Report to:
Maine Department of Health and Human Services

Report of Progress Since 2003 Original Olmstead Roadmap for Change

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Bloom

Contact: Kirsten Smith
ksmith@bloomconsult.org
(406) 570-0058

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Executive Summary

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. Olmstead originated with two individuals with mental illness and developmental disabilities who were voluntarily admitted to a state hospital. After completing their treatment, providers recommended they move to community-based treatment. Despite this, the individuals remained confined to the state-run institution for several years. They filed suit under the Americans with Disability Act (ADA) for release from the hospital. The Supreme Court determined that unjustified segregation of individuals with disabilities violates the ADA.

Maine formed a collaborative workgroup to define the state's response to the Olmstead decision, and in 2003 published a roadmap outlining recommendations for long term services and supports (LTSS) in nine areas:

1. Support individual in finding their voice and speaking for themselves
2. Help people control and deliver needed services and supports
3. Organize services around the person served
4. Integrate access to services so that there is no wrong door
5. Create a single, integrated system of coordinated services, including: 5.1 coherent system of services; 5.2 responsive service coordination; 5.3 waiting lists; and 5.4 funding and planning
6. Build standards for quality and accountability, including: 6.1 direct care providers; and 6.2 quality of services
7. Improve access to and availability of integrated, affordable housing
8. Improve access to and availability of transportation
9. Improve access to and availability of jobs

Purpose

This report provides a broad-based, cross-disability Olmstead progress report and assessment of outstanding opportunities. Researchers analyzed and aggregated data to identify perception of and progress toward recommendation areas from the 2003 roadmap for change. This report does not provide an overall independent evaluation of progress in meeting Olmstead goals. Rather, it summarizes and communicates government program manager, participant, provider, advocate, and other interested party and data perspectives on Maine's progress toward 2003 roadmap recommendations.

Accomplishments and Opportunities

The State of Maine strongly believes in the values of meaningful community integration and participation represented by the Olmstead decision. Maine shows its commitment to these values by dedicating significant resources to home and community based services (HCBS) LTSS. Maine is a national leader in financial investment in home and community-based long term services and supports.[1]

- **In top 10 LTSS expenditures per state resident nationally** – Maine is ranked 9th overall in HCBS expenditures per state resident, 7th nationally in 1915(c) expenditures per state resident, 2nd nationally for 1915(c) waivers for individuals with intellectual disabilities, and 10th in the nation for total LTSS expenditures per state resident.
- **High proportion of LTSS expenditures on HCBS** – Maine is above the national average in its percentage of long term services and supports spent in HCBS versus institutional spending (ranked #15 nationally with 55.0 percent versus national average of 49.5 percent). Additionally, Maine had the seventh greatest increase in percentage of LTSS funds spent on HCBS nationally, increasing by 5.4 percent between 2010 and 2012.
- **Decrease in institutional LTSS spending** – Maine reduced its total spending on institutional LTSS by 15.3 percent from 2010 to 2011, and another 3.5 percent from 2011 to 2012.
- **Highest investment in mental health services** – Maine leads the nation in mental health services expenditures per person.[2]

Interviewees and survey respondents generally observed progress by the state in implementing Olmstead recommendations.

The figure below represents survey respondents opinions on recommendation implementation. Stakeholders were asked to rate their perspective on how well the state of Maine currently meets priorities for people receiving long term services and supports. They were asked to rank their perspective on a scale of 1 to 4, with one being the lowest (Not at all), and four being the highest (Completely). The weighted average of responses across all priorities was fairly distributed between 1.98 and 2.4.[3] The priority of supporting individuals in finding their voice and speaking for themselves had

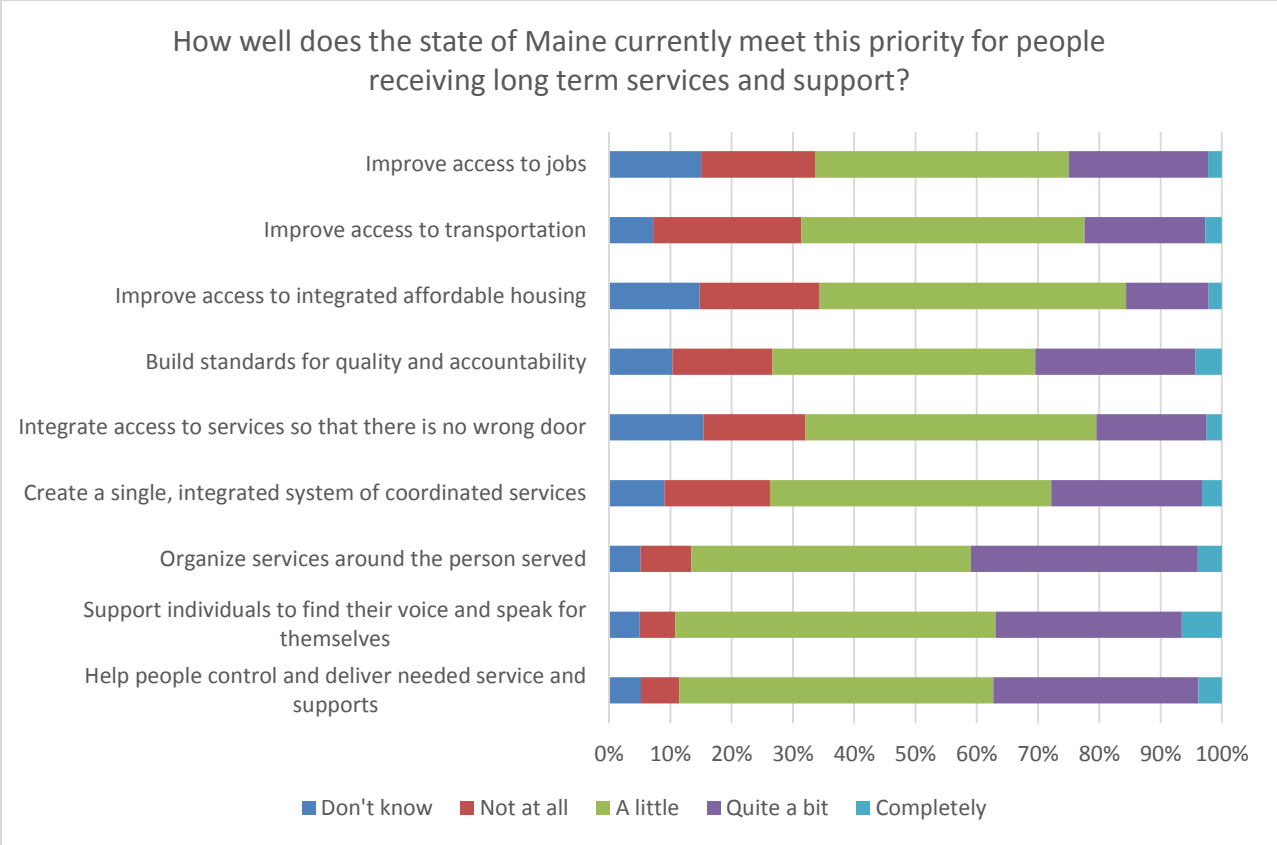
[1] Medicaid Expenditures for Long-Term Services and Supports in FFY 2012, April 28, 2014, CMS and Truven Health Analytics.

[2] Kaiser Family Foundation, State Mental Health Agency (SMHA) Per Capita Mental Health Services Expenditures, FY 2013.

[3] Weighted average or weighted mean shows the average response on the Likert scale. It is calculated by multiplying the number of responses in each response category (e.g. completely or quite a bit) by the associated weight (0-4), totaling the products, and dividing by the total number of responses.

the highest weighted average of 2.4. And the priority related to improving access to and availability of integrated, affordable housing had the lowest weighted average of 1.98.

Figure 1: Survey Respondents' Summary of DHHS Olmstead Accomplishments



The table on the following pages outlines specific accomplishments and opportunities cited by interviewees and survey respondents for each Olmstead recommendation area, broken down by LTSS participant group as applicable.

Table 1: Summary of Olmstead Accomplishments and Opportunities by Recommendation Area and Population

Olmstead	Population	Accomplishments	Opportunities
Supporting individuals in having a voice and speaking for themselves	General	• Provide financial support to advocacy community • Publicize grievance process, rights, and regulations • Created plain language materials • Implementing Balancing Incentives Program • Made advocacy positions independent of the state through contract with Disability Rights Maine • Encourage open communication between participants and policymakers	• Working to deepen commitment • Participants and families could benefit from training or skill development to become more effective at advocating • Increased access to advocates and self-advocacy could promote voice and advocacy • Disability Rights Maine pool of advocates reportedly has high turnover • DHHS websites can be challenging to navigate
	Aging/ Physical Disabilities	Strong advocacy organizations, including, but not limited to: • Center for Independent Living • Aging and Disability Resource Centers • Maine Coalition on Aging	• Increased opportunities could support elders and adults with physical disabilities in being heard
	Intellectual Disabilities/ Autism	Strong advocacy organizations, including, but not limited to: • Speaking Up for Us • Maine Developmental Disabilities Council • Maine Development Services Oversight and Advisory Board • Maine Coalition for Housing and Quality Services	

	Mental Health/ Substance Abuse	• Strong advocacy organizations, including, but not limited to:
		  ○ Quality Improvement Council
		  ○ Consumer Council System of Maine
		  ○ National Alliance for Mental Illness-Maine
		  ○ APS Healthcare Member Advisory Council
		• Fund adult peer support through social clubs and drop-in centers
		• Released peer support RFP to support improvements in health, home, purpose, and community for participants	

	Children/	• Obtain federal grants to support youth advocacy	

Olmstead	Population	Accomplishments	Opportunities
	Youth	• Families participate in intellectual disability, mental health, and substance abuse groups and OCFS workgroups, including QIC • Maine Alliance of Family Organizations formed as alliance of family organizations to strengthen family voice • Increased focus on youth participation including through Youth Move organization • Funded family support information and referral, youth self-help/peer support, and crisis stabilization since 2005 • Released peer support RFP to support improvements in health, home, purpose, and community for participants	
Help people control and deliver the services and supports they need	General	• Moving toward participant-direction option	• Choice is constrained by service unavailability, particularly provider staffing and housing in urban areas • Need for continued focus on individual voice, choice, and control
	Aging/Physical Disabilities	• Strong tradition and history of self-direction programs for individuals who are elderly or have physical disabilities • Portability across funded programs or providers allows individuals to move onto and off self-direction • ORC participants participate in selecting and hiring their direct care workers	• Additional support for individuals using LTSS services with a participant directed model to make self-direction a feasible option
	Intellectual Disabilities/ Autism	• Use person-centered planning to support individual choice • Supporting Individual Success intended to make the system more person-centered and provide more individual choice • Added assistive technology to Section 21 and 29 waivers	• Provide more autonomy to these participants and families, and increase choice through self-direction • Concerns around Supports Intensity Scale budget cap for individuals with complex needs
	Mental Health/ Substance	• Mental health and substance abuse disorder services have choice	

Olmstead	Population	Accomplishments	Opportunities
	Abuse	• Participants can use representatives	
	Children/ Youth	• Parents have choice regarding their children's services • Participants can use representatives	
Organize services around the person served	General	• Person-centered planning is a core of the philosophy in LTSS programs	• Person-centered planning works within the constraints of the LTSS system in Maine, including housing availability, service provider staffing availability, and MaineCare regulations
	Aging/Physical Disabilities		• Care coordination instead of case management may limit ability for person-centered planning to meaningfully occur
	Intellectual Disabilities/ Autism	• Person-centered planning is institutionalized in Developmental Services	• Person-centeredness of process varies based on the case manager and planning team • Person-centered planning may conflict with Supports Intensity Scale
	Mental Health/ Substance Abuse	• Occurs through Individual Support Plans and treatment plans	• Unclear whether all community providers use person-centered services well
	Children/ Youth	• Families and their teams use wraparound services to create an integrated plan • TIP case management develops core competencies to help youth transition successfully into adulthood	• Increase focus on person-centered planning • Need for more transition-focused programs or initiatives
Integrate access to services so there is no wrong door into the system	General	• Office for Family Independence supports no wrong door priorities through integrated eligibility processes and satellite eligibility services • Maine 211 certified 8 staff through Alliance of Information and Referral Systems	• LTSS access is based on numerous variables, making it confusing for some individuals to access • Historical issues with Maine211 related to accurate and complete information
	Aging/Physical Disabilities & Intellectual Disabilities/ Autism	• BIP supports three no wrong door organizations providing informed resource and referral information: Maine211; ADRCs; and CIL • Maine211 working to strengthen its presence • ADRCs and Alpha One provide options counseling	• Stakeholders do not universally work together well • ADRCs not sufficiently funded to integrate disability work into their scope

Olmstead	Population	Accomplishments	Opportunities
		• Five ADRCs have a single website and statewide toll free number • BIP created LTSS pre-screening tool	
	Mental Health/ Substance Abuse	• Help line, crisis line, warm line, and 211 provide information and referral services	
	Children/ Youth	• Most access Medicaid services through targeted case management, to which families receive referrals through a variety of sources	• Easier for families to enter the LTSS system outside of the school system
Coherent system of services	General	• EIS used across most LTSS programs to communicate, and includes a transition business process for youth transitioning between OCFS and OADS services • Electronic assessment system used across many LTSS programs • Data shared across departments to measure work supports and employment services • Worked to develop common vocabulary across LTSS programs	• Outdated information technology is slow and not able to support data-informed decision making or quality management • DHHS has many information technology systems that do not consistently share information • Information technology systems may not have reliable data because of manual input and system transitions • Maine's health information exchange, HealthInfoNet, may provide an opportunity for broader data integration
	Mental Health/ Substance Abuse	• Replaced substance abuse information technology system with more reliable option • Use APS Healthcare utilization management system	
	Children/ Youth		• School district data is not shared with OCFS or OADS
Responsive service coordination	General	• Merger establishing DHHS created more efficient service delivery • General move toward conflict free assessment and case management	• Despite progress, LTSS programs can still work independently with limited cross-program collaboration • State Plan resources could be better coordinated with waiver programs
	Aging/Physical Disabilities	• New waivers for brain injury and other related conditions implemented to serve additional people	• Care coordination in Section 19 waiver can be insufficient to support responsive service coordination

Olmstead	Population	Accomplishments	Opportunities
		• Money Follows the Person implemented to support transitions from institutions to home and community settings	
	Intellectual Disabilities/ Autism	• Created 1915(c) waiver support services (§29) • Implementing Supports Intensity Scale • Expanded case management to include community-based, private providers	• Shortage of service providers available in rural areas or for individuals with complex needs
	Mental Health/ Substance Abuse	• Use strengths-based multidimensional assessment, American Society of Addiction Medicine criteria, for substance abuse assessment • Piloting the Adult Needs and Strengths Assessment for mental health assessment • Work starting to support improved transitions for youth to adult mental health and substance abuse disorder services • Implemented a behavioral health home model • Contract with Administrative Services Organization (ASO), APS Healthcare, to ensure responsive service coordination	• Case managers could be assigned more quickly • Insufficient conflict-free case management • No prior authorization process
	Children/ Youth	• Children's services within OCFS for increased coordination between children's behavioral and autistic disorder, child protective services, and juvenile justice services • Integrated access to residential treatment • Privatized children's targeted case management to lower caseloads and improve support for children with intellectual disabilities or autism • Use Child and Adolescent Needs and Strengths (CANS) assessment • Contract with APS Healthcare to ensure responsive service coordination • Improved transitions to adulthood through improved case management and leadership focus	• Youth transitioning to adulthood can be vulnerable to gaps in services • Behavioral health model may not sufficiently adapted to children's needs

Olmstead	Population	Accomplishments	Opportunities
Waiting lists	General	• Significant focus on reducing waiting lists over last few years	• Changes in eligibility have affected waiting lists
	Aging/Physical Disabilities	• No wait list for the elderly and adults with physical disabilities 1915(c) waiver	• Wait lists exist in state funded programs • Staffing shortages create waits for MaineCare participants eligible for services
	Intellectual Disabilities/ Autism	• Invested significant resources in Section 21 comprehensive and Section 29 support services 1915(c) waivers to keep wait lists minimized • Targeted case managers work to keep people connected to services while on waiver waiting lists	• New services added to the Section 29 supports services waiver could reduce some of the pressure from the comprehensive waiver • Families could benefit from education about waiver eligibility and waiting list management • Expanding State Plan personal assistance services could reduce waiting lists
	Mental Health/ Substance Abuse	• $5.7 million of consent decree funds used to alleviate the mental health wait list • State hospitals instituted weekly discharge meetings to reduce waiting lists	• Determining how to better manage waiting lists for mental health and substance abuse services • Delays in case manager assignment, related to staffing and funding issues, can cause individuals to fall through the cracks and not be connected to services • Waiting lists exist for housing support programs • Waiting lists exist for state hospital placements
	Children/ Youth	• Katie Beckett option for children with long term disabilities or complex medical conditions • Instituted central enrollment to reduce waiting list from 2004 to 2011, until waiting list transitioned to ASO • Families can choose under the family choice provision to wait for a specific agency • ASO closely monitors wait lists and communicates with families	• Insufficient child psychiatrists to meet demand for services
Funding and planning	General	• Use multiple information technology systems to manage LTSS programs • State has leveraged federal funding through multiple grants	• DHHS has limited staffing resources • Budgets could be more based on projected need
	Aging/Physical	• Use a projection model for LTSS needs	• Demographics demand heavy investment in aging

Olmstead	Population	Accomplishments	Opportunities
	Disabilities	• Maine Coalition on Aging is a coalition working on aging issues to support increased planning	programs
	Intellectual Disabilities/ Autism	• Invest significant financial resources for this population • SIS will increase funding flexibility for individual participants	
	Mental Health/ Substance Abuse	• Spends most in nation on mental health expenditures per capita, including significant funds toward state-funded programs • Working to stabilize and increase funding for mental health and substance abuse services • Obtained increased funding for its Shelter Plus Care housing vouchers	• Limited state grant dollars to meet demand for services • Revising rules to ensure Section 17 community support services are consistently serving the intended population
	Children/ Youth		• Could benefit from increased flexibility in funding services for youth with complex needs
Direct care providers	General	• Developed cross-discipline core competency training • Aligning employment specialist requirements across state offices and departments • Offering online professional development and continuing education • Direct support professionals required to earn certifications through Maine's training and certification program • Analyzing provider rates through rate studies	• Low wages for direct support workers • High turnover for direct support workers • No face-to-face component of training may be detrimental
	Aging/Physical Disabilities	• Conducting personal support specialist rate study	• Low, disparate reimbursement rates for direct support workers • Insufficient staff available to provide services
	Intellectual Disabilities/ Autism	• Tend to receive higher wages • New rate setting associated with the implementation of the SIS • Newly hired state social workers must be licensed social workers • DHHS holds quarterly, district level training	

Olmstead	Population	Accomplishments	Opportunities
	Mental Health/ Substance Abuse	• Redesigning requirements for mental health direct service workers	• Insufficient mental health workforce • State hospitals rely to large extent on locum tenens, mandated and voluntary overtime, and heavy use of floating staff
	Children/ Youth	• Direct service providers in Section 65 Home and Community Based Treatment required to have Bachelor's degree • Revising training curriculum including behavioral health training	• No registry of service providers
Quality of services	General	• Created dedicated quality improvement/assurance units in OADS, OCFS, and SAMHS • Increased cross program communication and cooperation to address quality issues • Person-centered planning incorporates many participant level recommendations	• Data and information technology inconsistencies persist • Families unable to obtain information about the quality of services with a specific provider
	Aging/Physical Disabilities	• Quality review committee supports quality oversight • Participating in the National Core Indicators project	• Increase in Adult Protective Services referrals and investigations
	Intellectual Disabilities/ Autism	• Have robust quality management team for participants • Participating in the National Core Indicators project • Revised behavior regulations • Developed crisis services	
	Mental Health/ Substance Abuse	• Implementing national models published and supported by SAMHSA • Conduct site visits for mental health and substance abuse provider agencies • Incorporating performance measures into all direct service contracts	• Insufficient staff and inadequate information technology analytics to conduct quality management
	Children/ Youth	• Use youth outcome questionnaire • Use evidence-based/informed practices throughout services • Conduct quality assurance reviews of all Section 28 agencies and targeted case management programs	

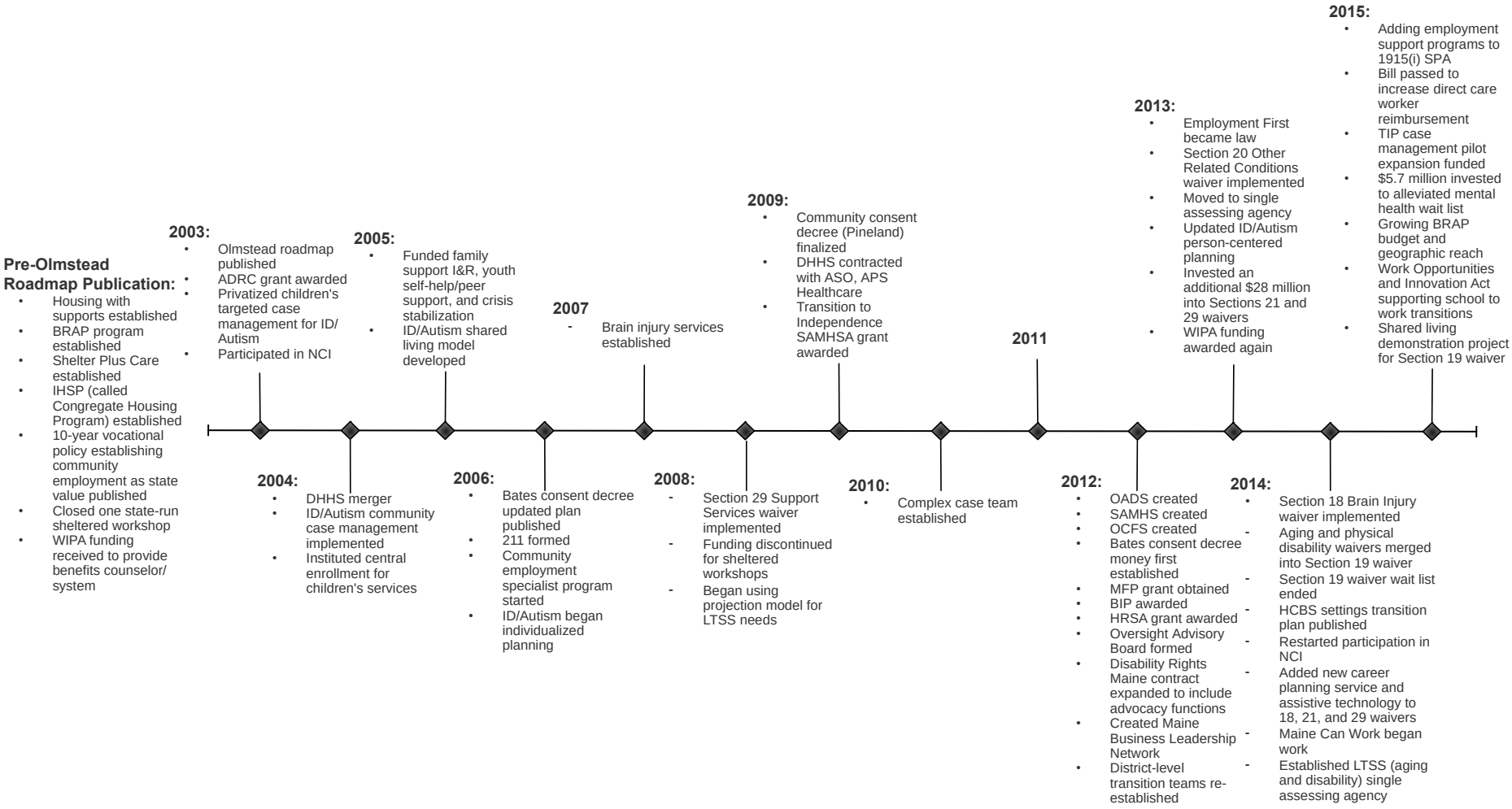
Olmstead	Population	Accomplishments	Opportunities
Accessible, available transportation	General		• Medicaid transportation services available to medical appointments or MaineCare services, not to community employment or integrated activities • Decreased access to transportation through regional networks and fewer transportation options for individuals not receiving MaineCare
Integrated, affordable, accessible housing	General	• Addressing CMS HCBS requirements through transition plan • Increased housing stakeholder coordination under MFP program • Provide support across a very complete spectrum of housing options	• One of the oldest housing stocks in the nation • Housing subsidy system is hard to navigate • No comprehensive housing plan defining needs across LTSS populations • Affordable housing is often not located close to transportation and services • Analyzing residential care facilities in Medicaid policy
	Aging/Physical Disabilities	• Fewer seniors and individuals with physical disabilities reside in nursing facilities • Implementing shared living demonstration project for potential Section 19 waiver inclusion • Crisis services are widely available • Bond proposed to rehabilitate housing for older adults and adults with disabilities • Majority of low income housing tax credits for housing dedicated to elderly	• Many older individuals live in more house than they need or can maintain • Some day settings isolate individuals
	Intellectual Disabilities/ Autism	• SIS is projected to increase housing options • Waivers provide housing modification funding • Shared living model was developed as additional option for residential support • Peer centers providing day services are less isolated	• Serve a high percentage of individuals with intellectual disabilities and autistic disorder out of their homes • Significant changes required to comply with CMS HCBS setting regulations
	Mental Health/ Substance Abuse	• Use housing first philosophy • De-linked housing from service provision • Robust housing supports available including Shelter Plus Care Program, Bridge to Recovery Program (BRAP), Projects for Assistance in Transition from Homelessness,	• Unclear whether Maine has sufficient supports and services to meet the needs of the long-term homeless population • Limited availability of substance abuse treatment beds

Olmstead	Population	Accomplishments	Opportunities
		and 1907 rental subsidy program • Expanding BRAP budget and geographic reach • Housing units meet HUD quality standards • 95% of participants are in the community	
	Children/ Youth	• Reduced the number of children in residential settings • Increased focus on youth transition	• Residential care is in process of right-sizing to provide adequate support to children with complex needs and families closer to home
Jobs	General	• Implementing Employment First initiative and activities across disabilities	• Increasing employer awareness through Maine Business Leadership Network
	Intellectual Disabilities/ Autism	• Significant work to implement Olmstead community integration values through employment policies and practices • No state funding to sheltered workshops since 2008 • Created Benefits Counseling services and statewide system • Created Maine Business Leadership Network to promote diversity hiring among Maine businesses • Created Maine WorkForce Development system • Career Planning service added to MaineCare waivers • Employment outcome data tracked quarterly • Provide employment support services and adding employment support programs to the upcoming 1915(i) State Plan Amendment • Received BIP funding for Benefit Navigator trainings • Received Employment Policy Technical Assistance award	• Some participants transitioned to day habilitation programs rather than community-based employment with end of sheltered workshop funding • Normalizing expectations around work through Employment First initiatives that provide opportunities to align policies, practices, and funding to support employment as the preferred day outcome
	Mental Health/ Substance Abuse	• Provide mental health long term supportive employment • Implemented community employment specialist program • Working to change norms so employment is seen as viable option • Conduct workforce development	• Lowest competitive employment rate of the nation • Adding employment support programs to the upcoming 1915(i) State Plan Amendment • Participants are fearful of losing MaineCare benefits if employed • Working to improve employment performance metrics with Assertive Community Treatment program

Olmstead	Population	Accomplishments	Opportunities
		• Work with employers through Maine Leadership Business Network • Track employment outcome data	
	Children/ Youth	• Employment First subcommittee focusing on transition age youth • Workforce Investment Act also focusing on transition age youth	

The timeline in the following figure shows a timescale for a subset of the accomplishments from the previous summary table.

Figure 2: Maine's LTSS Accomplishments Timeline



Methodology

The progress report and needs assessment used a mixed qualitative and quantitative methods framework incorporating multiple data sources and collection methods.

Table 2: Project Approach

Conduct kick off meeting	Bloom Consulting met with DHHS representatives from OADS, OCFS, SAMHS, and the Office of Continuous Quality Improvement to define project scope and objectives.
Conduct key informant interviews	Researchers conducted key informant interviews with 36 stakeholders in DHHS and other organizations associated with the Olmstead objectives. Interviewees discussed long term services and supports, what is working well, accomplishments since the 2003 roadmap was published, outstanding needs, and the reason for these gaps. Insights from interviewees are included throughout the analysis. Appendix C contains the list of interviewees.
Conduct survey	A survey was used to collect information on long term services and supports from a broad array of stakeholders including participants, family members, providers, advocates, and other interested parties. We received 368 responses. Analysis of results is included throughout the assessment, the survey tool is included in Appendix A, and a summary of respondents is included in Appendix B.
Examine administrative data	DHHS and other organizations provided administrative data to understand issues impacting Maine's long term services and supports. Data included information related to program caseloads, funding, strengths, and gaps.
Review secondary data	Secondary data sources included a multitude of background information from federal and state government agencies as well as research organizations with data on long term services and supports. A full list of these sources is included in Appendix D.
Review contextual data	Researchers reviewed and incorporated information from similar projects conducted nationally to assist in the analysis of issues and trends.
Define accomplishments	Bloom Consulting analyzed data gathered through all of the previous steps to identify strengths of Maine's long term services and supports.
Define opportunities	Researchers also identified opportunities for improvement. These opportunities are defined in terms of the gap between how systems currently operate and the vision outlined in the 2003 Olmstead roadmap.

Researchers analyzed and aggregated the diverse data to identify perception of and progress toward recommendation areas from the 2003 roadmap for change.

When possible, findings were validated by cross-verifying observations from two or more data sources. This triangulation combines multiple observations from different sources to improve confidence in findings, however, this report does not provide an overall independent evaluation of progress in meeting Olmstead goals. Rather, it summarizes and communicates perspective on this progress from diverse data sources and stakeholders.

Issues, Assumptions, and Constraints

The following issues, assumptions and constraints formed the context for this analysis:

- **Large scope with high degree of complexity** – It is an ambitious task to define the accomplishments and outstanding needs associated with the statewide spectrum of long term services and supports in a usable format. This analysis could be much longer and more comprehensive, but possibly at the expense of readability and utility.

- **Medicaid focus** – This analysis focuses primarily on Medicaid-funded programs. A more comprehensive analysis of state and grant funded LTSS programs was beyond the scope of this project.

- **Inability to quantify progress or establish causal relationships.** The progress report is intended to describe the current context of service delivery and provide a qualitative summary of progress made toward recommendations established in the 2003 Olmstead roadmap. It does not provide discrete measures of change in outcomes over this time, or causally link progress with any specific program or policy. A more rigorous evaluation framework would be required to provide causal or impact statements.

- **Limited primary, quantitative data** – In general, there was limited quantitative data available to support the progress report analysis. Data used in the analysis comes from disparate sources, and is generally not coordinated across issue-areas in the various LTSS systems. The lack of quantitative data made it challenging to objectively analyze progress and prioritize outstanding needs.

- **Limited capacity to incorporate direct participant voice –** The participant voice is an integral component of understanding service provision and progress. Progress report resources precluded a more comprehensive focus on participants directly, though participants were included as key informants in

interviews and participated in the web-based stakeholder survey. Stakeholders self-selected to participate in the survey, creating a self-selection bias. More comprehensive participant focus during the data collection process was outside the scope of the project.

Report Organization

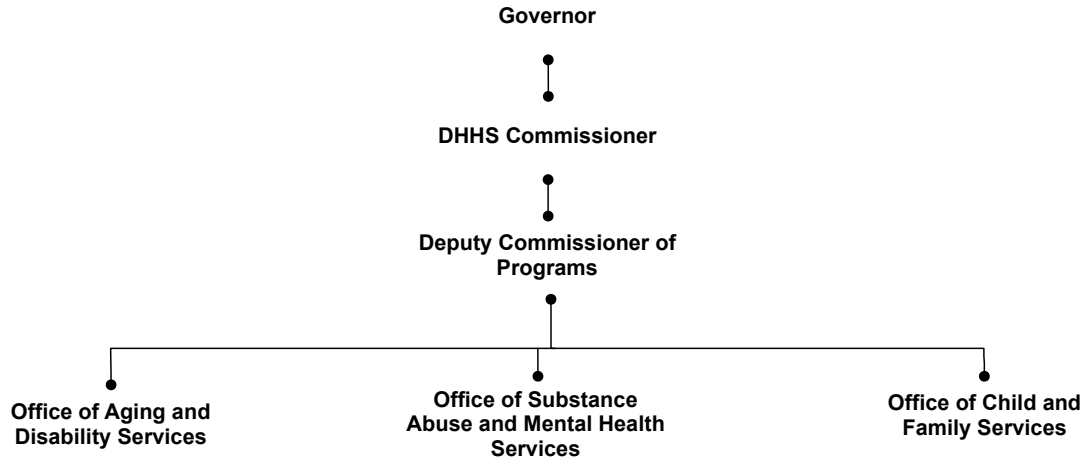
The majority of this report is organized around the objective areas defined in the 2003 Olmstead roadmap report. Each section addressing a recommendation provides an overview of the 2003 recommendations, accomplishments made between 2003 and 2015, and further opportunities where the 2003 recommendations have not been fully realized. These accomplishments and opportunities are divided into LTSS program areas where applicable.

Maine's Long Term Services and Supports Systems

Maine provides Medicaid-funded long term services and supports (LTSS) primarily through three offices at the Department of Health and Human Services (DHHS):

- **Office of Aging and Disability Services** (OADS) – OADS provides LTSS to individuals who are elderly, have physical disabilities (including brain injuries), intellectual disabilities, and autistic disorder.
- **Office of Substance Abuse and Mental Health Services** (SAMHS) – SAMHS provides LTSS to individuals with serious persistent mental illness and substance abuse disorders.
- **Office of Child and Family Services** (OCFS) – OCFS provides LTSS to children with mental health disorders, behavioral health problems, substance abuse disorders, intellectual disabilities, and autistic disorder.

Figure 3: DHHS LTSS Organizational Chart



The organization of DHHS has evolved over time through mergers and reorganizations. The goal of these mergers was to create a more integrated and efficient service delivery system.

- **2004**: The Department of Health and Human Services is the result of a merger between two legacy agencies: the Department of Human Services and Department of Behavioral and Developmental Services.
- **2012**: The Office of Substance Abuse merged with the Office of Adult Mental Health Services to form SAMHS. Substance abuse, mental health, and developmental services have been managed in many configurations – they have been run as one office, three offices, and now two offices.
- **2012**: The Office of Elder Services merged with the Office of Adults with Cognitive and Physical Disability Services to form OADS.
- **2012**: The Bureau of Children's Behavioral Health Services and the Bureau of Child Welfare merged to become OCFS.

Service by Population

The spectrum of long term services and supports participants in Maine includes:

- Individuals who are elderly
- Individuals with physical disabilities (adults and children), including:
    - Individuals with brain injuries
    - Individuals with other related conditions
- Individuals with intellectual disabilities or autistic disorder (adults and children)
- Individuals with mental illness or disorder (adults and children)
- Individuals with substance abuse disorder (adults and children)

The table below outlines the MaineCare (Maine's Medicaid program) long term services and supports associated with each population group.

Table 3: High Level View of Maine's LTSS Participants and Associated MaineCare Services[4]

Adults (Age 18+)	
Individuals who are elderly or have physical disabilities (including brain injury and other related conditions)	• State Plan consumer-directed attendant services (§12) • State Plan private duty nursing and personal care services (§96) • State Plan day health services (§26) • State Plan home health services (§40) • 1915(c) waiver home and community based services for adults with brain injury (§18) • 1915(c) waiver home and community benefits for the elderly and adults with disabilities (§19)

[4] Department of Health and Human Services Chapter 101: MaineCare Benefits Manual, Provided by: APA Office, Department of the Secretary of State (Maine).

	• 1915(c) waiver home and community based services for adults with other related conditions (§20) • State Plan nursing facilities (§67) • State Plan private non-medical institution services (§97) • State Plan hospice services (§43)
Individuals with intellectual disabilities or autistic disorder	• State Plan targeted case management services (§13) • State Plan private duty nursing and personal care services (§96) • 1915(c) waiver home and community benefits for members with intellectual disabilities or autistic disorder (§21) • 1915(c) waiver support services for adults with intellectual disabilities or autistic disorder (§29) • State Plan private non-medical institution services (§97) • State Plan ICF-IID (IID) (§50)
Individuals with mental illness or substance abuse disorder	• State Plan community support services (§17) • State Plan behavioral health services (§65) • State Plan targeted case management services (substance abuse) (§13) • State Plan home health services (§40) • State Plan behavioral health home services (§92) • State Plan private non-medical institution services (§97) • State Plan psychiatric hospital services (§46)
Children (Birth to Age 18)	
Children with intellectual disabilities or autistic disorder	• State Plan rehabilitative and community support services (§28) • State Plan behavioral health services (§65) • State Plan targeted case management services (§13) • State Plan private non-medical institution services (§97) • State Plan ICF-IID (§50)
Children with mental disorders	• State Plan rehabilitative and community support services (§28) • State Plan behavioral health services (§65) • State Plan targeted case management services (§13) • State Plan behavioral health home services (§92) • State Plan private non-medical institution services (§97) • State plan psychiatric facility services (§46)
Children with physical disabilities	• State Plan targeted case management services (§13) • State plan private duty nursing and personal care services (§96) • State Plan early and periodic screening, diagnosis, and treatment services (§94)

The sections below outline the MaineCare LTSS within the relevant State Plan and waiver programs for each population in more detail.

Elderly and Adults with Physical Disabilities Services

Medicaid State Plan Services (group residential services):

1. Nursing Facilities
2. Residential Care Facility – Case Mix Facilities

Medicaid State Plan Services (individual community-based services):

1. Consumer Directed Attendant Services (individuals with physical disabilities only)
2. Care coordination

3. Private Duty Nursing
4. Personal Assistance
5. Home Health
6. Durable Medical Equipment
7. Medical Transportation
8. Therapy Services (Occupation Therapy [OT], Physical Therapy [PT], Speech Therapy, etc.)
9. Psychologist and Psychiatrist

Medicaid 1915(c) Section 19 Home and Community Based Services (HCBS) Waiver Services (group community-based residential services with capped enrollment):

1. None

Medicaid 1915(c) Section 19 HCBS Waiver Services (individual and group community-based services with capped enrollment)

1. Adult Day Health
2. Care Coordination
3. Environmental Modifications
4. Homemaker Services
5. Non-Medical Transportation
6. Personal Care – Agency
7. Self-Directed Personal Care/Fiscal Management/Support Brokerage (only Maine 1915(c) waiver with formal participant directed services option)
8. Personal Emergency Response Systems
9. Respite Care – Institutional and Non-institutional

Medicaid 1915(c) Section 18 HCBS Waiver Brain Injury Services (group community-based residential services with capped enrollment):

1. Waiver Group Home

Medicaid 1915(c) Section 18 HCBS Waiver Brain Injury Services (individual and group community-based services with capped enrollment)

1. Care Coordination
2. Career Planning
3. Home Support
4. Reintegration
5. Assistive Technology
6. Work Support
7. Non-Medical Transportation
8. Employment Specialist Services

Medicaid 1915(c) Section 20 Waiver "Other Related Conditions" Services are generally the same as those in the Section 18 and Section 19 Waivers. However, the Other Related Conditions waiver does not contain career planning at this time.

Adults with Intellectual Disabilities or Autistic Disorder

Medicaid State Plan Services (group residential services):

1. Intermediate Care Facility for the Mentally Retarded (Individuals with Intellectual Disabilities (ICF-IID) – Nursing
2. ICF-IID – Group Home
3. Residential Care Facility – Non Case Mixed Medical and Remedial Services

Medicaid State Plan Services (individual community-based services):

1. Private Duty Nursing
2. Personal Assistance
3. Home Health
4. Durable Medical Equipment
5. Targeted Case Management
6. Medical Transportation
7. Therapy Services (OT, PT, Speech Therapy, etc.)
8. Psychologist and Psychiatrist

Medicaid 1915(c) Section 21 HCBS Waiver Services (group community-based residential services with capped enrollment):

1. Shared Living or "Adult Foster Home"
2. Waiver Group Home

Medicaid 1915(c) Section 21 HCBS Waiver Services (individual and group community-based services with capped enrollment)

1. Community Support
2. Career Planning
3. Work Support
4. Home Support
5. Crisis Intervention
6. Employment Specialist Services
7. OT, PT, Speech Therapy (Maintenance)
8. Assistive Technology and Equipment

Medicaid 1915(c) Section 29 HCBS Waiver Services (individual and group community-based services with capped enrollment)

1. Services similar to those in the Section 21 Waiver with the addition of Respite Care

Adults with Mental Illness or Substance Abuse Disorder Services

Medicaid State Plan Services (group residential services):

1. Residential Care Facility – Community Residences for Persons with Mental Illness
2. Psychiatric Hospital (inpatient 21 and younger or 65 and older)

Medicaid State Plan Services (individual community-based services):

1. Community Integration
2. Daily Living Support Services
3. Adult Community Integration (ACT)
4. Behavioral Health Services
5. Medication Management
6. Crisis Stabilization Residential Facility
7. Crisis Stabilization Mobile Response
8. Outpatient Services
9. Opioid Treatment
10. Private Duty Nursing
11. Personal Assistance
12. Home Health
13. Behavioral Health Home
14. Psychologist and Psychiatrist

Maine has no waiver services for adults with mental illness or substance abuse disorder.

Children's Services

Medicaid State Plan Services (group residential services):

1. Residential Care Facility – Child Care Facilities
2. ICF-IID – Group Home
3. Psychiatric Hospital

Medicaid State Plan Services (individual community-based services):

1. Targeted Case Management
2. Social Integration Skill Building
3. Home and Community Based Treatment
4. Behavioral Health Day Treatment
5. Outpatient Services
6. Family Psychoeducational Treatment
7. Assertive Community Treatment
8. Behavioral Health Home
9. Psychologist and Psychiatrist

Support individuals in finding their voice and speaking for themselves

Original Roadmap Recommendations

This portion of the 2003 roadmap focused on participant voice and organized participant advocacy, and included 13 recommendations.

1. Support the recruitment and training of consumers to participate on state and provider boards.
2. Train employers, community leaders, churches and others to be open and receptive to self-advocacy.
3. Develop more user-friendly advocacy organizations and materials.
4. Provide supports for protecting individual rights.
5. Develop alternative advocacy models to support increased participation.
6. Create advocacy organizations independent of the State.
7. Eliminate barriers to participating in public policymaking.
8. Pay for support services necessary for participation.
9. Make available funding to support out-of-pocket expenses for participation.
10. Develop and publicize alternative means for giving input into the political process with use of technology and assistive technology.
11. Support coalitions of advocacy groups around key issues.
12. Support clearinghouse and information exchange between advocacy groups.
13. Support leadership training.

Accomplishments

General Accomplishments

Maine embraces the idea of participant advocacy – it is part of the DHHS ethos. The assumption is that participant voice and advocacy are important and valuable. In general, according to survey respondents and interviewees, this has been demonstrated through:

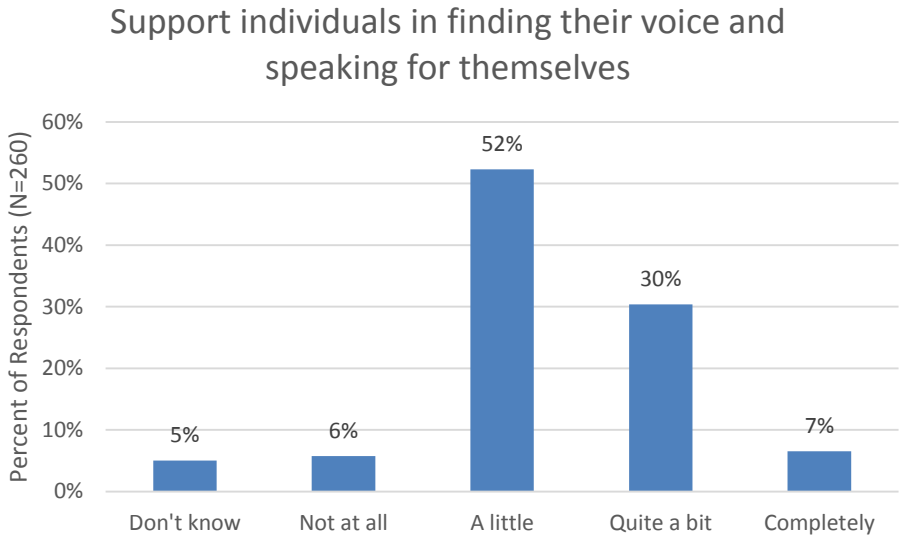
- **Financial support provided to advocacy community** – The state has long-standing commitment to providing financial support to the advocacy community without a lot of restrictions, including transportation support.
- **Well publicized grievance process, rights, and regulations** – All DHHS offices have a well-publicized grievance process, which is discussed during person-centered planning and is available online. Participant rights as well as comprehensive lists of

services, providers, and advocacy organizations are also published in multiple formats.

- **Plain language materials** – DHHS has worked hard to simplify the language of its materials.
- **Balancing Incentives Program (BIP)** – A central component of BIP is participant voice, which is used to address and improve system issues.
- **Advocacy positions made independent of the state** – Disability Rights Maine, previously called the Disability Rights Center, is Maine's protection and advocacy organization. Prior to 2012, DHHS directly employed advocates, focused on OADS participants. These positions were eliminated in 2012, and DHHS expanded its contract with Disability Rights Maine to include many of the advocacy functions previously fulfilled by state employed advocates. Disability Rights Maine represents individuals across the spectrum of LTSS needs, including two children's advocates. The organization is involved in various activities including coordinating cases, updating regulations, and systems-level initiatives.
- **Open communication between participants and policymakers** – Participants are encouraged to communicate with policymakers through letters from the DHHS Commissioner and other mechanisms.

A majority (52 percent) of survey respondents felt that Maine meets the priority of supporting individuals in finding their voice and speaking for themselves "a little". On a 1 to 4 scale, where 1 is "Not at all" and 4 is "Completely", the weighted average for this priority was 2.4, suggesting that respondents felt, on average, the state met this priority slightly better than "A little", and not yet "Quite a bit".

Figure 4: Survey Respondents' Evaluation of Voice and Advocacy Recommendation Progress



Aging and Physical Disabilities Accomplishments

Participants who are elderly or who have physical disabilities are able to self-advocate:

- **Directly** – Individuals are always invited to participate in work groups or advisory councils.
- Through the **Center for Independent Living (CIL)** – Alpha One is the state's Center for Independent Living. Participant voice, peer support, and self-advocacy are central to Alpha One's work.
- Through **Aging and Disability Resource Centers (ADRCs)** – Dignity and self-advocacy are strong components of ADRCs.
- Through the **Maine Coalition on Aging** – It is a coalition working on aging issues to ensure planning and funding decisions are being made to reflect the issues associated with the aging population of Maine.

Intellectual Disabilities and Autistic Disorder Accomplishments

Participants with intellectual disabilities and autistic spectrum disorder have a wide array of advocacy organizations in which to participate or advocate. DHHS meets regularly with all of these organizations, in addition to Disability Rights Maine listed in the general section, to ensure participants', families', and advocates' voices are a part of policy decisions.

- **Speaking Up for Us (SUFU)** – SUFU is run for and by adults with developmental disabilities.
- **Maine Developmental Disabilities Council (MDDC)** – Established as part of the federal Developmental Disabilities Assistance and Bill of Rights Act of 2000, MDDC works to ensure participants are included, supported, and valued in their communities.
- **Maine Development Services Oversight and Advisory Board (DSOAB)** – DSOAB is an independent, all volunteer board appointed by the Governor to monitor Maine's system for adults with intellectual disabilities and autism spectrum disorder.
- **Maine Coalition for Housing and Quality Services** – The coalition was organized in 2006 and created the continuum of care model in 2010.

Mental Health and Substance Abuse Accomplishments

Participants with mental illness and substance abuse disorder also have strong voices in policymaking. Stakeholders indicated that individuals have been active participants in the new quality management plan, which will be published in 2015. In addition to Disability Rights Maine, which was the plaintiff's counsel in the consent decree, individuals, families, and advocates participate through:

- **Quality Improvement Council (QIC)** – QIC is the Mental Health Planning Council required by the Federal Mental Health Block Grant, and works to improve the system of care for adults with mental illness and children with serious emotional

disturbance. Participants run the QIC, and stakeholders suggest that it has been a great avenue for participant voice.

- **Consumer Council System of Maine (CCSM)** – CCSM is responsible for providing an independent and effective participant voice into mental health public policy, services, and funding decisions. The CCSM consists entirely of past/present recipients of mental health services (participants/peers), including all Statewide Consumer Council representatives and paid staff.[5]
- **National Alliance for Mental Illness-Maine (NAMI-Maine)** – NAMI-Maine is an active voice for individuals and families impacted by mental illness and provides a wide variety of services including an information and referral help line and family-to-family training.
- **APS Healthcare Member Advisory Council (MAC)** – MAC members review published material for clarity, discuss service improvements, and suggest trainings. Members must be using MaineCare behavioral health, intellectual disabilities, or substance abuse disorder services in the past two years.

SAMHS has funded **Adult Peer Support** in Maine as part of social club and drop-in center programs for over twenty years.

SAMHS and OCFS recently released a **peer support request for proposals** to provide peer services to youth and adults with the goal of improving functioning and well-being, enhancing relationship and social connections, and increasing engagement and participation in meaningful community activities.

Children/Youth With Disabilities Accomplishments

Youth and their families actively participate in policymaking.

- **Federal grants** – OCFS has two federal grants related to youth transition. The first allowed Maine to set up youth advocacy infrastructure.
- **Participate in intellectual disability, mental health, and substance abuse groups** – Children and families are often included in the groups listed above related to intellectual disabilities, autism spectrum disorder, mental health, and substance abuse disorder. OCFS meets with the parent organizations regularly to hear their concerns.
- **QIC** – Children are included in the QIC through children's representatives participating in the full QIC and a children's subcommittee.
- **Maine Alliance of Family Organizations (MAFO)** – MAFO was formed as a statewide alliance to strengthen family voice to better serve families of children with disabilities.
- **Youth Move** – This is a youth-led organization that ensures young people have a say in the decisions that impact their lives. OCFS meets regularly with Youth Move. DHHS has contracted with Youth Move to provide peer support under the

[5] Substance Abuse Block Grant Behavioral Health Assessment Plan 2014, SAMHS, DHHS.

Transition to Independence Process (TIP) grant from the Substance Abuse and Mental Health Services Administration (SAMHSA).
- **OCFS workgroups** – OCFS often incorporates parent representatives in large policy activities.

OCFS has funded **family support information and referral**, **youth self-help/peer support**, and **crisis stabilization** since 2005.

OCFS and SAMHS recently released a **peer support RFP** to support improvements in health, home, purpose, and community for youth and adults.

Opportunities

General Opportunities

Maine has worked hard to make participant voice and advocacy part of its LTSS culture. The next step is to **institutionalize this effort**. Stakeholders indicate a need for broader culture change at provider agencies so staff members consistently embrace these ideals.

Additionally, feedback suggests that participants and family members could benefit from **training or skill development to become more effective at advocating**. Advocating well requires education.

Survey respondents spoke to the need for **increased advocates and access to self-advocacy** across all geographic areas of the state.

Other specific gaps expressed through interviews and survey respondents include:
- **Disability Rights Maine has an unstable pool of advocates** because of high attorney turnover.
- **DHHS websites could be improved** through universal design and improved search-ability.
- **Elders and adults with physical disabilities have fewer opportunities to be heard** compared to other LTSS populations.

Help people control and deliver the services and supports they need

Original Roadmap Recommendations

The original roadmap focused primarily on self-direction within the category of choice and control. Self-direction and the subsequent recommendations regarding person-

centered planning are the ways in which participant voice and advocacy are operationalized. Specifically, the 2003 roadmap recommended:

1. Expand self-directed services by providing individuals and families with the power to control and direct the services delivered.
2. Offer individual budgets for the entire range of long term care and home and community based services needed, basing the level of support on health, functional status, and living situation.
3. Allow and promote the use of independent employment management services and other types of supports for persons directing their own care.
4. Develop intermediate supports so that self-directed care is an option for persons who do not want all the responsibilities of self-direction.
5. Develop standards for offering the self-directed care option to persons not legally competent to direct their own care.
6. Define "allowable expenses" while permitting individuals and families to use their budgets to meet individual needs.
7. Develop strategies for reducing the reliance on forced medication and involuntary hospitalization.

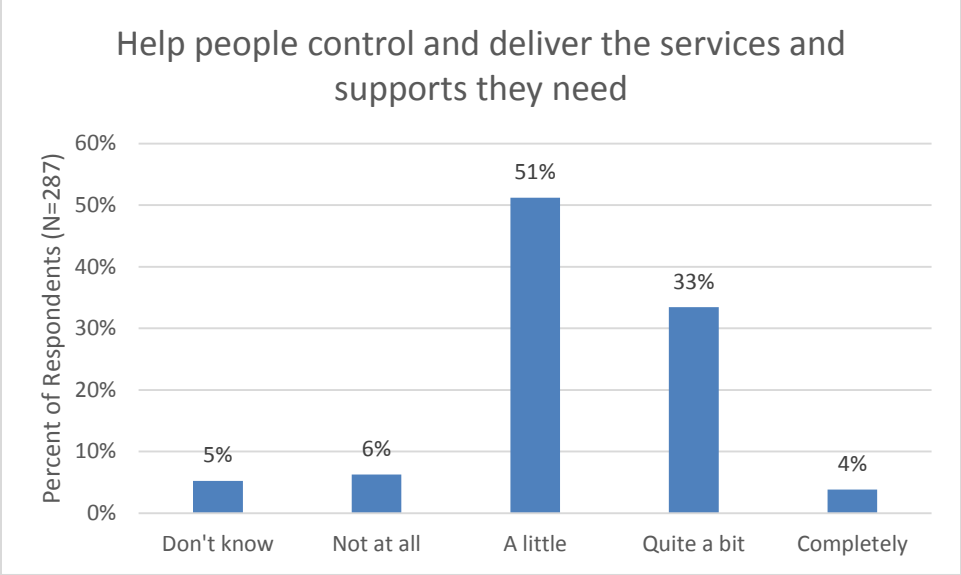
Accomplishments

General Accomplishments

Self-directed services means participants or their representatives have decision-making authority over certain services or take direct responsibility to manage services. It is an alterative to agency managed and delivered services. Self-direction and choice have grown over time in Maine with increased options. DHHS is **moving toward participant-direction options**. Many of Maine's LTSS programs support individual choice through person-centered planning processes, which is discussed in the subsequent report section.

Thirty-seven percent said the state met this priority "Quite a bit" or "Completely". A majority (51 percent) of survey respondents felt that Maine meets the priority of supporting individuals in finding their voice and speaking for themselves "A little". The weighted average for this priority, on a scale of 1 to 4, was 2.37.

Figure 5: Survey Respondents' Evaluation of Participant Control/Self-Direction Recommendation Progress



Aging and Physical Disabilities Accomplishments

According to interviewees, Maine has a **strong tradition and history of self-direction programs for individuals who are elderly or have physical disabilities**. All of the following programs managed by OADS have an option for self-direction. OADS is working toward these programs all having a surrogacy option.

- State Plan consumer-directed personal assistance services (§12)
- State Plan private duty nursing and personal care services (§96)
- 1915(c) waiver home and community benefits for the elderly and adults with disabilities (§19)

The 1915(c) waivers for adults with brain injury (§18) and adults with other related conditions (ORC) (§20), as well as State Plan residential services (residential care and nursing facilities) do not have explicit options for self-direction. However, through care coordination, the entire process of planning and control of that plan from the beginning is in the hands of the individual participant. **ORC participants assist in selecting and hiring their direct care workers**, but do not handle payroll.

Legislation was passed requiring more portability across funded programs and providers. This **portability allows participants to move onto and off self-direction**.

Intellectual Disabilities and Autistic Disorder Accomplishments

Neither the Section 21 comprehensive waiver nor the Section 29 support services waiver for adults with intellectual disabilities and autistic disorder have self-direction. However, both waivers use **person-centered planning to support individual choice**. The **Supporting Individual Success initiative is intended to make the system more person-**

centered and provide more participant choice. The Supports Intensity Scale (SIS) determines the resource allocation, and a participant can use the budget to procure services from their choice of providers. OADS **added assistive technology** into these waivers to support increased participant independence. The concept and opportunities for people to have choice and control is integral to the planning process.

Mental Health and Substance Abuse Accomplishments

Mental health and substance abuse disorder services have **choice**. According to interviewees, choice equates to self-direction, in that, with the exception of involuntary hospitalization, individuals direct their services. Participants decide when to receive services, what services they want to receive, and from which provider they will receive them. Individuals do not have to receive all of their services with one provider or agency. A pending rule change will require assessing agencies to be separate from providing entities, further supporting choice.

Participants are also able to use **representatives** to support their planning process.

Children/Youth with Disabilities Accomplishments

Similar to mental health and substance abuse disorder, **parents have a right to choice** regarding their children's services. Parents can select providers/agencies and can refuse services at any point. Families are also able to use **representatives** to support youth in their planning.

Opportunities

General Opportunities

Stakeholders indicate that **choice is often constrained by service unavailability**, particularly because of insufficient provider staffing and housing statewide.

Many providers and advocates spoke about the need for the state and the LTSS system at large to be less protective. This transition is occurring through increased focus on self-direction and person-centered planning, however, there needs to be **continued focus on individual voice, choice, and control**. Self-direction and choice need to be balanced with state oversight or quality management requirements to ensure health and welfare.

Aging and Physical Disabilities Opportunities

Stakeholder feedback suggests that individuals using LTSS services with a participant directed model **may need more support to make self-direction a feasible option**. Individuals may need more training on recruiting, hiring, training, and supervising caregivers, as well as help managing service budgets.

Intellectual Disabilities and Autistic Disorder Opportunities

Some participants and advocates believe the **lack of self-direction is a significant problem**. Providers generally drive service decisions for these individuals, many of whom have significant and complex needs. Self-direction would provide more autonomy to these participants and families, and could increase choice.

Additionally, participants, families, and advocates have **concerns around the service budget cap associated with the SIS**. While this cap works well for the majority of individuals, it is may not be sufficient for the small percentage with higher needs requiring more full time support.

Organize services around the person served

Original Roadmap Recommendations

This recommendation area focused on person-centered planning and services.

1. Organize services around the person served.
2. Provide option of having one comprehensive resource plan.
3. Provide option of independent person facilitating service integration and coordination.
4. Create a "circle of accountability" for comprehensive resource plan.
5. Adopt accountability standards that require individuals and families to actively participate in planning, to register complaints, make informed choice, and document progress.

Both this and self-direction are operationalizing individual voice and advocacy from the first recommendation area.

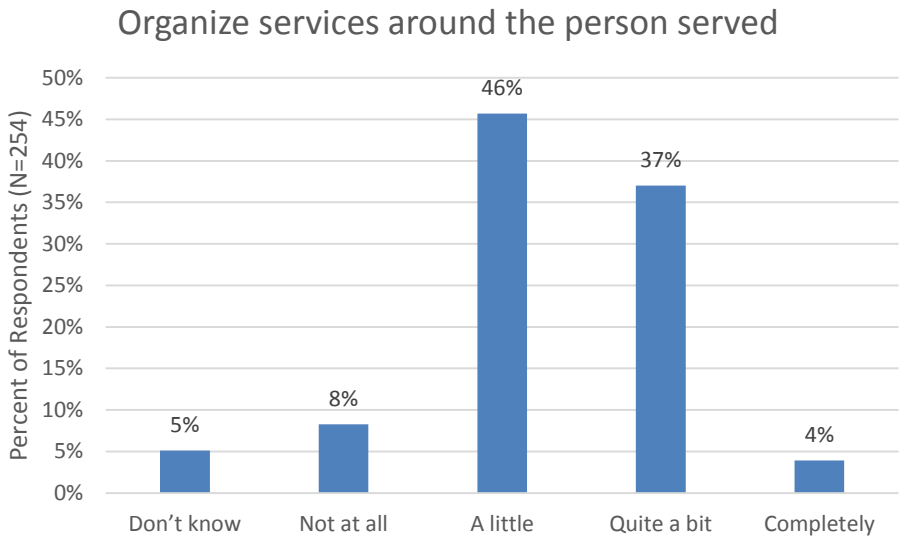
Accomplishments

General Accomplishments

According to many interviewees, person-centered planning is a **core of the philosophy** in waiver and State Plan LTSS programs. Person-centered planning will be strengthened as Maine implements new federal HCBS settings regulations. The emphasis will clearly be a focus on the individual's wants and needs, rather than provider preferences. Maine is reviewing regulations, policies, and practices to make person-centered planning more robust throughout LTSS programs.

Just under half of all respondents (46 percent) felt Maine met this priority "A little", and almost as many (41 percent) felt the State met this priority "Quite a bit" or "Completely". The weighted mean for this response was 2.39.

Figure 6: Survey Respondents' Evaluation of Person-Centered Planning and Services



Intellectual Disabilities and Autistic Disorder Accomplishments

Person-centered planning is institutionalized in Developmental Services. A highly developed person-centered planning process drives service provision. In 2006, Developmental Services instituted "Five Essential Service Accomplishments" by John O'Brien as the framework and basis of individualized planning, focused on individual goals instead of services. OADS updated the process in 2013 to ensure the independence of plan facilitators, meaningful goals to the person, participant control over the planning process, and to have a universal plan on the Enterprise Information System (EIS) accessible by all providers on the plan. OADS has recently been reviewing and enhancing the model through new tools and enhanced training for staff. There is a standard process for collecting feedback from participants about the planning process, the resultant plan, and the progress made toward goals in the plan.[6]

Mental Health and Substance Abuse Accomplishments

Person-centered planning and participant-directed care occurs through **Individual Support Plans (ISPs)** and treatment plans. Participants are expected to work collaboratively with service providers to create and implement these plans, which are

[6] Olmstead Roadmap for Change, Update for Developmental Services, 2014, OADS, DHHS.

based on individuals' self-identified goals. The ISP process is flexible and responsive to individual needs and wants.[7]

Children/Youth with Disabilities Accomplishments

OCFS implemented **wraparound services** to create an integrated plan developed by families and their teams. All targeted case management contracts require the use of wraparound, adherence to SAMHSA System of Care principals, and integration of trauma informed principals. "Nothing about me without me" is a core principal of wraparound.

OCFS and SAMHS jointly obtained a SAMHSA grant in 2009 to implement the Transition to Independence Process (TIP), which includes a model of case management for young adults with mental health and substance use disorders. **TIP case management develops core competencies** in youth ages 16 to 25 to help them transition successfully into adulthood. It is youth guided and youth driven. TIP was piloted in 2009 – 2015 in Androscoggin County, and is being expanded in the 2015 – 2019 grant to two additional counties.

Opportunities

General Opportunities

Person-centered planning works **within the constraints of the LTSS system in Maine**. Interview and stakeholder feedback suggests that there are limitations in terms of staffing at service providers, housing availability, and regulations. The State is working to enhance person-centered planning services and training in response to federal HCBS regulations, and is examining its regulations as a part of this effort.

Aging and Physical Disabilities Opportunities

Participants who are aging or have physical disabilities in the Section 19 waiver work with care coordinators rather than case managers. It is a less intensive service providing higher-level coordination versus in depth guidance. According to some, the **lack of true case management limits the ability for person-centered planning to occur meaningfully**.

Intellectual Disabilities and Autistic Disorder Opportunities

Case managers are integral to the person-centered planning process in terms of meeting facilitation, creating, and overseeing implementation of the plan. Participants, families, and advocates observe that **the person-centeredness of the process varies based on the case manager** and planning team. Recent changes in person-centered planning

[7] Substance Abuse Block Grant Behavioral Health Assessment Plan 2014, SAMHS, DHHS.

have meant that the system has evolved from annual meetings to a series of meetings with relevant stakeholders. OADS is also working with providers to ensure the process is more than just filling out a form, but is truly person-centered. These changes are helping to make person-centered planning more effective, consistent, and ultimately person-driven.

Person-centered planning may conflict with the SIS. Participants, families, and advocates worry that the SIS is driving service decisions more than the person-centered planning process. It is not clear how these tools coordinate to support individual choice and control.

Mental Health and Substance Abuse Opportunities

According to interviewees, it is **unclear whether all community providers use person-centered services well**. The quality oversight process does not incorporate a review of all participant charts during site visits because of limited staff, and ISPs are not available through information technology systems.

Children/Youth with Disabilities Opportunities

OCFS plans to **increase its focus on person-centered planning** through:

- Introducing person-centered planning to child-serving systems.
- Conducting wraparound or person-centered planning and monitoring.

The mismatch between children's and adult services create transition issues, which require special attention. Survey respondents expressed a desire for **more transition-focused programs or initiatives** to better serve these individuals. DHHS is responding to this demand through multiple, cross-agency, transition-focused projects.

Integrate access to services so that there is no wrong door into the system

Original Roadmap Recommendations

The original roadmap envisioned an integrated information and referral system using service centers, a website, and a toll-free hotline.

1. Create a statewide, integrated information and referral system that covers all disability-related services through an interactive, searchable website and a statewide toll-free hotline.

2. Develop integrated service centers to serve as entry points and information sources about services across programs, including an integrated application process for those who choose it.
3. Conduct education and outreach to make sure people know where they can obtain services.
4. Conduct follow-up surveys to identify opportunities for improvement in information and referrals.

Accomplishments

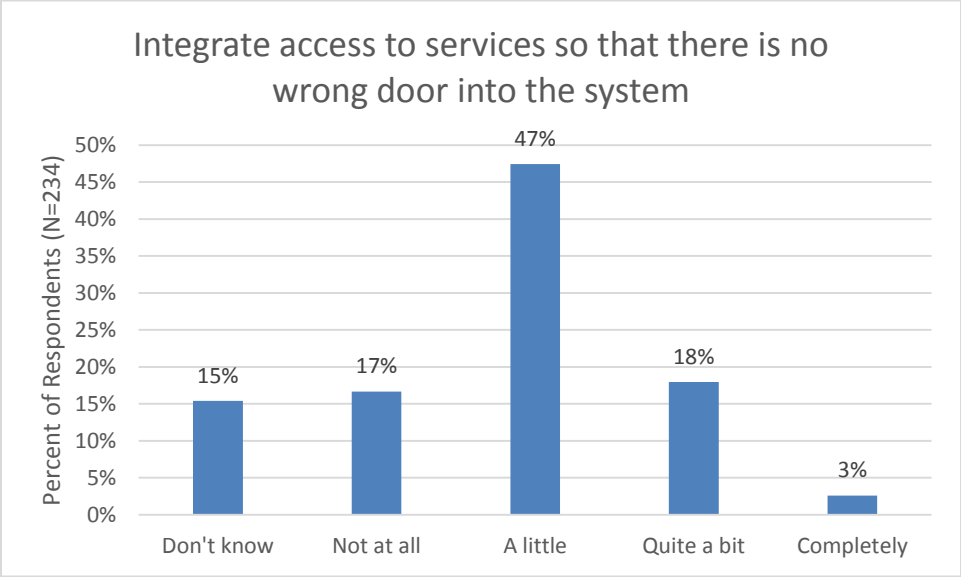
General Accomplishments

Many people enter the LTSS system through the Office of Family Independence (OFI) to determine MaineCare eligibility. **OFI supports no-wrong door priorities** by:

- Determining financial eligibility for all federally funded programs.
- Having a seamless Medicaid/CHIP application.
- Supporting MaineCare applications at the Social Security Administration Office, hospitals, and schools.
- Providing self-serve kiosks in offices.

Almost half of survey respondents felt Maine met this priority "A little". Nearly one-fifth each felt that Maine met this priority "Not at all" (17 percent), or "Quite a bit" (18 percent). Fully 15 percent of respondents selected "Don't know", which is much higher than other Olmstead recommendation areas. The weighted average for this priority was 2.08, suggesting a strong convergence on "A little" based on the distribution of responses.

Figure 7: Survey Respondents' Evaluation of No Wrong Door



Aging, Physical Disabilities, and Intellectual Disabilities and Autistic Disorder Accomplishments

Maine's Balancing Incentives Program supports **three no wrong door organizations providing informed resource and referral information: Maine211; ADRCs; and CIL**.

Maine211 is working to strengthen its presence, website, and understanding of LTSS resources for children as well as adults, so people can more easily find the information they need. Maine211 has four resource coordinators across the state who work full time to keep resources updated. Eight staff Alliance of Information and Referral Systems (AIRS) certified.

ADRCs and Alpha One, Maine's sole CIL, provide **options counseling** for individuals who are elderly or have disabilities. Maine's five Area Agencies on Aging (AAAs) became ADRCs to serve individuals across the spectrum of disabilities.

BIP is supporting marketing to help Mainers more easily find resources. The five **ADRCs now have a single website and statewide toll free number**.

BIP also created a **LTSS pre-screening tool** called MaineLink. The tool provides individuals with resources based on their responses to a series of questions. The pre-screening tool will be able to provide overview information on resources, attach documents, direct people to websites, and provide a link to Maine211. The second phase of the project will be automated, facilitated referrals to agencies.

Mental Health and Substance Abuse Accomplishments

The state and its partners provide mental health and substance abuse disorder targeted information and referral services through several mechanisms, including the **help line, crisis line, and warm line**. Maine211 often refers mental health and substance abuse disorder inquiries to these resources.

Children/Youth with Disabilities Accomplishments

Although there is no central, universal screening or a single assessing agency, **most families access the system through targeted case management**. Families typically receive referrals to case management through:

- Outpatient providers
- Parent organizations
- Schools
- OCFS' Family Information Specialist who works with families and schools
- Mental health program coordinators who work with families
- Primary care providers who have been trained to make appropriate referrals

Opportunities

General Opportunities

Stakeholder feedback indicates that it **can be very confusing for individuals trying to access LTSS** because the path is determined by a lot of variables. The right door depends on the funding source, type of disability, where the individual lives, and to whom the individual speaks. Housing, heating assistance, Social Security, and other needs, are not necessarily well coordinated with MaineCare, and agency caseworkers are not always well trained in services provided by other agencies. Websites can be hard to navigate.

The state is working to improve Maine211 through BIP to make better use of this resource. **Historically, Maine211 has struggled to help individuals navigate complex LTSS systems** for children and adults. Interviewees and survey respondents discussed inaccurate information referrals and customer dissatisfaction.

Aging, Physical Disabilities, and Intellectual Disabilities and Autistic Disorder Opportunities

Stakeholders do not consistently work together well. According to interviewees and survey respondents:

- OFI may not share information with other community partners, including ADRCs. Regulations can a barrier to information sharing.
- Alpha One and ADRCs could improve collaboration to further benefit participants.

Stakeholders indicate that **ADRCs are not sufficiently funded** to integrate disability work into their scope. Adding disability-focused work without additional funding has negatively impacted everyone served by ADRCs because fewer resources are available for information and assistance provision.

Children/Youth with Disabilities Opportunities

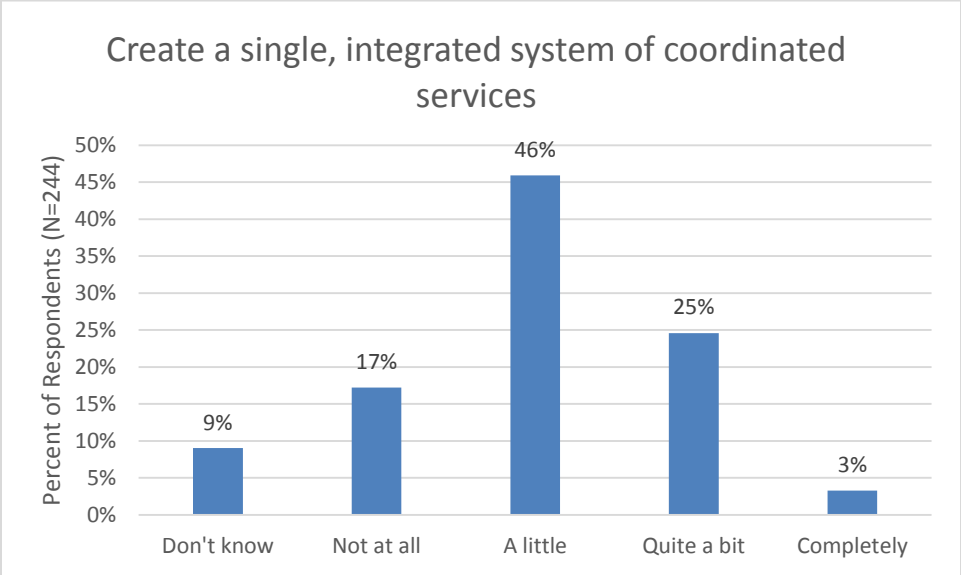
Stakeholders indicate that it is **easier for families to enter the LTSS system outside of the school system**. If a family is only receiving special education services through the school, they may struggle to learn about the broader services available because schools are often not as knowledgeable about them.

Create a single, integrated system of coordinated services

This recommendation area contains four supporting recommendations: coherent system of services; responsive service coordination; wait lists; and funding and planning. The analysis is broken down into these respective areas for clarity.

Almost half of survey respondents felt that Maine met this priority "A little", and one quarter felt it met the priority "Quite a bit". Nearly one-fifth (17 percent) did not feel that it met this priority at all. Almost one-third (28 percent) felt the state met this priority "Quite a bit" or "Completely". The weighted average for this priority was 2.15.

Figure 8: Survey Respondents' Evaluation of Single, Integrated System of Coordinated Services



Coherent system of services

Original Roadmap Recommendations

The coherent system of services recommendations in the 2003 roadmap are focused on data, measurement, and information technology systems.

1. Develop common vocabulary across systems.
2. Develop a common set of measures for assessing the effectiveness of the State's services.
3. Develop the capacity to integrate data, as well as the capacity to maintain the infrastructure to use and evaluate integrated data.
4. Develop standards for measuring and improving community integration.
5. Integrate information sources across systems, while protecting individual control over privacy.

Accomplishments

General Accomplishments

DHHS uses the **Enterprise Information System (EIS)** across most LTSS programs including intellectual disabilities and autistic spectrum disorders, mental health, aging, physical disabilities, and children's services. Participant information is integrated from planning to service delivery to support provider communication and collaboration.

Within the application, EIS has a **business process for youth transition** used by OCFS and OADS. This business process tracks and documents service needs of youth age 16 until their transition into adulthood. Training was recently completed for use of the business process.

Maine also uses an **electronic assessment system, ME-Care**, across many of the LTSS programs that captures information about individual needs, including activities of daily living and instrumental activities of daily living, other services, and level of informal supports.

OADS, SAMHS, and OCFS also use **APS Healthcare's utilization management system, CareConnection** for prior authorization, wait list management, utilization review and management, and data analysis.

Data is being shared across departments to **measure work supports and employment services**. OADS, SAMHS, and Department of Labor are sharing data to monitor system performance and individual employment outcomes.

Maine has done a lot of work to develop a **common vocabulary across LTSS programs**, so there is less confusion on what a term means from one area to another.

Mental Health and Substance Abuse Accomplishments

SAMHS **replaced Treatment Data System (TDS)** because it was not meeting Department needs. The new substance abuse and treatment system is called Web Infrastructure Technology (WIT).

Opportunities

General Opportunities

The world of technology has changed dramatically since the original roadmap was published in terms of speed, accessibility, and data analytics. DHHS' information technology systems and tools have not evolved in step with these advancements. DHHS' **outdated information technology is slow and not able to support data-informed decision making or quality management**.

Interviewees indicated that DHHS has **fragmented information technology systems**. Many programs use EIS and CareConnection, but in addition there is eligibility information in ACES, financial information in Advantage, adult protective system information in MAPSIS, and substance abuse information in WIT, formerly TDS. These systems are not integrated. Data is not easily shared between them. However, the Maine Information Health Management System (MIHMS) interfaces with a number of applications, including CareConnection, ACES, and Advantage.

Additionally, interviewees said that **information technology systems may not have reliable data**. EIS data does not always align with data tracked externally by providers. Case managers manually populate EIS, and do not necessarily use the system consistently. Information technology system transitions have created additional reliability challenges.

Maine's **health information exchange, HealthInfoNet**, is integrating healthcare information across the state. All hospitals and most primary care offices are participating in HealthInfoNet. There is an opportunity to consider broader data integration with LTSS services and providers.

Children/Youth with Disabilities Opportunities

The Department of Education and Maine Administrators of Services for Children with Disabilities **do not share school district data** with OCFS and OADS. This is due to lack of data integration within the education system. Progress is being made as the Department of Education and Maine Association of Directors of Special Education have become engaged in transition-focused work.

Responsive Service Coordination

Original Roadmap Recommendations

These recommendations focus on effective care management and coordination.

1. Identify gaps in eligibility for service coordination services.
2. Explore new ways of providing service coordination, including strategies for ensuring the independence of support and providing service coordination at neutral sites.
3. Improve quality through training and quality monitoring.
4. Explore the appropriateness of combining counseling and care management services.

Accomplishments

General Accomplishments

From a systems level, the **2004 merger creating DHHS** from the Department of Human Services and Department of Behavioral and Developmental Services formed the foundation for a more efficient and effective LTSS delivery system.

DHHS is moving toward **conflict free assessment and case management** to provide more choice and control to participants and their families. The 1915(i) State Plan Amendment is creating a wall between assessing agencies and providing entities to support this change.

Aging and Physical Disabilities Accomplishments

OADS created **two new waivers** focused on physical disabilities since the 2003 roadmap was published to provide HCBS to individuals previously ineligible for them.

- 1915(c) home and community based services for adults with **brain injury** (§18)
- 1915(c) home and community based services for adults with **other related conditions** (§20), including cerebral palsy, epilepsy, or other conditions, not including mental illness, that impair intellectual functioning or adaptive behavior.

Maine implemented a **Money Follows the Person** demonstration grant project, called Homeward Bound, in 2012 to help individuals who are elderly or have physical disabilities transition from institutions to home and community based settings.

Intellectual Disabilities and Autistic Disorder Accomplishments

OADS created a **new waiver** in 2008, the 1915(c) waiver support services for adults with intellectual disabilities or autistic disorder (§29) to increase services available to this population.

OADS is **implementing the supports intensity scale**. Using SIS allows for the system to be more graduated and flexible, rather than a one-size-fits-all approach.

OADS **expanded case management to include community-based, private providers**. Before 2004, only state employees provided case management services. Currently 60 percent of case managers are community-based.

Mental Health and Substance Abuse Accomplishments

SAMHS **refers participants with intellectual disabilities or autism spectrum disorder to OADS** because SAMHS case managers are not trained to work with these individuals.

SAMHS uses a **strengths-based multidimensional assessment, the American Society of Addiction Medicine (ASAM) criteria**, for substance abuse assessment. The ASAM criteria are an objective approach that provides comparable information across participants.

SAMHS is **piloting the Adult Needs and Strengths Assessment (ANSA)** to replace the LOCUS assessment for mental health services. The ANSA is an evidence-based assessment, intended to be a more objective tool to support consistent assessment and service delivery across the state.

SAMHS **implemented a behavioral health home model** to better address physical health issues that impact community integration for adults with severe and persistent mental health issues. DHHS is funding this work through a CMS State Innovation Models (SIM) grant. The new MaineCare funded service is a virtual health home that coordinates care through a team approach.

Children/Youth with Disabilities Accomplishments

The 2012 merger between the Department of Behavior and Developmental Services and the Department of Human Services resulted in **children's services being united within OCFS** within the new DHHS. OCFS works across children's and families' needs including children's behavioral health, child welfare, early childhood, and community services. This merger meant children in state and parent custody have the same service systems. Previously, families would try to get children into state custody in order to access services.

OCFS also **works closely with juvenile corrections**. OCFS has staff members physically located at corrections offices and facilities to ensure close coordination.

Access to residential treatment was integrated through OCFS for children across child protective services, juvenile corrections, behavioral health services, and intellectual disability/autism spectrum disorder services. OCFS conducted, and now APS Healthcare conducts, utilization review to ensure all appropriately least restrictive opportunities have been tried and access to residential care is equal.

Maine **privatized children's targeted case management** for intellectual disabilities and autism in 2002-2003, with the result of vastly lower caseloads and more attention and service provided to children receiving services. Children's mental health targeted case management was privatized since its inception in the early 1990s. Mental health targeted case management grew as a service when it became widely reimbursed by Medicaid.

OCFS uses the **Child and Adolescent Needs and Strengths (CANS) assessment** in targeted case management. OCFS staff are using the data for quality assurance work.

DHHS **contracts with APS Healthcare** as its Administrative Services Organization (ASO) to ensure responsive service coordination for OCFS as well as SAMHS. APS Healthcare conducts prior authorization and utilization review, in addition to ensuring children are placed in services as quickly as possible.

DHHS is focusing a lot on transition from child-serving systems to adulthood. The wait list for adult intellectual disability/autism spectrum disorder waiver services and the complete separation of children and adults in this disability service area had historically created gaps in services for youth aging out of children's services. In recent years, **youth targeted case managers are better supporting young people in making transitions** by determining Medicaid and SSI eligibility, applying for waiver services, and recording information through the EIS youth transition business process. **OCFS and OADS leadership are working closely together to support improved transitions** for developmental services.

Opportunities

General Opportunities

Despite some progress, according to interviews and survey responses, Maine's **LTSS system is somewhat siloed**, with insufficient coordination across program areas and funding sources. Transition work between children's and adult developmental services is positive work that is increasing coordination.

State Plan services are not well coordinated with waivers. According to interviewees, it appears that many participants receive waiver services exclusively, and do not access State Plan funded personal care or personal assistance services. This particularly impacts individuals who are elderly or have intellectual disabilities or autistic disorder, creating increased demand for waiver services and sometimes inappropriate matches between individual needs and services provided. Interviewees discussed inadequate State Plan services available for individuals with intellectual disabilities and autistic disorder on the wait list, creating an issue where targeted case managers scramble to connect youth to any adult services they can access, even if not completely appropriate for the individual's needs. Because of wait list for the Section 21 waiver for intellectual disabilities and autistic disorder, children's targeted case managers apply for multiple other types of benefits to make sure children are covered in some manner in the adult system. The implementation of the 1915(i) State Plan Amendment will help to address this by incorporating some services currently only available in waivers into the State Plan. Additional changes to the Section 17 State Plan will also ensure intended individuals receive services for severe and persistent mental illness.

Aging and Physical Disabilities Opportunities

Care coordination in Section 19 waiver may not support responsive service coordination well. According to interviews and survey responses, care coordinators are often not sufficiently involved with participants to effectively identify and respond to unmet or shifting needs. OADS is actively working to address this gap by improving person-centered planning through its implementation of CMS' HCBS regulations.

Intellectual Disabilities and Autistic Disorder Opportunities

As discussed earlier in the person-centered planning section, the cost caps associated with the SIS may be problematic for individuals with more complex needs. The cost caps mean that individuals needing full time, one-on-one support may not be able to receive that in the community. It is not clear how the waiver services wrap around State Plan personal assistance services to support this population.

According to interview feedback, services cannot always be well coordinated because there are not sufficient services available. The **shortage of services available to participants living in rural areas or with more complex needs** creates issues of individuals ending up in nursing facilities or putting additional stress on families as they wait for their children to get a waiver slot. This is particularly true for individuals with intellectual disabilities needing significant physical support.

Mental Health and Substance Abuse Opportunities

SAMHS and OCFS are beginning to look at how to **support improved transitions for youth to the adult mental health and substance abuse systems**. This effort is just beginning, and there is nothing systemic in place. There is a complex case coordinator who works with families on some of these cases.

According to stakeholders and administrative data, **case managers are assigned too slowly** for mental health participants. The state strives to assign case managers to 90 percent of hospitalized and community-based participants within two or three days respectively. The shortage of available case managers has meant that the state consistently falls short on this goal. Per the February 2015 consent decree progress report, SAMHS only met this goal for 70 percent of hospitalized and 77 percent of community-based participants. This means that some individuals fall through the cracks and never get connected to services at all. Some providers use an open access model with warm handoffs to ensure individuals are immediately connected to case managers in addition to virtual warm handoffs made with behavioral health home teams.

The state is working to address **insufficient conflict-free case management**. Many case managers conducting assessments work for private agencies, many of which also provide direct services to which the plan of care may refer participants.

The state **does not use a prior authorization process**. Limitations in the information technology systems mean that tools do not exist and data is not available to support. The ASO is only able to analyze previous utilization for behavioral health services.

Children/Youth with Disabilities Opportunities

As discussed in the accomplishments and opportunities above, **youth transitioning to adulthood can be vulnerable to gaps in services**. The youth and adult systems are not aligned in terms of case management, eligibility criteria, regulations, and services. DHHS has the opportunity to continue to address these gaps through improved utilization of youth targeted case management and exploring opening up adult systems for children where appropriate. Multiple interviewees discussed incorporating youth into intellectual disability and autistic spectrum disorder waivers for continuity of care and the ability to better meet complex needs of youth.

Children were included as one of the target populations in the behavioral health home design under the leadership of the Office of MaineCare Services. Providers believe the **behavioral health model is not sufficiently adapted to children's needs**, although the move toward integrated care is a positive and necessary step.

Waiting lists

Original Roadmap Recommendations

Wait list recommendations focus on effective and fair management of the lists.

1. Develop standards for collecting consistent data on waiting lists.
2. Develop standards for maintenance of provider waiting lists.
3. Develop standards for the fair administration of waiting lists, including how people get on a waiting list, how persons are prioritized, how persons are notified of their status, etc.

Accomplishments

General Accomplishments

Historically, DHHS had long waiting lists. The state has **focused a lot of attention on reducing waiting lists**, and it has paid off. According to interviewees, waiting lists are shorter now than they have been in many years.

Aging and Physical Disabilities Accomplishments

The **wait list for the elderly and adults with physical disabilities 1915(c) waiver ended** in December 2014.

Intellectual Disabilities and Autistic Disorder Accomplishments

While there are waiting lists for both the Section 21 comprehensive and Section 29 support services 1915(c) waivers, **OADS has invested significant resources** in these programs, which has kept wait lists minimized. In state fiscal year (SFY) 2013, DHHS invested an additional $28 million in both waivers, allowing the state to serve over 150 additional participants.[8]

Participants and targeted case managers seem to do a relatively **good job managing wait lists and keeping people connected to services** while waiting. Section 21 waiver slots are prioritized based on individual vulnerability and Section 29 slots are allocated on a first-come, first-served basis. Participants may:

- Apply for the adult waivers at age 18, and continue to receive children's State Plan services while waiting for a slot to become available.
- Receive State Plan or state funded services while on the wait list, including targeted case management, medical, dental, hospital, medical transportation, and crisis services.
- Receive Section 29 waiver support services while waiting for a Section 21 comprehensive waiver slot to become available.

In September 2014, 1,008 people were on the Section 21 comprehensive wait list, and 450 people were on the Section 29 support services wait list. Of the 1,008 people on the Section 21 waiting list, 586 were receiving Section 29 services. Two hundred and ninety people were on both waiver waiting lists.[9] As of September 30, 2015, the Section 21 waiting list has grown to 1,185 individuals. Section 29 applications have been on hold since July 1, 2015 with no waiting list begun.[10]

Mental Health and Substance Abuse Accomplishments

There are wait lists for mental health and substance abuse disorder services. Throughout all of SFY 2012 there were 2280 individuals on the waiting list to enter treatment. In June 2012, 189 people were on wait lists to enter treatment at SAMHS contracted provider agencies.[11] In SFY 2014, the average wait time was 23 days for substance abuse disorder services and 14 days for mental health services.[12] In SFY 2015, SAMHS received **$5.7 million of consent decree funding to alleviate the mental health wait list**.

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[8] Olmstead Roadmap for Change, Update for Developmental Services, 2014, OADS, DHHS.

[9] Adults with Intellectual Disabilities and Autism Spectrum Disorder: Population and Service Use Trends in Maine 2014 Edition, Muskie School of Public Service, University of Southern Maine.

[10] Email from DHHS OADS Waiver Manager for Developmental Services, October 23, 2015.

[11] Substance Abuse Block Grant Behavioral Health Assessment Plan 2014, SAMHS, DHHS.

[12] APS Healthcare, data prepared June 9, 2015 for SAMHS.

The state hospitals previously had significant waiting lists for individuals wanting to leave and enter the hospital. Over the past decade, the hospitals **instituted weekly discharge meetings to reduce waiting lists** and keep populations appropriately placed for their needs.

Children/Youth with Disabilities Accomplishments

Maine has the **Katie Beckett option** allowing children with long term disabilities or complex medical needs to be eligible for Medicaid. Katie Beckett eligibility is an additional option through which children can connect to MaineCare services, using the child's income rather than the family's to determine financial eligibility.

Children are entitled to medically necessary services. In the 1990s, Maine had capacity issues, which resulted in children having to wait for services. Maine instituted **central enrollment** from 2004 through 2011 in response to a lawsuit related to the wait for services. The state managed the waiting list under central enrollment rather than provider agencies. Agencies reported availability, families submitted referral information, and the state matched the two. This process significantly reduced the wait list according to stakeholders. The state transitioned the waiting list to its ASO, APS Healthcare, in 2011. Families **can choose under the family choice provision to wait for a specific agency**. There are at times 80 percent more families waiting for a specific provider than in the central wait list.[13]

APS Healthcare monitors wait lists. If APS Healthcare finds that a family has waited four months for service, and there is a provider with capacity across town, they contact families to let them know. OCFS oversees APS' work.

Eighty-three percent of non-hospitalized youth applying for targeted case management received a case manager within seven days during SFYs 2013 and 2014 (SFY 2013: 5,631 out of 6,738; SFY 2014: 5,738 out of 6,943).[14]

Opportunities

General Opportunities

Changes in Medicaid eligibility, financial and non-categorical, **have affected waiting lists**. According to interviewees, MaineCare waiting lists have reduced and wait lists associated with state and grant funded programs/services have increased.

[13] SFY 13 & 14 APS Healthcare, CareConnection.

[14] SFY 13 & 14 APS Healthcare, CareConnection.

Aging and Physical Disabilities Opportunities

Although there are no waiting lists for waiver services, **wait lists exist in state-funded programs**. State funded programs have had their budgets cut over the past 20 years. Stakeholders report that many participants have transitioned onto State Plan and/or waiver programs as a result. But, for those ineligible for MaineCare, it is not atypical to wait more than two years to receive home-based services. This may result in individuals being at risk of institutionalization or hospitalization and strains on other resources like adult protective resources and families.

Staffing shortages create waits for MaineCare participants eligible for services. Individuals may be approved for care, but there is insufficient staff available to meet the need fully or at all. Participants could end up cobbling services together between multiple agencies because of staffing shortages, increasing case management complexity.

Intellectual Disabilities and Autistic Disorder Opportunities

Interviewees say that it is very hard for individuals to get onto the Section 21 comprehensive waiver unless individuals are coming from residential settings. **New services added to the Section 29 supports services waiver could reduce some of the pressure from the comprehensive waiver**. Interviewees and survey respondents cited the Section 29 low participant budget cap and a provider shortage related to markedly lower rates compared to Section 21 services as reasons why individuals with lower needs on Section 21 have not stepped back to receiving Section 29 services.

According to stakeholders, families caring for children with intellectual disabilities or autism spectrum disorder need **education about waiver eligibility and waiting list management**. Families should be planning for when they are no longer able to care for children at home. Families should have verification of the disability and be filing events that occur at home to ensure their children are prioritized correctly.

Additionally, the state could **expand State Plan personal assistance services** to provide increased activities of daily living and instrumental activities of daily living support for individuals with intellectual disabilities or autism. This could potentially alleviate some of the demand for waiver services and reduce waiting lists.

Mental Health and Substance Abuse Opportunities

SAMHS is **determining how to better manage waiting lists for mental health and substance abuse services**. There is currently a statewide wait list divided between grant funded and MaineCare services for mental health services. SAMHS is working on an open access model for mental health waiting lists, which some providers have already implemented. The substance abuse services waiting list is manually compiled. The new

substance abuse information technology system (WITS), will manage the substance abuse wait list.

Administrative data and stakeholders indicate that there is often a **delay in the assignment of caseworkers** for mental health services. The consent decree requires that caseworkers be assigned within two days for individuals in the community and three for those in psychiatric state hospitals. The state does not comply with this provision. Per stakeholder interviews, there currently are more than 500 people statewide waiting for community integration caseworker assignment. This list is pretty evenly divided between individuals who are eligible for MaineCare and those who are not. Individuals generally wait 40 to 50 days for caseworker assignment. According to interviewees, this is due to staffing shortages, which are related to **inconsistent funding for mental health services**. It is hard for provider agencies to hire caseworkers with little confidence in ongoing funding for the positions.

The **lack of a quick connection to services has meant that some individuals are falling through the cracks**. SAMHS has been attempting to contact individuals on the waiting list for mental health services to analyze wait list issues, and is often unable to locate them. Interviewees discuss how it is hard to keep individuals engaged while waiting for services. To address this, **some providers are moving to open access** on a subset of services. These providers are engaging participants immediately, and letting the paperwork catch up later.

Waiting lists exist for housing support programs, including Shelter Plus Care/Continuum of Care (approximately 140 people on the waiting list as of May 2015) and BRAP, recently renamed the Bridge to Recovery Program (approximately 200 individuals as of May 2015).[15] There is a waiver system, which allows individuals transitioning out of hospitals or residential care facilities to move to the top of the waiting list for BRAP funding. The state is considering increasing funding for BRAP by more than $1 million, for a total budget of about $6.6 million.

Administrative data and stakeholders cite a **waiting list for state hospital placements**, both on the civil and forensic side. Riverview is operating below capacity because of insufficient staffing. These waiting lists result in individuals languishing in jails, crisis placements, emergency departments, or in the community.

Children/Youth with Disabilities Opportunities

According to interviewees, there are **not enough children's psychiatrists to meet demand**. The waiting list for these services is long. Anecdotally, the state hears the waiting list can range from three months to more than a year depending on location.

[15] Interview with Chester Barnes, SAMHS, DHHS, June 1, 2015.

Many families find other solutions and do not remain on psychiatry wait lists, including receiving care from primary care physicians and developmental pediatricians.

Funding and Planning

Original Roadmap Recommendations

The 2003 roadmap included recommendations to better use data for service planning and funding.

1. More accurate measures for how many people have a disability.
2. Define "need for services" to services necessary to support sustained community living and participation.
3. Collect data on place of residence, community integration barriers, and individual preferences.
4. Link data across programs so that the state has the information it needs to effectively manage the allocation of its resources.
5. Improve measures of the future need for services by enhancing data collection efforts in schools and evaluating trends that influence the need for services.
6. Develop other measures of unmet need.
7. Expand the statutory requirement that state budget requests be based on anticipated need for services.
8. Explore other opportunities to leverage federal funding.
9. Advocate at the federal level to eliminate cost neutrality requirements in HCBS waivers.
10. Advocate at the federal level for people with mental illness to have reasonable access to Medicaid options that support integrated living.

Accomplishments

General Accomplishments

As stated in the Coherent System of Services section above, **Maine uses multiple information technology systems to manage LTSS programs** and understand the needs (met and unmet) of these individuals. DHHS continually enhances EIS to better share data between DHHS offices and with external stakeholders. Data from these systems is used within DHHS as well as to report to the Maine Legislature and academic institutions.

The state has **leveraged federal funding through multiple grants**, including Money Follows the Person (2012-2016), Balancing Incentives Program (2012), ADRC (2003), two State Innovation Model (SIM) grants (2013 and 2015), a Health Resources and Services Administration (HRSA) grant (2012 – 2015), and others.

Aging and Physical Disabilities Accomplishments

As stated earlier, OADS has refined its 1915(c) HCBS waivers to maximize federal funding for target populations. OADS added the other related conditions waiver in 2013 and the brain injury waiver in 2014 to ensure these special populations are able to receive services in their homes and communities. The aging and physical disabilities waivers were merged in 2014 to more efficiently use resources.

OADS uses a **projection model for LTSS** needs in Maine across the full spectrum of settings. The state is updating the model to have projections through 2025.

The **Maine Coalition on Aging is a coalition working on aging issues** to ensure planning and funding decisions are being made to reflect the issues associated with the aging population of Maine.

Intellectual Disabilities and Autistic Disorder Accomplishments

Maine invests **significant financial resources** into programs for this population. Maine spends the second most per capita nationally on waiver services for individuals with intellectual disabilities and autism spectrum disorder.[16] The state implemented the Section 29 support services waiver in 2008 to increase services available for this population.

Use of the **SIS will increase funding flexibility** for individual participants so resources are more efficiently used, which will allow for more individuals to be served.

Mental Health and Substance Abuse Accomplishments

SAMHS **spends the most per capita** in the nation on mental health services.[17] Maine **commits significant funds toward state-funded programs** for individuals with mental illness. DHHS is **working to stabilize and increase funding for mental health and substance abuse services** to address the shortage of community integration caseworkers, shift to unit-based and acuity-based staffing in state hospitals, and increase forensic capacity at state hospitals.

SAMHS **obtained increased funding for its Shelter Plus Care housing vouchers** from the US Department of Housing and Urban Development (HUD).

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[16] Medicaid Expenditures for Long-Term Services and Supports in FFY 2012, April 28, 2014, CMS and Truven Health Analytics.

[17] Kaiser Family Foundation, State Mental Health Agency (SMHA) Per Capita Mental Health Services Expenditures, FY 2013.

Opportunities

General Opportunities

According to interviewees, **DHHS is very under-resourced in terms of staff**. Individuals may not be replaced when they leave state government, leaving fewer people to do the jobs of many. State staff spend a lot of time dealing with day-to-day issues, and have little time left to conduct meaningful planning and quality management. The limited resources don't allow state staff to be as thoughtful as they need and want to be.

Budgets are not consistently based on projected needs and resultant plans. Interviewees discussed how budgetary decisions are based on a multitude of things including historical spending, political/budgetary mood, public relations, and the realities of balancing priorities while retaining a balanced budget, rather than projected needs.

Aging and Physical Disabilities Opportunities

Demographics demand heavy investment in aging programs. Administrative data shows that Maine has one of the oldest and most quickly aging populations in the nation. MaineCare programs should be ready to support the increasing demands with sufficient LTSS resources and staffing.

Mental Health and Substance Abuse Opportunities

Changes in Medicaid eligibility are exacerbated by **limited state grant dollars**. According to interviewees, because MaineCare eligibility was previously more inclusive, the state made the deliberate choice to reduce state grant dollars since people were covered through Medicaid. With Medicaid eligibility changes related to financial eligibility and non-categorical eligibles, some individuals are left without service and support options. Limited state grant dollars cannot cover the unmet needs. Per interviewees, some individuals are put into crisis without their medications, and are losing jobs or ending up homeless.

Because Maine delivers its mental health and substance abuse services through its State Plan, it serves all individuals who qualify. Anyone meeting medical and financial eligibility criteria is able to receive outpatient therapy or receive psychiatric medications for a period of time. States define severe and persistent mental illness (SPMI) because there is no federal definition. In 1999, Maine broadened its SPMI definition, allowing many additional individuals receive MaineCare services under Section 17. Having such a broad population qualify for services means that individuals with more acute and complex needs are not always able to access needed services and supports because of finite provider capacity. The state is currently **revising rules to ensure Section 17**

community support services are consistently serving the intended population of individuals with mental illness or substance abuse disorder. The vast majority of individuals who would lose Section 17 services are eligible for care under other MaineCare sections.

Children/Youth with Disabilities Opportunities

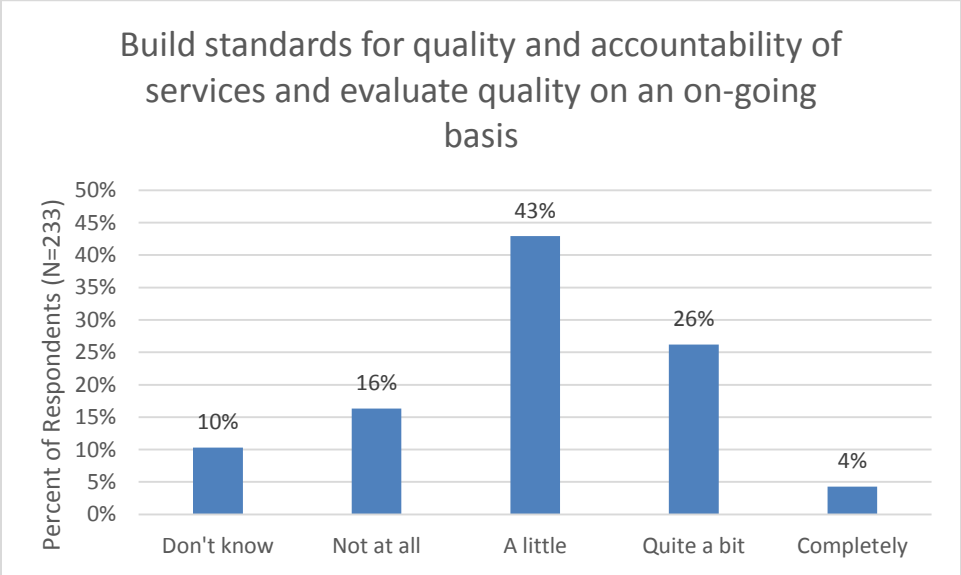
Maine could **benefit from increased flexibility in funding services for youth with complex needs**. As discussed in the waiting list section, children are sometimes being sent out of state because Maine is not able to meet their needs under current programs, making community integration more difficult to achieve. Additional flexibility in funding could help providers create flexible approaches that work with children's shifting, episodic needs.

Build standards for quality and accountability of services and evaluate quality on on-going basis

This recommendation area contains two supporting recommendations: direct care providers and quality of services. The analysis is broken down into these respective areas.

Just over 40 percent (43 percent) of survey respondents felt Maine met this priority "A little", and 30 percent indicated that Maine met the priority "Quite a bit" or "Completely". Sixteen percent of respondents did not feel that Maine met this priority at all. The weighted average for this priority was 2.21.

Figure 9: Survey Respondents' Evaluation of Quality, Accountability, and Ongoing Evaluation



Direct Care Providers

Original Roadmap Recommendations

The 2003 Olmstead response discussed approaches to improving provider quality, recruitment, and retention.

1. Build respect for direct-care workers.
2. Explore increasing the educational and training requirements.
3. Improve recruitment and training.
4. Consider increasing the direct-care educational and training prerequisites.
5. Define and develop professional growth opportunities.
6. Encourage employers of direct-care staff to improve wages and benefits.
7. Explore whether or not to create a statewide or regional association to support direct-care workers.

Accomplishments

General Accomplishments

Maine has done a lot of work related to direct care worker training and credentials. Maine is one of six states to receive a HRSA grant to **develop core competency training across disciplines**. The state developed curriculum encompassing core competencies for working with individuals who are elderly, have intellectual disabilities or autistic disorder, and have mental illness. Workers then can focus on specialties on top of the core training, rather than starting all over again when wanting to work across LTSS populations. This training approach supports direct care workers with their career lattice, and also better serves individuals with complex needs and co-occurring diagnoses.

Additionally, the state has increased training and credential requirements by:

- **Aligning employment specialist requirements** across OADS, SAMHS, and Maine's Department of Labor Bureau of Rehabilitation Services, allowing employment specialists to work across systems.
- Offering **online professional development** and continuing education.
- Requiring all direct support professionals (DSPs) to **earn certifications through Maine's training and certification program**.

DHHS is currently **conducting a rate study**. The state recognizes that some provider rates need to be higher in order to recruit and retain a qualified workforce.

Aging and Physical Disabilities Accomplishments

OADS is **conducting a personal support specialist rate study**. Low reimbursement and disparity in wages are significantly impacting staffing for OADS funded services. The rate study is a first step in addressing this issue.

Intellectual Disabilities and Autistic Disorder Accomplishments

Direct care staff working with individuals with intellectual disabilities or autism spectrum disorder **tend to receive higher wages** than staff working with other LTSS populations.

New rate setting associated with the implementation of the SIS demonstrates DHHS' commitment to increasing wages for direct care workers.

Since 2012, OADS requires all newly hired state case managers be **licensed social workers**. DHHS also holds **quarterly training sessions** for all case managers at district level.

Mental Health and Substance Abuse Accomplishments

SAMHS is **redesigning requirements for mental health direct service workers**. Part of this redesign is to focus more on person-centered planning.

Children/Youth with Disabilities Accomplishments

OCFS requires all direct service providers to have certification as a Behavioral Health Professional (BHP). BHPs for Section 65 Home and Community Based Treatment services must have a **bachelor's level education**. OCFS also contracts with a vendor to **revise its training curriculum** including behavioral health training, and administer the training program for all direct service providers.

Opportunities

General Opportunities

According to survey respondents and interviewees, **wages are insufficient** to attract and retain qualified direct care workers for adult participant services. **Agencies struggle to hire and retain qualified workers** with low wages. According to interviewees, these staffing issues may result in adult participants' needs not being consistently met, increasing risks to individuals, and increasing physical risks to workers.

All training through the college of direct support is online. Some stakeholders worry that the **lack of a face-to-face component may be detrimental** to the training.

Aging and Physical Disabilities Opportunities

OADS has not increased rates for some direct support workers in many years. The reimbursement rates for personal care assistants and personal support specialists were $15.14/hour in 2001 and $15/hour in 2015. **Low, disparate reimbursement rates for direct support workers** make it difficult for agencies to hire and retain qualified staff. As a result, there are **insufficient direct support workers to provide services** for participants. The Maine Legislature passed a bill in 2015, which was not yet finalized at the time of this report, to increase reimbursement for direct care worker services to approximately $25/hour. The increased reimbursement is not required to be passed down to workers through higher wages.

Mental Health and Substance Abuse Opportunities

According to stakeholders, there is an **insufficient mental health workforce** to meet the needs of individuals, particularly those with complex needs.

DHHS is working to increase staffing in state hospitals by hiring acuity specialists who have the additional training and experience to work with challenging individuals, in addition to hiring full time psychiatric and nursing staff across hospital units. Both **state hospitals rely to a large extent on locum tenens** who work at the hospital for three to four months, as well as **mandated and voluntary overtime** and **heavy use of floating staff**. This means staff are not familiar with residents and their individual needs and issues.

Children/Youth with Disabilities Opportunities

OCFS **does not have a registry of service providers** containing education, training, and reviews. Direct care workers are certified through OCFS' training vendor, but there is no systematic way to track them after this.

Quality of Services

Original Roadmap Recommendations

The 2003 Olmstead roadmap included quality recommendations from a systems level as well as an individual participant level.

1. Build standards for quality and accountability into the design of services and evaluate quality on an ongoing basis.
2. Develop a consumer-driven approach to quality management.
3. Develop a comprehensive definition of quality that includes a complete view of a person's life.

4. Measure the contribution of all supports in a person's life at home, at work, or in daily living activities, and community.
5. Measure quality focusing on what the person values as being most important.
6. Require providers to assess and evaluate satisfaction with services.
7. Develop quality indicators with consumer input.

Accomplishments

General Accomplishments

DHHS has made significant gains in terms of quality and accountability. When the original Olmstead roadmap was published, limited oversight activities were conducted. Now, there are **substantial resources devoted to conducting quality oversight**.

- There are numerous internal and external stakeholders focused on quality, including **dedicated quality improvement or quality assurance units in OADS, OCFS, and SAMHS**.
- There is **increased cross program communication and cooperation to address quality issues** as they arise with individual participants and systemically.

The state's progress in implementing **person-centered planning** incorporates many of the participant level recommendations from the 2003 roadmap. Person-centered plans define individual goals and quality measurements.

Aging and Physical Disabilities Accomplishments

There is a **quality review committee** (QRC), which was established by statute, comprised of external stakeholders. It was established when the care coordination function was created to replace case management.

OADS **participated in the National Core Indicators (NCI) project** from 2002 through 2012, and again in 2014.

Intellectual Disabilities and Autistic Disorder Accomplishments

OADS has a **robust quality management team** for individuals with intellectual disabilities and autistic disorder. This team created a quality plan based on needs assessments, strategic initiatives, and interviews they conducted with stakeholders across OADS program areas. This team was instrumental in implementing the SIS program.

Developmental Services **participated in the National Core Indicators (NCI) project** from 2002 through 2012, and again in 2014 with the other OADS program areas. The Developmental Disability Council collected NCI data including interviews and focus groups with participants in 2014.

Developmental Services revised **behavior regulations** to increase accountability and transparency with improved monitoring of behavior treatment, management, and safety plans.

Additionally, OADS developed **crisis services** for anyone with intellectual disabilities and autistic disorder or a brain injury.

Mental Health and Substance Abuse Accomplishments

SAMHS is moving toward increased use of **national models published and supported by SAMHSA**. An example of this transition is the move away from the Differential Substance Abuse Treatment (DSAT) curriculum across all substance abuse treatment providers. Once the level of care and treatment placement is determined using ASAM, providers are able to create individualized treatment plans using an SAMHSA supported model that makes the most sense for the individual's needs.

SAMHS conducts **site visits** for mental health and substance abuse provider agencies. Substance abuse site visits are more thorough with reviews of charts and policies consistently a part of these evaluations.

SAMHS is **incorporating performance measures into all direct service contracts** beginning in SFY 2016.

Children/Youth with Disabilities Accomplishments

OCFS uses the **youth outcome questionnaire (YOQ)**, which youth and parents complete regarding their experience with home and community treatment services. Therapists learn how well therapy is progressing from participants' and families' perspective. It also contains a system of red flags for risk management. OCFS is planning to expand the use of this tool.

OCFS has made significant progress in using **evidence-based practices** throughout its programs.

OCFS' quality assurance unit **reviewed all Section 28 agencies** in 2013 and 2014, and started **reviewing all targeted case management programs** in July 2015. OCFS plans to expand reviews to additional services.

Opportunities

General Opportunities

According to interviewees, quality work seems to be better within individual offices, rather than across programs. This is related to issues of continued **data and information technology inconsistencies** as well as separate units within each office charged with quality management.

As a willing provider state, almost anyone can provide services. According to stakeholder interviews, families are **not able to obtain information about the quality of services with a specific provider**. DHHS does not have a mechanism to help people make informed decisions. The state is analyzing national core indicators as one possible approach to addressing this gap. Survey respondents cited a need for a dashboard or quality assurance checklists so participants and families could evaluate programs themselves with standard criteria.

Aging and Physical Disabilities Opportunities

There has been an **increase in Adult Protective Services (APS) referrals and investigations** for adults who are elderly and have physical disabilities.

Table 4: APS Referrals and Investigations 2009 – 2014[18]

Year & Intervention	Adults Receiving Developmental Services	All other Adult Population	Total
2009-2011* Referrals	1,541	4,036	5,577
2012 Referrals	1,541 (estimate)	4,414	5,955
2013 Referrals	1,572	4,868	6,440
2013 Investigations	372 (24%)	2,346 (48%)	2,718 (42%)
2014 Referrals	1,435	5,795	7,230
2014 Investigations	289 (20%)	2,760 (48%)	3,049 (42%)

*Annual average

Mental Health and Substance Abuse Opportunities

According to interviews, because of insufficient staff, SAMHS conducts **fewer and less in depth mental health provider agency site visits** than with substance abuse treatment providers, although there is a review for each provider at least once annually. Because there is no centralized information technology system that can be queried, in-person site reviews are the only means through which the state can conduct quality management. Two state staff complete site visits in the field, and are only able to review a percentage of client files.

[18] Data queries from EIS for developmental services numbers and MAPSIS for 'all other adult' information.

Improve access to and availability of transportation, housing, and jobs

This recommendation area contains three supporting recommendations: accessible, available transportation; integrated, affordable, accessible housing; and jobs. The analysis is broken down into these respective areas.

Accessible, Available Transportation

Original Roadmap Recommendations

The 2003 roadmap recommendation discuss approaches to increasing transportation options, coordination, and oversight.

1. Support the recruitment and training of consumers to participate in consumer advisory boards for regional transportation organizations.
2. Petition for regional transportation boards to develop consumer advisory boards and committees.
3. Improve coordination between the Department of Transportation and other state agencies to maximize the effective and efficient use of resources.
4. Experiment with more flexible MaineCare policies to allow use of Medicaid dollars for transportation services beyond medical appointments.
5. Explore the development and operation of rural programs.
6. Identify departmental representatives to participate in a cross-system transportation funding development and oversight.
7. Undertake an audit of consumer-led cross-departmental transportation policies and programs.
8. Hire a director of statewide driver training to coordinate regional training programs.

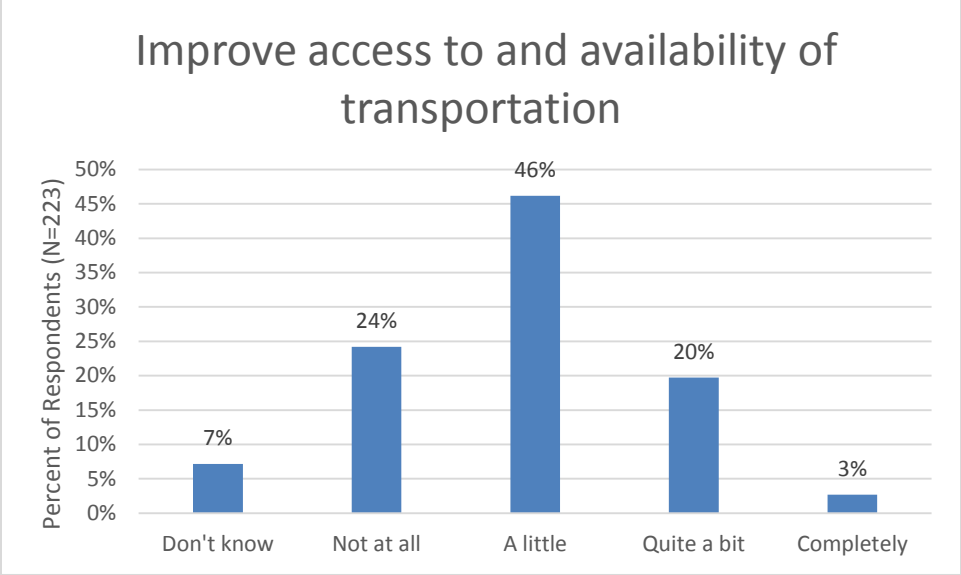
Accomplishments

General Accomplishments

No accomplishments were cited for transportation by interviewees and survey respondents.

Nearly half (46 percent) of survey respondents felt that Maine met this priority “A little”, one-quarter (24 percent) indicated “Not at all”, and one-fifth (20 percent) selected “Quite a bit”. The weighted average for this priority was 2.01.

Figure 10: Survey Respondents' Evaluation of Accessible, Available Transportation



Opportunities

General Opportunities

Maine is a rural state with a small population, making transportation an **inherent challenge**. The lack of transportation can lead to isolation and depression.

Transportation is a service within each of the waivers and is also available as a State Plan service. However, according to interviews and survey responses, the service has been **interpreted to only support transportation to medical appointments or Medicaid Services, not to community employment or integrated activities**. Transportation is less available to support other services related to community integration such as shopping for necessities or employment.

Stakeholders indicate this interpretation is associated with the state's transition to a transportation broker system. Prior to the broker system, regional transportation networks coordinated transportation in their geographic areas using a combination of Maine Department of Transportation (MDOT) funding matched by MaineCare dollars. MDOT funding has remained consistent for many years, without any influx of funds to expand services, and the MaineCare funding became a larger part of the overall regional transportation funding over time. Regional transportation coordinators organized volunteer drivers, friend and family rate payments, and provided wheelchair accessible vehicles, such as minivans and buses.

Interviewees explained that the federal government mandated the state switch to a broker system. Of the ten regional transportation providers, three are now brokers, and the other seven work under a broker. All MaineCare dollars now flow through the

brokers, which has shrunk regional transportation provider budgets. This has resulted in **decreased access to transportation through regional networks** in terms of service days, times, and routes. According to interviews, without MaineCare funding, particularly the administrative fees, buses and minivans previously used to transport participants in wheelchairs are too expensive to run and maintain.

Interviewees also cite **fewer transportation options for individuals not receiving MaineCare** through regional transportation networks. These wheelchair accessible vehicles, which are operating less often, were also used to transport non-MaineCare individuals for efficiency. The large broker doesn't provide buses to transport except as a last resort. Instead, participants are given money by the broker to locate their own rides. Individuals who previously provided volunteer or friends and family rides under the regional system are now being contacted by participants to provide rides for a fee, lessening access to these other options.

Integrated, Affordable, Accessible Housing

Original Roadmap Recommendations

The 2003 roadmap included 18 housing related recommendations, including increased community integration, communication, education, consumer participation, transition support, and affordability.

1. Expand the Bridging Rental Assistance Program (BRAP) to cover all who need it.
2. Educate bankers, realtors, and other housing professionals about home ownership options and support programs for people with disabilities.
3. Make sure resources are available to pay for home modification.
4. Support the recruitment and training of consumers to participate on public housing boards and planning.
5. Expand legal resources to advise people on how to protect their housing rights.
6. Support training programs to educate people about their housing rights.
7. Support training programs for landlords to educate them about disabilities and different accommodations.
8. Advocate to remove the federal barrier to housing assistance for persons in recovery who have a conviction for a drug-related offense.
9. Identify departmental representatives responsible for ensuring that the relationship between the location of housing, services and access to transportation are taken into account in the planning and development process.
10. Give people options about where to live and with whom.
11. Break the link between housing and services.
12. Break the link between residential settings and the level of services available.
13. Review and modify regulations to ensure transitional support is available.
14. Make sure that service coordination are available to assist in a transition up to 180 days in advance of the move from an institutional setting.

15. Define "most integrated setting," and track whether the people are served there.
16. Make sure all people are provided option of receiving services in the most integrated setting within a reasonable period of time.
17. Increase the affordability of homeownership by supporting homeownership loan programs.
18. Examine all MaineCare housing options to only use those that maximize integration.

Accomplishments

General Accomplishments

A lot of the housing recommendations **align with CMS HCBS setting regulations**, which Maine is addressing through its transition plan. Maine is already in compliance with many of the new requirements, particularly for older adults and individuals with physical disabilities, including brain injury and other related conditions.

Maine has **increased housing stakeholder coordination under its MFP program**. The program housing coordinator has been working with the Maine State Housing Authority.

Maine **provides support across a very complete spectrum of housing options** for LTSS participants, including home-based services, group homes, shared living arrangements, residential care, and nursing facilities. Residential care facility types include substance abuse treatment facilities, medical and remedial treatment services facilities, child care facilities, community residences for persons with mental illness, and non-case mixed medical and remedial facilities.

The chart below outlines the number of settings and waiver participants in these settings (participant numbers are in parentheses). Individuals who are elderly or who have physical disabilities residing in residential care facilities or nursing homes are not included in the chart since these facilities are State Plan funded and not waiver services for these individuals.

Table 5: Number of residential settings and waiver participants in setting types[19]

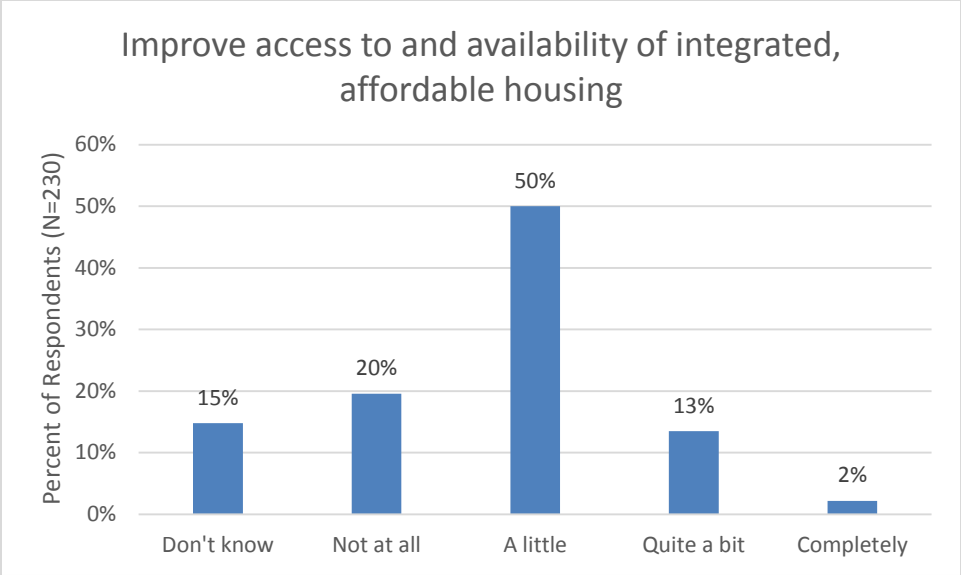
Setting	§18	§19	§20	§21	§29
Group home	0 (0)	NA	6 (6)	554 (1,322)	NA
Shared living	NA	NA	NA	537 (541)	NA
Family-centered support*	NA	NA	NA	96 (147)	NA
Residential care facilities				21 (62)	62 (197)

*The Family centered support arrangement model is being phased out; no new Family Centered Support programs have been approved since 2007. These settings are not licensed.

[19] Draft Transition Plan for Complying with New HCBS Rules, December 15, 2014, DHHS.

Exactly half of survey respondents felt that Maine met this priority "A little". One-fifth (20 percent) felt that Maine met this priority "Not at all", and 13 percent indicated "Quite a bit". Fifteen percent of respondents chose "Don't know" for their response. The weighted average for this priority was 1.98, or slightly less than "A little".

Figure 11: Survey Respondents' Evaluation of Affordable, Accessible, Integrated Housing



Aging and Physical Disabilities Accomplishments

Administrative data shows that **fewer seniors and individuals with physical disabilities reside in nursing facilities**. The average number of nursing facility residents fell between 2005 and 2010 by 10 percent or 855 (from 8,368 to 7,513 participants).[20] Nursing facility expenditures decreased by 13.4 percent between 2010 and 2011.[21] This is related to Maine having the most restrictive nursing facility eligibility in the nation. In the mid-1990s, the state moved to a single assessing agency with an automated assessment tool, and based programs on function, not diagnosis.

The state supports a variety of non-institutional housing options for individuals who are elderly or have physical disabilities, including assisted living facilities, congregate housing, and shared living. The state has seven assisted living facilities with 504 residents. Maine created the Independent Housing with Services Program (IHSP) in 1979 to develop two congregate housing demonstration projects. Currently, there are

[20] Chartbook: Older Adults and Adults with Physical Disabilities: Population and Service Use Trends in Maine 2012 Edition, Muskie School of Public Service, University of Southern Maine.

[21] Medicaid Expenditures for Long-Term Services and Supports in FFY 2012, April 28, 2014, CMS and Truven Health Analytics.

six IHSP facilities statewide serving 89 individuals. Assisted living and IHSP facilities do not provide medication administration/ management and have eligibility independently determined, not using the standard assessment process.[22] Additionally, OADS is implementing a **shared living demonstration project** to potentially include in the Section 19 waiver.

Crisis services are widely available for the individuals who are aging and have physical disabilities. Between 2010 and 2013, the average statewide vacancy rate for crisis beds was 52 percent.[23] In 2010 and 2011 all crisis teams received training in brain injury services and subsequently began providing crisis services to this population in residential settings.

The Maine Council on Aging put forward a **bond to rehabilitate housing for older adults and adults with disabilities** to create more housing options for these populations. Additionally, a **majority of low income housing tax credits for housing is dedicated for the elderly**.

Intellectual Disabilities and Autistic Disorder Accomplishments

The implementation of **SIS is projected to increase housing options** for individuals with intellectual disabilities and autistic disorder. The previous system was more of a one-size-fits-all approach that generally placed participants in group homes. The state is now looking to technology to meet the safety needs previously requiring staff, in addition to emphasizing the dignity of risk for individuals.

Section 21 and 29 **HCBS waivers provide housing modification funding** for participants to ensure homes are adapted to meet health, safety, and welfare needs.

The **shared living model was developed as additional option for residential support** in the Section 21 comprehensive waiver in 2005. Individuals can share a home with someone providing direct support services.

Peer centers providing day services are less isolated. Many are working hard to engage participants in community activities.

Mental Health and Substance Abuse Accomplishments

SAMHS offers robust housing supports for individuals with mental illness, substance abuse disorder, and co-occurring diagnoses. SAMHS has used a **housing first philosophy** for all of its housing programs since the 1990s. Regardless of treatment options, the primary goal is to get individuals in housing because recovery begins with a safe, decent

[22] Long Term Care Narrative – ALF & IHSP, OADS, DHHS, 2015.

[23] Crisis Prevention and Intervention Services, 2010-2013 Report, OADS, DHHS.

place individuals can call home. SAMHS **de-linked housing from service provision** whenever possible since housing programs inceptions.

SAMHS supports the **Shelter Plus Care Program**, also referred to as Continuum of Care. The office manages approximately 20 grants to provide housing subsidies to 1,100 to 1,200 homeless individuals. Shelter Plus Care has grown a $1 million to an $8.5 million dollar program since it was established in 1992 until now. Maine has more vouchers per capita than any other state in the nation. The state spends over 62 percent of its HUD Continuum of Care funds on the Shelter Plus Care Program.

The **Bridge to Recovery Program (BRAP** – formerly called Bridging Rental Assistance Program) is used to provide transitional and permanent housing to participants. BRAP was originally designed as transitional housing program. However, the program does not evict clients who are stably housed for more than 24 months. BRAP serves approximately 850 individuals and is **growing the program from a $5.37 million to a $6.6 million annual budget in 2016**, a significant increase from the $500,000 program budget supporting 50 vouchers when BRAP was established in 1999. SAMHS is working to **expand BRAP to more rural locations** in the state to identify participants before they burn bridges with local service providers and migrate to city centers. Fifty percent of BRAP funds are dedicated to homeless individuals, and the other half are used for individuals transitioning from institutional settings including psychiatric hospitals and group homes.

SAMHS now manages the **Projects for Assistance in Transition from Homelessness (PATH)** in order to coordinate housing and outreach work. Approximately 80 percent of the long term homeless population is mentally ill. PATH engages individuals where they are and meets with providers throughout the state, including in smaller communities, to extend opportunities for these local providers to serve their citizens with resources provided by SAMHS.

Maine also has a **1907 rental subsidy program**, which is a project-based voucher system with seven contracted providers (144 units) statewide. Housing owners understand the special needs and considerations of individuals with mental illness.

All SAMHS housing programs require that **housing units meet HUD quality standards**, which means the units have to be clean with services located nearby. Housing contracts require that each unit be inspected at move in, annually, and move out.

Ninety-five percent of participants with mental illness or substance abuse disorder are in the community. This is a significant improvement since the consent decree. There are approximately 150 beds at the two state hospitals and 622 residential care facility beds in 102 locations (92 percent occupancy in SFY 2014), in addition to general

psychiatric beds in three nursing facilities with 53 beds (94 percent occupancy in SFY 2014) and short-term beds in community hospitals.[24]

Children/Youth with Disabilities Accomplishments

OCFS' goal is to have **children at home with their families**. Home is the most integrated setting, and always the objective. Maine has **significantly reduced the number of children in residential settings** and kept children at home with supports and services. DHHS reduced children in out of home placements from approximately 700 in SFY 2012 to approximately 350 in SFY 2014.[25]

DHHS is putting considerable **focus on youth transition** to adulthood. OCFS has local, internal meetings about transitioning youth. Additionally, DHHS recently obtained a federal grant on youth transition.

Opportunities

General Opportunities

Maine has **one of the oldest housing stocks** in the nation. In 2012, the median age of a home was between 33 and 42 years. Approximately 31 percent of units were built before 1950.[26] Housing often needs significant modifications to be accessible.

According to interviewees, the **housing subsidy system is hard to navigate**. Housing authorities all operate independently under the State Housing Authority. Individuals need to apply locally with each local housing authority when seeking subsidies.

DHHS does not have a c**omprehensive housing plan defining needs across LTSS populations**. A plan analyzing need and supply could support effective collaboration with MaineHousing and ensure resources are directed where they are needed.

Affordable housing is often not located close to transportation options and services. Providers and advocates spoke about individuals having to leave city centers to find affordable housing, which means they must travel to access services. Portland, Maine is a very tight housing market, with less than one percent availability in the rental market. It is nearly impossible to find affordable and accessible housing in Portland. Subsidies are not adequate in this market.

DHHS is **analyzing residential care facilities in Medicaid policy** to determine how to best align these services with HCBS requirements and national and state best practices.

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[24] APS Healthcare, CareConnection.

[25] APS Healthcare, CareConnection.

[26] A Profile of Maine's Older Population and Housing Stock, Abt Associates.

Aging and Physical Disabilities Opportunities

A lot of **older individuals live in more house than they need or can maintain**. These older, large homes are challenging for individuals to keep up with taxes, heating, insurance, and maintenance costs. Per interviewees, financial support for home modification is limited.

Adult day health programs do not universally comply with CMS HCBS rules. **Some day settings isolate participants**. DHHS is modifying regulations and policy to require that these settings offer individuals the opportunity to engage in the community.[27]

Maine was forced to find another residential option for individuals living in nursing facilities who would no longer be eligible to reside there under the increased eligibility standards. According to interviewees, this was the impetus behind the **residential care facilities licensed with nursing facilities as multi-level facilities**. There are over 100 of them in Maine. Many of these are physically attached to nursing facilities as a wing or a floor of the building. These facilities range in size from a few beds to 150, and average at about 40 beds. As nursing facility usage decreased, residential care facility usage increased.

Table 6: Nursing Facility and Aging Residential Care Facility Resident Counts 2005 and 2010[28]

	# Residents 2005	# Residents 2010	Difference
Nursing Facilities	8,368	7,513	-855 (-10%)
Residential Care Facilities	3,089	4,006	917 (30%)

Because residential care facilities are funded under the State Plan, they do not have to comply with CMS HCBS setting requirements. If the HCBS settings requirements are seen as a means of implementing the Olmstead vision of community integration, then **the State is working to determine how align these settings with Olmstead values** through transitioning these facilities to residential habilitation under the 1915(i) State Plan Amendment currently being written.

Intellectual Disabilities and Autistic Disorder Opportunities

Maine **serves a high percentage of individuals with intellectual disabilities and autistic disorder out of their homes**. In 2010, 24 percent of individuals receiving intellectual disabilities/autistic disorder services lived in their own homes or with family, compared

[27] Draft Transition Plan for Complying with New HCBS Rules, December 15, 2014, DHHS.

[28] Chartbook: Older Adults and Adults with Physical Disabilities: Population and Service Use Trends in Maine 2012 Edition, Muskie School of Public Service, University of Southern Maine.

to 78 percent nationally.[29] In 2014, there were 34 residential care-IID facilities with 210 beds and 17 ICF-IID's with 197 beds.[30] Adult residential care facility beds for individuals with intellectual disabilities, autistic disorder, or mental illness were at 94 percent occupancy in SFY 2014.[31]

Many more participants live in group homes and shared living arrangements. The table below outlines the number of non-ICF-IID and non-residential care settings and individuals in each setting in 2005 and 2010. There is a clear shift toward participants living in smaller settings.

Table 7: Non ICF-IID and Non-Residential Care Facility Out-of-Home Settings and the Number of Participants Served 2005 and 2010[32]

Residential Setting	2005 Settings	2005 Residents	2010 Settings	2010 Residents
Group home 4-6	172 (15%)	956 (36%)	189 (15%)	649 (29%)
Group home 1-3	511 (44%)	939 (36%)	680 (55%)	1,201 (53%)
Shared living/family centered 4-6*	38 (33%)	135 (5%)	4 (3%)	17 (1%)
Shared living/family centered 1-3*	444 (38%)	593 (23%)	353 (29%)	401 (18%)
Total	1,165	2,623	1,226	2,268

*New family centered support programs have been approved since 2007.

Maine has identified significant changes that need to be made to bring waiver services for individuals with intellectual disabilities and autistic disorder into **compliance with CMS HCBS setting regulations**, including:[33]

- Participants have control over personal resources.
- Participants have option for non-disability specific setting and an option for a private unit.
- There is documentation of setting options.
- Participants receive education on resource options for financing room and board.
- Standards are incorporated for individual control over daily activities and interactions.
- Staff must facilitate choice.
- Unlicensed facilities must use residential agreement satisfying CMS HCBS requirements.
- Residential units must be modified to meet CMS HCBS requirements.

[29] Chartbook: Older Adults and Adults with Physical Disabilities: Population and Service Use Trends in Maine 2012 Edition, Muskie School of Public Service, University of Southern Maine.

[30] Chartbook: Older Adults and Adults with Physical Disabilities: Population and Service Use Trends in Maine 2012 Edition, Muskie School of Public Service, University of Southern Maine.

[31] APS HealthCare, Report 18 & 19 PNMI Bed Capacity/Occupancy, Report Source: Authorization data from APS CareConnection, Report dates 7/1/2013 – 6/30/2014.

[32] Chartbook: Older Adults and Adults with Physical Disabilities: Population and Service Use Trends in Maine 2012 Edition, Muskie School of Public Service, University of Southern Maine.

[33] Draft Transition Plan for Complying with New HCBS Rules, December 15, 2014, DHHS.

- Staff must document positive interventions and supports used prior to any modifications
- DHHS prohibits reimbursement from settings that isolate individuals.

Mental Health and Substance Abuse Opportunities

Maine has a small population of individuals who are chronically homeless. In SFY 2013 there were 262 long term stayers in shelters across the state.[34] According to interviewees, it is **not clear that Maine has sufficient supports and services to meet the needs of the long-term homeless population**.

Per stakeholder interviews, **substance abuse treatment beds are generally full** in the state because of a decrease in these services. There is a waiting list for in-patient residential services. These individuals either languish in emergency departments or are discharged back into the community. DHHS has community-based rehabilitation services where individuals live at home with daily, intensive case management, which could help fill in this gap. However, rigid eligibility parameters have meant that few individuals have been able to access these services.

Children/Youth with Disabilities Opportunities

According to stakeholders, the system of **residential care is in the process of right-sizing to provide adequate support to children with complex needs and families closer to home**. Ten years ago there were approximately 400 residential care facility beds for children. That number was halved with the expansion of community services. There was insufficient planning about capacity needed in geographic regions of the state. Some children not able to access these services because of waiting lists go to local hospitals, crisis beds, or juvenile youth development centers. Others are sent out of state (28 children in SFY 2014 and 42 in SFY 2015 were sent out of state to three facilities in New Hampshire[35]). The state has recognized this issue, and is actively working to correct it.

[34] White Paper Medicaid Waiver for People Who Have Experienced Long Term Homelessness, Statewide Homelessness Council.

[35] APS HealthCare, CareConnection.

Jobs

Original Roadmap Recommendations

The 2003 roadmap included 14 recommendations related to employment, with a strong emphasis on meaningful community integration through paid work. Recommendations highlighted methods of engaging employers and changing employment norms for individuals with disabilities.

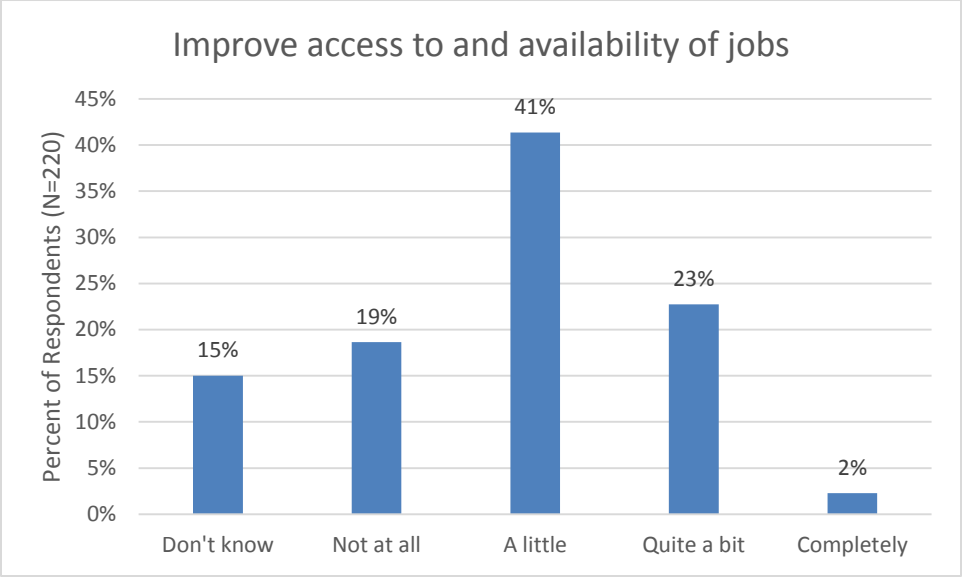
1. Expand legal resources to advise people on how to protect their employment rights.
2. Support training programs to educate people about their employment rights.
3. Explore current personal assistance service offerings and additional policy options.
4. Modify personal assistance services assessment tools to identify what a person specifically needs in the home to prepare for work and at work to complete job tasks.
5. Expand supported employment services to all who need them.
6. Eliminate sheltered workshops and enclaves.
7. Improve and expand coordination between schools and vocational rehabilitation services.
8. Increase awareness and understanding of disability to eliminate stigma and fear.
9. Educate providers on their role in protecting an employee's rights under the ADA.
10. Increase support within local secondary schools to provide employment, internship, and work-study assistance.
11. Make better use of existing Plan for Achieving Self-Support (PASS) and Impairment Related Work Expenses (IWRE) procedures.
12. Develop and sustain additional means of involving employers in leadership networks, which allow them to both define and oversee employment preparation and support services.
13. Promote and support alternative and flexible work options that meet the needs, skills and availability of workers with severe disabilities, including telecommuting, job-sharing arrangements, and use of assistive technology.
14. Explore and develop strategies to increase employment options for people with disabilities who have criminal records.

Accomplishments

General Accomplishments

Forty-one percent of survey respondents felt that Maine met this priority "A little", and almost one-quarter (23 percent) selected "Quite a bit". Nearly one-fifth (19 percent) selected "Not at all", and 15 percent chose "Don't know". The weighted average for this priority was 2.10.

Figure 12: Survey Respondents' Evaluation of Accessible, Available Employment



Maine is the only state in the nation to implement the **Employment First** statute and policies that encompass change **across disabilities**. The Employment First Act follows significant employment work conducted in intellectual disability and autistic disorder programs (outlined below). Maine passed the Employment First law in 2013, and has had six workgroups advancing implementation since then that are focused on DHHS, Department of Labor, and Department of Education. The state received an associated grant this year, which is providing intensive technical assistance.

Intellectual Disabilities and Autistic Disorder Accomplishments

Developmental Services has done significant work to implement Olmstead community integration values through employment policies and practices.

- **1999:** The final report from a three-year systems change grant focused on employment by Maine Medical Center Vocational Services was published. The recommendations from this report drove employment initiatives for the next 13 years. This was the juncture for the end of facility-based employment.
- **2000:** DHHS created a ten-year vocational policy, which said that community employment is the state's value. DHHS asked agencies that provided sheltered employment to stop and to submit transition plans.
- **2000 – 2002:** The state closed its one state-run sheltered workshop. It took 2.5 years to transition the last 38 people out.
- **2005 – 2006:** The state passed legislation that had DHHS analyze how services were funded, what was funded, and to make changes to support Olmstead values.

- **2008:** The state stopped funding sheltered workshops and applied for Section 29 HCBS 1915(c) supports services waiver. At this point, about 1,300 people were receiving freestanding day habilitation and state dollars. Section 29 support services waiver went live later in the year, and the 1,300 day habilitation participants were transferred onto the waiver on July 1, 2008. Additionally, employment definitions were aligned across 1915(c) waivers and vocational rehabilitation.
- **Since 2008:** When individuals identify that they want to work, it is DHHS' responsibility to determine what they need to overcome barriers and enlist the services they need. This is done with benefits counselors, waiver services, and vocational rehabilitation. The state has been looking at the quality of services provided, and uses employment outcome data. The state only supports community-based, community-integrated employment where individuals have the same access to benefits and resources as other employees. **MaineCare funding does not pay for segregated employment**. DHHS updated its Employment of People Served Policy and created practice guidelines.
- **2011:** Maine WorkForce Development was created to provide all employment services training, as well as certification and mentoring to Employment Specialists across all state systems.
- **2012:** Began working on Employment First initiative and created the Maine Business Leadership Network (Maine BLN) an affiliate of the National Business Leadership Network. Maine BLN is a business-to-business coalition that promotes diversity hiring among Maine businesses.
- **2013:** Employment First law passed in Maine and the Social Security Administration's Work Incentives Planning and Assistance cooperative agreement was again awarded to Maine Medical Center Department of Vocational Services to continue to provide benefits counselors and statewide system in place through grant funding since 2001.
- **2014:** DHHS adopted updated Employment of People Served Policy to implement Employment First requirements, a new service of Career Planning was added to sections 18, 21, and 29 waivers, and the Office of Disability was awarded employment policy technical assistance to increase integrated, community-based employment.
- **2015:** Working to add employment support programs to the upcoming 1915(i) State Plan Amendment and creating new Benefit Navigator program including Balancing Incentives-funded trainings for 100 staff each year to reduce misinformation and support people to go to work.

Mental Health and Substance Abuse Accomplishments

SAMHS provides **mental health long term supportive employment**, which is job coaching for individuals. This program tries to build on natural supports, while at the same time recognizing that some individuals will need ongoing support to maintain employment.

The **community employment specialist program** started in 2006. In this program, employment specialists are integrated into mental health agencies, and employment support, including job development, is provided within the context of these agencies.

SAMHS collaboratively works with mental health agencies to create system transformation to fight the stigmas and myths about people with mental illness that keep individuals isolated and trapped in poverty. Collectively SAMHS and mental health agencies are **changing the norms so employment is seen as a viable option** for individuals. DHHS began a peer-led self-help facilitated group called Maine Can Work in 2014, where peers are changing the conversation around employment. This curriculum is being implemented in psycho-social clubhouses.

SAMHS conducts **workforce development** work to ensure case managers and direct service professionals discuss community inclusion through employment with individuals.

SAMHS has had good success with the **Maine Leadership Business Network**, which is aimed at employing individuals with disabilities (including intellectual, autistic, and physical). Because some of the highest costs to employers are related to mental illness, SAMHS is working with this network to relay the value of investing in employees with mental illness, particularly in a graying state.

APS Healthcare tracks **employment outcome data** for SAMHS.

Children/Youth with Disabilities Accomplishments

OCFS is just beginning to look at employment issues. There is an **Employment First** subcommittee focusing on transition age youth. The **Workforce Investment Act** is also **focusing on transition age youth**.

Opportunities

General Opportunities

Survey respondents discussed the **need for increased employer incentives and partnerships**. There is interdepartmental work being done to break down barriers to make employment a real option under Employment First. Maine BLN addresses the business-to-business discussions to increase employment. Over the past four years the Maine BLN has hosted ten business events sharing information on hiring practices, diversity awareness, the Americans with Disabilities Act, and success stories in Maine. Increased focus on business as a customer continues to be a priority.

Intellectual Disabilities and Autistic Disorder Opportunities

When funding for sheltered workshops stopped, **many participants transitioned to day habilitation programs** in conjunction with or instead of community-based employment. Significant funding goes to day programming for this population, meaning some providers of this service may have a vested interest in retaining participants in their services, according to interviewees. During person centered planning all individuals have support to discuss employment and the services available to them through DHHS, the Department of Labor, and other entities to get them on a pathway to employment. The Employment First Act is working to normalize expectations around work for individuals with intellectual disabilities and autistic disorder, to avoid the need for transition work from day habilitation to employment, and rather transition individuals directly into employment. Many providers are supportive of this effort, and are getting licensed to offer employment supports. Individuals transitioning from school will be supported to go directly to work as part of the implementation of the 2015 Work Opportunities and Innovation Act along with an Employment First practice.

Mental Health and Substance Abuse Opportunities

Maine has the **lowest competitive employment rate** of the nation, at 8.4 percent compared to 17.9 percent nationally.[36] DHHS is adding **employment support programs to the upcoming 1915(i) State Plan Amendment**, which will create a more robust approach to community employment.

Individuals are often **fearful of losing their MaineCare benefits** with employment according to interviewees and help line data. Participants and advocates seek clear guidance in how much individuals can earn before losing their benefits.

SAMHS is looking at the Assertive Community Treatment (ACT) program, which provides team-based community support services for individuals who are hospitalized frequently. SAMHS requires employment specialist to spend at least 90 percent of their time on employment-related activities, and that **15 percent of participants receiving ACT services are competitively employed**. Most ACT teams are not meeting the 15 percent benchmark per stakeholder interviews.

[36] Maine 2014 Mental Health National Outcome Measures, SAMHSA Uniform Reporting System.

Appendix A – Olmstead Survey Tool

Updating Maine's Response to the *Olmstead* Decision

External Stakeholder Survey
April 23, 2015

Introduction

Olmstead is a 1999 Supreme Court decision that requires states to eliminate unnecessary segregation of individuals with disabilities and ensure people receive services in the most integrated setting possible.

In response, the Maine Department of Health and Human Services formed a work group on community-based living to develop a plan to implement *Olmstead*. The group published the "Roadmap for Change: Maine's Response to the *Olmstead* Decision" in 2003. The 2003 Roadmap for Change identified core values that drive long term services and supports.

Maine is updating its response to the *Olmstead* decision. This update includes an analysis of progress made since 2003 and the development of a plan for the next ten years. As part of that effort, this survey is designed to capture stakeholders' perspectives and input on core roadmap values, as well as suggestions for areas of focus moving forward.

DHHS is seeking input from participants, family members, providers, advocates, and interested parties on:

- Accomplishments related to 2003 roadmap goals; and
- Where there is room for improvement

You do **NOT** need to be familiar with the 2003 Roadmap for Change document to provide valuable input to the survey.

Survey responses are anonymous; we encourage you to provide candid feedback. Your feedback from this survey will provide valuable insight into Maine's long term services and supports. We appreciate your completion of the survey by Friday, May 22nd. If you have any questions about this survey, please contact Nicole Rooney at 207-287-9221 or Nicole.Rooney@maine.gov.

Your Background

To help us understand the diversity of respondents, please answer a few questions about yourself:

1. What best describes your connection to DHHS? (Check all that apply.)
   - I am a consumer.
   - I am a family member of a consumer.

- I am a potential or former consumer (not currently receiving services).
- I am an advocate.
- I am a direct caregiver.
- I am an enrolled Medicaid provider.
- I am a case manager.
- I work for a state agency. Name of agency:_____
- I am a policy maker.
- I fund human services.
- Other: _____

2. Where do you live or work?
   - Aroostook County
   - Hancock, Washington, Penobscot, or Piscataquis County
   - Kennebec or Somerset County
   - Knox, Lincoln, Sagadahoc, or Waldo County
   - Androscoggin, Franklin, or Oxford County
   - Cumberland County
   - York County

3. Where do you receive or provide the majority of your services? (Check all that apply.)
   - At home
   - At work
   - In the community
   - At a medical office
   - In a hospital
   - In a nursing facility
   - In an assisted living facility
   - In a professional, non-medical institution
   - In a foster home or group home
   - In jail or other correctional facility
   - Other:

4. Have you heard of the *Olmstead* Supreme Court decision?
   - Yes
   - No

Progress on Priorities

The 2003 *Olmstead* Roadmap for Change identified the following priorities as the foundation of comprehensive, integrated response to serving persons with disabilities and the community as a whole. Examples are provided for each priority in the questions

below. These examples are goals from the 2003 roadmap. The examples do not represent a comprehensive list of goals related to each priority; rather they are meant to clarify what the priority means.

For each of these underlying priorities, please provide your perspective on how well the State of Maine currently meets this priority, examples of related programs or strategies, and additional services or policies that would help to better fulfill each priority.

1. Help people control and deliver the services and supports they need. For example, support and expand self-directed care options.
- For the statement above, how well does the state of Maine currently meet this priority for people receiving long term services and support?
    - Not at all; A little; Quite a bit; Completely; Don't know
- Please identify programs or strategies currently in place to help meet this priority.
    - Text box
- Please identify or suggest additional services or policies that would help to better meet this priority.
    - Text box

2. Support individuals in finding their voice and speaking for themselves. For example, support consumer advocacy and consumer participation on state and provider boards.
- For the statement above, how well does the state of Maine currently meet this priority for people receiving long term services and support?
    - None; A little; Quite a bit; Completely; Don't know
- Please identify programs or strategies currently in place to help meet this priority.
    - Text box
- Please identify or suggest additional services or policies that would help to better meet this priority.
    - Text box

3. Organize services around the person served. For example, person-centered planning, informed choices by consumers, and the option of independent facilitation.
- For the statement above, how well does the state of Maine currently meet this priority for people receiving long term services and support?
    - None; A little; Quite a bit; Completely; Don't know
- Please identify programs or strategies currently in place to help meet this priority.
    - Text box

- Please identify or suggest additional services or policies that would help to better meet this priority.
    - Text box

4. Create a single, integrated system of coordinated services. For example, service coordination and neutral sites and quality improvement through training and monitoring.
- For the statement above, how well does the state of Maine currently meet this priority for people receiving long term services and support?
    - None; A little; Quite a bit; Completely; Don't know
- Please identify programs or strategies currently in place to help meet this priority.
    - Text box
- Please identify or suggest additional services or policies that would help to better meet this priority.
    - Text box

5. Integrate access to services so that there is no wrong door into the system. For example, integrated information and referral system and integrated service centers serving as entry points.
- For the statement above, how well does the state of Maine currently meet this priority for people receiving long term services and support?
    - None; A little; Quite a bit; Completely; Don't know
- Please identify programs or strategies currently in place to help meet this priority.
    - Text box
- Please identify or suggest additional services or policies that would help to better meet this priority.
    - Text box

6. Build standards for quality and accountability of services and evaluate quality on an on-going basis. For example, a comprehensive definition of quality includes a complete view of a person's life and her/his values.
- For the statement above, how well does the state of Maine currently meet this priority for people receiving long term services and support?
    - None; A little; Quite a bit; Completely; Don't know
- Please identify programs or strategies currently in place to help meet this priority.
    - Text box
- Please identify or suggest additional services or policies that would help to better meet this priority.
    - Text box

7. Improve access to and availability of integrated, affordable housing. For example, everyone is served in the most integrated setting appropriate her/his needs and home ownership and home modifications are more affordable.
- For the statement above, how well does the state of Maine currently meet this priority for people receiving long term services and support?
    - None; A little; Quite a bit; Completely; Don't know
- Please identify programs or strategies currently in place to help meet this priority.
    - Text box
- Please identify or suggest additional services or policies that would help to better meet this priority.
    - Text box

8. Improve access to and availability of transportation. For example, there is a link between location of services and transportation planning.
- For the statement above, how well does the state of Maine currently meet this priority for people receiving long term services and support?
    - None; A little; Quite a bit; Completely; Don't know
- Please identify programs or strategies currently in place to help meet this priority.
    - Text box
- Please identify or suggest additional services or policies that would help to better meet this priority.
    - Text box

9. Improve access to and availability of jobs. For example, modify personal assistance services to support consumer employment and support alternative and flexible work options that meet the needs, skills and availability of workers with severe disabilities.
- For the statement above, how well does the state of Maine currently meet this priority for people receiving long term services and support?
    - None; A little; Quite a bit; Completely; Don't know
- Please identify programs or strategies currently in place to help meet this priority.
    - Text box
- Please identify or suggest additional services or policies that would help to better meet this priority.
    - Text box

Additional Input

1. How well do current long-term services and supports serve the following population groups? LIKERT SCALE: Very poorly; poorly; adequately; well; very well

- Persons with mobility and/or physical impairments, including spinal cord injuries
- Persons with acquired or traumatic brain injury
- Persons with vision or hearing disability
- Children or youth with developmental or intellectual disability
- Adults with developmental or intellectual disability
- Children or youth with mental health disorder (OR serious emotional disturbance OR psychological disorder)
- Adults with mental health disorder (OR severe and prolonged mental illness OR psychological disorder)
- Persons with substance addiction disorder

2. What are common obstacles to delivering long term services and supports?
    a. Textbox

3. What else should DHHS consider as it re-envisions long term services and supports?
    a. Textbox

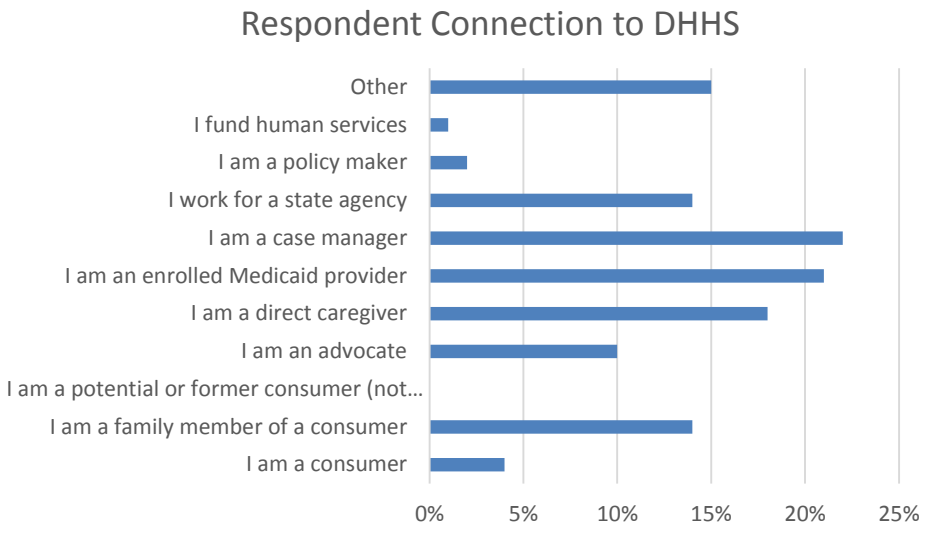
Thank You

Thank you for taking the time to respond to this survey. Your answers will help us understand the strengths and weaknesses of Maine's long term services and supports, which will help define the next steps for the *Olmstead* planning.
Please use the space below if you have any other additional comments you would like to share with the state regarding *Olmstead* and Maine's long term services and supports.

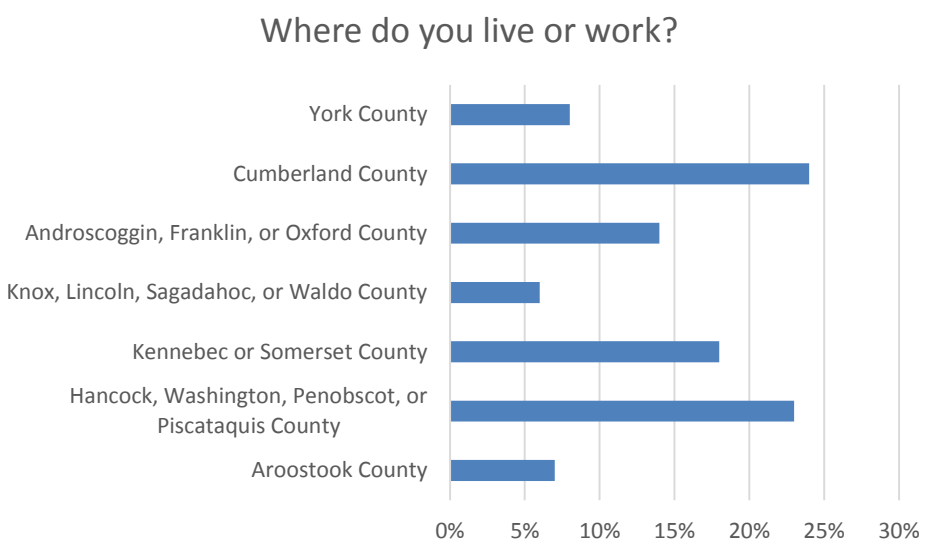
- Textbox

Appendix B – Survey Respondent Composition

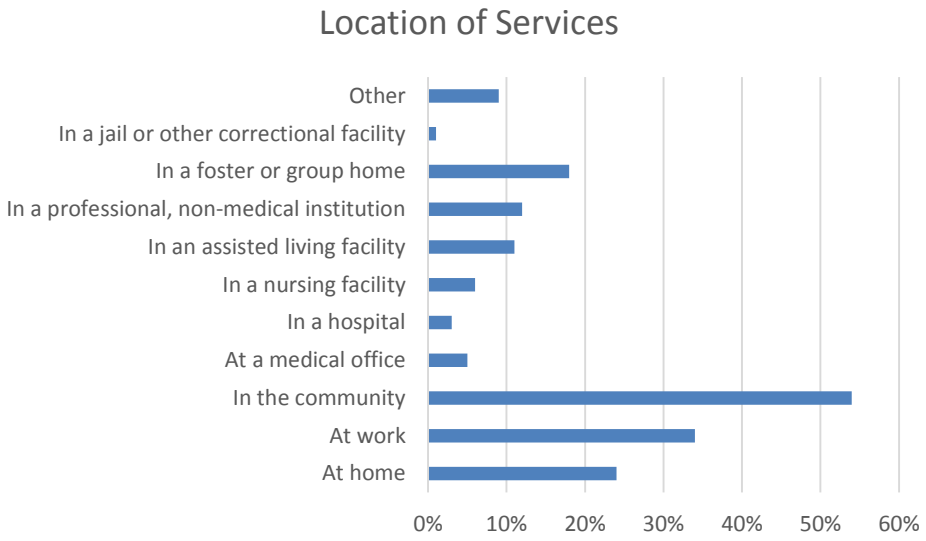
The total number of respondents to the web-based stakeholder survey was 368. The following tables provide a brief summary of the composition of survey respondents based on their connection to DHHS, location of services, and geographic location of home or work.



The greatest share of respondents were case managers (22 percent), enrolled Medicaid providers (21 percent), and direct caregivers (18 percent). Relatively few respondents were participants (4 percent), but 14 percent of respondents were family members of participants.



One quarter of respondents live or work in Hancock, Washington, Penobscot, or Piscataquic County (23 percent) or Cumberland County (24 percent), with nearly one-fifth in Kennebec or Somerset County (18 percent).



The majority of survey respondents (54 percent) indicated that they receive or provide services in the community. A third of respondents (34%) receive or provide services at work, and one quarter (24 percent) receive or provide services at home.

Appendix C – Interviews Conducted

The table below contains the list of individuals interviewed for the Olmstead progress report and their representative organizations. The majority of interviews were conducted in April and May 2015. A small number occurred in August and September 2015.

Table 8: Olmstead Progress Report Interviewees

Interviewee	Organization
Alice Preble	Program Specialist, OCFS, DHHS
Amy Mayhew	Substance Abuse Treatment Specialist, Criminal Justice/MaineCare Liaison
Bill Olsen	Supportive Housing Loan Officer, MaineHousing
Catherine Ryder	Executive Director, Tri-County Mental Health Services
Chester Barnes	Rental Assistance Manager, SAMHS, DHHS
Connie Jones	Community Services Director, SeniorsPlus
Cullen Ryan	Executive Director, Maine Coalition for Housing and Quality Services
Daniel Dunovan	Executive Director, Aroostook Regional Transportation System
Daniel Wathen	Court Master of Mental Health Consent Decree, Pierce Atwood, LLP
David McCluskey	Program Director, Community Care
David Projansky	Housing Resource Developer, OADS, DHHS
Deb Halm	Associate Director, OADS, DHHS
Dennis Fitzgibbons	Executive Director, Alpha One Center for Independent Living
Doreen McDaniel	Adult Protective Services Manager, OADS, DHHS
Elizabeth Gattine	Former Long Term Care Services Manager, OADS, DHHS
Eric Meyer	Executive Director, Spurwink
Gary Wolcott	Director, OADS, DHHS
Ginger Roberts-Scott	Children's and Waiver Manager, Office of MaineCare Services
James Martin	Director, OCFS, DHHS
Jeanne Tondreau	OCFS, DHHS
Jenna Mehnhart	Executive Director, National Alliance on Mental Illness Maine
Julita Klavins	Office of Continuous Quality Improvement, DHHS
Karen Mason	Associate Director, OADS, DHHS
Leticia Hutman	Employment and Workforce Development Manager, SAMHS, DHHS
Lisa Sturtevant	Employment Services, OADS, DHHS
Lori Geiger	Information Services Manager, OCFS, DHHS

Interviewee	Organization
Melissa Tremblay	Clinical Director, Tri-County Mental Health Services
Nicole Rooney	BIP Manager, OADS, DHHS
Peter Rice	Counsel, Disability Rights Maine
Rachel Dyer	Associate Director, Maine Developmental Disabilities Council
Rachel Posner	Behavioral Health Services Team Leader, OCFS, DHHS
Sheldon Wheeler	Administrator, SAMHS, DHHS
Steve Farnham	Executive Director, Aroostook Area Agency on Aging and Aging and Disability Resource Center
Terry Sandusky	Information Services Manager, OADS, DHHS
Valerie Smith	Executive Director, Maine Developmental Services Oversight and Advisory Board
Wanita Page	Quality Services Manager SAMHS, DHHS

Appendix D – Data Sources

The table below contains secondary data sources used in this assessment.

Table 9: Data Sources

Data Source	Organization/Author
A Cross-System Profile of Maine's Long Term Support System: A New View of Maine's Long Term Services and Supports and the People Served, March 2009	Muskie School of Public Service, University of Southern Maine
A Profile of Maine's Older Population and Housing Stock, January 2015	Abt Associates
Adult Mental Health Services Plan: Consent Decree Plan: Pursuant to paragraphs 36, 37, 38 and 279 of the Settlement Agreement in Bates v. DHHS, October 13, 2006	Office of Substance Abuse and Mental Health Services, Maine Department of Health and Human Services
Bates and Olmstead: Court-initiated Strategies to Implement Community Inclusion of Persons with Psychiatric and Other Long-term Disabilities, 2004	Theresa A. Laurie, Maine Policy Review, Volume 13, Issue 1
Bates v. DHHS Consent Decree: October, November, December 2014: 2nd Quarter, SFY 2015: Consent Decree Report	Office of Substance Abuse and Mental Health Services, Maine Department of Health and Human Services
Biennial Plan 2013-2014 for Adults with Intellectual Disability or Autism, December 15, 2013	Office of Aging and Disability Services, Maine Department of Health and Human Services
Blueprint for Action on Aging	Maine Council on Aging
Blueprint for Effective Transition, February 9, 2015	Maine Coalition for Housing and Quality Services
Chartbook: Adults with Intellectual Disability or Autism Spectrum Disorder: Population and Service Use Trends in Maine 2014 Edition	Muskie School of Public Service, University of Southern Maine
Chartbook: Older Adults and Adults with Physical Disabilities: Population and Service Use Trends in Maine 2012 Edition	Muskie School of Public Service, University of Southern Maine
Child Fiscal Year End Report FY 2014	APS Healthcare
Crisis Prevention and Intervention Services, 2010-2013 Report	Office of Aging and Disability Services, Maine Department of Health and Human Services
Draft Transition Plan for Complying with New HCBS Rules, December 15, 2014	Maine Department of Health and Human Services
Final Report of the Commission on Independent	State of Maine, 126th Legislature,

Data Source	Organization/Author
Living and Disability, December 2014	Commission on Independent Living and Disability
Maine Can Work, Second Edition, January 2014	Office of Substance Abuse and Mental Health Services, Maine Department of Health and Human Services
Maine Stand-Alone Senior Community Service Employment Program (SCSEP) State Plan, 2012-2015	State Unit on Aging, Office of Aging and Disability Services, Maine Department of Health and Human Services
Maine Supporting Individual Success: Analysis of Individual Expenditures for those Receiving the Supports Intensity Scale, June 26, 2013	Human Services Research Institute
Medicaid Expenditures for Long-Term Services and Supports in FFY 2012, April 28, 2014	Centers for Medicare and Medicaid Services and Truven Health Analytics
Olmstead Community of Practice and Learning Community Primer,	Substance Abuse and Mental Health Services Administration
Olmstead Roadmap for Change: Update for Developmental Services, March 14, 2014	Office of Aging and Disability Services, Maine Department of Health and Human Services
Roadmap for Change, Maine's Response to the *Olmstead* Decision, Summary and Appendices A – K, October 2003	Work Group for Community-Based Living
Recommendations Submitted to the Employment First Maine Coalition, September 2014	Employment First Maine, Systems Development/Capacity Building Work Group
State Plan for Alzheimer's Disease and Related Dementias in Maine, June 2012	Office of Aging and Disability Services, Maine Department of Health and Human Services
State Plan on Aging, October 1, 2012 – September 30, 2016	Office of Aging and Disability Services, Maine Department of Health and Human Services
Substance Abuse Block Grant Behavioral Health Assessment Plan 2014	Office of Substance Abuse and Mental Health Services, Maine Department of Health and Human Services
The Vital Role of State Psychiatric Hospitals, July 2014	National Association of State Mental Health Directors Medical Directors Council
White Paper – Medicaid Waiver for People Who Have Experienced Long Term Homelessness, December 20, 2013	Statewide Homelessness Council

Data Source	Organization/Author
White Paper – Medicaid Waiver for People Who Have Experienced Long Term Homelessness, Addendum: Anticipated Costs and Cost Savings, September 10, 2014	Statewide Homelessness Council

Appendix E – Acronyms

Below is a table of the acronyms used in this report.

Table 10: Acronyms

Acronym	Definition
AAA	Area Agency on Aging
ACT	Assertive Community Treatment
ADA	Americans with Disability Act
ADRC	Aging and Disability Resource Center
AIRS	Alliance of Information and Referral Systems
ASO	Administrative Services Organization
BHP	Behavioral Health Professional
CANS	Child and Adolescent Needs and Strengths
CCSM	Consumer Council System of Maine
CDS	College of Direct Support
CIL	Center for Independent Living
DHHS	Department of Health and Human Services
DSOAB	Development Services Oversight and Advisory Board
DSP	Direct Support Professionals
EIS	Enterprise Information System
EPSDT	Early Periodic Screening, Diagnosis, and Treatment
HCBS	Home and Community Based Services
HRSA	Health Resources and Services Administration
HUD	US Department of Housing and Urban Development
ICF-IID	Intermediate Care Facility for Individuals with Intellectual Disabilities
IHSP	Independent Housing with Services Program
ISP	Individual Service Plan
MAC	APS Healthcare Member Advisory Council
Maine BLN	Business Leadership Network
MDCC	Maine Developmental Disabilities Council
MDOT	Maine Department of Transportation
MIHMS	Maine Information Health Management System
NAMI	National Alliance for Mental Illness
NCI	National Core Indicators
OAA	Older Americans Act
OADS	Office of Aging and Disability Services
OADS/DS	Office of Aging and Disability Services/Disability Services
OCFS	Office of Child and Family Services
OFI	Office of Family Independence
ORC	Other Related Conditions
OT	Occupational Therapy

Acronym	Definition
PATH	Projects for Assistance in Transition from Homelessness
PRTF	Psychiatric Residential Treatment Facility
PT	Physical Therapy
QIC	Quality Improvement Council
QRC	Quality Review Committee
SAMHS	Substance Abuse and Mental Health Services
SAMHSA	Substance Abuse and Mental Health Services Administration
SFY	State Fiscal Year
SIM	State Innovation Models
SIS	Supports Intensity Scale
SUFU	Speaking Up for Us
TCM	Targeted Case Management
TDS	Treatment Data System
TFC	Treatment Foster Care
TIP	Transition to Independence Process
WIT	Web Infrastructure Technology
YOC	Youth Outcome Questionnaire


Bloom