroup identified in its recommendations strategies for service coordination must take into account neutral and independent coordination with appropriate levels of training for staff providing these key functions. These significant challenges, which are being addressed, will continue to require attention and resources to improve quality and consistency.

Community-Based Case Management

At the time of the 2003 Roadmap, case management for intellectually and developmentally disabled individuals was provided exclusively by State employees. In 2004, OADS/DS expanded the case management system to include community-based, private providers. The development of the community-based case management system has grown rapidly over the past ten years, with currently over 60% of the targeted case management provided through the community-based system. To promote this expansion while assuring quality services, OADS has adopted a standard practice for

approving agencies seeking to provide case management services to consumers with intellectual and developmental disabilities. Approval requires completion of a certification process that includes all core agency business practices. OADS/DS requires the use of the EIS by all case management providers to assure consistency and compliance with case management standards. Quality service coordination through the use of a common application remains the goal in developing the conflict-free case management system. For detailed description see <http://www.maine.gov/dhhs/oads/disability/ds/comm-cm/Certification/introduction.html>.²⁰

The expansion of the case management system has enhanced the system of service coordination for people receiving home- and community-based services and has responded to the need for conflict-free case management services. Quality assurance mechanisms built into the case management program include standard qualifications for case managers and supervisors. Since 2012, all newly hired State case managers must be licensed social workers. This new regulation raises the qualifications for those staff providing targeted case management and is part of the quality improvement strategy. The case management system meets the recently adopted federal requirements for conflict-free case management with case managers acting as neutral facilitators for planning and coordination of services. For additional information see <http://www.maine.gov/dhhs/oads/disability/ds/comm-cm/standards2/eligibility.html>

Training to Enhance Quality

A trained and qualified workforce is a critical component of a well-functioning community-based system of services and supports for people with disabilities. Case managers providing targeted case management services either as State employees or through community-based agencies must meet the qualifications outlined in the MaineCare Benefits Manual, Section 13 (See Maine Care Benefits Manual, §13.07-2(B)).²¹ For many years, OADS/DS has provided regular orientation training for newly hired case managers. OADS/DS has identified the improvement of case management services as an objective in its recent Biennial Plan. Currently, OADS/DS holds quarterly training sessions at the district levels, which are required for all new hires. Content for each session varies, but includes topics relevant to case managers promoting effective service coordination and linkage. Recent topics have included Individual Rights, Behavioral Regulations and Person-Centered Planning. In addition, OADS/DS is planning to convene a Best Practices in Case Management Conference in the coming year to promote quality training for incumbent case managers. In order to keep improving the knowledge and skills of the case management workforce, OADS/DS will need a regularly updated training plan and resources for implementing it. (Email, Karen Mason, Program Manager, OADS, February, 20, 2014).

Opportunities for Improvement

Young people transitioning from children's services to the adult service system can be vulnerable to gaps in service. Differing eligibility criteria, different funding streams, different regulations, different array of services and authorizing entities all can contribute to a less than seamless transition for some. The issue has received concerted attention in past years, and OADS/DS has recently spearheaded a renewed effort to improve the transition system as well as the individual experience. In 2012, internal staff from DHHS's Office of Child and Family Services (OCFS) and OADS/DS met at the district level to plan for and coordinate transition activities for individual consumers. With parental permission, the two offices shared information to develop a plan to support smooth transition to adult services for youth nearing the end of high school. In 2013, OADS/DS and OCFS built a "Youth in Transition" interface within EIS. Through this mechanism, tracking and documentation of service needs begin for youth aged 16 and continue through their transition years until the move to adult services. This process captures the current services as well as documents the projected needs of the youth. The district coordination work provides the primary information needed to facilitate the youth's move to adult services, and answers some of the historical shortcomings of the transition process. More recently, representatives from SAMHS have also been included in these Transition Committee meetings in an effort to better coordinate services for consumers who may have more complex needs or co-occurring disabilities.

Transition Committee members continue to reach out to partners in the Department of Education and local schools to identify youth who may need long term services and supports and begin their transition planning well before they are ready to leave school. While this approach is demonstrating success, more attention is needed to create systemic solutions so that the transition pathways are clear, parents know what to expect in this arena and eligible consumers receive the necessary services in a timely manner.

Funding and Planning

Using Data to Plan and Measure Progress

The 2003 Roadmap recognized that reliable data on the needs of the people with disabilities in Maine is a critical prerequisite to effective service planning and accurate budget requests. This is nothing new for OADS/DS. OADS/DS has collected information on the needs of those served since 1992, and, as discussed above, began leveraging the current EIS information management system to collect a variety of data starting in 2002. The information collected by OADS/DS is central to its work and is used in a number of ways. In addition to daily usage of data to oversee the provision of

services to its consumers, OADS/DS shares data with the Maine Legislature to inform decision-making regarding resource allocation for the OADS/DS service system.

OADS/DS also reports the data to several academic institutions that track developmental disability services nationwide. Maine's data is aggregated with data from other states and then published—in the annual *State of the States in Developmental Disabilities Report*²² and the University of Minnesota's annual *Residential Services for Persons with Developmental Disabilities: Status and Trends* report²³—allowing OADS/DS to compare its efforts to those of its sister agencies in other states, and thereby measure the State's progress. Finally, it should be noted that the service need and utilization data from EIS was the fundamental information used to validate compliance with Maine's Community Consent Decree, which came to a close in 2009.

Linking Data Across Programs

Within DHHS, information is now being shared by OADS, Office of Substance Abuse and Mental Health Services (SAMHS), Office of Child and Family Services (OCFS) and Office of MaineCare Services (OMS). Although there had been internal sharing of information in the past, it had mostly been through the exchange of paper reports. The development of electronic interfaces has improved the efficiency of the sharing and this internal sharing has been very useful to the efforts to improve transition from children's to adult services. Accessing and sharing data with school districts remains the greatest challenge. This is primarily due to the lack of integrated data across the 240 districts across the state. Overtures have been made by OADS and OCFS to both the Department of Education and the Maine Association of Directors of Special Education Services (MADSEC) to include them in the district level Transition Committees mentioned above which are now working across the state. Positive responses have very recently resulted in presentations at MADSEC's annual statewide meeting. Improving these relationships and assisting the required educational transition planning are considered important priorities for OADS and OCFS.

In the areas of work supports and employment services, data are currently being shared between OADS/DS, SAMHS and Department of Labor in order to monitor system performance and individual employment outcomes. Only data specific to employment services is shared through this agreement and other individual data remains confidential and secure. All three partners will gather data using the same assessment in the near future. Department of Labor uses a new large application for its consumers, but OADS and DOL are exploring the development of electronic interfaces so that employment data is shared in near real time using the same assessment currently used by OADS.

The goal is to have the interface in place by October 2014 so that all partners are entering, monitoring and reporting on the employment information.²⁴

Leveraging Federal Funds

OADS/DS has been very active in leveraging federal funding both to expand home and community-based programs for individuals with intellectual and developmental disabilities, and also to fund demonstration programs which can lead to improvements in the service system.

Home- and Community-Based Service Waivers

By far the primary and most effective means by which Maine has used federal funding to provide community-based services for people with intellectual and developmental disabilities is through the federal Home- and Community-Based Services Medicaid waivers (often referred to as “1915(c) waivers”). These waivers allow the use of Medicaid funds to provide comprehensive, community-based supports and avoid unnecessary institutionalization. Maine implemented its first 1915(c) Home- and Community-Based Services waiver for intellectually and developmentally disabled individuals (known as the “Section 21 Waiver”) in 1983.

Since the 2003 Roadmap was released, Maine has added a second waiver for individuals with intellectual and developmental disabilities, known as the Supports Waiver (or “Section 29 Waiver”). First implemented in 2007, the Supports Waiver is designed to provide supplemental supports for individuals who live with their family or are able to live independently. The purpose of the Supports Waiver is to provide additional supports in community, work or home supports to ensure that individuals served can continue to live successfully in the community. Like Section 21, this waiver is also funded through a combination of state and federal dollars. Maine is in the process of refining the waiver so that it can also provide flexible, supplemental home support services, making the services more versatile and useful to a broader population.

In 2013, the State introduced a Home- and Community-Based Services waiver for individuals with “Other Related Conditions,” and is currently preparing another waiver for individuals with acquired brain injury. While neither waiver is primarily oriented towards individuals with intellectual and developmental disabilities, they offer more choices for individuals with co-occurring diagnoses, and may ultimately free up resources to allow the Section 21 and 29 waivers to serve additional individuals.

Part 1: What Has Been Accomplished, 2003-2013

In addition to the waivers, individuals served by OADS/DS also access services through other programs, including State Plan services such as medical and hospital services, and other Home- and Community-Based Services waivers.

Federal Grants

In addition to the core Home- and Community-Based Service waiver programs, Maine's DHHS has leveraged a number of federal grants over the past decade to improve its long term support system. These include:

Real Choices Systems Change grants funded by Centers for Medicare and Medicaid Services (CMS) 2001-2007.

- *Quality Choices*. Project activities included a comparative analysis of personal assistance programs; and a focus on access to transportation, housing, recreational activities and strategies for integrated information systems.
- *Money Follows the Person* (2003). Developed a rate structure as a foundation for building consumer directed services for persons with intellectual and developmental disabilities. Provided foundation for current MFP grant activities.
- *Independence Plus* (2003). DHHS developed information, training materials and other tools for persons with intellectual and developmental disabilities to support their participation in consumer directed services. However, the waiver was never implemented due to budget constraints.
- *Medicaid Infrastructure Grants* (MIG) (2000-2009). Authorized under Ticket to Work and Work Incentives Improvement Act grant this program focused on enhancing and streamlining infrastructure to maximize employment for people with disabilities.

Funded jointly by Administration on Aging and CMS:

Maine Aging and Disability Resource Centers (ADRC) (2003). The purpose of the program is to streamline access to long-term services and supports for elders and persons with disabilities. DHHS piloted an ADRC in three of Maine's five Area Agencies on Aging. Now each of the five Area Agencies on Aging are ADRC's and have integrated information on aging and disability services and supports.

Maine is currently participating in two grants funded by CMS intended to increase options for community living for people with disabilities.

- *Money Follows the Person* (2012-2016). Grant program to expand options for people living in institutions to transition to community settings and give people with disabilities more choice in where to reside and receive long term services and supports.

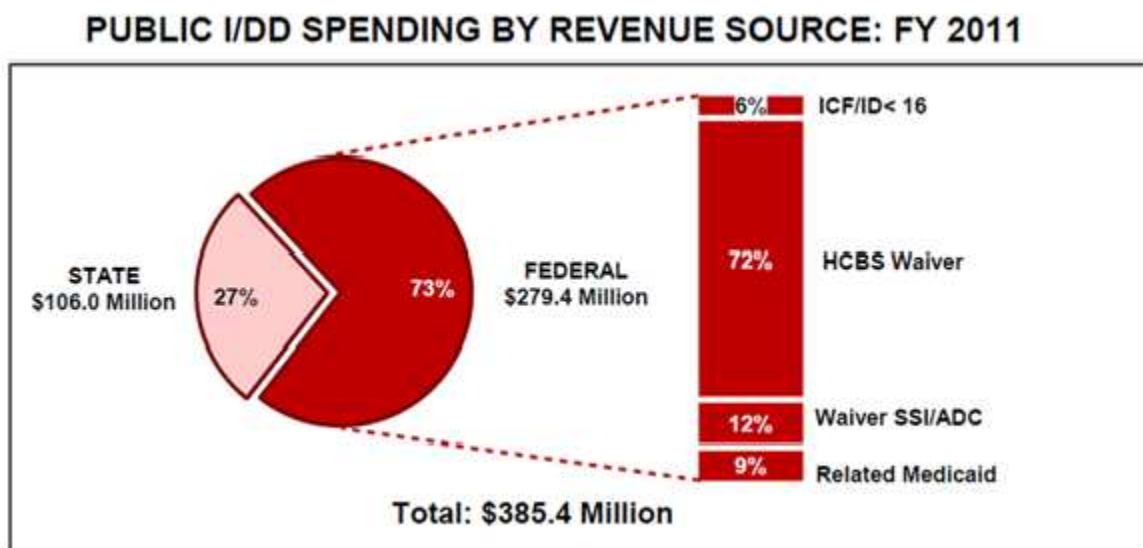
Part 1: What Has Been Accomplished, 2003-2013

- **Balancing Incentive Payment Program (BIP) (2012)** As described earlier, this program is aimed at re-balancing the system of services and supports to reduce reliance on institutional settings toward a community-based system that provides more choice for consumers to live in the least restrictive and appropriate settings.

Overall Federal and State Spending

As is shown in the following charts, the largest revenue source for Maine's services for individuals with intellectual and developmental disabilities is the federal government. This trend has been increasing over time. The most recent data on disability services show that Maine ranks second in the nation in per capita spending on community services for individuals with intellectual and developmental disabilities.²⁵

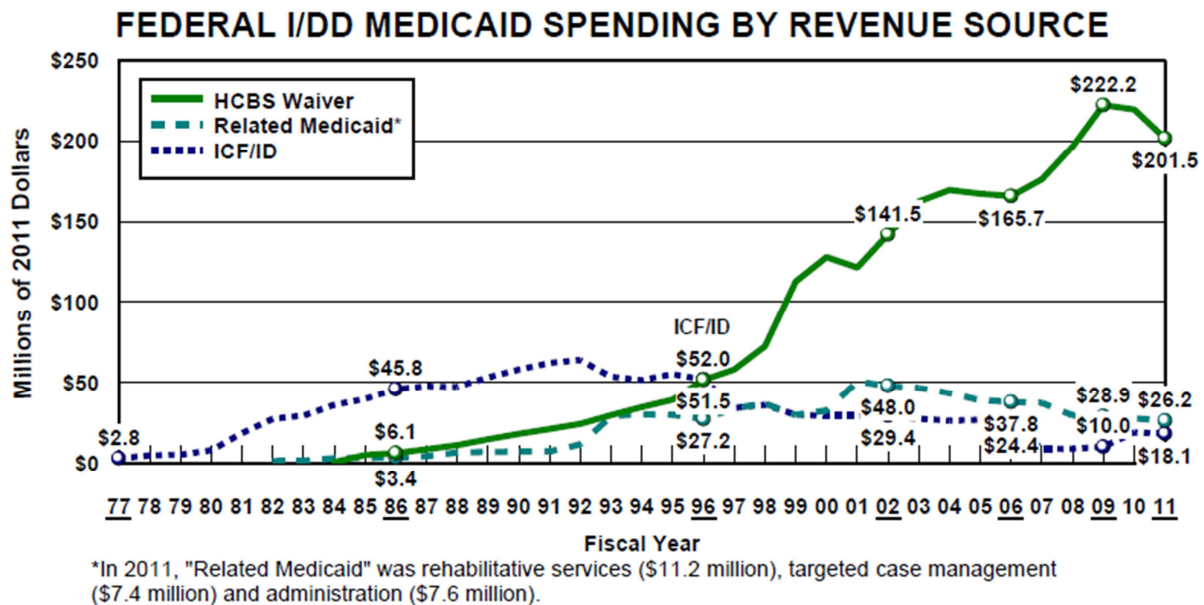
Object #1 This chart shows the proportion of state and federal dollars funding major service categories in Maine.



Source: *The State of the States in Developmental Disabilities: State Profiles for I/DD Spending During Fiscal Years 1977-2011: Maine.*²⁶

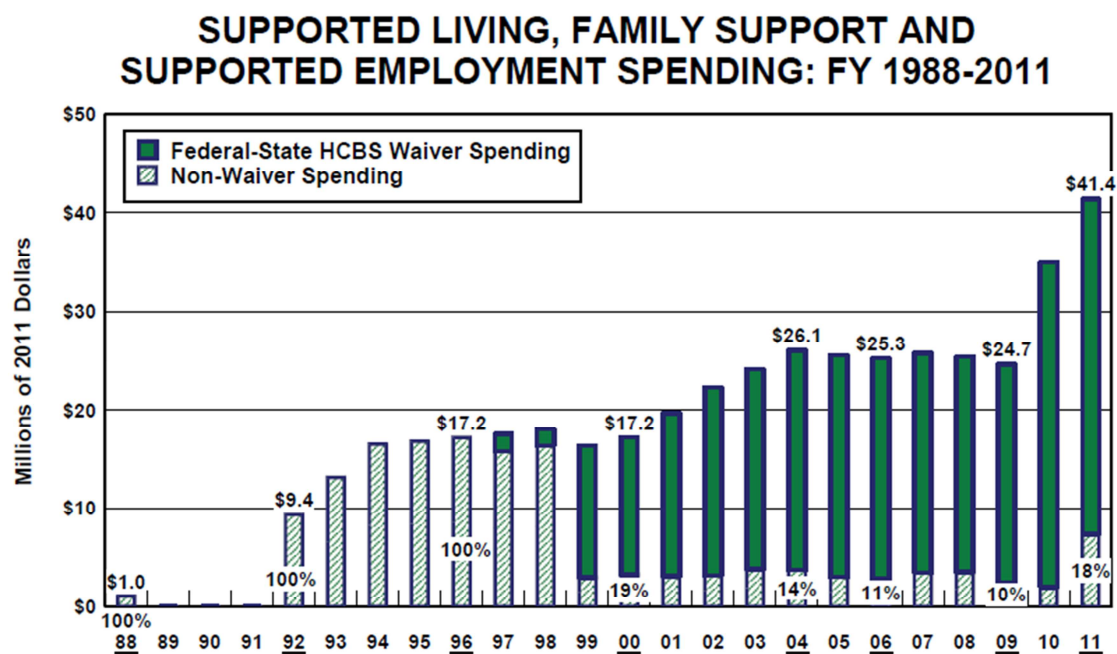
Part 1: What Has Been Accomplished, 2003-2013

Object #2 This chart shows federal spending over time in Maine.



Source: *The State of the States in Developmental Disabilities: State Profiles for I/DD Spending During Fiscal Years 1977-2011: Maine.*²⁵

Object #3 This chart shows the change in spending in Maine from non-waiver to waiver over the course of 23 years.



Source: *The State of the States in Developmental Disabilities: State Profiles for I/DD Spending During Fiscal Years 1977-2011: Maine.*²⁵

Wait Lists

Wait lists for OADS/DS waiver services were first established in 2008, and have been growing since. The combination of the finite number of waiver slots approved by the federal government and the limits of State funding have created long waits for services for many people. Despite Maine's robust participation in the federal waiver programs, the demand for services far outstrips the current supply.

Given limited capacity within the current system, it is critical both that access to services is provided in a fair, predictable manner and that services remain available to respond to those individuals with immediate, dire needs. To this end, OADS/DS has established policy and practice for how waiting lists are established and maintained for both the Section 21 and Section 29 waiver programs. As described below, the waiting lists for the two programs are handled in different manners, consistent with their distinct orientations.

For Section 21, priority for services is based on a hierarchy of need, with the most vulnerable members receiving a higher priority for accessing services first. Any member who is determined to be in need of adult protective services (APS) and is eligible for developmental services is assigned a Priority 1. Members who are at risk for abuse in the absence of services as identified in his or her individual service plan are assigned a Priority 2. And finally, members who are on the waiting list but not at risk of abuse are assigned a Priority 3.

When openings become available in the Section 21 waiver, OADS/DS staff review current assessments and other information maintained on EIS to identify the individuals who present with the highest need for services. Additional factors taken into consideration include the availability of capable service providers to adequately meet the member's service needs and the comparative degree of abuse, neglect or exploitation that each member will likely experience if they do not receive the services. Using this method, OADS/DS seeks to ensure that those consumers most vulnerable receive services first.

The wait list for Section 29 services, by contrast, is processed on a first come, first served basis. Members who are on the wait list for these services are served chronologically based on their date of eligibility for the waiver.

The chart below shows the current figures for both waivers. The total number of individuals on the waiting list for the Section 21 and Section 29 waivers—872 and 474, respectively—conveys only part of the picture. Some individuals have applied for and

Part 1: What Has Been Accomplished, 2003-2013

are on waiting lists for **both** waivers (n=286). (Ultimately, they would be served by one or the other of the waivers, not both; members can only receive services under one wavier program at a time.) Other individuals are currently receiving services under Section 29 but want to receive services under Section 21 (n=486). Finally, there are some individuals (n= 386) waiting for Section 21 but NOT receiving services under Section 29.

Stated another way:

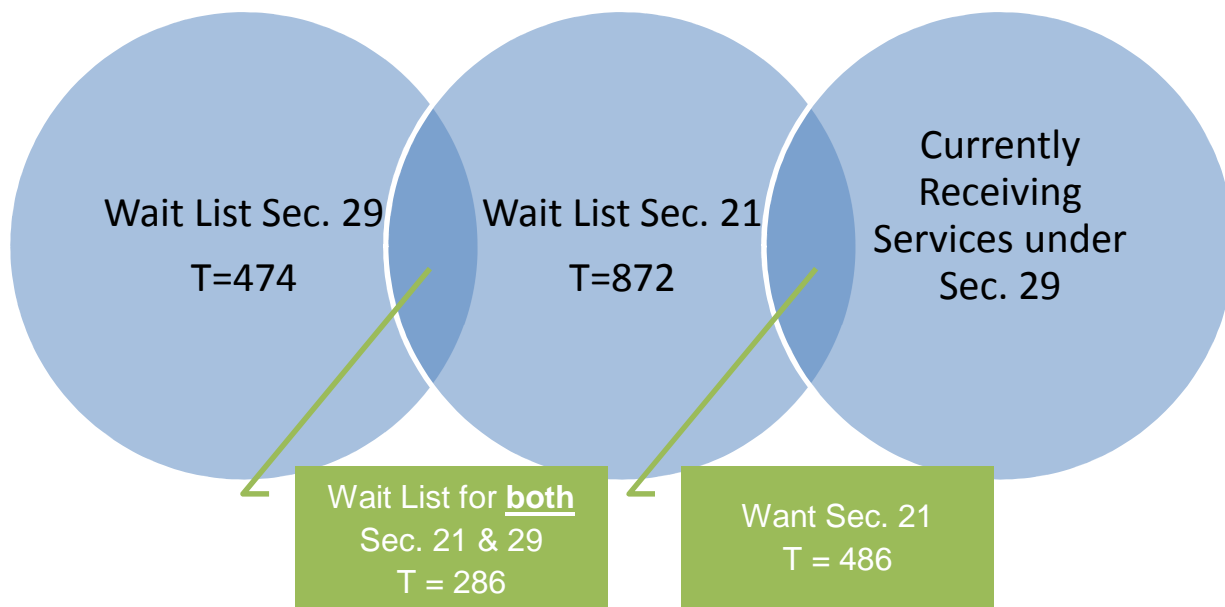
- Over half of the people waiting for services under the Section 21 waiver are currently receiving services under Section 29.
- Over half of the people waiting for services under the Section 29 waiver are also on the wait list for services under Section 21.

While on Wait Lists for waiver services, eligible individuals receive other funded services through OADS/DS. All people on the wait list can receive:

- Case management services
- Crisis services
- Medicaid State Plan Services (MaineCare) including: medical; dental; and hospital services as well as transportation to medical services.
- Guardianship services, if court ordered

Object #4 Maine

Wait List Current View



Source: Wait List Data (Email correspondence from Bridget Bagley, OADS, December 17, 2013)

The wait lists have been a growing concern since their inception. The Department has been concerned about how to address this and has worked with its' partners to seek solutions. In FY 2013, the department secured an additional \$28 million (state and federal match) in funding for the Section 21 and 29 waiver programs. With this additional funding, to date, OADS has served an additional 150 individuals. (Email, James Martin, Office Director, OADS, March 12, 2014.)

Availability of Direct Care Providers

In the 2003 Roadmap for Change report,⁴ Maine's Work Group for Community-Based Living highlighted a statewide shortage of direct care workers to support individuals with disabilities, and recommended that the State commence a number of new activities to expand the pool of qualified workers providing community-based services in Maine. Specifically, Maine's Work Group encouraged the State to:

- Build respect for the direct care worker profession;
- Improve recruitment and training practices;
- Create opportunities for growth and advancement;
- Solicit outside funding and grant support to develop sustainable solutions;
- Improve wages and benefits;
- Expand access to consumer-directed care options; and
- Collect data across departments to measure and track workforce shortages.

In the past decade, OADS/DS has made significant advancements in many of these areas and has work to do in others.

Build respect for the profession

In 2003, Maine's Work Group wrote of the need to enhance the status of the direct service worker to "a professional occupation commensurate with teaching, social work, or nursing." The Work Group suggested several possible strategies for doing this, including developing a communication plan to educate employers, consumers, and their families on the key responsibilities and importance of direct service workers.

In recent years, OADS has undertaken a number of initiatives aimed at educating direct service workers, potential workers, and the public about the importance of direct service positions and their critical role in Maine's current and future long term service and supports system.

With funding from the Health Resources and Services Administration (HRSA), DHHS, in partnership with the Muskie School of Public Service, developed a website for direct

Part 1: What Has Been Accomplished, 2003-2013

service workers, employers, and consumers.²⁷ The site contains video clips and shows Maine's direct service workers in action, serving in different job titles and carrying out various essential responsibilities. The site also outlines qualifications and training needed for different types of workers and contains information for consumers on what to look for and how to work with a direct service worker.

In the past, OADS/DS worked with provider agencies to plan biennial conferences for direct support professionals (DSPs). These were discontinued due to budgetary constraints. However, in the upcoming year (FY 2015), OADS/DS plans to resurrect the DSP conference with the dual goals of:

- 1) providing more opportunities for learning and mutual support and
- 2) recognizing the important efforts of this workforce in delivering high quality services and supports.

These goals are echoed in the current OADS Biennial Plan,²⁸ where next steps for improving developmental services include:

- 1) validating the importance of DSPs and their work and
- 2) transforming their role from "caretaker" to "supporter."

Improve Recruitment and Training Practices

While low retention rates continue to be a problem among direct support professionals (DSPs), OADS has launched a number of initiatives aimed at clarifying and streamlining DSP training requirements and strengthening training programs.

All DSPs, regardless of where they work, are required to earn certification through Maine's approved training and certification program. Since 2009, the approved training program has been provided through the College of Direct Support (CDS)/Elsevier. The training is largely online and consists of 46 lessons, including several that are specific to Maine's service systems and policies. All newly hired DSPs must complete this training within their first six months of employment.

In addition to Maine's College of Direct Support basic certification, DSPs who serve specialized functions must complete supplemental lessons and earn additional certifications. For instance, DSPs providing work supports must complete four additional on-line lessons, including Supporting Jobs and Careers in the Community and Exploring Individual Preferences for Job Attainment. DSPs working as Certified Residential Medication Aides (CRMAs) or performing First Aid, CPR, and/or Behavioral Interventions complete additional coursework as well.

Part 1: What Has Been Accomplished, 2003-2013

Maine's College of Direct Support basic training is offered through provider agencies. An OADS Training Manager manages the contract with the College of Direct Support/Elsevier and monitors trainings statewide.

Training has also been revised and strengthened for another category of direct service worker, the Employment Specialist. Employment Specialists provide direct support to individuals with disabilities as they find and maintain employment in integrated settings. Recently, OADS/DS changed training requirements for this job title to align with requirements set forth by Maine's Office of Substance Abuse and Mental Health Services (SAMHS) as well as Maine's Department of Labor's Bureau of Rehabilitation Services. This change allows workers who meet Employment Specialist requirements to work across systems (i.e., provide services to clients served by the Bureau of Rehabilitation Services, OADS/DS, or SAMHS.)

This coordinated training and certification effort has allowed Maine to certify an average of 100 new Employment Specialists per year, provide advanced training to 200 staff, and mentor up to 12 Employment Specialists annually.²⁹ It is an important forward step in expanding the workforce and elevating the credentials for this segment of the workforce.

Create Opportunities for Growth and Advancement

In recent years, OADS/DS has expanded the number of professional development activities and continuing education offerings aimed at direct service workers.

In 2010, OADS/DS worked with the Muskie School of Public Service to produce videos and toolkits designed to teach direct service workers practical strategies for involving consumers in their communities. The toolkits were used to enhance the level of knowledge among staff about the potential for individuals with intellectual and developmental disabilities to have meaningful involvement in their communities. Examples included volunteerism, job shadowing, employment and recreation and others.

Within the past year, with the support of a grant from the Health Resources and Service Administration (HSRA), OADS has again worked with the Muskie School of Public Service to launch four online continuing education modules aimed at DSPs and other direct service workers. Topics include: Infection Control and Prevention, Dementia Basics, Brain Injury Basics, and Substance Abuse. Each continuing education module is available to any direct service worker at no cost, 24 hours a day.

In addition to these modules, a project website provides educational materials about different career options for direct service workers and includes a quick roadmap for accessing training programs for various direct service positions.²⁶

OADS has begun exploring additional re-certification requirements mandating ongoing learning and professional growth. One such requirement would be targeted at Direct Support Professionals serving Home and Community Based Waiver recipients and would require a set number of continuing education hours per year.³⁰

Solicit Outside Support to Develop Sustainable Solutions

For the past three years, OADS has participated in a large, cross-agency project intended to streamline direct service training requirements for Maine's three largest categories of direct service workers. In 2010, DHHS was one of six states awarded a demonstration grant funded by the Health Resources and Services Administration (HRSA) to develop an integrated, competency-based model of training for direct service workers. Now entering its fourth year, the project has produced and piloted a competency-based core training module for entry level workers serving elders and consumers with intellectual and developmental disabilities, serious and persistent mental illness, and physical disabilities.

The training program, which blends traditional classroom training with online learning to enhance worker access to curriculum, allows workers to complete core and specialized modules while reducing redundant requirements and increasing opportunities for cross-training. The competency-based approach includes competencies identified through Maine's earlier training programs as well as those identified at the national level. Through the core training and associated specialized modules, workers can become certified as Mental Health Rehabilitation Technicians I, Personal Support Specialists, or Direct Support Professionals.

This project demonstrates OADS engagement in cross-agency collaboration and commitment to pursuing outside funding to develop sustainable solutions to Maine's direct service workforce shortage. Anticipated benefits of this integrated, competency-based training program include increased training opportunities for potential workers, improved worker mobility across multiple job categories, increased worker competence with consumers with complex health and service needs, and a more flexible workforce that can adapt quickly and apply skills to locations and populations where there is an immediate workforce shortage.

Quality Services

In the 2003 Olmstead Roadmap for Change, the Workgroup for Community-Based Living had several recommendations aimed at improving the quality of services provided. Some had an emphasis on consumers defining quality and an expanded perspective of measuring quality across all domains of a person's life. The recommendations also encouraged a framework that defined standards for quality and accountability with an ongoing effort to evaluate quality. OADS/DS has made significant progress on its Quality Management strategy and has specific goals for the coming years.

National Core Indicators project

Maine's Office of Aging and Disability Services has participated in the National Core Indicators project (NCI)³¹ developed by the National Association of State Directors of Developmental Disability Services (NASDDDS) and the Human Services Research Institute (HSRI) between 2002 and 2012. In 2014, OADS resumed participation. NCI measures states' performance and outcomes in the intellectual and developmental disability service systems. This effort allows Maine to benchmark its performance against other participating states, identify trends and track changes over time.

The surveys are designed to explore specific aspects of the service system's capabilities and effectiveness. Service planning; access and delivery of supports; opportunities for choices and input; connections with the community and outcomes of services received are areas that are included in the survey.

Members of the Developmental Disability Council are conducting NCI interviews and collecting the data from consumers in 2014. Subsequent years may also include surveys for families and guardians in order to collect data and enable Maine to benchmark against other states, to identify areas needing improvement and to steer program redesign. Maine's most recent report (2011-2102) can be found at http://www.nationalcoreindicators.org/upload/core-indicators/2011-12_Maine_ACS_State_Report.pdf

Additionally, HSRI is spearheading a parallel effort to develop a national set of core quality indicators for elders receiving services from aging program services. Maine's OADS is also participating in early pilot testing of these instruments.

On-going Quality Assurance Efforts

All Home- and Community-Based Services waivers for elders and adults with disabilities administered by OADS/DS require reporting to the federal Centers for Medicare and

Medicaid Services about quality and accountability. In addition, OADS/DS created a new Quality Assurance/Quality Improvement unit in 2012 that evaluates core services, conducts review and certification of community case management agencies serving adults with intellectual and developmental disabilities, administers assessments for adults with intellectual and developmental disabilities, participates in waiver reporting, and provides training to improve quality.

Expanding the Quality Domains

The 2003 Roadmap called for Maine to expand the scope of quality measurements to include the contribution of all supports in a person's life at home, at work, or in daily living activities, and community. This is being accomplished for adults with intellectual and developmental disabilities via the Supports Intensity Scale (SIS). The SIS is a standardized assessment that measures the support needs of an individual in the home, work, and community settings. Respondents in the assessment process include those providing direct supports to the adult at home, at work and in community programs. The assessment does not differentiate between formal paid supports and unpaid supports.

Integrated, Accessible, Affordable Housing

Affordable housing continues to be a challenge, varying geographically across Maine, and remains a significant barrier to providing alternatives to institutional level care. In the 2003 Roadmap for Change, workgroup members identified eighteen recommendations to improve community-based options for people with disabilities.

Measuring Housing Needs

OADS/DS systematically collects data on residential needs for persons served. Through EIS, OADS/DS tracks data on requests and needs for residential services along with current data on type and location of consumers' residences. These data are collected routinely through the person-centered plan and used to project service funding needs as well as types of residences requested and needed. These data are provided to partners including the Developmental Disabilities Council, Disability Rights Center, Oversight and Advisory Board and others to inform policy and rule changes in order to meet these system challenges.

Partnerships to Address Challenges

In the past decade, OADS/DS has formed strong partnerships with several housing organizations in order to strengthen the supply of housing options for adults with intellectual and developmental disabilities. Among those, Maine Housing has been a vital partner, along with community provider organizations, in developing housing options.

OADS/DS has also worked with the Maine Coalition for Housing and Quality Services (CHOM), which formed in 2006, on exploring and developing various housing models. Consisting primarily of parents of youth and adults with disabilities, CHOM has conducted advocacy and outreach around the need for quality housing and services, expanding resources and options across the state. OADS/DS staff regularly attends the CHOM monthly meetings, providing program updates and also participating in discussion about issues critical to families supporting members with intellectual and developmental disabilities. This vital partnership holds much promise for future service system improvements.

Community-Based Living

Maine has a strong system of community-based residential options for people with intellectual and developmental disabilities and a long and robust history of waiver participation. According to the most recent data available, in the past decade OADS/DS has almost doubled the number of consumers served through the waiver programs and is on track to continue substantial growth in these programs.

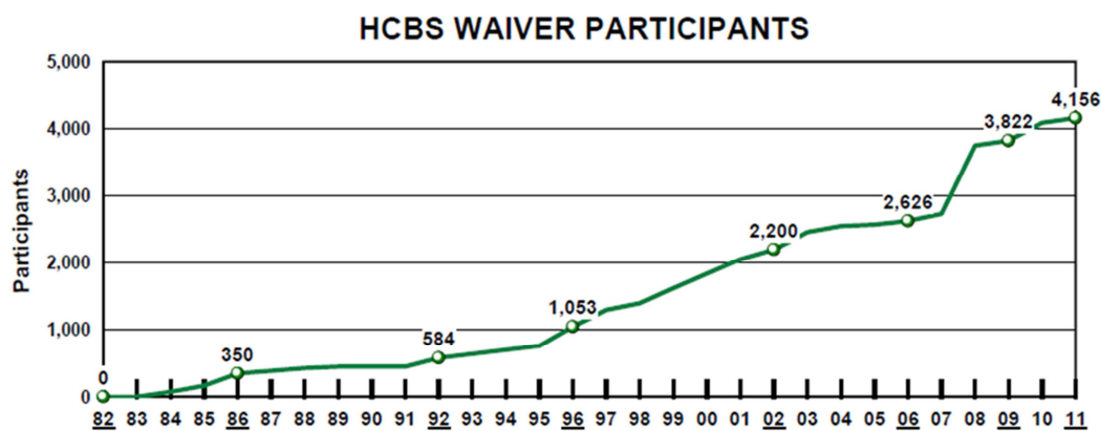
As noted earlier in this report, OADS has operated a Home- and Community-Based Services Waiver for individuals with intellectual and developmental disabilities since 1983. The purpose of these waiver programs is to provide long term services and supports in community-based settings under the Medicaid program. This has been the primary vehicle to provide services in community settings as opposed to relying on institutional settings. With guidance from the Centers for Medicare and Medicaid Services, the waiver program is designed to promote “choice, control and access to a full array of quality services that assure optimal outcomes such as independence, health and quality of life.” Maine’s comprehensive waiver (often referred to as the “Section 21” waiver) provides home, community and work supports. Using the Person-Centered Planning approach, individual plans for waiver services are developed with the person receiving services driving the planning process; the process is coordinated by a case manager who does not work for an agency that provides direct services to the person. This allows for more choice in service providers.³²

Choice of residence is a key component of a self-determining life. Maine’s residential options for individuals with intellectual and developmental disabilities include:

- Supported living;
- Shared living;
- Family centered support;
- Group living; and
- Non-waiver residential services.³³

The chart below shows the growth in waiver participation from the earliest days to 2011, most recent data available. Figures include members receiving services under both waivers; Sections 21 and 29.

Object #5 Maine waiver participation.



Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2013.

<http://stateofthestates.org>

Source: *The State of the States in Developmental Disabilities: State Profiles for I/DD Spending During Fiscal Years 1977-2011: Maine.*²⁵

Growing Residential Options

OADS/DS continues to develop an expanded array of residential models which can provide the supports necessary, meet the personal choices of individuals being served and maximize community inclusion. In 2005, OADS/DS developed the Shared Living model as an additional option for residential supports under the Section 21 waiver. In the Shared Living model, an adult with intellectual and developmental disabilities shares a home with a person who provides direct support. The home may belong to the member or to the provider. The person providing the supports must become certified as a Direct Support Professional and provides the home supports under a contractual relationship with an oversight agency. There has been strong growth in this residential model with currently over 617 individuals with intellectual and developmental disabilities using this service. (Email from Terry Sandusky, Information Services Manager, November 7, 2013).

Increasing Choice

OADS/DS has recently introduced changes to both Section 21 and 29 waiver programs to promote more flexibility in services. Included in those changes are remote supports—which include a range of monitoring and support services provided remotely by means of a data connection—and other technologies which can enhance consumer

Part 1: What Has Been Accomplished, 2003-2013

independence. Also recently added were respite services, which provide respite care to support family caregivers while allowing consumers to remain in the family home.

OADS/DS currently includes home modification funding in both Section 21 and 29 of the waiver programs.³⁴ Members receiving services under Section 21 can receive up to \$10,000 in a 5-year period in order to make adaptations to the home to ensure the health, safety and welfare for the member. The funding limit is capped at \$5,000 for members receiving services under Section 29.

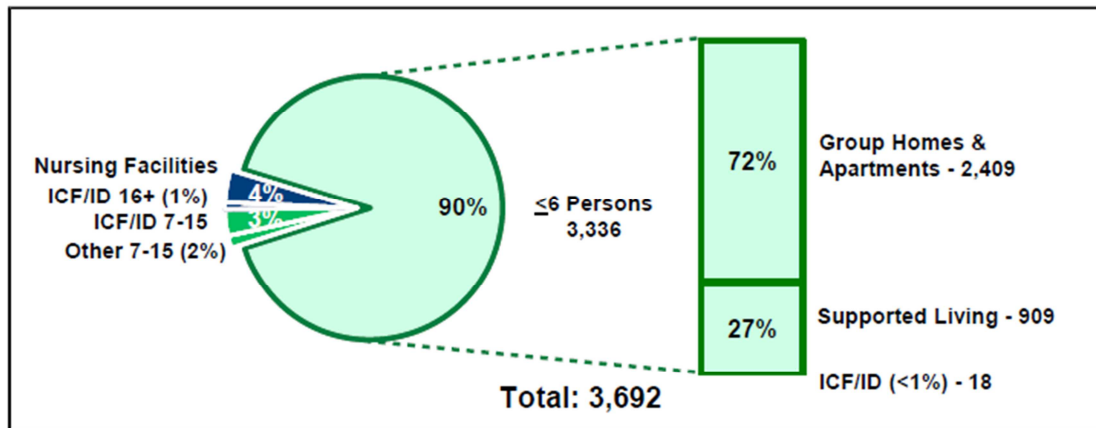
OADS/DS continues to use federal dollars through specific programs to help reduce the reliance on institutional settings. OADS received a Money Follows the Person grant from the Centers for Medicare and Medicaid Services in State Fiscal Year 2012. This grant is another tool to expand access for home- and community-based services and reduce reliance on institutional settings. It is designed to help Medicaid beneficiaries who want to transition from institutional settings to community-based settings, and to make system-wide changes to support Medicaid beneficiaries with disabilities living and receiving services in the community. Currently Maine's plan calls for one hundred and one individuals to be supported in their transition from institutional setting to community setting over the course of five years. MFP is serving people with complex needs and it is possible to serve more than the projected numbers as there is no cap established for this program. (Email from Francis Ryan, OADS, March 10, 2014).

Using the most recent data available the charts below show the distribution of residential settings for individuals served in Maine. Object 6 represents where individuals served by OADS/DS reside. As this chart shows the vast majority (90%) of individuals served live in residences with 6 or fewer people.

Part 1: What Has Been Accomplished, 2003-2013

Object #6 Maine

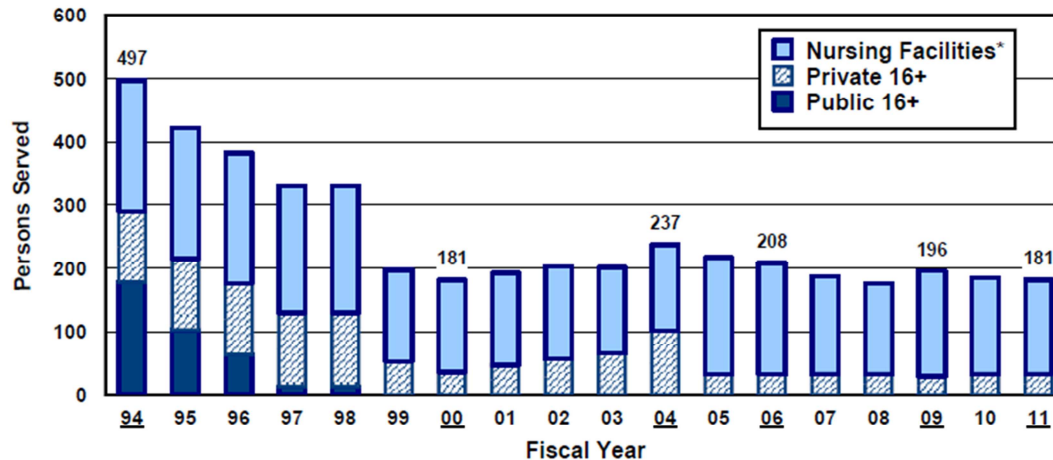
PERSONS BY SETTING IN FISCAL YEAR 2011



Source: *The State of the States in Developmental Disabilities: State Profiles for I/DD Spending During Fiscal Years 1977-2011: Maine.*²⁵

Object #7 represents the numbers of individuals residing in institutional settings over time.

PERSONS IN PUBLIC AND PRIVATE 16+ INSTITUTIONS: FY 1994-2011



*Nursing facility data data for 1990-2004 were provided by the state; data for 2005-09 are from the CMS OSCAR online survey.

Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2013.

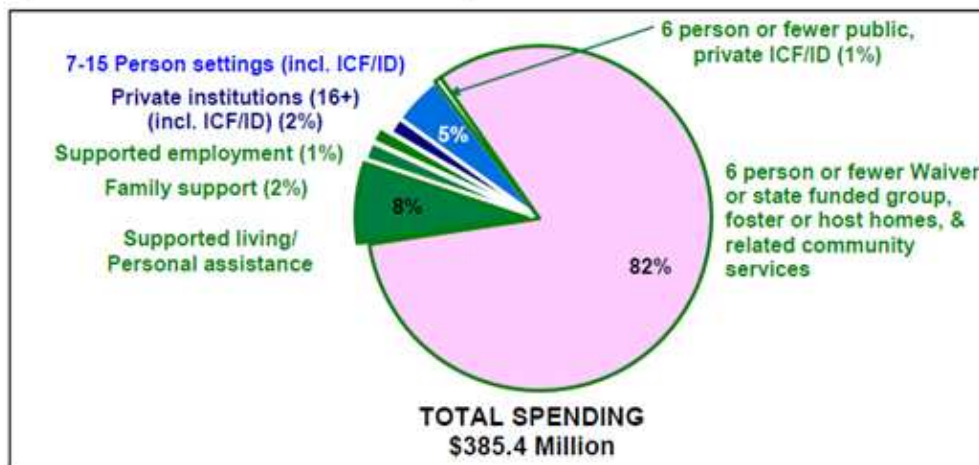
<http://stateofthestates.org>

Source: *The State of the States in Developmental Disabilities: State Profiles for I/DD Spending During Fiscal Years 1977-2011: Maine.*²⁵

Part 1: What Has Been Accomplished, 2003-2013

Object #8 shows the proportion of spending by residential setting. It also includes spending for Supported Employment.

**SUPPORTED LIVING, FAMILY SUPPORT, AND SUPPORTED EMPLOYMENT
(INDIVIDUAL AND FAMILY SUPPORT) WAS 10.7% OF TOTAL SPENDING: FY 2011**



Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2013.
<http://stateofthestates.org>

Source: *The State of the States in Developmental Disabilities: State Profiles for I/DD Spending During Fiscal Years 1977-2011: Maine.*²⁵

Jobs

Employment for people served by OADS/DS has been an area of focus that dates back to the Vocational Policy crafted by the Department of Behavioral and Developmental Services in 2000. Since that time OADS, sometimes in partnership with the Office of Adult Mental Health Services (now Substance Abuse and Mental Health Services), and the Bureau of Rehabilitation Services in the Department of Labor, and sometimes as a single state agency, has made significant strides to make employment in integrated, community-based settings a real option for people with intellectual and developmental disabilities. The closure of the State-operated sheltered workshop, Freeport Towne Square, and the elimination of state funding for any sheltered workshop programming are two of the many policy decisions which paved the way for the current efforts to support employment in integrated settings. These are highlighted in a recent report to the Maine Legislature, the *2012 Report in Response to LD 28, resolve, To Improve Employment Opportunities for Persons with Intellectual Disabilities and Autistic Disorders.*³⁵

Numerous policy and practice changes have been implemented over the past decade that facilitate community integration through employment. In November 2010, DHHS adopted a policy related to employment of people with disabilities. "Employment of

People Served” set the direction for the expansion of employment outcomes across DHHS in coordination with other state agencies and employment service providers. OADS/DS has built capacity in the service delivery system by providing best practice training for case management, direct support professionals and employment specialist staff to improve knowledge and skills for working with consumers to find and maintain employment.

OADS/DS eliminated funding for sheltered employment in 2008. In that same year Section 29, the Supports Waiver, was developed to increase supports for integrated, community-based employment options. The new waiver was the culmination of work undertaken between 2006 and 2008 to increase employment options for people with intellectual and developmental disabilities supported by MaineCare. The Support Waiver offers supportive services to consumers who live with their families or on their own, with a focus on Community Support and Work Support.

Under both Home- and Community-Based Services waivers, MaineCare covers work supports necessary to assist a person in the home setting to get ready for work. Work supports can also be used at the place of employment for assistance with personal hygiene and personal care based on the needs identified in the Person-Centered-Plan.

An Innovative Model

For a two-year period (2008-9), OADS/DS partnered with the Maine Developmental Disabilities Council and individuals with intellectual and developmental disabilities and the Muskie School to develop an educational program about employment opportunities for waiver participants. “*It’s Your Life*” was a peer-to-peer model focused on identifying opportunities for community-based employment in integrated settings. By using real stories from consumers who were successfully employed, consumers in segregated work settings had the opportunity to learn about wider options for employment as well as learn about supports available for them to pursue alternatives. Seventy consumers participated in these educational offerings to explore the possibilities of community-based employment. This was an important strategy to educate consumers about employment outside of segregated settings as a viable option regardless of diagnosis or disability.³⁶

Integrated Work Settings

Most supported employment efforts offered by OADS/DS focus on individual placement. Currently, only two models of small group employment are allowed under federal Dept. of Labor standards. These models are intended for between 2-8 workers with disabilities. Enclaves are business based workgroups and mobile work crews work in regular business, industry and community settings. These models do not include

vocational services provided in a facility based work setting. The overarching goal is to promote individual jobs in integrated, community-based settings at or above the state's minimum wage.

Under the federally funded Medicaid Infrastructure Grant (MIG), OADS/DS, in conjunction with partners from DHHS Adult Mental Health Services, the Department of Labor's Bureau of Rehabilitation Services, the Muskie School of Public Service, community providers, people with disabilities and other stakeholders, created a cross disability, one-stop informational clearinghouse on employment and disability. A website, www.employmentforme.org provides current, relevant information for people with disabilities, community providers and businesses. While providing a broad spectrum of information, the site specifically includes information for consumers to aid them in understanding their employment rights.

In expanding integrated employment options for individuals for disabilities, it is important to be cognizant of the manner in which additional income may impact consumer's existing services. To this end, OADS/DS helps fund Benefits Counseling provided by Maine Medical Center to assist consumers receiving either SSI or SSDI benefits to assess how earnings from employment will affect their federal and state benefits. The program works with consumers to navigate the rules regarding employment and disability benefits and provides analysis as well as linkage to other supportive resources which can aid consumers in attaining community employment.

Expanding Partnerships to Improve Employment Outcomes

Most recently, OADS has been a partner in Maine's Employment First initiative, a cross-disability legislative collaborative. The coalition includes representatives of various state agencies including DHHS, the Department of Education, the Department of Labor, as well as community service providers, advocacy organizations and persons with disabilities. The initiative's focus is on improving and enhancing employment outcomes for Maine citizens with disabilities by exploring employment goals as the first and preferred option when setting goals with people who have disabilities.

Significantly, Maine's Employment First coalition is cross-disability.²⁸ While these efforts nationally have sprung from the intellectual and developmental disability community; Maine has chosen to include a wide variety of disability groups. The Employment First Coalition reports to the Governor, the Legislature and the Joint Commissioners at least annually with recommendations for enhancing employment outcomes for people with disabilities. See <http://www.employmentfirstmaine.org/> for additional information.

Part 1: What Has Been Accomplished, 2003-2013

The Employment First Coalition promotes the value of employment for young people with disabilities and seeks to ensure that their employment experiences are typical of their non-disabled peers. In line with this focus, OADS/DS also partners with the Department of Labor to participate in the Youth Mentoring Day held annually each October. Through these efforts young adults with disabilities are partnered with businesses, learn from business panels or spend a day job shadowing in a business.

Part 2: How We Move Forward, 2014 – 2024

Introduction

As we look ahead to the next decade, our resolve to continue to strengthen the community integration efforts for people served through OADS/DS remains firm. Building upon earlier efforts to provide high quality community-based services that enable individuals to remain in their homes and communities we have identified these key areas of focus:

Employment

Employment is a core component of the services and supports to individuals served by OADS/DS. OADS/DS considers employment to be the first and preferred service or support option for each person. In the coming decade, OADS/DS seeks to expand integrated, community-based employment options (meaning employment in the competitive labor market that is performed on a full or part time basis or through self-employment, at or above the minimum wage) and improve employment outcomes for individuals served. OADS/DS will coordinate its efforts with other state and federal agencies to ensure maximum benefit for the individuals it serves. OADS/DS's specific employment-related goals include the following:

- Every person served is offered the opportunity to work, based on the idea that each individual can work.
- OADS will collect annual data reports from providers to analyze and assess employment outcomes for the state.
- OADS will ensure that individuals working at sub-minimum wage will transition to competitive wages.
- OADS will ensure that the Person Centered Planning processes will include consideration of employment in the community and the identification of barriers to employment.
- The Department will introduce new approaches, such as career planning and peer support models, to support individuals to successfully engage in employment. Where those approaches succeed - they will be added to the Comprehensive waiver (Section 21) and the Supports waiver (Section 29) programs.
- Working with the Department of Labor/Bureau of Rehabilitation Services. OADS will support business development and collaboration efforts to employ persons with disabilities.

- The Department will partner with Department of Labor/Bureau of Rehabilitation Services and other community support provider agencies to improve preparation for each individual for employment. The Department will engage these partners in discussion to identify barriers to employment and to create solutions.
- The Department will continually improve our ability to produce outcomes based on data in partnership with community providers. Individual employment sites, size of settings and wages will be electronically tracked and utilized for system improvement and measurement.
- The Department will improve training opportunities for professionals supporting individuals with intellectual and development disabilities in employment settings and improve mentoring programs based on ongoing needs and with guidance from the WorkForce Development Advisory Council.
- OADS will develop incentives to expand independence and community-based employment through a focus on alternative service delivery models, such as Assistive Technology. The Department will also explore increasing the amount of available work supports offered in the Sections 21 and 29 waiver programs.

Transition to Adult Services

Individuals entering Developmental Services deserve an improved process of transition that supports movement into adult life. OADS is committed to continual engagement with schools, case managers, parents and individuals to assist with planning and accessing appropriate services.

- Improve the transition process for eligible youth moving to the adult service system.
 - The Department is establishing early support and planning for individuals and their transition to and through adulthood. Beginning at the moment the youth is identified as potentially needing some type of support, there will be early intervention with an eye toward community integration and adulthood success. Collaboration will occur in all systems so that planning for transition is lifelong and comprehensive.
 - OADS will seek to continue to improve coordination with Department of Education and local school districts to ensure that the youth's future goals and need for adult services are in sync with the youth's educational plan and activities.
 - Maintain full Memorandums of Understanding between Department of Education and DHHS/OADS regarding sharing and dissemination of information.
 - Continually evaluate and identify gaps in the Department systems (i.e. child and adult services).

- OADS & Office of Child and Family Services will continue to move toward a common data system.
- Braid child and adult services during adolescence, incorporating full, person centered planning no later than the age 16.
- Enhance the ability of parents/family members to refer their adolescent for review of services needs in the adult service system.
- OADS will continue to streamline its intake and eligibility system to ensure a simple, direct and efficient process.

Supporting Individual Success

Each person will receive a standardized, individualized assessment of his or her strengths and needs which will inform the Person-Centered Planning process. Each person will be assessed for the natural support potentially available to them and every effort will be made to maximize all of these opportunities. A broad menu option model will be established to match the amount and kind of paid support services needed by each individual within both Section 21 and 29 waiver programs.

- Ensure that people with intellectual and developmental disabilities get the services and supports they need to live the life they prefer in their community.
- Establish an independent, conflict-free, service assessment process for each person.
- Maintain a person-centered, community-oriented approach to deliver services for people with intellectual and developmental disabilities. The approach emphasizes:
 - That people with intellectual and developmental disabilities be in charge of their lives as much as possible.
 - That people with intellectual and developmental disabilities have opportunities to use resources flexibly and in ways that enhance their lives and help them participate in their communities.
 - A shared responsibility for the wise use of public dollars and the contribution that people with intellectual and developmental disabilities and their families can make.
 - That the system is managed in a way that is efficient and fair to everyone
 - That the development of the Person-Centered Plan is completely individualized and reflects the specific values, goals and needs of the individual.
- Support for each person in further developing the skills to advocate for their own unique goals and need will be incorporated into the Person-Centered Plan. OADS will provide specific training in self-advocacy for all persons with

intellectual and developmental disabilities, and training for caregivers to support, enhance and encourage self-advocacy in each person served.

- Explore broadening the use of a standardized assessment tool and resource allocation model within the Supports Waiver (Section 29).

Reduce and Eliminate Wait Lists for Services; Fairness & Equity

In-home community support services should be provided under a streamlined, single program with a priority for persons with the greatest need, and the lowest cost of services:

- Improve the distribution of resources through efficiencies of a standardized approach to assessment of need, fair and equitable payment for services, and
- OADS will continue to implement performance based contracts with service providers, and improve forecasting of persons aging into the adult system.
- OADS will refocus and rewrite rules on quality and person-centered outcomes for each individual.
- OADS will explore alternatives to fee-for-service payment system with the goal to free up funds to add individuals to services.
- OADS will provide training and consultation to identify other services available for individuals with complex needs/issues.
- Increase appropriation for the intellectual and developmental disabilities waivers to meet the needs of additional individuals who qualify for home and community services.
- Reduce the wait lists for both waivers through instituting a process whereby every individual on a waitlist is regularly informed (at least annually, through Person-Centered Planning meetings) of alternative services that might meet their needs. Also, through regular reporting to the legislature on the status of waitlist, including the expected appropriation needed in order to reduce the waitlist.
- Reduce institutional use by providing significant, robust alternative home and community based services.

Improve the Independence and Self-sufficiency of Each Person Served

- Implement budgetary and rule changes to promote the use of technology to improve the independence of individuals through adaptations of communication, environmental control, and remote safety supports.
- OADS will actively recruit consumers, family members and advocates for participation in all aspects of the organization, including decision-making, program design, program implementation and evaluation of services provided.

Part 2: How We Move Forward, 2014 - 2024

- OADS will encourage and support provider agencies and state programs to eliminate barriers to consumer participation and input by making accommodations available as needed, including readers, note-takers, drivers and personal-care attendants and by providing reasonable reimbursement to consumers.
- OADS will work with provider agencies and advocacy organizations to train employers, community leaders, and others on the rights of individuals with disabilities, as individuals who have little or no representation.
- OADS will work with agencies and advocacy organizations to make advocacy materials more user-friendly so it is possible for more people to advocate on their own.

Improve the Direct Service and Frontline Supervisory Workforce

OADS seeks to enhance and improve the value of and respect for direct care workers and their supervisors.

- Strengthen partnerships with educational departments and colleges to increase the workforce development and build training or career opportunities.
- Identify and increase opportunities for improving the integrity of current and future training programs.
- Create measurable outcome data on the core competencies within training programs.
- Streamline and enhance efficiencies training programs within DHHS.
- Develop strategies to import to Maine necessary workforce to provided critical services.
- Create and build career ladders through ongoing communication and partnerships with universities and colleges.

Further Enhance the Quality Assurance/Quality Improvement Efforts

- OADS will establish easy access to a clearing house of information about services for persons with intellectual and developmental disabilities. This will be designed to provide clear, understandable descriptions of the service system and it will be thorough and continuously updated.
- OADS will continue to streamline and consolidate Medicaid waivers to improve consistency and quality, and enhance benefits.
- OADS will implement the new CMS Home and Community Based Services definition and requirements.
- OADS will insure that payment rates for services are both efficient and sufficient through the establishment of a regular schedule of rate reviews/adjustments.

Support for Families and Persons in Their Own Homes

- OADS/DS will work to “right-size” the capacity of institutional settings vs. home and community settings.
- Seek new models to improve coordination and engagement of volunteer resources.
- Seek creative ways to enhance transportation support for members who live in rural parts of Maine.
- Explore opportunities for support through participation in virtual communities.
- Provide transition services in times of need for individuals and families through innovative models for respite and intermittent support.

Improve access to health and dental care

OADS/DS will work with stakeholders to understand the scope of the issues, identify challenges and collaborative opportunities to access to health care for persons with intellectual and developmental disabilities.

- Maximize the health of each individual through improved health monitoring, communication among caregivers and effective care coordination.
- Reduce Medicaid costs through improved health and independence. Reduce unnecessary medical services or institutionalization.
- Achieve integration of electronic health records of persons with intellectual and developmental between their healthcare providers and their home and community-based service providers.

Understand the Issues of Persons with Intellectual Disabilities or Autism Who Become Involved in the Criminal Justice System.

- Work with stakeholders to understand the scope of the issue, identify challenges and collaborative opportunities to protect the public and meet the needs of these individuals. Issue a report with recommendations.
- Work with State Government partners to study the systems issues and create possible solutions to be proposed for legislative action.

Endnotes

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